Access to Healthcare: Investigating the Barriers to Accessing Antiretroviral Treatment at a Public Sector Antiretroviral Clinic in Durban, South Africa.

By

Yolandie Kriel

Supervisor: Dr Susan de la Porte

Co-Supervisor: Dr Nombulelo P. Magula

Thesis submitted in partial fulfilment for the requirement of the degree Master of Health Science in the School of Health Science, College of Health Science.

University of KwaZulu Natal

November 2013

<u>Declaration</u>

I hereby declare that unless stated otherwise in the text, this thesis is my own original work.

Yolandie Kriel

Signed: _____   Date: _____

Yolandie Kriel
Durban
December 2013

Abstract

South Africa has the largest HIV/AIDS epidemic in the world and due to the rapid scale up of access to antiretroviral drugs now has the largest antiretroviral program in the world. However access to antiretroviral treatment remains a challenge and the scale up of the drug programs has caused an additional burden on an already stretched and stressed public healthcare sector.

At present there are only two lines of drug regimens available to the general public that rely on the public healthcare sector for the supply of their antiretroviral drugs. Resistance to the current regimens is a major concern that is not effectively being addressed. One of the major aspects that can contribute to a rise in resistance is barriers to continually accessing antiretroviral treatment.

This ethnographic investigation into the barriers to accessing antiretroviral treatment was conducted in a public health sector clinic based at a large hospital in Durban. The specific objectives of the study were to elucidate the major barriers to accessing the treatment as perceived by the patients of the clinic, to understand the structural drivers behind the barriers and to capture the patients' reactions to these obstacles that they face on a continuous basis.

Unlike most studies that focuses only on adherence this study's focus was rather on the concept of access to healthcare and how barriers perceived by the patients influence their ability to effectively access their treatment. Thus the concept of access to healthcare is explored in detail and an argument is made for the importance of understanding and applying the holistic concept of access to healthcare within the ART setting.

An ethnographic approach was adopted to conduct this study, and the study utilized a triangulation of data collection techniques including participant observation, in-depth interviews, focus groups and a questionnaire. The research was done over a period of seven months and focused on adults who were already part of a regimen for a period of at least one year.

Antiretroviral treatment regimens are for life and once people start with these regimens they cannot stop. However this study found that a range of barriers exist that present obstacles for patients to continually access ART drugs. Structural violence theory provided the framework for contextualizing the specific barriers that were reported and is important in terms of situating the barriers within the larger structures that create them. What is evident is that poor healthcare related policies, stigma, discrimination, economic inequality, gender and poverty are the structural drivers behind barriers to accessing ART. By incorporating a broader understanding of access to healthcare a deeper understanding of the barriers is gained and better interventions can be created to prevent disengagement from life-long ART services.

Acknowledgements

There are many people who I would like to acknowledge and thank for their help and support in completing this project.

Firstly I would like to thank my supervisor, Dr Susan de la Porte for taking me on as a student and for agreeing to be part of this project. Her guidance, advice, comments and encouragement is what helped me to complete this research project. Thank you for opening the door to Anthropology to me all those years ago and for introducing me to the subfield of Medical Anthropology. Your interest and passion inspires me to delve further into this fascinating subject.

Then I would like to give a big thank you to Dr Nombulelo Magula, my co-supervisor. Dr Magula epitomises what a healthcare worker should be and she is an inspiration for anyone who works within the healthcare field. Her expert skill in providing medical care is matched by her compassion for her patients, and she is a true example of what every healthcare professional should strive to achieve. Despite her very busy schedule she still found time to discuss my project and offer her expert advice and insight. I thank you from the bottom of my heart for your support and encouragement; this project would not have existed without you.

I would then like to give a big thank you to Professor Fatima Suleman, who created a marvellous master's degree that allowed me the opportunity to further my education while being employed; and for allowing me to embark on this multi-disciplinary research project.
I would also like to thank Professor Christine Varga who generously gave her spare time to give invaluable comments and insights to this project. I appreciate all the help and advice that you have given me. I would also like to thank Ms Phindile Nene for all her administrative advice and guidance and always having an answer for me.

Table of Contents

Table of Figures

CHAPTER ONE: Introduction

"It does not matter how many people can access treatment if we cannot keep them alive and receiving treatment" (Michel Sibide in UNAIDS, 2012: 11).

1.1) An Overview of the HIV/AIDS Pandemic

In 1981 the first four reported cases of Acquired Immune Deficiency Syndrome (AIDS) were documented in the United States of America. Initially thought to be a disease that only affected homosexual males, AIDS has become the plague of our modern times (Oldstone, 2010, Shilts, 1987). In 1983 the virus that caused AIDS, known as the Human Immunodeficiency Virus (HIV) was isolated and identified. Despite the discovery of a new virus the response to the new disease by governments, institutions and civil society was slow and mirrored the pathological latency of the virus itself (Shilts, 1987, Barnett and Whiteside, 2006). By the time governments and institutions took notice of what was happening it was too late; the virus that was thought to only occur in an isolated group was now also reportedly infecting the general population and was on its way to developing into the pandemic it is today (Shilts, 1987, Abdool Karim and Abdool Karim, 2010, Barnett and Whiteside, 2006).

1.2)   Epidemiology: From Global to Local

Thirty years after the first reported cases in Los Angeles, USA, there is no country in the world that is not affected by this devastating disease (Barnett and Whiteside, 2006, Abdool Karim and Abdool Karim, 2010). More than 60 million people across the world from all races, economic sectors and cultures have been infected with the virus and nearly half of those have died due to AIDS related illnesses (Abdool Karim et al., 2010, UNAIDS, 2012)[1].

Globally women comprise half of all people living with HIV (49%) and it is the leading cause of death for women between the ages of 15 and 49 years worldwide. It is estimated that one young women is infected with HIV every minute (UNAIDS, 2012).

Sub-Saharan Africa has a generalized epidemic. The main mode of transmission remains a predominantly heterosexual epidemic with unprotected sex, multiple concurrent partners, gender inequalities, poverty, mother to child transmission, and high levels of stigma and discrimination identified as key drivers behind the region's epidemic (UNAIDS, 2012). 23.5 million people of the global total of 34 million people infected with HIV live in sub-Saharan Africa but the region only holds 10 % of the world's total population (UNAIDS, 2012). This area remains disproportionately affected by the disease and continues to have the highest prevalence, incidence and mortality rates due to HIV infection on the global stage. More than 17 million people have already died in this region due to AIDS related diseases and most of all the new infections worldwide occurred in this region in 2011, with 1.5 million new infections occurring that year alone (UNAIDS, 2012). Women continue to be unevenly affected in this region where 6 out of 10 infected individuals are female, comprising an estimated 59%, which is significantly higher than the global trend of 49%. 92% of all pregnant women infected with HIV live in this region (UNAIDS, 2012).

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[1] UNAIDS: Joint United Nations Programme on HIV/AIDS

South Africa, considered to be the epicentre of the pandemic within the sub-Saharan region, similarly has a generalized epidemic with heterosexual transmission being the dominant form of infection followed by mother to child transmission. The country has the largest HIV epidemic in the world with an estimated 5.6 million people living with HIV/AIDS (PLWHA) (UNAIDS, 2012). The estimated prevalence rate for the general adult population is 17% and the antenatal prevalence rate has levelled off at an estimated 30%. An estimated 380 000 new infections occurred during the 2011-2012 year and the annual number of deaths due to AIDS related illnesses was 270 000 people during the same period (NDOH, 2012)[2]. Women, in South Africa like in sub-Saharan Africa, remain disproportionately affected by the disease and comprise more than half of all people living with HIV/AIDS. The age group 30-34 years shows the highest antenatal prevalence rate of 42.6% (NDOH, 2012).

Key drivers behind HIV transmission in South Africa are intergenerational sex, multiple concurrent partner, low condom use, alcohol use, and low rates of male circumcision (NDOH, 2012, Van Dyk, 2012) . A significant statistic is the difference in age prevalence categories for women and men where women tend to become infected at a younger age than men (Abdool Karim and Abdool Karim, 2010).

The province of KwaZulu Natal (KZN), the province in which this study was conducted, is particularly affected by the epidemic. An estimated 38% of women attending antenatal classes in KZN are infected and the province is home to an estimated 1 600 000 people living with HIV, the largest epidemic in the country (NDOH, 2012, Abdool Karim and Abdool Karim, 2010). Prevalence is highest in KZN amongst the adult population aged 15-49 years where prevalence is estimated to be at 39.5% (NDOH, 2012).

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[2] NDOH: National Department of Health

1.3) HIV/AIDS Prevention and Treatment: The Global Perspective

According to Barnett and Whiteside (2006) there is no sector in the global and local society that has not been affected by the HIV/AIDS epidemic. The widespread devastation of the disease has resulted in a global response to curb the pandemic. The epidemic is being challenged on two fronts; by prevention, and by treatment.

Like all sexually transmitted diseases, HIV infection is in theory totally preventable. Correct and consistent condom use, it has exhaustively been argued, is highly effective in preventing the transmission of HIV infection (Myer in Abdool Karim et al., 2010, Van Dyk, 2012), yet new infection rates remain high, especially in sub-Saharan Africa where there is a relatively low condom use rate (Van Dyk, 2012). Despite the limited success of male condoms, behaviour change strategies have constantly been heralded as key in fighting HIV/AIDS on a global level (UNAIDS, 2012) The most popular prevention strategy is known as the ABC of HIV prevention. The acronym stands for A to be abstinent, B to be faithful to one partner, and C to condomise if being faithful to one partner (B) is not a viable option (Epstein, 2007).

Although the ABC campaign had potential by sending an informative message to people on how to protect themselves from HIV infection, the campaign has largely failed, especially in sub-Saharan Africa (Epstein, 2007). The Global HIV Prevention Working Group (2007) noted that: "We should be winning in HIV prevention. There are effective means to prevent every mode of transmission; political commitment on HIV has never been stronger; and financing for HIV programs in low-and middle-income countries increased six-fold between 2001 and 2006. However, while attention to the epidemic, particularly for treatment access, has increased in recent years, the effort to reduce HIV incidence in faltering" (Global HIV Prevention Working Group in Boler and Archer, 2008: 46).

Some of the contributing factors to the failure of prevention campaigns in sub-Saharan Africa include poverty, gender-based violence, stigma, and the generalized nature of the epidemic in the region (Leclerc-Madlala, 2009). The generalized nature of the epidemic makes it difficult to identify 'risk groups' who engage in 'risky sexual behaviour', as defined by UNAIDS and WHO[3], since most individuals who are engaged in long-term concurrent relationships do not perceive their behaviour to place them at risk for infection since they do not identify with the definitions of risk groups (Boler and Archer, 2008, Epstein, 2007). In addition the term 'risk group' coined by epidemiologists has become a taboo category in HIV/AIDS discourse because of the stigmatising nature of the externally imposed category and the repercussions of imposing the category upon certain groupings, such as, sex workers and individuals engaged in sexual networks. Stigma thus has negated the possibility of individuals identifying themselves as being a 'risk group' and has severely impacted upon prevention efforts. However, despite the problems inherent in prevention campaigns, long-term concurrent relationships remain the greatest contributor to the spread of HIV in this region (Epstein, 2007, Leclerc-Madlala, 2009).

While prevention efforts have experienced only limited success, the emphasis on antiretroviral treatment (ART)[4] has changed the course of the epidemic by changing a death sentence into a chronically manageable disease. In 1987 Zidovudine (AZT) was the first antiretroviral drug to show clinical benefits against the virus (Abdool Karim and Abdool Karim, 2010). Mono-drug therapy [5] showed short term benefits but it became clear after further drug trials that mono-therapy was not sufficient, as the levels of mortality and

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[3] WHO: World Health Organisation
[4] ART: Antiretroviral Therapy refers to the class of drugs used to treat HIV-infection.
[5] Mono-drug Therapy: Using only one ART drug. This was the treatment at the beginning of ART and the drug most commonly used was Zidovudine (AZT). Mono-drug therapy has now been shown to be ineffective and as contributing to drug-resistance. It should not be used under any circumstances.

morbidity did not improve significantly (Wood, 2010). Dual-drug therapy [6] in a similar vein did not show much improved clinical efficacy either. Initially the stance was to 'hit early- hit hard' with the mono-therapy regimens but the HI virus quickly mutated and soon resistant strains to mono and dual therapy drugs were encountered. Over time longitudinal studies showed that high levels of toxicity were reported without much clinic benefit such as increased mortality and morbidity rates and decreased CD_4+T-cells[7] (CD_4) cell counts (Abdool Karim et al., 2010). Several years later in 1995 Highly Active Antiretroviral Therapy (HAART) [8]showed to have effective clinical results and the triple use of drug classes were recommended as treatment for those infected with the HI-virus (Wood, 2010, WHO, 2013).

In 1995 the WHO recommended that patients should be commenced on ART at a CD_4 count level of 500 cells/mm^3 and less and that the use of triple combination therapy (HAART) should be the standard care of treatment for HIV infection (Wood in Abdool Karim, 2010). These guidelines are produced by the WHO to standardize treatment regimens but are better suited to an individualistic treatment plan, such as those in so-called developed countries. In countries, like South Africa, where generalized care is the standard treatment plan for all the citizens of the country who utilize the public healthcare sector, the individualistic treatment regimens of the 'developed nations' are ill suited. The major reason behind this situation is the cost factor. Before ART was made available in South Africa to the general public, the South African government cited that the lack of funding prevented the acquisition of ART drugs, and therefore ART drugs were not available to the general public (Govender, 2009).

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[6] Dual-drug Therapy: This refers to two classes of ART drugs being used. Like Mono-drug Therapy it was ineffective and contributed to resistance. It is now used only for prevention of mother to child transmission.
[7] CD_4+T-cells count is the measure of the immunological response to HIV infection. The CD_4+T-cells are the main cells responsible for initiating an immune response to infections and pathogens in the immune system. They are the cells most affected by the HI-virus that causes a depletion of CD_4+T-cells (Abdool-Karim 2012).

[8] Highly Active Antiretroviral Therapy (HAART): This is the current ART therapy that has been shown to be most effective in treating HIV infection. It is the combination of three or more classes of antiretroviral drugs that work together.

In South Africa the CD_4 count level was initially set at 200 cells/mm^3 but was changed in 2011 to 350 cells/mm^3 and less for adult patients (NDOH, 2013). This change in the CD_4 count level greatly improved the accessibility of ART drugs by the general population. ART is a lifelong commitment by both the person needing the drugs and by the healthcare system providing the service. For this reason when commencing treatment careful attention is paid to the person's willingness and readiness to commit to lifelong treatment (WHO, 2011, Van Dyk, 2012). To start a patient on ART is a lengthy and complicated process and is never considered as an emergency, except in cases of post-exposure prophylaxis (NDOH, 2013, Van Dyk, 2012). To be considered for ART the patient must meet the clinical indicators of WHO staging, laboratory markers, psychosocial factors, have access to laboratory facilities and have access to health care services for the treatment of opportunistic infections and side effects of the drugs (NDOH, 2013).

The "3 by 5" Initiative was the first plan implemented in 2003 by the World Health Organization and UNAIDS as a collective global response to combat the devastating effect that the HIV/AIDS epidemic had caused across the world. The "3 by 5" Initiative laid the foundations for the global reaction and effort that would be required to get all those eligible for ART onto treatment (UNAIDS et al., 2011). The main objective set by the "3 by 5" Initiative was to get 3 million people onto ART by 2005. At this stage, in 2003, only 400 000 people in low and middle income countries had access to ART. By the end of 2005 1.4 million people were receiving ART globally. While the nations[9] who had committed to the challenge of Universal Access fell short of achieving this goal lessons were learnt especially about service delivery of the drugs to low and middle income countries as well as the economic and political effort that would be required to provide treatment for those who need it (UNAIDS et al., 2011).

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[9] Nations: these include the Member States of the United Nations.

Universal Access to ART is one of the main goals set by The World Health Organization and the United Nations Joint Programme on HIV/AIDS (UNAIDS) and is a central concern for the Millennium Developmental Goal Number 6 to combat HIV/AIDS, malaria and other diseases (UN, 2013, UNAIDS et al., 2011). The Millennium Development Goals (MDG) were established and accepted by all member states of the United Nations in the year 2000. The goal to combat HIV/AIDS has two broad targets: to increase access to ART and have 15 million people who require ART on treatment by 2015; and to halt new infections and reverse the spread of the disease by the same year (UN, 2013).

In 2010 The Treatment 2.0 Initiative was launched by the WHO and UNAIDS to continue with the effort to reach the targets set by the MDG Goal 6. Five key pillars were established namely: to create a better ART pill and diagnostics; to use treatment as prevention especially in the prevention of mother to child sector; to stop health care and treatment costs from being an obstacle; to improve HIV testing and linkage to care; and to strengthen community mobilization to better reach key risk populations and assist them to access ART and care (UNAIDS and WHO, 2011, UNAIDS et al., 2011). In 2010 more than 6.65 million people were receiving ART and by 2012 the number had increased to more than 8 million people (UNAIDS, 2012). But with 2.5 million new infections in 2011 and an increase in the eligibility criteria to commence on ART for specific populations, such as pregnant women who are positive, this target seems to be shifting (UN, 2013).

The Global Health Sector Strategy on HIV/AIDS 2011-2015 implemented by the WHO and UNAIDS was endorsed by all member states in 2011. It stipulates the next steps that should be taken to begin the reversal of the epidemic in the next five years and to get all those eligible for ART onto treatment. The main vision guiding this plan is to achieve zero new infections; zero AIDS-related deaths; and zero discrimination towards PLWHA (WHO, 2011). The four main strategies proposed by the Global Health Sector Strategy on HIV/AIDS

2011-2015 include: optimizing HIV prevention, diagnosis, treatment and care; leveraging broader health outcomes through HIV responses; building strong and sustainable health and community systems; and reducing vulnerability and removing structural barriers to accessing services (WHO, 2011, UNAIDS et al., 2011).

Treatment 2015 is the latest framework created by the WHO and UNAIDS to reach the MDG Goal 6 of having halted all new infections and to have all those eligible for ART on treatment within the next thousand days. It also lays the foundation for achieving zero new infections, zero AIDS related deaths and zero discrimination (UNAIDS, 2013). The priority now shifts towards greatly increasing access to treatment. However, the goal post keeps moving for the member states, especially the developing countries who face economic restraints, as the latest WHO guidelines on The Use of Antiretroviral Drugs for Treating and Preventing HIV Infection recommends an increase of the CD_4 count to 500 cells/mm^3 resulting in greatly increasing the number of people living with HIV who are eligible to start treatment, but with the result of fewer AIDS related deaths (WHO, 2013, WHO, 2011, UNAIDS, 2013) .

Antiretroviral Treatment halts the progression of HIV infection into AIDS, and therefore has the potential to turn a life-threatening infectious disease into a chronic, manageable one. ART is life-long therapy and the initiation of drugs is only one of the first steps in access to treatment and care. Expanded access to ART has resulted in an increased number of people living with HIV for longer. In 2012 the global total of people living with HIV/AIDS was estimated to be more than 34 million. This is the largest number of people living with the disease since the start of the epidemic (UNAIDS 2012). The increased access to ART has decreased the mortality rate[10] due to AIDS. The total estimated number of deaths due to AIDS related causes was 1.7 million people in 2011 worldwide as compared to a peak in

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[10] Mortality rate: This is the number of deaths due to AIDS divided by the number of people at risk, multiplied by 1000, as mortality rates are taken per 1000 people of the population.

2005 at 2.3 million deaths, but it still remains one of the leading causes of death due to an infectious disease worldwide (UNAIDS 2012).

1.4) South Africa and Antiretrovirals

According to the Constitution of the Republic of South Africa (see The Constitution of the Republic of South Africa Act 108 of 1996) all citizens have a right to access health care services. To gain access to antiretroviral drugs, activists, and specifically the Treatment Action Campaign (TAC), protested until the government finally relented and started supplying antiretroviral therapy in 2004. Roll-out of ART to the general population began in 2004 when the National Department of Health began providing ART to adults, adolescents and pregnant women with a CD_4 count of less than 200cells/mm^3 or a World Health Organization (WHO) stage IV AIDS defining illness[11], irrespective of CD_4 count (DOH, 2004).

Access to treatment has been drastically scaled-up over the past couple of years. On 1 December 2009 President Jacob Zuma announced the change in policy that would allow all pregnant women and people co-infected with tuberculosis (TB) who have a CD_4 count below 350cells/mm^3 to be commenced on ART. In April 2012 it was announced that in accordance with the World Health Organizations' recommendation, all patients with a CD_4 count below 350cells/mm^3 are eligible for ART and that those with a CD_4 count below 200cells/mm^3 should be fast tracked[12].

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[11] WHO staging of AIDS defining illness: The WHO established clinical stages in which to classify HIV disease. Each progressive stage is an indication of severity of infection and decreased chances of survival. See Appendix 1 for the staging classification tables.

[12] Fast tracked: This refers to the procedure that patients have to undergo to start ART. The usual waiting period for a person who is eligible for ART is two weeks or more. Those individuals who have a CD_4 cell count of

On 1 April 2013 new South African Antiretroviral Treatment Guidelines were implemented in an effort to further expand access to ART. The new guidelines established the procedure to implement the new Fixed Dose Combination (FDC) tablets and entailed a revision of eligibility criteria (NDOH, 2013). CD_4 cell count remained at 350cells/mm^3, but WHO clinical staging now includes stage III and IV infection regardless of CD_4 cell count along with drug sensitive and drug resistant TB infection. The most significant change came for pregnant women. Pregnant women with a CD_4 cell count of 350cells/mm^3 and below are eligible for lifelong ART which should be commenced on the day of HIV diagnosis while those with a CD_4 cell count greater than 350cells/mm^3 will also be started on ART but their regimens will only last for as long as they are breastfeeding (NDOH, 2013).

Currently there are only two ART regimens available to people who utilize the public health care system (Van Dyk, 2012, NDOH, 2013). If patients develop resistance due to treatment failure, for whatever reason, referral to a specialist is indicated as the route to follow (NDOH, 2013). However, there are only a few HIV specialists available and these doctors are located in the private health care sector or in tertiary hospitals that are far from the rural public health clinics (NDOH and HST, 2012).

As a result of these expanded eligibility criteria together with drastic turnabout in terms of ART policy, South Africa now has the largest anti-retroviral programme in the world with approximately 1 500 000 people receiving treatment at the end of 2012 (UNAIDS, 2013, UNAIDS, 2012).

The increased workload of the HIV/AIDS epidemic on the public health care sector is well documented (Barnett and Whiteside, 2006, Abdool Karim and Abdool Karim, 2010, Zelnick and O'Donnell, 2005). According to the National Health Care Facilities Audit in 2012, 82.5%

200cells/mm^3 or less, Stage IV WHO defining illness regardless of CD_4 count, any Tuberculosis infection, and pregnant women eligible for lifelong ART should start treatment within two weeks.

of South Africa's total population utilizes the public health care sector as their primary health care facility with only 17.6% of the population using private medical care (NDOH and HST, 2012). This imbalance of healthcare service utilization has resulted in the public healthcare sector bearing the majority of the HIV/AIDS workload (Barnett and Whiteside, 2006). The rapid expansion of the ART program has resulted in an increase in the work and patient load, and has placed additional financial strain on the health care budget (Barnett and Whiteside, 2006). Clinics have been particularly affected by this and are struggling to meet the targets set by National Government, UNAIDS and WHO in the plan to address the HIV epidemic by having 3 million people who are eligible for ART on treatment by 2016 (NDOH, 2012). This figure stipulated by the National Department of Health (NDOH) translates to nearly double the current number of people on treatment to be commenced on ART within the next two years.

1.5) <u>Access to Health care and its related Barriers</u>

In her address to the 64th World Health Assembly in April 2011 Margaret Chan, the Director-General of the World Health Organization, said that "at a time of multiple calamities in the world, we cannot allow the loss of essential medicines, essential cures for many millions of people, to become the next global crisis" (Chan in Rossouw et al., 2013: 5). This warning gives rise to the need to expand the limited use of the definition of access to HIV/AIDS health care beyond the availability of drugs, and by doing so to incorporate a more holistic understanding about the barriers to continually accessing ART (Posse et al., 2008, Fried et al., 2012).

Merten el al., (2010) note that : "Although it has been shown that adherence (to ART) in SSA (sub-Saharan Africa) can be comparable or even superior to that in Western countries, retention in programs still poses problems" (Merten et al., 2010). Much of the success achieved in scaling up the availability of ART over the next couple of years will depend on whether continuous access to ART can be maintained at levels high enough at the local setting to significantly decrease deaths due to AIDS-related diseases.

Access to health care is a complex concept that involves five main dimensions, namely: availability, accessibility, affordability, acceptability, and accommodation (Penchansky and Thomas, 1981). The barriers to accessing ART related health care can be classified into four main categories, namely: physical, organisational, social, and economic barriers. The five dimensions and the related barriers are often interlinked and overlap in their definitions and operationalization. This has, in much of the literature, erroneously led to the synonymous use of the five dimensions with *each other* and with the term *access to health care*; as well as to the overlap in the usage of the terms of the identification of barriers to *accessing* ART healthcare with barriers to *adherence* to antiretroviral drugs.

Much focus has been placed on adherence to ART in the literature to reflect whether people are taking their drugs or not, and adherence is often used as a measure to indicate that treatment is now more accessible. However the term adherence is limited in its definition, since it is focused on individual behaviour and ability to comply with the prescribed drug regimen (Hardon et al., 2006). Adherence to ART is considered a personal patient perspective, since it involves the individual patient's reaction to the drug regimen that the patients receive. The WHO defines adherence as: "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider".(WHO, 2003: 3). Considering this definition it then becomes clear that adherence forms part of the larger concept of access to

13

healthcare, and falls under the user characteristics of access and the perceived need, adopting the 'sick role' and agreeing to care and instruction of the health care provider. While adherence remains an important concept it merely is the end point of access to ART healthcare services (Posse et al., 2008).

In the HIV/AIDS setting the scale up of accessing ART drugs has expanded rapidly over the past couple of years and is often used in the context of availability of antiretroviral drugs (van Dyk, 2010). While it is true that antiretroviral drugs are more available it does not necessarily mean that access to HIV/AIDS related treatment and care has scaled up. There is an overlap of identified barriers to adherence and access to health care in the literature. The argument made in this study is that the confusion and overlap between access and adherence is occurring because proper attention is not being given to the actual definitions of these two very important concepts. However, barriers to accessing ART does impact on adherence as Mukherjee et al., (2006) found it their study about barriers to accessing ART in resource poor settings. According to these actors the larger structural barriers and factors present in society play a larger role in discontinuation or interruption of treatment than individual patient factors (Mukherjee et al., 2006).

Van Dyk (2010) identified four main barriers to adherence, namely: the treatment regimen, environmental and service related constraints; patient centred barriers; and the relationship with health care workers. Although van Dyk (2010) mentioned all four of these as barriers to adherence, it should perhaps be recognised that environmental and services related constraints along with the relationships with health care workers speak more to the dimensions of access to health care and are perhaps better defined as barriers to accessing care, rather than barriers to adherence.

The distinction is important since the factors that influence access are usually embedded within the larger social structure within which the patients live and the health care service is situated, and therefore the patients have very limited control over these aspects. Personal barriers such as alcohol consumption or injection drug use that lead to non-adherence are personal factors that the patient can address (van Dyk, 2010). However service related factors such as stock short outs or discrimination from health care workers are beyond the control of the patient, and therefore to categorize a patient as non-adherent due to these causes is not just.

Adherence is a measurable entity and the result of non-adherence is the development of resistance to ART. However, measuring adherence is complicated and not exact as it is embedded within the biomedical paradigm which is not adept to consider the larger context in which the concepts of health and access to health care are situated, or the barriers that affect these concepts. Techniques for measuring adherence include: pill counts, interviews, self-reporting, pharmacy records, monitored computerized medication caps, and using biological markers such as viral load[13] testing (Reda and Biadgilign, 2011, WHO, 2003). In resource poor countries like South Africa, computerized caps are not available because it is such an expensive tool (Stott et al., 2013). Viral load monitoring is also expensive but is recommended as the technique to measure adherence. However, due to the expense and specialised lab facilities required viral load monitoring is not yet available in all clinical settings (Stott et al., 2013).

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[13]Viral Load: This refers to the amount of virus particles in a millimetre of blood plasma.

For anti-retroviral treatment to be effective a 95% adherence rate is required (van Dyk, 2010, Wood, 2010). Some studies have shown that adherence to ART in sub-Saharan Africa is comparable with that in middle and higher income countries, but according to van Dyk (2010), "we have no accurate record of what percentage of patients may fall in the 'danger zone' rate of ARV adherence (between 70% and 90%)" (van Dyk, 2010: 236). In her 2010 study van Dyk found that in South Africa only approximately 40.1% of patients were able to adhere to the optimal level of 90%. 49% managed to adhere between 70% and 90% of the time and 10.9% could not manage to adhere above 70% (van Dyk 2010).

For this reason a more holistic definition of access to health care (and the barriers that affect access) that looks beyond the confines of mere adherence and individual health related behaviour is required. This is necessary to understand the complex barriers to accessing HIV/AIDS related health care and to contextualize these barriers in a more comprehensive way that considers all aspects of the concept of access to health care.

1.6)   **The Research Problem**

Studies have shown that loss to follow-up[14] in the clinical ART setting is a growing concern, however, not much attention is being paid to this issue nor to the reasons why patients stop coming to collect their treatment after a period of time (Brinkhof et al., 2009, Ware et al., 2013). This loss to follow-up has significant implications for the ART programme, both globally and locally, as ART resistance is already emerging against the first and second line triple drug regimens (Rossouw et al., 2013, Brinkhof et al., 2009).

In South Africa this presents a potential problem since there is limited third line treatment available for the general public at this time and patients who stop taking their ART will contribute to the AIDS mortality rate since they are no longer taking their life-saving medication (NDOH, 2013, Brinkhof et al., 2009). Despite this harrowing fact not much research had been done within the South African setting on the large group of virologically stable patients who experience barriers to continuous access to care and who may result in lost to follow-up cases.

From working in the ART clinic, the site of this research, for the past four years it has come to my attention that the patients attending the clinic on a monthly basis experience difficulty when they come to collect their ART. This is of great significance as by identifying the specific barriers to accessing ART early, interventions can be shaped around these local barriers which can potentially assist in retaining the virologically stable patients in the ART program. This study is an investigation into the barriers to *accessing* antiretroviral treatment as experienced by the patients who attend a public health clinic located at one of Durban's largest public health sector hospitals, on a monthly basis.

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[14] Lost to follow-up - This refers to the patients who have not returned to the ART clinic for some time, usually six months, after initiating treatment and consequently have stopped taking their ART drugs.

1.7)   The Aim and Objectives of the Study

The aim of this research is thus to elucidate the specific barriers to accessing HIV/AIDS related health care services encountered by individuals enrolled in an ART programme in a public health clinic located at a large public hospital in Durban, South Africa. Understanding and identifying these obstacles is important in the ART setting to ensure continued access to health care services is maintained by those receiving life-long ART.

This study has four central objectives; namely:

1) To identify the most important barriers as perceived by the patients once they have been on ART for longer than a year.
2) To identify the drivers behind the barriers to continuous access to care.
3) To understand the impacts that these barriers have on the patients' ability to continually access their treatment.
4) To understand the patients' reactions to the perceived barriers in the clinic.

1.8)   The Research Setting

As previously noted, the high level of HIV/AIDS prevalence has resulted in an increased burden on the public health care sector which has in turn led to an increased demand for services. The public health clinic, where the research for this thesis was conducted, was therefore established at the hospital to provide services for people diagnosed with HIV/AIDS who are in need of care.

Initially this particular clinic was restricted to providing only supporting medical care and treating opportunistic infections related to HIV/AIDS. However, from 2004 an ART roll-out

program[15] was established at the clinic and patients in need of HIV related care was referred to the clinic from the hospital and from nearby clinics. The clinic presently offers services to paediatric, maternity, and adult patients.

The clinic is located at the top end of the hospital grounds and occupies its own building. The health care professional staff of the clinic comprises of one operational manager, two registered professional nurses, seven enrolled nurses and five enrolled nursing assistants; with one phlebotomist to collect the blood samples. There are three medical doctors allocated for the adult population of the clinic. Furthermore there are six lay counsellors who provide the counselling services and who are responsible for the adherence counselling and monitoring. The clinic also has a contingent of administrative personnel consisting of three data capturers, four social support officers and one admin clerk. There are also two general orderlies who are in charge of keeping the clinic neat and clean. Associated with the ART clinic is a pharmacy that deals only with antiretroviral drugs and treatment related to HIV care such as Bactrim and vitamin B-Complex supplements. The pharmacy is run by two senior pharmacists, two pharmacy assistants and two pharmacy interns. All other medications prescribed by the doctors must be collected at the hospital's main pharmacy. There are also supplemental services related to the clinic that are situated in other parts of the hospital. These services include dietetics and social services.

Since the establishment of the ART roll-out program at the clinic an estimated 7700 adult[16] patients have been enrolled into care. This figure does not include the paediatric or maternity sections. Approximately 5100 of the 7700 are female, and 2600 are male. An estimated 3000 of the 7700 total patients enrolled since 2004 have been lost to follow-up or classified as

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[15] Roll-out Program: This refers to the Comprehensive Health Care Program for HIV care implemented by the government and overseen by the National Department of Health. The rollout program offers HIV services that range from pre-diagnosis, wide supply of ART, and palliative care if required.

[16] These figures were supplied by the data capturers of the clinic.

'defaulting' patients. These patients have not returned to the clinic over the past year. It is not clear how many of these have died as only 170 have been recorded as having demised. Approximately 1400 patients have been transferred out to locally situated clinics that are geographically closer to the patients' homes. This transfer to primary health care facilities is in line with departmental policy that prescribes that patients should attend health care services within their local districts and be referred to higher order facilities if more specialized care is required. Currently there are approximately 3100 active adult patients in the clinic.

An earlier study on adherence in the clinic was conducted by Magula (2006), who found that sixty per cent of the first 100 patients enrolled in the rollout program had treatment adherence levels above 95 per cent for the first three months, but only 41 per cent had the same levels after 12 months on treatment. Of the first one hundred patients who were eligible to start ART, 30 per cent did not and over half of these were lost to follow-up (Magula, 2006). This lost to follow-up presents a particular concern for the ART program in the clinic as it is a significant statistic.

The current research project aims to understand the barriers to accessing ART in this particular clinic from a more holistic perspective in order to provide a clearer image of the problems patients encounter when attempting to access ART. Understanding the barriers can also shed light on possible reasons for lost to follow-up patients.

1.9)   Moral and Ethical considerations

Ethical permission for this study was a requirement before any data could be collected. The first ethical requirement was to obtain a Good Clinical Practice (GCP) certificate. This certificate requires a researcher to do a course on human subject treatment and protection in the research setting and is mandatory for all researchers in the Health Sciences who use human subjects as their research participants. The importance of protecting the participants especially those who fall into vulnerable[17] categories is a key point of the course. In protecting vulnerable categories the course hinges on the four pillars of ethics in health care, namely: autonomy, beneficence, non-maleficence, and justice (Beauchamp and Childress, 1994). The certificate was obtained through the University of KwaZulu Natal.

Permission to conduct the study was then sought and obtained from the Social Sciences Research Ethics Committee. Permission was granted and an application was then submitted to the Medical Manager of the hospital where the research would be conducted. After provisional permission was granted, the application was forwarded to the Provincial Department of Health's Research Unit who gave the final permission to conduct research within the Public Health Care sector, using their facilities. Their written permission was then once again forwarded to the medical manager of the hospital who granted full permission for the research to be conducted.

The various bodies mentioned above are the official gatekeepers for the research site but final permission to begin the research project had to be obtained from the Nursing Unit Manager who is in charge of the ART Public health clinic at the hospital. Without her permission and assistance this project would not have been possible.

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[17] Vulnerable groups: HIV/AIDS infected individuals are considered vulnerable due to high levels of stigma and discrimination attached to their disease status.

A consent and information sheet was created and given to all participants prior to any data collection. Informed consent is one of the main aspects of research ethics and all the participants of this project participated freely and were informed that they could withdraw at any point. Confidentiality was maintained by using coded pseudonyms for participants.

1.10) Outline of the thesis

Chapter One: Introduction

This introduction has set the theme for the remainder of the thesis. This has been done by providing the background, clarifying the research problem and introducing the aim and the objectives of the study. The ethical considerations have been discussed. It also describes the research setting and provides a chapter outline for the rest of the thesis.

Chapter Two: The Meaning of Access to Healthcare and Antiretroviral Drugs

In Chapter Two, the concept of access to healthcare is defined and its various components described.

Chapter Three: Literature Review and Theoretical Framework

Chapter Three provides a review of the existing literature conducted in the area of barriers to accessing HIV related treatment and care so as to highlight research already done and to identify gaps in the literature. The theory of structural violence is also introduced and discussed in this chapter and forms an important framework upon which ethnographic findings presented in Chapters Five and Six are hinged.

Chapter Four: Methodology

This chapter details the methods used to collect the data, and describes the data collection process.

Chapter Five: The Barriers to Continuous Access to ART Care in the Clinic

Chapter Five discusses the results from the quantitative and qualitative data analysis regarding the main barriers to ART that patients experience in the clinic. Accordingly, it addresses the physical, organizational, social and economic barriers experienced in relation to accessing ART.

Chapter Six: The Effects of the Barriers to Accessing ART Care

Chapter Six discusses how the barriers identified are experienced by the patients and the reactions these barriers cause in the patients. The chapter also addresses how these barriers impact on the patients' ability to continuously access their treatment and how the barriers influence the main categories of access, namely: availability, accessibility, affordability, acceptability, and accommodation.

Chapter Seven: Conclusion and Recommendations

The final chapter includes the conclusions drawn based on the research and makes recommendations for further studies.

CHAPTER TWO: The Meaning of Access to Healthcare and Antiretroviral drugs

2.1) Access to Health Care: A Difficult Concept to Define

"The proof of access is use of services, not simply the presence of a facility. Access can, accordingly, be measured by the level of use in relation to 'need'. One should recognize, however, that clients and professionals evaluate 'need' differently. Further, one must distinguish two components in use of service: 'initiation' and 'continuation'. This is because different factors influence each, though any one factor may influence both. It is hardly necessary to emphasize that barriers to access are not only financial but also psychological, informational, social, organisational, spatial, temporal, and so on." (Donabedian in Aday and Andersen, 1974: 219)

The concept of access to health care has largely been difficult to define and understand (Aday and Andersen, 1974, Penchansky and Thomas, 1981). This is evident in the words of Gulliford et al., (2002) who state "that access is a complex concept" (Gulliford et al., 2002: 186), and Penchansky and Thomas (1981) who note that "access is thus difficult to define and measure operationally…" (Penchansky and Thomas, 1981: 127). Likewise Clark and Coffee (2011) remark that: "Access is an important concept in health policy and health services research, yet it is often not defined or employed precisely" (Clark and Coffee, 2011).

The problem surrounding the use of the concept of access has a long history and to date no all-embracing definition has been accepted and the concept has been broadly used. As early as 1974 in their seminal work on access to health care services, Aday and Andersen (1974) created a framework for the study of access to health care. In this framework they suggested that to understand access to health care it is best to "consider access in terms of whether those who need care get into the system or not" (Aday and Andersen, 1974: 218). This view highlighted two very important aspects involved in access to health care, namely: whether people have access, or whether they have gained access. They further clarify these concepts in terms of potential and actual entry and utilization of health care services, when they note

that access consists of "those dimensions which describe the potential and actual entry of a given population group to the health care delivery system"(Aday and Andersen, 1981: 6).

Potential realization of access is characterized by the health care system and the population at risk and also includes the idea that the availability of services is a central component to the concept of access. This aspect of potential access according to Bashshur et al (1994) includes the notion that "persons with a regular source of care are less likely to encounter difficulties as compared to those without such as source" (Bashshur et al., 1994: 410). Andersen (1995) defines *potential access* as "the presence of enabling resources" and *realized access* as the "actual use of services" (Andersen, 1995: 4).

Although there exists some confusion surrounding the different meanings of whether a person has access, or whether she/he has gained access (Gulliford et al., 2002), Aday and Anderson's (1974) framework does present a useful way to understand how all the varying components of the concept of access fit together. They argue that access to health care starts with health care policy which then influences the health care system and the population at risk. The characteristics of the health care system and the characteristics of the population at risk then in turn influence utilization and satisfaction with health care services and access (Aday and Andersen, 1974). The two themes highlighted in the literature as having an influence on all the other aspects of access are the characteristics of the population who utilize the health care services, and the characteristics of the health care system itself (Penchansky and Thomas, 1981, Gulliford et al., 2002, Aday and Andersen, 1974). These two concepts are discussed in more detail further in the chapter.

From analysing the Aday and Andersen's (1974) framework for the study of access to healthcare it becomes clear that the various components[18] of access influence each other and have the potential to overlap. This is important to consider since the various components of access are often used interchangeably. This synonymous use of the various components can then result in the holistic meaning of the concept of access being lost and/or limited to the use of one component only. Aday and Andersen's (1974) Framework for the study of access to health care is presented in Figure 2.1 below.
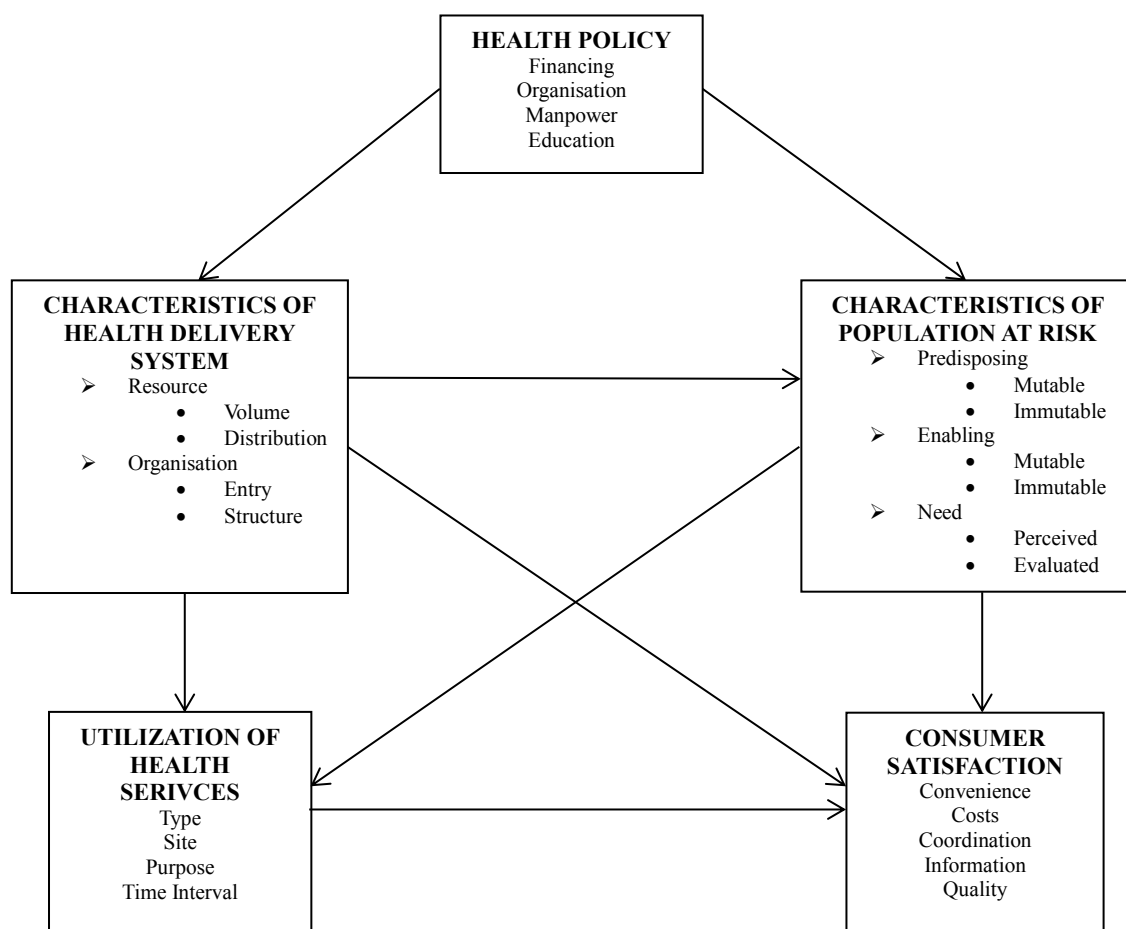
Figure 2.1 Aday and Andersen's Framework for the Study of Access to Health Care (1974)

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[18] Components of access include: availability, accessibility, affordability, acceptability and accommodation. (Penchansky and Thomas, 1981)

2.2)   Access starts with Health Care Policy

The concept of access to care is embedded within the realm of health care policy (Penchansky and Thomas, 1981). In Aday and Andersen's (1974) framework for studying access to health care they note that policy variables are changeable and amendable and as health policy has the ability to affect all other aspects of access including the health care system and the population at risk it should therefore be the starting point when access is considered (Aday and Andersen, 1974).

Interventions and policies can therefore, Aday and Andersen (1981) maintain, either enable or prevent people from accessing health care services. One of the main goals for many health care policies, including South Africa's health care policy, is to improve equal access to health care for all (NDOH, 2011a). In the South African scenario the link between policy and access has been particularly obvious as for many years all that stood between people in need of ART and actually receiving it was policy (Fassin, 2007, Barnett and Whiteside, 2006). Policy directly prevented the distribution of ART to those who needed it, but once policy changed, access to ART was theoretically available. In this way policy influenced the health care system and the population.

Likewise, policies regarding drug patents have played a major role in the scale up of access to ART. (see for example WHO et al., 2010)[19]. After ART showed its efficacy as a viable treatment option for HIV and AIDS infection, it became clear that only those who could afford the high cost of the lifesaving drugs would benefit from it (Barnett and Whiteside, 2006).

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[19] World Health Organisation: WHO, UNAIDS & UNDP: *Using TRIPS Flexibilities to Improve Access to HIV treatment.*

The World Trade Organisation Agreement on Trade-Related Aspects of Intellectual Property Rights (TRIPS) was the first major global policy change to improve access to ART (WHO et al., 2010). The flexibilities allowed in the agreement resulted in the South African government importing cheaper generic drugs that posed competition to the larger pharmaceutical companies. This competition resulted in a marked decrease in the price of ART drugs in South Africa (WHO et al., 2010).

In the South African HIV/AIDS setting the effect of inefficient policies was severely felt. According to the SAHRC report of 2009, the ministry of health was well informed of the devastating effects that awaited the South African public health care service, and the population in general, but chose to deny the extent of the problem (SAHRC, 2009). Instead of focusing on strategies to combat the coming epidemic, debates were held over the effectiveness of ART and the cause of AIDS (Epstein, 2007). This ensuing debate only concluded in 2010, and for the critics of the government and those inflicted with the disease this was a blatant act by the government to deny the general population of South Africa access to health care and to life-saving drugs (Ige and Quinlan, 2012).

Policy can also be used to target the population at risk by either stimulating change in the mutable factors of the population directly or through the health care system (Aday and Andersen, 1974) in the form of prevention campaigns that encourage behaviour change in the population at risk. Policy however is not always effective in changing behaviour as is demonstrated in the failure of HIV/AIDS prevention campaigns especially in the sub-Saharan setting. A major contributor to this is the fact that the epidemic is so generalizable and not only confined to 'risk groups', as mentioned in Chapter One. This fact, has however eluded policy makers who continue to focus on improving 'risky behaviour' (Epstein, 2007).

2.3) Characteristics of The Health Care System

The health care delivery system is characterized into two main components, according to Aday and Andersen's (1974) framework. These two components are resources and organisation (Aday and Andersen, 1974). Resources include the capital and human resource component; and organisation involves the function and utilization of the resources aspect and how well the resources are organised to work towards providing access to patients. Organisation also refers to aspects such as gaining entry into the system, travel time, and waiting times. The second component of organisation is structure and refers to the path taken by the patient once he/she has entered the health care system and from which components of the system he/she receives services (Aday and Andersen, 1974).

The health care system affects utilization and consumer satisfaction directly. It is the structure of the health care system itself that causes the effect on access rather than the characteristics of the population, but, the health care system can also effect the population at risk by implementing health programs such as anti-smoking campaigns, to decrease the risk of disease (Aday and Andersen, 1974).

According to Aday and Andersen (1974), "the time interval for a visit can be expressed in terms of contact, volume, or continuity measures" (Aday and Andersen, 1974:214). Contact is concerned with the time it takes for an individual to gain entrance into the health care facility and also pertains to those individuals who do not gain entry at all. Volume refers to the number of contacts and revisits with the health care system in a given time and "reflects who gets into the system and how often he uses it" (Aday and Andersen, 1974:214). Continuity refers to the coordination and link between health services and the patient. If this link is fragmented and poorly organised, a decreased level of access is achieved. Continuity

furthers permits the operationalization of the integration of services (Aday and Andersen, 1974).

The ART program is situated within the biomedical Western health sector. This view focuses on the individual with a particular concern for the biological aspects of diseases. The biomedical view argues that diseases are caused by pathogens that are impersonal and have a negative effect on the normal functionality of the human body (Pool and Geissler, 2005). Pool and Geissler (2005) explain the position of the biomedical system well when they say that "biomedicine is seen as mystifying social, economic and political problems by making them appear individual, biological, natural. It hides (or ignores) the social causes of sickness…" (Pool and Geissler, 2005: 84).

Foucault (1975) also reminds us about the spatiality of diseases and argues that diseases do not only exist within the biological body, but also in other spaces located outside the body such as the society in which people live (Foucault, 1963).This is an important point since people frequently interpret diseases as illness and understand their afflictions through cultural interpretations. People are however not only biological but cultural beings and as a result are also informed about illness behaviour from the society in which they live (Pool and Geissler, 2005). If the health care sector wants to communicate effectively with the population at risk and influence behaviour change then a more holistic view of illness is required.

For the purposes of this study it is important to consider the biomedical view point of the health care system as this has implications for addressing adherence to ART. Adherence as a concept is constructed in biomedical terms and is focused on the individual person and the individual's own ability to follow instructions given about treatment. However how adherence fits into the broader concept of access to health care is seldom considered by a

purely biomedical approach. In order to fully comprehend access and the barriers to access faced by ART patients, a more holistic bio-psycho-social perspective is required.

2.4) The Population at Risk: Characteristics of those in need of care and its influence on access

Characteristics of the population at risk also determine the level of access to healthcare. Components of the population at risk include predisposing, enabling, and need factors. These characteristics include mutable and immutable factors (Aday and Andersen, 1974).

The predisposing component includes properties of the patient that exist prior to illness manifestation. This includes demographic factors such as gender, age, religion and ethnicity; social structure factors; and health beliefs (Aday and Andersen, 1974). Posse et al., (2008) further note that predisposing factors could also include marital status, and attitudes towards treatment, health care workers and disease. Health beliefs include "attitudes, values, and knowledge that people have about health and health services" (Andersen, 1995: 2).

Social structures such as social networks and social interactions are now also considered as important predisposing factors for access to care (Andersen, 1995). Within the ART setting, social networks have been shown to be of particular importance in access to ART. Henderson's (2011) account of the troubling time between the unavailability and subsequent availability of ART in South African health care facilities highlights the importance that social networks and interactions have on a patient's ability to access ART (Henderson, 2011).

Social structures, culture, health beliefs and demographic factors such as ethnicity, gender, and age are considered immutable predisposing variables in accessing ART since they cannot be influenced or changed by health care policy (Andersen, 1995, Posse et al., 2008). Illness behaviours and economic factors such as out-of-pocket health care costs are considered to be

mutable since these can be influenced and changed to a certain degree by health policy interventions (Andersen, 1995, Posse et al., 2008).

The enabling characteristics refer to "the means that individuals or their community may have available to facilitate (or in their absence, hinder) the use of services" (Posse et al., 2008: 906). This includes resources enabling the patient to reach facilities. The individual, the family, and the community in which the patient lives are taken into account as enabling factors (Aday and Andersen, 1974). At the individual level these characteristics may include finances, health information and family responsibilities, while at the community level social support and community resources are included (Posse et al., 2008).

The need characteristic of the population at risk refers to the immediate need of the patient to access health care services according to her\his evaluated illness level (Aday and Andersen, 1974, Posse et al., 2008). The need component is perceived by the patient and evaluated by the health care system and may be assessed differently by the patient and the health care provider (Aday and Andersen, 1974, Donabedian, 1972).

Perceived need of care by the patient is the beginning of the process to accessing health care services on an individual level. The health beliefs and attitudes will determine at what point each individual considers the need appropriate to seek health services (Gulliford et al., 2002). It is at this stage that the patient will first adopt what is known as the sick role. The sick role as first described by Parson (1951) suggests that when a person becomes ill she\he adopts the sick role that exempts the individual from normal social responsibility but also signifies that she\he willingly subjects herself\himself to medical care and advice until a normal level of health is regained (van Staden and du Toit, 2003). It is this position that patients assume when first engaging with the health care system where they acknowledge that they have a

need for health care service. This need is influenced by personal, biological, cultural and environmental factors (van Staden and du Toit, 2003, Andersen, 1995, Gulliford et al., 2002).

Gulliford et al., (2002) also note that the patient's perceived need for service can be different from that calculated by the health care system. This becomes evident in instances where the health care system implements interventions to change health related behaviours though policy, but the patients' do not respond accordingly. This can clearly be seen in the prevention of HIV/AIDS. Prevention strategies such as safer sexual practices, including condom use and monogamous relationships have not materialized as the health care policies predicted. This, according to Gulliford et al., (2002) could well be because people and users of the health care system simply do not see the need for behaviour change as laid out by the health care system (Gulliford et al., 2002).

2.5) The Five Pillars of Access: Availability, Accessibility, Affordability, Acceptability, and Accommodation

While Aday and Andersen's (1974) framework is useful to understand how the various aspects comprising the concept of access to health care fit together, Gulliford et al., (2002) note that the model is largely based on the availability of services. As a result Gulliford et al., (2002) continue, it does not effectively cover the fact that availability does not always result in utilization of services because in some instances services are available but difficult to reach or under-utilized due to a variety of reasons, and thus the potential ability of access to health care services is compromised (Gulliford et al., 2002).

Penchansky and Thomas (1981) are widely acknowledged for developing a more comprehensive definition of the concept of access (Clark and Coffee, 2011, McLaughlin and Wyszewianski, 2002). Penchansky and Thomas (1981) recognised that availability of

services does not always result in utilization and developed a definition that incorporates this fact (Gulliford et al., 2002, Penchansky and Thomas, 1981).

In many instances access is synonymously used with availability and accessibility of health care (Aday and Andersen, 1974, Penchansky and Thomas, 1981, Gulliford et al., 2002). Penchansky and Thomas (1981) however argue that this is confusing and misleading since availability and accessibility of services forms part of the larger concept of what access truly entails. Penchansky and Thomas (1981) therefore proposed that access should be understood as: "a concept representing the degree of 'fit' between the clients and the system" (Penchansky and Thomas, 1981: 128). According to Penchansky and Thomas (1981) "access is a measure of the 'fit' between characteristics of providers and health services and characteristics and expectations of clients, and that this concept includes five reasonably distinct dimensions: availability, accessibility, accommodation, affordability, and acceptability" (Penchansky and Thomas, 1981: 139).

Harris et al., (2011) used Penchansky and Thomas' definition of access in their own explanation of the concept when they said that "access is therefore the opportunity and freedom to use services, and encompasses the circumstances that allow for appropriate service utilization, plus sufficiently informed individual or households (demand-side), empowered to exercise choice within the health system (supply-side). The 'degree of fit' between demand-and supply-sides, rather than each in isolation, determines the degree of access achieved" (Harris et al., 2011). Posse et al., (2008) drawing on the original definition proposed by Penchansky and Thomas (1981) further define access as "entry to the health system and continuation of the treatment process, and is determined by characteristics of the system and of the population at risk" (Posse et al., 2008: 905).

The five access dimensions formulated by Penchansky and Thomas (1981) are interrelated and influence each other. Furthermore, some dimensions are more relevant for certain settings than others. In some settings availability can be an issue, where in other locations services may be available but not accommodative to the patients' specific needs. Due to the interrelatedness of the five dimensions they are often synonymously used under the umbrella term of access (Penchansky and Thomas, 1981), yet this is somewhat misleading as they do not mean one and the same thing but in actuality each component comprises a single piece in the access puzzle.

2.5.1) Availability

Penchansky and Thomas (1981) define availability as: "the relationship of the volume and type of existing services (and resources) to the clients' volume and types of needs. It refers to the adequacy of the supply of physicians, dentists, and other providers; of facilities such as clinics and hospitals; and of specialized programs and services such as mental health and emergency care" (Penchansky and Thomas, 1981: 128).

The UNAIDS Handbook of Access to HIV treatment and care describes treatment availability as services that can be found anywhere in a given community. Harris et al., (2011) further note that availability can include distances travelled to health services and the mode of transport required and used to reach services. Anyinam (1987) similarly describes availability of health services as either the total supply of services or personal and the geographical distribution of the services (Anyinam, 1987). Availability of resources and personnel are usually calculated as ratios. In South Africa health care resources and personnel are markedly skewed in this aspect.

South Africa's political past has left the health care system in a fragmented state (Harris et al., 2011). During the Apartheid Regimen health care was segregated according to race. Today however the health care system is divided along economic lines between a world class private health care sector and a struggling public health care sector (SAHRC, 2009). This divide has resulted in great inequality in the availability of healthcare and has resulted in a healthcare situation that Barnett and Whiteside (2006) describe as being based upon: "those who can purchase well-being and those who cannot"(Barnett and Whiteside, 2006: 6).

In South Africa there are more health care professionals working in the private sector than in the public sector, even though more than seventy per cent of South Africa's population utilizes the public health care sector. Three out of ten doctors, four out of ten professional nurses, one out of ten pharmacists, and one out of twenty psychologists work in the public health care sector (NDOH, 2011b). In KwaZulu Natal the public health care personnel to patient ratios stand at 28: 100 000 for doctors and 111: 100 000 for registered nurses, as compared to the private sector where one specialist doctor attends to fewer than 500 patients per year (KZNHEALTH, 2010, Harris et al., 2011).

This great inequality of available health care personnel in the public health care sector has major implications for the expanding ART programme since the number of patients are increasing but the number of staff necessary to deliver the services are not meeting the requirements (KZNHEALTH, 2010, NDOH, 2011a)[20].

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[20] NDOH 2011a. Government Gazette No. 35423 National Health Act, 2003 Policy on National Health Insurance.

2.5.2) Accessibility

According to Penchansky and Thomas (1981) accessibility can be defined as: "the relationship between the location of supply and the location of clients, taking account of client transportation resources and travel time, distance and cost" (Penchansky and Thomas, 1981:128). Accessibility here refers to the physical accessibility in terms of location and building structure. Clark and Coffee (2011) in a similar stance define accessibility as: " the ease of approach from one location to another measured in terms of distance travelled, the cost of travel or the time taken" (Clark and Coffee, 2011: 3).

Anyinam says of accessibility that: "the capacity of any social service is limited by the number of people who can reach and use it" (Anyinam, 1987: 805). According to Anyinam (1987) there are three aspects to accessibility, namely: Coverage accessibility that refers to the capacity of a service to treat patients, locational accessibility that refers to space occupied by the facility and takes into account the physical distance travelled, and revealed accessibility which reflects the actual utilization of that service (Anyinam, 1987).

The patterns of referral for KwaZulu Natal are also a significant contributor to the accessibility of health care services. KwaZulu Natal is bordered by the Eastern Cape Province and as a result there is a migration of people from the Eastern Cape Province who utilize health services in KwaZulu Natal. The larger tertiary hospitals are particularly affected by this as they offer specialised services that few centres can provide (KZN Strategic Plan 2010-2014 KZNHEALTH, 2010). The rural areas of the province provide fewer services than the urban centres and this results in the rural areas having less coverage of ART treatment than the better resourced and serviced urban centres, but, at the same time, adds to the burden of work load in the urban centres (Fried et al., 2012).

The natural features of the province are also a factor to consider when discussing accessibility. The province is home to mountain ranges, numerous rivers and distant homesteads that present difficulties in terms of physically reaching health care facilities. The terrain especially presents difficulties for those health care services that are located in the deep rural areas that provide services to their local communities (KZN Strategic Plan 2010-2014, KZNHEALTH, 2010). Despite differences in accessibility between rural and urban areas Fried et al., (2011) found that while patients' experiences of the health care system and provision of ART was varied between rural and urban centres the effect on their ability to access their ART was comparable between the two (Fried et al., 2012).

2.5.3) Accommodation

Penchansky and Thomas (1981) define accommodation as "the relationship between the manner in which the supply resources are organised to accept clients (including appointment systems, hours of operation, walk-in facilities, telephone services) and the clients' ability to accommodate to these factors and the clients' perception of their appropriateness" (Penchansky and Thomas, 1981: 128). These authors noted that long waiting times, long travelling times, and inability to get an appropriately timed appointment all affect satisfaction negatively. Further, patients with high health concerns tend to be less satisfied with the accommodative ability of access to health care as they tend to be more sensitive about their health care needs (Penchansky and Thomas, 1981).

Accommodation thus refers to the extent that the health care service will go to negotiate the services offered to suit the individual needs of the patients. The issue of health care protocols comes into effect with the aspect of accommodation. In the public health care sector following protocols is a standard practice. Patients are classified into groups according to the various protocols and are treated according to the instructions of the protocols. Human (2011)

related how restrictive following protocols are in diagnosing and providing treatment to patients. Protocols do not allow for individual assessment or flexibility in regards to providing services to patients (Human, 2011). This inflexibility of the health care system to engage on a more personal level with patients has a negative impact on the accommodative factor of access to health care.

2.5.4) Affordability

Affordability as defined by Penchansky and Thomas (1981) is: "the relationship of prices of services and providers' insurance or deposit requirements to the clients' income, ability to pay, and existing health insurance. Client perception of worth relative to total cost is a concern here, as is clients' knowledge of prices, total cost and possible credit arrangements" (Penchansky and Thomas, 1981: 129). Affordability is identified by factors such as personal income levels, subscription to medical aid schemes, and the expenses involved in transport costs to reach health care facilities (Penchansky and Thomas, 1981). Gulliford et al., (2002) likewise note that the "availability of services may be measured in terms of the costs to individuals of obtaining care" (Gulliford et al., 2002) and may include factors such as transport costs, travelling time, and time taken off work to seek medical care.

As noted in South Africa, healthcare is divided into the private sector and the public health care sector. Antiretroviral drugs are provided free of charge in South Africa for people who utilize the public health care system. However, the concept that it is free medicine is misleading. Out-of-pocket expenses (OOP) present a major challenge for people who are economically constrained and seek ART in resource limited settings (Mukherjee et al., 2006).

Harris et al., (2011) found in their study on inequality in access to health care in South Africa that half of their respondents reported that because they do not have to pay for primary health care services the public health care sector is their only choice when selecting where to seek treatment. However, 21.1% of their respondents said that they had to delay seeking medical treatment because of expensive transport costs while the inability to get time off from work for those who were employed presented a further challenge in the affordability component of accessing health care. (Harris et al., 2011). Thus, despite the fact that Primary Healthcare and ART is free in public clinics and hospitals in South Africa, affordability is an important criterion that needs to be considered on a number of levels when dealing with access as the parameters of affordability extend beyond the boundaries of free healthcare.

2.5.5) Acceptability

The aspect of acceptability is defined by Penchansky and Thomas (1981) as: "the relationship of clients' attitudes about personal and practice characteristics of providers to the actual characteristics of existing providers, as well as to provider attitudes about acceptable personal characteristics of clients. In the literature, the term appears to be used most often to refer to specific reaction to such provider attributes as age, sex, ethnicity, type of facility, neighbourhood of facility, or religious affiliation of facility or provider. In turn, providers have attitudes about preferred attributes of clients or their financing mechanisms. Providers either may be unwilling to service certain types of clients (e.g. welfare patients) or, through accommodation, make themselves more or less available." (Penchansky and Thomas, 1981: 129).

Acceptability of care plays an important part in access to health care. It is perhaps the most abstract dimension of the concept of access as it is influenced by the patient and the health care provider's ethnicity, culture, religion, economic class, and sex. Other factors are more about the facility itself such as the type of service, its location, diagnosis, and extent of service coverage (McLaughlin and Wyszewianski, 2002). These factors are largely immutable and inform both parties' healthcare provider and patient, about the extent of services offered; female patients might be more comfortable to be examined by female health care providers for instance. Acceptability can however also be projected from the health care provider's perspective. In the HIV setting this has often manifested in stigma and discrimination towards HIV infected patients in instances where health care providers either refuse to treat HIV positive patients or offer limited services, such as withholding surgery or denying admission to Intensive Care Units (Timsit, 2005, Sadoh et al., 2009).

2.6) The Proof of Access is in Utilization of services and User Satisfaction

Utilization of services is often considered as the measure of access to health care. The aspects of utilization include the *type, site, purpose*, and *time interval* (Aday and Andersen, 1974). *Type* refers to the kind of service, *site* refers to the location where the patient is treated, *purpose* refers to the reasons behind the care given, and *time interval* refers to the contact time with health care services (Aday and Andersen, 1974).

Aday and Andersen (1974) highlight three components related to the purpose of service, namely: preventive care, custodial (palliative) care and illness-related care. Preventive care includes efforts to stop disease process and custodial care refers to end-of-life type care as seen in hospices. Illness-related care concerns curative and chronic care. When access to health care is considered, the purpose of care is an important factor to take note of.

HIV/AIDS occupies a peculiar place in the purpose of care as it involves all three aspects of purpose: preventive, curative, and palliative (UNAIDS and WHO, 2003). Initially, HIV infection was treated with a curative stance, but ART is changing this to a chronic, long term purpose of care. The importance of this is that the three aspects of purpose of care require different demands from the health care system and have different patterns of care linked to each aspect. Therefore if HIV/AIDS was initially treated with a curative purpose it would have certain patterns of care. One of these patterns of care is the global drive to get all those who need ART onto treatment. This places a sharp focus on initial entry into the system with a special focus on treating as many people as possible. The changing nature of the epidemic to a chronic, long-term, irreversible condition will now result in different patterns of care and different demands being placed on the health care system. These patterns of care are linked to continuous access to health care, with a long term view. More and more patients will enter the system, but unlike most other diseases, HIV patients will remain within the system adding an increasing demand on services and resources, and as Stott et al., (2013) note: "There is evidence that continued ART scale up may exacerbate the health system crisis in South Africa" (Stott et al., 2013).

HIV infection, at the same time, also requires preventative care, as prevention of infection still remains the only hope of 'cure'. Preventative services require different service from the health care sector that can often be seen as falling outside the medical domain. In the case with HIV, preventative services seem to have fallen to the volunteers and community workers; actors placed outside health care services. However, prevention, that includes testing for HIV, has been shown to be instrumental to bring patients into contact with health care facilities. Yet under Aday and Andersen's (1974) model, preventative services form part of the concept of health care service utilization, but the biomedical health care system cannot,

at this stage, provide a prevention service to those seeking protection from HIV infection since there is no vaccine available.

The time aspect related to utilization of services is another important aspect in accessing ART and includes contact time, volume, or continuity of utilization (Aday and Andersen, 1974). Contact time refers to the amount of time it requires for people to enter and use the services while volume refers to the number of appointments, and reflects if people get into the care system and how often it is used (Aday and Andersen, 1974). Continuity of service is particularly important in the ART setting since much depends on continuous service delivered to patients. Continuity refers "to the degree of linkage and coordination of medical services associated with a particular illness experience or episode – important because if the process of receiving care is fragmented and poorly organised, people may be considered to lack appropriate access to the system" (Aday and Andersen, 1974: 215)

Gulliford et al., (2002) however notes that just using utilization of health care services as a measure for access can be misleading, and states that: "poor-quality services may be associated with high levels of utilization" (Gulliford et al., 2002:187). They suggest that other health outcomes such as consumer satisfaction should also be considered when access is measured.

2.7)   Access is an Issue of Equality

As noted equitable access to HIV treatment remains an unmet challenge globally (UNAIDS 2012). Several studies have shown that the availability of the drugs does not automatically translate into accessibility or utilization of the treatment (UNAIDS 2009). According to UNAIDS (2012), the global target is to have 15 million people on ART by 2015. Currently it is estimated that 8 million people are receiving anti-retroviral therapy globally but a further 7 million are in need of treatment (UNAIDS 2012).

According to Mottair (2012), "HIV/AIDS related service delivery in South Africa is inextricably linked to socio-economic rights…" (Mottiar in Ige and Quinlan, 2012: 84). Further to this, the UN notes that "in many parts of the world the spread of HIV/AIDS is a cause and consequence of poverty" (UNAIDS in Mottiar, 2012: 89).

Inequality in access to health care is increasingly drawing attention to the unethical aspect about peoples' inability to receive health care when they need it. Common principles of equity to health care access include: "equal access to health care for those in equal need of health care; equal utilization of health care for those in equal need of health care; and equal (or equitable) health outcomes" (Oliver and Mossialos, 2004: 655).

Aday and Andersen (1981) define equity of access to care as "when services are distributed on the basis of people's need for them… and the inequality exists when services are distributed on the basis of demographic variables, such as race, family income, or place of residence, rather than need" (Aday and Andersen, 1981: 6).

Jones (2010) highlights in his study investigating access to ART that the rights-based approach alone does not always result in the best understanding or operationalization of access to care, even though access is placed within the rights-based movement. For access to

be realized as a human right, he argues, a more multi layered and complex understanding of the concept is necessary. Once all the aspects of access have been considered a more holistic understanding of the concept of access is achieved without which, access as a human right is prone to failing at the implementation stage. Jones (2010) further notes with regard to understanding access to HIV/AIDS related services that: "elaborating on the meaning of 'access' to treatment, and by implication a rights-based approach, produces a more rounded picture of the dilemmas, anxieties, community, and institutional and contextual pressures – the grey areas – that the people-living-with-AIDS encounter" (Jones, 2010: 34).

Barnett and Whiteside (2006) further add to the discussion on the importance of equity in healthcare and this is evident in their words: "With the development of antiretroviral therapies (ARTs), the epidemic defines who is saved – and who is left to die from the disease and its impacts. In its distribution across the continents and in relation to access to drugs that can save lives, it is a global epidemic that defines the excluded of the world – the wretched of the earth. Above all, HIV/AIDS defines those who can purchase well-being and those who cannot" (Barnett and Whiteside, 2006:6).

Equity of access to health care services is thus perhaps the ultimate level of measure of who gets treated and who does not. But equity, like access, remains a complex concept to both define and measure. According to Gulliford et al., (2002) "equity introduces the notion of fairness or social justice" (Gulliford et al., 2002: 189). A common measure is that there should be equal access to equal need, and it uses the utilization and needs ratios. However Gulliford et al., (2002) note that "analyses have shown surprisingly little evidence of horizontal inequity in utilization of care, even in countries where access to care is considered to be severely rationed to income" (Gulliford et al., 2002:189). Gulliford et al., (2002) further argue that inequality is more readily shown when availability and health outcomes are added

to the equation and argue that conclusions based on utilization alone should be interpreted with caution (Gulliford et al., 2002).

Universal access is not necessarily something that can be achieved in all local contexts as within the local context barriers to accessing health care services may be present that constrain patients' ability to fully engage and utilize their treatment (Jones, 2010, Penchansky and Thomas, 1981). In this chapter the comprehensive concept of access to healthcare has been explored. As is evident from this chapter and the literature, access to healthcare is a broad concept that consists of five dimensions that are interrelated but also independent. Often in the medical literature the comprehensive term of access is synonymously used with one of its constituent dimensions that results in a constricted understanding of the broader concept. It is therefore important that when access to healthcare is discussed that it is understood from all its dimensions, and not just one of them independently. In the next chapter the barriers to accessing healthcare will be defined and the four categories of barriers (physical, organisational, social and economic) will be examined.

CHAPTER THREE: Literature Review and Theoretical Framework

Having outlined the problems associated with the concept of access in the previous chapter, this chapter now focuses directly on the relevant literature pertaining to the barrier to accessing antiretroviral therapy in the context of the HIV/AIDS pandemic.

3.1)   The Importance of Continued Access in the ART setting.

"'The clinic is your last option.' He nods. 'A cure is better.'
'Is that the problem with the clinics? They don't offer a cure?'
'I have three problems with the antiretrovirals,' he replies crisply.
'First, people do not know about them. We don't know them here. Second, it seems you must get sick before they give you the antiretrovirals. You must wait until you are sick. I do not like that. Why must you get sick first?'… 'The third reason is the biggest reason. I feel terrible for the people living with this disease inside them. It is there for their whole lives…I wonder… whether anyone can cope with that. A cure is much better.'" *(Excerpt from Three Letter Plague, 'Sizwe Magadla' in Steinberg, 2008: 74).*

It would appear that the initial struggle to get people onto ART has been won, but now awaits perhaps the biggest challenge yet to keep all those patients who started on ART enrolled in the ART program and to ensure that access to health care is not compromised in any way. Fox and Rosen's (2010) systematic review of retention in ART programs in sub-Saharan Africa is extremely significant in this respect as their review revealed that at 2 years there is an average retention rate of only 60% in ART programs in the region (Fox and Rosen, 2010).

Continued access to HIV care and treatment is however essential for the HIV program to succeed (UNAIDS, 2012). Ideally, these drugs should be supplied in a simple and efficient way to ensure the transition of HIV from a deadly infectious disease to a chronic manageable one (Rossouw et al., 2013). This stated, the increased workload in the public health sector in many resource poor countries along with poor policies, unsupported health care workers, poor organization, unreliable supply of drugs, and limited specialized services has resulted in

barriers that make it difficult for patients to access their ART (Posse et al., 2008, Gari et al., 2013).

The literature reveals that little attention is being paid to the large group of virologically stable people who attend ART clinics on a monthly basis (Wilkinson, 2013). Currently the rate of retention for people on ART in the public health sector in South Africa is less than 70%. Fried et al. (2012) report that "nearly one in six in a recent study- at some point interrupt treatment, becoming so-called 'defaulters' or lost-to-follow-up" (Fried et al., 2012: 147), and according to Brinkhof et al., (2009) nearly 40 % of people started on ART in sub-Sahara Africa drop out of their ART programs in the first two years, and are lost to follow-up. Ware et als., (2013) observation that an estimated one in six patients enrolled onto an ART program were not taking treatment after a two year period (Ware et al., 2013), presents a similar picture.

These findings , and the fact that not much attention is being given to this group of people, is worrying in the face of rising ART drug resistance that is now becoming a reality in many clinics across South Africa (Rossouw et al., 2013). The main focus of the ART program at this time is to initiate people onto treatment regimens without much consideration for the long-term retention in the ART program. This focus is embedded in the vague usage of what *access* to health care really means[21] and as a result using *availability of ART drugs* is frequently used interchangeably with *access to treatment.*

One of the major concerns for this need for continuous access to ART is the fact that sub-Saharan Africa still imports more than eighty per cent of ART drugs that are needed (UNAIDS, 2012). This has major implications for the longevity of the program since global funding is already receding (Barnett and Whiteside, 2006, Fox and Rosen, 2010). In addition,

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[21] The issue of access: This has been extensively discussed in Chapter Two

Mukherjee et al.,(2006) found that in resource poor settings like South Africa "the context of poverty factors such as lack of access to transport, food insecurities, and user fees for medical care, posed more significant barriers to adhering to long-term therapy than a patient's individual behaviour" (Mukherjee et al., 2006: 123).

3.2)   The issue of barriers to continually accessing ART

As Reuter (2008) cited in Steinberg (2008:87) succinctly points out "…whether a person embraces a health-care service is determined primarily by the accessibility of that service". This statement draws attention to access as being a broader concern which supersedes the more limited issue of adherence. This is similarly explored by Penchansky and Thomas (1981) who specifically state that problems with any component of access will influence patients and the health care system in three ways: "1) utilization of services…will be lower; 2) clients will be less satisfied with the system and/or services they receive; and 3) provider practice patterns may be affected." (Penchansky and Thomas, 1981: 130).

Barriers to accessing care, as highlighted in the literature, are regarded as crucial in understanding ART. Posse et al., (2008) define barriers to accessing ART as: "any factor occurring at the population level or health system level that restricts patients' initiation of and continuation into ART" (Posse et al., 2008: 905). In keeping with Aday and Andersen's (1974) framework they also recognise that both health system factors and patient factors influence barriers to accessing ART, and that barriers affecting the patient level are related to predisposing, enabling, and need factors. (Posse et al., 2008, Aday and Andersen, 1974).

Posse et al., (2008) further highlight that barriers are context specific and that health care facilities should explore the barriers that are more pertinent to their specific community in order to influence policy changes and provide more effective, quality care that will ensure the continuation of ART service accessibility (Posse et al., 2008). The generalized epidemic in

resource poor settings, or developing countries like South Africa, presents unique challenges to providing access to ART (Posse et al., 2008, Jones, 2010). Mukherjee et al., (2006) further note that: "a multitude of structural barriers prevent access to health care and the regular supply of antiretroviral drugs" (Mukherjee et al., 2006: 123). Posse et al., (2008) remark: "developing countries… the nature of their generalized HIV/AIDS epidemic and of their often fragile health system poses different problems when compared with developed countries" (Posse et al., 2008: 905).

The UNAIDS (2003) Handbook on Access to ART identified the types of healthcare systems, economic and political factors, as well as the stage of the epidemic in a specific region as factors that can affect the extent to which people living with HIV/AIDS (PLWHA) can access treatment and care (UNAIDS and WHO, 2003, Mukherjee et al., 2006). Further to this Mukherjee et al., (2006) highlight that these barriers can also include medical care costs, lack of integration of primary health services with HIV services, long distances that contribute to transport costs making it difficult to attend the clinic monthly, family responsibilities and the expense of transport (Mukherjee et al., 2006).

Posse et al., (2008) reviewed the barriers to accessing ART and found that lack of awareness of ART, patient level barriers including stigma, perceived high costs of ART and services, and lack of financial means were cited most commonly while fear of side effects and permission from a husband or partner were cited less frequently (Posse et al., 2008). Health system level barriers most commonly cited include length of travel time and distance to health facility, lack of consistency and coordination of services, and the "limited involvement of the community in the programme planning process"(Posse et al., 2008: 908). Posse et al., (2008) further note that health system barriers were less cited in the literature reviewed due to the fact that patient level barriers were more frequently investigated.

The barriers to accessing care, the literature reveals, affect the five components of the concept of access[22]. Physical barriers influence the accessibility and availability dimensions; organisational barriers affect the accommodative, acceptability, accessibility, affordability and availability dimensions; social barriers impact the acceptability, affordability and accommodative dimensions; and economic barriers can influence the affordability and accessibility dimensions. What is evident though is that the barriers, like the five components, are interlinked and affect each other as well. The various barriers identified in the literature can be classified into four broad categories namely; physical, organizational, social, and economic (UNAIDS 2003, UNAIDS 2009).

3.2.1) Physical Barriers

Physical barriers as discussed in the existing literature include factors such as distance to healthcare services; long travel distances and transport costs; difficult terrains to negotiate; limited transport availability; and danger (UNAIDS, 2003; Mukherjee et al., 2006; Harris et al., 2011).

Transport and long travelling distance have been identified as some of the more significant physical barriers encountered by patients seeking ART treatment and care. Mukherjee et al., (2006), van Dyk (2010), and Jones (2010) mention that the physical distance between the location where people live and where the clinic or health care service is situated impacts on people's ability to access their treatment especially if it results in increased transport costs (van Dyk, 2010). Ware et al., (2013) also found that travelling distance and increased expense resulted in disengagement with HIV services.

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[22] The five components of access were discussed in the previous chapter.

Jones (2010) however presents a different perspective on physical barriers. In his study about access to ART he uses a geographic perspective to understand the barriers that people face when they want to access their treatment. Jones (2010) argues that a more geographical perspective allows for a broader understanding about the concept of access to health care and also about the barriers to access. Jones (2010) highlights in particular the geographical boundaries drawn around municipalities creating theoretical separation between areas. These boundaries capture the local people within a certain radius and according to primary health care policy prevents them from seeking health care in other districts. This in some cases can be very limiting, especially if some clinics in certain areas provide better quality service as compared to others (Jones, 2010). These administrative boundaries affect the concept of universal access to health care for all in particular since some people who fall within certain boundaries will be limited in their ability to access ART (Jones, 2010).

A further concern about the locality of health services expressed in the literature is the fact that it does not accommodate well for the mobile population (Jones, 2010). The health policy states that people should seek health services that are situated within the communities where they live, a fundamental aspect of primary health care aimed at reducing the impact of distance on access to care (KZNHEALTH, 2003, Dennill et al., 1999). However, in the ART and mobile community setting this can present a challenge for individuals who are often away from their local community. Since the healthcare system, and especially the primary health care system, is fragmented patients are not able to collect ART at any other clinic, but rather they are constrained by the locality of their own clinic where they are living (Jones, 2010).

These boundaries mentioned by Jones (2010) have a further effect on access by confining people to a certain area. In light of a highly stigmatised disease such as HIV/AIDS, this can be problematic for access since some patients feel self-conscious and are not willing to be seen at the local clinics for fear of gossip and discrimination among the community members (Jones, 2010).

3.2.2) Organisational Barriers

Organisational barriers, as highlighted in the literature, are factors such as lack of healthcare services; poor organisation and administration of healthcare services; lack of integration of services such as Tuberculosis and women's health services; staff shortages; unreliable supplies of materials and drugs; lack of information about policies to support effective treatment; poor referral systems; long delays and time consuming procedures that result because of poor administration and record keeping; lack of confidentiality; inadequate counselling; lack of follow-up and the politicization of HIV and AIDS (UNAIDS, 2003; Sanjobo, et al., 2008; Mukherjee, et al., 2006).

Barriers in the organisation can also be caused by national policies that inform protocols in the health care setting. Protocols are tools used to standardize treatment and care. These are particularly used in the public health care sector. Due to the generalized HIV epidemic in the country the department of health has standardized the treatment regimens for the general population. These standardizations are presented in protocols that are then operationalized at the local clinic level. However, policies and protocols are developed by government which is removed from the local ground level setting, and which does not always have the best understanding of the actual daily activities of the life in the clinic setting. This is evident in the work of Blaauw in Ige and Quinlan (2012) who mentions that "A national official noted: 'Some of the weaknesses inherent in any national programme… (are) that you are slightly

removed from the implementation level and essentially… you're creating guidelines and policies and standards for something you are not involved in every single day" (Ige and Quinlan, 2012: 92).

Human (2011) moreover documented how strict adherence by clinic staff to protocols can create barriers to accessing care. In his account Human (2011) captures the difficulty encountered by patients to be correctly diagnosed and prescribed appropriate medications when they fall out of the protocol guidelines (Human, 2011). Similarly protocols can be so strictly adhered to by clinic staff that little flexibility is given to address individual needs that might be related to factors other than biological disease.

Sadoh et al., (2009), further document the effect that poor staff attitudes have on creating barriers to accessing HIV care by creating stigma and discrimination within the healthcare system. Further, Abdool Karim & Abdool Karim (2010) as well as Barnett & Whiteside (2006) point out that the expansion of the ART programme increases the volume of patients that the public healthcare system has to cope with while Brinkhof et al., (2008) indicate that facilities are unable to monitor defaulting patients closely or follow up on their adherence to treatment.

The South African Human Rights Commission led a public inquiry into the accessibility of health care in South Africa. In their report released in 2009 they state that "The SAHRC has received many complaints with regard to poor service delivery in the public health care system in all provinces of South Africa. These complaints point to the lamentable state of many public hospitals in the country due to many factors, including a shortage of trained health care workers, a lack of drugs in clinics, lengthy waiting periods that patients endure before receiving treatment, poor infrastructure, a disregard for patients' rights, a shortage of ambulance services and poor hospital management" (SAHRC, 2009: 4). The report further

notes that "access to health care services, especially for the poor, is severely constrained …
by long waiting times at clinics and other health care service providers" (SAHRC, 2009: 6).

Long waiting lists and waiting times have in fact, been cited as the most common complaints
against the administrative aspect of organisational barriers (Gulliford et al., 2002). The
monthly visits required by the ART policies are also a major barrier for people to continue
their treatment as is the treatment by clinic staff. Ware et al., (2013) reported that one of their
respondents remarked: *"they [staff] told me, ''you are late.'' Now, there are problems
people face. I don't know how they perceive it but for me this thing is very difficult. Attending
clinic every month is very difficult, because you have to leave your work, sometimes report
[to work] late—reasons like these. Everyone has problems. They are supposed to solve these
problems with love, not harshly like they do. Until people are afraid of their words—abusive
words. They behave as if we are there to beg for meds. It's our right to get the meds.
[Female, age 34]* (Ware et al., 2013: 5). Ware et al., (2013) thus found that once patients
have defaulted their treatment they become reluctant to return to the health care facility due
to fear of being reprimanded by health care workers. They identify the reluctance to return to
health services as a barrier to continuous access to care.

These administrative barriers are important to consider as they can have real consequences on
access to health care services. Gulliford et al., (2002) remark that: "organisational barriers to
access may result in delays in treatment, which can cause dissatisfaction among users and
may lead to worse clinical outcomes" (Gulliford et al., 2002: 187).

3.2.3) Social Barriers

Social barriers outlined in the literature include personal beliefs; attitudes towards treatment; the stigmatising category of 'risk group' identification and labelling; false cures; lack of social and family support; lack of education; community attitudes towards PLWHA; religious beliefs; and culture (UNAIDS, 2003). In addition Sanjobo et al (2008) identify factors such as side-effects; pill burden; forgetfulness; lack of emotional and social support; and general improvement in health as barriers to adherence.

The patient's own health and illness beliefs have also been identified as key aspects that could influence access to HIV related health care services (Jones, 2010). In Jonny Steinberg's account about HIV services in the Eastern Cape, he captures the resistance of 'Sizwe' to have an HIV test and to engage with the HIV health care system (Steinberg, 2008). 'Sizwe's' fear of ART is not limited to him alone. Many patients access ART when it is too late, and their CD$_4$ count is already too low. Furthermore, limited information about ART, the literature indicates, has led to widespread rumours about the drugs. These rumours are closely linked to the assumption in the communities that ART is synonymous with dying (Jones, 2010). When patients commence ART at such a late stage of disease progression, the drugs are ineffective or cause the life-threatening Immune Reconstitution Inflammation Syndrome (IRIS) and when they die the families and communities associate it with the usage of ART drugs (Steinberg, 2008, Jones, 2010).

The fear of the side effects of ART has been influenced by the damaging reviews of the effectiveness of ART by the South African government. The fear and doubt about the toxicity of the drugs expressed by the political leaders, including the national minister of health, has spread to the population (Jones, 2010, Ige and Quinlan, 2012, Steinberg, 2008). Jones (2010) reports that in his study patients expressed concern about the government's perception of the

drugs and some felt that the "government was deliberately hiding information from them" (Jones, 2010: 32). Even though the political leadership has changed and the government, along with the minister of health is now in favour of using ART, the unfortunate messages about ART are embedded within the living memories of the people in local communities (Fassin, 2007). While it was relatively simple for political leadership to change the policy regarding supply of ART to the general public, it remains a lasting challenge to change formed perceptions that people now have about the drugs (Fassin, 2007). Jones (2010) reports that one respondent in his study said that: "our leaders should not say negative things about ARV's. People were going to go for ARV's freely without fear. But we are not free" (Jones, 2010: 32).

Social responsibilities have also been identified as barriers to accessing ART services (Ware et al., 2013, Merten et al., 2010, Gari et al., 2013). In some instances patients are obligated to attend to family matters or engagements which results in them missing their appointments at the ART clinics (Ware et al., 2013). Gari et al., (2013) and Ware et al., (2009), however, found that social relationships and ties are vital for patients to be able to access their treatment by providing social and financial support. These social relationships create a sense of obligation to improve their health which further helps with adherence to ART (Ware et al., 2009). However in instances where social support does not exist, patients experience greater difficult in accessing their ART (Gari et al., 2013).

Gender as a social phenomenon has implications on accessibility to HIV related treatment and this is given much attention in the literature. Women make up more than 50% of all people infected with HIV, and HIV is now the leading cause of death for women between the ages of 15-49 years worldwide (UNAIDS, 2010). This statistic indicates that females are less able to access ART for a host of reasons including economic oppression; disempowerment; limited education and lack of decision making power. Their role as primary caregivers in the

family structure often means that females are not able to attend to their own illness (Murray et al., 2009). Being female was furthermore found to be a barrier to accessing ART (Gari et el., 2013). Merten et al. (2010) in their meta-ethnography reviewing barriers to adherence found that women often do not have the power to decide over household resources which limits their ability to access ART. Further to this men can deny them access by withholding resources or by blaming them for infection with the virus (Merten et al., 2010).

Gender does however also impact upon men. In the literature the discrepancy between the female and male ratios is noticeable. Jones (2010) noted is his study that the ratio between the female and male patients was 60 per cent females as compared to 40 per cent males. The lack of men coming forward to start treatment has been identified as being a point of concern is other ART clinics (Jones, 2010).

Stigma is another social barrier that has been identified by UNAIDS (2010) as one of the key social barriers to accessing HIV-related health care (UNAIDS 2010). Stigma not only prevents people from testing but can also prevent them from taking their treatment. This is evident in the words of Abdool Karim et al., (2010) who point out: "Stigma, and its concomitant discrimination, are some of the most critical reasons for the failure of prevention programmes providing a major barrier to accessing HIV prevention, care and support services" (Abdool Karim and Abdool Karim, 2010: 588).

The main area where patients experience stigma is in their local communities. Jones (2010) noted that a lack of accurate information about the ART drugs and a skewed message from the government has contributed to the discrimination that patients feel. Stigma has implications for access because of the heavy focus on adherence and counselling. Patients are encouraged to have a treatment supporter, someone whom they can confide in and share their disease burden with. Although it has been found that a treatment supporter can greatly assist

with adherence and access to ART, it does require disclosure of a patient's HIV sero-status (Jones, 2010, Van Dyk, 2012). Disclosure of HIV status has implications for accessing ART. Some patients are too afraid to disclose their status and, from a lack of accurate information supplied by the department of health to communities, some patients assume that a 'treatment buddy' is a necessary requirement (Jones, 2010). This assumption is however often founded on reality as Jones (2010) points out that some patients are actually turned away from health care facilities if they do not have a treatment supporter (Jones, 2010). Their fear of disclosure does not only hold relevance in the initial access to ART, but has implications for continuous care as well. If a patient does not feel secure enough to disclose her/his status and share the disease burden with a family member or trusted relative, then life-long commitment to an ART regimen is in jeopardy. This discrimination and fear leads to behaviours such as hiding ART drugs from family members (Van Dyk, 2012, Jones, 2010). Discovery of the drugs can have devastating consequences for some patients who live in stressful and highly stigmatized environments, thus limiting their ability to continue accessing their ART (Jones, 2010).

Stigma and discrimination is not limited to the communities where the patients live. Stigma is also found within the healthcare sector itself. This has consequences for access to health care, in particular HIV related services and treatment (Jones, 2010).

Jones (2010) notes that confrontation of stigma and discrimination can start as soon as the patient enters the health care facility, where they firstly have to face the hospital clerks (Jones, 2010). This is the first point of entry into the health facility and as a result also represents one of the most important operational aspects of access to treatment. Jones (2010) found that patients felt discriminated against by hospital clerks who gossip about their HIV positive status amongst themselves and with other patients and staff (Jones, 2010). This, according to Jones (2010), has implication for access to ART since HIV positive patients feel too afraid to return to the same health care facility for fear of discrimination (Jones, 2010).

Fear and guilt imposed onto the patients for missing visits or not complying as they were initially instructed to do also creates barriers for patients to remain and return to care (Ware et al., 2013). Terms such as *defaulter* and *lost to follow-up* that are used within the clinics to identify those patients who have interrupted their treatment visits further perpetuate the discrimination of HIV positive patients by health care workers.

Ware et al., (2013) further report that patients are often treated harshly by health care workers if they do not comply exactly as they are instructed. One male participant in their study remarked "*I felt humiliated. I felt very bad. After receiving the services I was full of pain. After that incident I didn't go back to the hospital. I decided to leave everything and opt for fruits and food…and until now I am not taking it [ART]." [Male, age 60]* (Ware et al., 2013: 5). This finding is likewise expressed by Jones (2010) who reports that patients are often judged by health care workers, not only because of their HIV status but also by their inability to adhere to treatment regimens; this judgment will often result in decreased levels of care being offered to the patients (Jones, 2010).

Sadoh et al., (2009) found that health care workers were far more agreeable to treat patients who are HIV positive than to receive care by a colleague whom they know is HIV positive (Sadoh et al., 2009). This is a significant finding for stigma in the health care sector since health care workers are supposedly best educated regarding the modes of HIV infection (Sadoh et al., 2009).

Even more important than the perpetuating discrimination by such attitudes is the limit that health care workers are willing to place on the extent to which they are prepared to provide care for those patients who are HIV positive. Holzemer et al., (2006) found that the healthcare sector provides an opportunity for stigma since: "they are primary settings in which stigma can be triggered and also where stigma can manifest" (Holzemer et al., 2006).

This opportunity for stigma has resulted too often in the denial of care to those patients identified as being HIV positive, as Holzemer et al., (2006) further noted: "sometimes the patient is denied the right health care simply because he/she is infected with the HIV virus" (Holzemer et al., 2006: 546).

The literature moreover identifies certain cultural practices and beliefs about HIV/AIDS and its related treatment as a barrier. Some of these cultural barriers include myths about HIV and AIDS, 'false cures', cultural concepts of health, traditional healing methods and treatments, and HIV/AIDS as a taboo subject (UNAIDS, 2003).

3.2.4) Economic Barriers

The strong economic emphasis in the literature further suggests that the fight against HIV/AIDS has also become the fight against poverty as there is a clear link between HIV/AIDS and poverty in the literature. Barnett and Whiteside (2006) thus highlight the effects of the commodification of health in terms of "those who can purchase healthcare and those who cannot" (Barnett and Whiteside, 2006: 6). This link between HIV/AIDS and poverty is clearly articulated in the words of Brundlant in Schwartlander et al., (2006) who state, *"Does anyone deserve to be sentenced to certain death because she or he cannot access care that costs less than US$2 a day? Is anyone's life worth so little? Should any family become destitute as a result? Should children be orphaned? The answers must be no, no, no and no! Yet this is what is happening. Every day." (Brundtland in Schwartlander et al., 2006: 544)*

The literature further states that for drugs to be available four key factors need to be met, namely: Firstly, good quality, safe, and effective drugs need to be selected. Secondly, the drugs must be affordable enough for the governments and the people who need them. Thirdly, the financing for these drugs needs to be sustained to ensure a continuous supply of

61

drugs. Fourthly, healthcare systems need to have policies in place that ensure that the drugs are made available at healthcare facilities, especially where they are needed most (UNAIDS, WHO, UNDP, 2011; UNAIDS, 2003).

Cost of drugs presented a major problem for developing countries to provide ART in the earlier years of the epidemic when ART was first made available. Indeed, one of the reasons given by the South African government for the delay in providing ART to the general population was due to the high cost of the drugs. The government claimed that it was unable to afford the costs to supply ART to the general population (Govender in Cullinan and Thom, 2009).

Since then major efforts by the international community, global organisations, and governments have resulted in reduced cost prices of the drugs and flexibilities has been created in terms of patent laws. In South Africa a ruling by the Constitutional Court and an earlier victory by the South African Government over pharmaceutical companies' restrictive prices, and the provision to allow for cheaper generic drugs to be imported along with the more expensive drugs, has resulted in the cost of ART in South Africa being remarkably reduced. This has resulted in the free provision of ART to the general population who rely on the public health care sector for treatment (WHO et al., 2010).

However, there still remain some monetary expenses involved when patients access their ART and Fried et al., (2011) note, that costs involved in accessing ART services presents a barrier for continuous access and retention in care. Posse et al., (2008) further note that: "The cost of drugs seems not to be the most important constraint of access to ART, as many of the drugs are provided free of cost to eligible patients through combined efforts by countries and bilateral and multilateral partners" (Posse et al., 2008: 904). Financial expenses for the patient, known as 'out-of-pocket' expenses, refer to those costs that are not thought of when

62

discussing free medical care. These costs may include paying a fee for the hospital cards, pharmaceutical products, or specialised services related to their illness (Gulliford et al., 2002). Further to these cost of transport, frequent trips to the clinics for medication refills, and cost of appropriate food to eat may present additional financial problems (Mukherjee et al., 2006, Posse et al., 2008).

Jones (2010), Merten et al., (2010), and Ware et al., (2013) all found that food, money and transport costs were concerns mentioned in their study when it came to the economic aspect of access to ART. Hunger and food insecurity remains a major concern as poverty continues to have a devastating effect on HIV positive patients. Hunger can present a very important barrier to accessing ART if money is scarce in the household. Patients have reported that they would have to sacrifice ART transport money for food money (Jones, 2010).

Jones (2010) further notes that a participant mentioned to him that: "she 'skips' treatment appointments because of lack of travelling funds" (Jones, 2010: 33). The cost of transport to clinics is proving to be a serious barrier for patients. Most participants in Jones' (2010) study complained that lack of money for transport presents a very real challenge for them to continually access their treatment. Gulliford et al., (2002) also notes that travelling costs and time off work also contribute to the financial expense to access ART, even though it is indirectly incurred.

However the economic costs are not just limited to the out-of-pocket expenses. Monthly visits can affect job security as well, thereby further contributing to the poverty cycle in which most HIV positive patients already find themselves. Jones (2010) noted how one participant in his study told him that: "she had lost her job because of the lack of flexibility in the system for treatment provision and subsequent need for time from work spent queuing" (Jones, 2010: 33).

The strong economic focus on access to ART in the literature skews the belief that access is merely a case of affordability and availability. This is further exacerbated by the use of quantitative research that only lists the barriers without contextualizing them with more in-depth understanding. Often in the literature about access to healthcare and ART the focus is shifted to adherence and there clearly is a need for these two concepts to be considered independently. This shifting of classification has resulted in the inappropriate use of the term *access* and on focusing only on the availability of actual ART drugs without considering the wider understanding of what access means. This further results in misclassification and incorrect use of the term barriers to access, which is limited most often to focus on the patient instead of considering the role that the healthcare system plays in creating and perpetuating the barriers to accessing ART. This study thus uses the broader definition of access to healthcare to better understand the meaning behind the barriers and the structural drivers that create barriers to access, as opposed to merely zooming in on factors related to adherence only.

Having outlined the key themes in the literature in terms of the barriers to accessing ART and the interrelatedness of the barriers; in the remainder of the chapter I now focus on the key theories that inform this particular study.

3.3) <u>Structural Violence Theory</u>

"Violence is present when people are prevented from reaching their potential" (Galtung, 1969: 168)

If we consider Aday and Andersen's (1981) definition of access to health care as the potential and actual entry into the health care system, then using Galtung's Structural Violence Theory becomes relevant in the pursuit of understanding the causes behind barriers to access.

In 1969 Johann Galtung asked what constitutes violence. According to Galtung (1969: 168) "violence is present when human beings are being influenced so that their actual somatic and mental realizations are below their potential realizations ". He further defines violence as "the cause of the difference between the potential and the actual, between what could have been and what is. Violence is that which increases the distance between the potential and the actual, and that which impedes the decrease of this distance" (Galtung, 1969: 168).

In his work, Galtung (1969) argues that the definition of violence should be extended beyond mere physical violence. He describes distinctions between different types of violence with the most important distinguishing factor being the subject who enacts the violence. For Galtung (1969) when there is an actor that commits direct violence it is described as personal or direct violence, but where there is no actor present it is defined as structural or indirect violence (Galtung, 1969).

Galtung (1969) further explains that if there is a situation where harm is experienced but it is avoidable then violence is present. He uses the example of a limited lifespan. During historic times a limited lifespan would be unavoidable and expected. In today's time with all the medical advances and technology available to increase lifespan, a limited lifespan is a result of structural violence. Similarly we can compare those who are infected with HIV. HIV is a preventable disease but people are infected daily. Moreover there is effective treatment

available that can restore the lifespan of those infected back to normal yet there are people dying because they do not have access to treatment, or they gain access which is then interrupted by obstacles that are caused by larger structural forces. Suffering and violence is brought into action everyday by those who suffer under these forces.

Structural violence can therefore be characterized by the structures that are present within society such as economic, political, legal, religious and cultural that prevents people from achieving their potential (Farmer et al., 2006). The violence is found in peoples' subjection to structures that create ways of being that have a negative effect in their lives. These processes are ubiquitous and mostly invisible, yet their frequent occurrence makes them ordinary and acceptable. For the person subjected to the violence there is no perceived threat. The violence is so embedded within the fabric of everyday life that those subjected to the violence are not aware of it.

Pool and Geissler (2011) further explain the concept of structural violence and highlight the importance of gender, socio-economic standing and race when they note "the constraints on behaviour and options imposed by institutionalized inequalities in wealth and power on those who are underprivileged: mainly women, the poor, and those of colour" (Pool and Geissler, 2011). Examples of structural violence include racism, poverty, sexism, ageism, pollution, under and unemployment, military invasions, and medical inequalities such as disparate access to healthcare services (Farmer et al., 2006).

By using this expanded definition of violence to include structural violence, a broader understanding can be gleaned about how the barriers to accessing HIV related healthcare prevent people from reaching their potential by limiting their ability to continually access ART drugs. The disruptions that these barriers cause, results in physical suffering in the form of opportunistic diseases that could lead to premature death.

Besides the physical disease threat, the structural barriers enforced by the healthcare institutions through policies that are not well informed, result in other suffering such as perpetuating poverty. HIV/AIDS has long been associated with poverty, and the link between the two phenomena has been established, (see for example Barnett and Whiteside, 2006). Most people who suffer from HIV infection live in poverty. This creates difficulties for them to access ART and to remain in the ART programs. Financial barriers pose a major problem for people especially in terms of reaching the healthcare facilities to collect their drugs as well as taking the treatment at home. Food insecurity is a problem for many of the PLWHA, and can result in difficulties in accessing ART and in remaining adherent due to the fact that they do not have enough food to eat.

Structural violence theory then can be used to identify the reasons behind inequalities to accessing healthcare services. Farmer (2001) has used this theory extensively in his work in Haiti and argues that HIV/AIDS is interlinked with social processes and therefore that the driving factors behind the epidemic must be understood from a structural point of view. Structural violence can be used to understand how forces such as poverty and sexism impact and fuel the epidemic, and it can help identify those people who are marginalized and suffer the greatest (Paul Farmer, 2004).

South Africa has one of the highest rates of inequality in the world and the healthcare system reflects this situation as it is sharply divided between those who can afford quality health care and those who cannot (Barnett and Whiteside, 2006). Farmer (2003) refers to this situation as the commodification of healthcare which further exacerbates the destructive forces of poverty that limit the ability of those living with HIV to access their treatment and remain compliant.

Adherence in the clinic and ARV-programs is often understood as a personal and individual activity. The risk then to default on treatment is consequently also explained in individual terms. Ware et al., (2013) elaborate on this when they remark that "lost to follow-up connotes clinics' difficulties in keeping track of patients, while patient-centred terms –the currently preferred 'disengagement' or the African term 'defaulter' –imply that missed visits result from patient choice" (Ware et al., 2013). This stance of placing the onus on the patients for missed visits stems from the biomedical viewpoint that the individual is responsible for her/his own health; a view which is supported by the commodification of healthcare. The individualistic model frequently overlooks the fact that heath is situated in the broader context of culture and society. This skewed view contributes to the mystification of biomedicine and thereby places the blame on the patients while protecting the health care system and those involved in producing policies and protocols related to functions of the health care system.

If we return to the definition of violence as proposed by Galtung (1969: 168) as being "present when human beings are being influenced so that their actual somatic and mental realizations are below their potential realizations" we can appreciate that people have it in them (the desire and personal ability) to be adherent and comply with their treatment regimens, but there are forces around them that can prevent them from realizing this goal.

Policies guiding the implementation of the ART program are constructed away from the reality of the setting and, quite often, those who make the policies do not have a thorough understanding and appreciation for the plight of the patients and the everyday constraints of the public health care system (Ige and Quinlan, 2012). By using structural violence theory we can try and understand that this 'individual risk' actually forms part of much larger socio-political and economic structures that create risk. Individual behaviours are embedded in the social settings and must therefore be understood and explained within these structures.

Hunter (2010) criticizes the use of structural violence in the HIV/AIDS setting by saying that the theory's main focus is on the larger socio-political forces that marginalize people but fails to address the daily-life inequalities that people experience, especially those who suffer from HIV and AIDS. Hunter (2010) further suggests that the use of structural violence in the context of HIV/AIDS fails to make a clear distinction between the victim and the victimizer (Hunter, 2010). Another critique of Galtung's definition relates to the invisibility of the violence. Galtung (1969) argued that because the violence subjected onto people is invisible it is difficult to act against it. Winter et al., (2012) however argue that the invisibility of the violence lies in the "normalcy of everyday violence that allows it to be inherited across generations and renders it 'invisible'" (Dilts, 2012). Dilts (2012) further argues that "structural violence's invisibility is more likely because of violence's ceaseless repetition in the open rather than because it has been hidden away in a dark or subterranean place" (Dilts, 2012: 192). It is however this 'normalcy in everyday violence', as first described by Scheper-Hughes (1992) that is manifested in the public healthcare setting, albeit difficult to identify, that presents barriers for patients to access their ART treatment.

In this chapter the various barriers to accessing ART healthcare have been highlighted. Further to this the use of structural violence theory has been discussed as a theory to understand the barriers to accessing ART for people living with HIV/AIDS. The barriers can be situated within the theory of structural violence and highlight the drivers behind the barriers.

CHAPTER FOUR: Methodology

4.1) The Ethnographic Approach in Health Care Research

This research was conducted using an ethnographic approach that falls under the broader classification of qualitative research. The aim was to obtain a holistic view of the people and place where patients collect their anti-retroviral treatment. More specifically the aim of this project was to elucidate the barriers to accessing HIV/AIDS related health care services in a public sector clinic. The objectives were to identify the most important barriers, as perceived by the patients once they have been on ART for some time, to assess the impact that these barriers have on the patients' ability to continually access their treatment and to capture the patients' reactions to the perceived barriers in the clinic.

The ethnographic approach allows for the research to be situated within the context of the collected data and is used to gain deep insight into the subjects studied. By using ethnography to describe the group or culture in detail the anthropologist makes use of thick description[23] to produce ethnographies. In-depth research reveals information that is hidden from mere surveys and questionnaires. The detailed analyses produced about the subjects and their interactions with their environment reveals the meaning and inter-related webs behind behaviours (Fetterman, 1989). The approach allows for data to be collected in a structured and logical manner. The holistic approach, the hallmark of ethnography, allows for the 'insider' and 'outsider' view to be taken into consideration and thereby facilitates a more robust understanding of a certain group of people and their behaviour (Pool and Geissler, 2005, Hansen, 2006).

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[23] Thick description 'entails the detailed investigations of webs of meaning; presentation of the different, inter-connected contexts that are relevant for understanding the phenomenon in question' (POOL, R. & GEISSLER, W. 2005. *Medical Anthropology,* New York, Berkshire, Open University Press.: 26)

A central feature of ethnography is thus the use of the insider's perspective, also known as the emic perspective (Pool and Geissler, 2005). This perspective is integral to understand why certain members of a group behave in a certain way. Those researchers who prefer emic data tend to be more idealistic and phenomenological in their perspectives. Although post-modernism theory argues that one can never truly adopt the perspective of another, ethnographers acknowledge this situation and thereby attempt to be as open-minded about their fieldwork as possible (Bernard, 2002). The etic perspective, in contrast, is the external view of the scientific researcher into the culture of the group studied (Pool and Geissler, 2005). This stance is materialistic and positivistic in philosophical terms. This viewpoint favours that of the researcher and scientific theory over that of the subject being studied. The aim of the anthropologist is to gather as much data as possible from the emic perspective but then to try and understand and explain it from the etic perspective. This shift between the emic and etic perspective is therefore very important in ethnography.

Ethnography has been used successfully in healthcare settings to conduct research. Although research in the health care setting is generally not conducted over as long a period as traditional anthropologists ascribe too, it remains a valuable method to use (Willis, 2010). Ethnography has been used to develop health focused interventions, to investigate illness behaviours and cultural practices dictating health behaviours, and has brought to light the specific health care needs of various populations. Despite the range of subjects that can be investigated using ethnography it has also been found to be a useful measure of the effectiveness of quantitative methods within healthcare research (Savage, 2006).

Gifford (1996) stated that "qualitative… health care research has the ability to describe in depth the experiences of the peoples' lives and the social context that strengthen, support and diminish health. It has the ability to humanize the research process and to lead the context specific strategies for the individual and collective change" (Gifford in Hansen, 2006: 47).

Increasingly qualitative research is being recognised for the value that it can add to healthcare research. In some instances it is mandatory to conduct a qualitative study prior to a quantitative study in order to obtain more detailed information about the research setting and to understand the problem in greater detail. Ethnography with its various and multiple methods of data collection and detailed descriptions then becomes one of the best qualitative methods to collect data when the research subject is new or unfamiliar (Savage, 2006).

The usefulness of ethnography in the healthcare setting is found in the perspective it offers on research problems. Quantitative methods of inquiry are removed and distant from the researched and often ask the 'wrong questions', according to participants, and miss what is actually happening in the healthcare setting (Savage, 2006, Greenhalgh, 2010). Ethnography allows for close interaction between the researcher and the researched and provides a unique insight into the setting. Its main strength in healthcare research lies in its ability to explain instead of merely just measure a problem. It also provides deep insight into problems identified and creates hypotheses to test. As Savage (2006) points out "it can reach the areas that quantitative research cannot reach" (Savage 2006: 391).

Although ethnographic research presents many positives in the health care setting there are however a few drawbacks when conducting an ethnographic study. As with all qualitative research, ethnographic evidence is not generalizable, is subjected to biases, is difficult to evaluate and is generally not very reliable in terms of repeatability. Time is another important factor. Traditionally ethnographies were conducted over lengthy periods of time. In the healthcare setting, as noted, this has presented as a challenge and as a result ethnographies have shortened; however these time-bound problems are not just confined to ethnographic accounts but affect all research done within this setting. Besides this problem, the rapidly changing healthcare system poses a threat to the validity of ethnographic accounts (Willis, 2010). In addition, testing ethnography remains a problem for those who wish to establish it

as a research method in the health care setting as due to the varied nature of ethnography there is no rigorous 'check list' available with which to test the results produced (Greenhalgh, 2010).

However, despite these drawbacks, ethnography has made and continues to make major contributions to the study of health care settings. The importance of the approach is evident in the words of Scheper-Hughes (2004: 4) following her use of ethnography in health care settings: "I wonder if any other discipline is better suited or situated than anthropology to interrogate values and practices from a position of epistemological openness and to offer alternatives to the limited pragmatic utilitarianism that dominate medical bioethical thinking today" (Scheper-Hughes, 2004).

There are two types of ethnographic viewpoints in the healthcare setting. One, being ethnography *within* the healthcare setting; the other being ethnography *about* the health care setting (Pool and Geissler, 2005).This research project's focus is about the health care setting. Van Dyk (2010) has criticized previous studies on access and adherence to treatment because of the 'artificial environment' that such studies have created (van Dyk, 2010). She further argues that for this reason a skewed image about access to treatment and adherence has been produced. In order to present a more holistic analysis an ethnographic approach that included mixed method techniques to collect data was employed. While the study was largely qualitative in nature, some quantitative data collection was also done to correlate some of the findings. This ethnographic research project therefore utilized a triangulation of research methods to collect the data required. Triangulation in qualitative research is common and often recommended. According to Thurmond (2001) triangulation of research methods consists of a combination of more than two data collection techniques, investigators, analytical methods, methodological approaches or theoretical approaches (Thurmond, 2001). Four different methods were used to gather the data required for this project. Participant

observation, focus groups, semi-structured interviews, and questionnaires were used to collect the data. The strength of triangulation provided support for the findings where one method alone would not have sufficed. Triangulation therefore allows for a more holistic view and increases the validity of the findings (Thurmond, 2001).

Combining qualitative and quantitative methods provided the opportunity for two perspectives of the research problem to be gained. The qualitative methods allowed for the identification of the barriers that people experience and it also provided a deeper insight into the extent that these barriers impact upon peoples' lives. The quantitative method provided a confirmatory perspective which showed how relevant the particular problems are to the clinic's adult population.

To identify the barriers and assess the impact that they have on the patient's ability to access their treatment, focus groups, semi-structured interviews and questionnaire were conducted. To capture and explore the patients' reactions to their perceived barriers, participant observation was done. The behaviour that was noticed in the clinic as a reaction to the perceived barriers was then further discussed during the focus groups and the semi-structured interviews.

4.2) Study area, population and inclusion and exclusion criteria

Patients were recruited for this study from the public health clinic that provides HIV/AIDS related services at the hospital. Only patients were included in this study since they are the users of the health care system and are thus best placed to evaluate whether they have access to health care services or not. As mentioned previously the clinic is located at a large public sector hospital in Durban that falls in the province of KwaZulu Natal. This particular clinic provides ART services for paediatrics, obstetrics and adult patients. The services include screening of eligibility to commence ART, adherence counselling, examination by a nurse and a doctor, referral to social services and referral to a dietician if required. Referral to specialised services, such as dermatology, is facilitated by the fact that the clinic is located within a large tertiary hospital.

The participants of the study reflected that of the clinic's adult population and consisted of adult men and women aged between 18 years and 65 years. The adult population in the clinic ranges from ages 18 to 65 years and mainly consists of isiZulu-speaking patients. Reflecting the national demographics of the epidemic, women make up more than half of the population of the clinic.

This project investigated barriers only experienced by the adult patients of the clinic. Adults are classified in the South African health care system as any person over the age of 18 years, which corresponds with the Children's Act of 2005 which states: "a child, whether male or female, becomes a major upon reaching the age of 18 years" (The Children's Act of 2005, Act no 38 of 2005). This age is significant since the clinic offers services to both paediatric and adult patients. Once paediatric patients turn 18 years old they are transferred over to the adult side of the clinic.

Criteria for patients to participate in the research project had to be uniform across the research methods. It was not possible to observe one category of adult patients as separate from another. A key reason for this is that all the adult patients are serviced in a particular area of the clinic and it was not possible to know, just from observation, which age categories they fall into, or to observe the male patients separately from the female. The focus groups and the semi-structured interviews also comprised of a variety of participants spanning the adult age range from 18 years to 65 years.

The inclusion criteria for the study then comprised of adult patients aged 18 years and over who were already enrolled in the ART programme and receiving anti-retroviral treatment for a period longer than one year. A period of one year on ART was chosen since this projected aimed to investigate the barriers to continuous access to ART health care services. New patients experience a different set of barriers that can overlap with the barriers that patients' experience who have been in the system longer, but, the focus of the study is on the barriers experienced over a longer period of time. Also, patients tend to experience more side-effects and complications due to the ART drugs within the first year of starting treatment. Exclusion criteria included any patient who did not voluntarily agree to participate. Patients were also excluded if they had been on treatment for less than twelve months.

4.3) <u>Sampling and size</u>

Non-probability, purposive sampling was used for the qualitative data collection. This form of sampling is consistent with sampling when using qualitative data. Purposive sampling is appropriate for sampling key informants required for interviews. Key informants are participants in a research study that can provide in-depth data, but does require good rapport being established between the researcher and the participant (Bernard, 2002). Good rapport is essential for ethnography as a whole. Having worked at the clinic for four years I have come to know some of the patients in the clinics well by working closely with them. Two of these patients became key informants for the study and they participated in the semi-structured interviews.

Initially during the questionnaire piloting phase sampling for the quantitative data was done using simple random sampling techniques, but this proved structurally difficult to do. The primary reason for this is that even after careful explanation about the research project some patients were suspicious as to why their particular file numbers were selected and others felt left out and insisted on participating in the project; this created some tensions amongst the patients. Bernard (2002) notes, that it is sometimes difficult to conduct random sampling in the real research setting, especially when the research involves humans. Bernard (2002) suggests that in such cases, "use a nonprobability sample and document the bias"(Bernard, 2002: 180).

The sampling method was then changed to convenience sampling to collect the quantitative data so as to avoid further complications in the setting and to ensure that the data would be collected within the stipulated time frame.

4.4) Data Collection Instruments and Process

4.4.1) Participant observation

"Participant observation means that you try to experience the life of your informants to the extent possible; it doesn't mean that you try and melt into the background and become a fully accepted member of a culture other than your own" (Bernard, 2002: 368)

Participant observation is one of the core methods of data collection for ethnographic studies. It gives the researcher the opportunity to interact on a more intimate level with the people being studied. This vantage point allows for a closer approximation to the real, everyday truth of the condition in which the subjects find themselves. Participant observation is an observational technique that is used to gain an insider's perspective into the community being studied. As an essential method in any ethnography, it provides the insight and perspective required for ethnographic approaches.

Participant observation is advantageous for placing the researcher in the research setting. This viewpoint allows for first-hand experience and the opportunity to observe what is actually happening instead of merely being told. This allows for a deeper understanding of the research setting, the population, and the problem being investigated. This further gives the researcher the opportunity to contextualize the data. Furthermore participant observation is very useful in establishing rapport with research participants, especially where rapport is essential for in-depth semi structured interviews. Another practical advantage is that little funding or equipment is required to collect the information.

Participant observation is useful for studying topics where little or limited information is available, where there are differences in the view points of 'insiders' vs. 'outsiders', where the problem is somehow obscured from outsiders, or hidden from public view. It has particularly usefulness for exploring and describing problems and the data collected. It is a relatively unobtrusive method by which to collect rich, detailed information from the

insider's point of view. What people say they do and what they actually do are often two different realities. For this reason, being present and participating in the research setting provides the researcher with the opportunity to see things for what they really are and approximate the data closer to the truth.

Participant observation was the first research method used for this research endeavour. This provided a better understanding of the clinic's population and the setting and continued until the end of the data collection period. In total participant observation was conducted for a period of six months.

Careful field notes were taken on a daily basis detailing the events of the clinic. Participant observation was not structured and this allowed for the natural flow of the clinic to unfold on a daily basis, however, some clear topics were outlined that assisted with observing. These topics included observing the flow and movement of patients throughout the clinic and detailing their interactions with the various health care personnel and their general actions when collecting treatment. Participant observation took place during the operating hours of the clinic from 07:00am to 16:00pm. Participant observation was conducted for an average of five hours every day during the six month period.

The data obtained was compiled in systematic field note entries into a journal and was then analysed and this provided a deeper understanding of the setting and the people who played a part in it. It provided me with the opportunity to experience on a daily basis how the clinic functions, how all the characters interact with each other, what processes are adhered to and how these factors influence access to treatment and health care services. The use of participant observation thus provided me with an insight into the everyday interactive experiences between the patients and the health care sector and their endeavour to access health care services. Participant observation was also the data collection method for

observing the patients' reactions to perceived barriers. These reactions were further explored by the focus groups and semi-structured interviews.

Participant observation further provided me, as a researcher, with the opportunity to develop close interactions with some of the patients of the clinic. This rapport was particularly helpful during the semi-structured interviews which were conducted post participant observation.

Participant observation can however be challenging and like most data collection tools has certain disadvantages. One major difficulty that I was confronted with was that I could not be everywhere simultaneously. Only one event could be observed and/or participated in at any given time. This forced me to be selective about where I wanted to be which introduces bias. Another major dilemma that I experienced is the dual role that I had to adopt while conducting participant observation. The method requires for the researcher to be both a participant of the group and a researcher. This became problematic when I wanted to write and record data that I had observed but was constrained by my role in participating with patient care. The presence of a researcher in the setting does influence the behaviour of the population being studied. The patients and staff of the clinic knew from the beginning that I was the 'research nurse', and not one of the clinic staff. This I felt changed their behaviour towards me somewhat. For those patients who came to know me I became an extra source of help. When they were facing some problem in the clinic, such as a lost file, or if they were in a hurry to get back to work and needed a script or note, they approached me for assistance. Some patients also felt the need to share information with me regarding their experiences with the ART clinic without me asking them. This I can only attribute to the fact that the patients understood that I occupied a unique role within the clinic. The staff also treated me differently. Some members of the staff were reluctant to interact with me while others chatted more freely to me, possibly because they saw me as a researcher and not a person of authority. While I could not participate fully in the activities of the clinic because of the

researcher role that I already occupied, this role did however allow me to adopt a unique position in the clinic and allowed me to observe and participate in the functioning and daily activities of the clinic rather unobtrusively.

When conducting research, and particularly ethnographic research, it is also essential to bear in mind that the viewpoint of the data collected will also be influenced by the researcher's own cultural and world views. Thus, while objectivity is always the goal, subjectivity is a reality of all research.

4.4.2) Focus groups

Focus group can be defined as a planned group discussion about a particular research topic that is used to collect data through a group discussion (Hansen, 2006). Focus groups should be used when a researcher is interested in a range of opinions, wants to achieve a better understanding of the cultural and social norms of the group, and want more information about the influences and motivations behind certain behaviours (Hansen, 2006).

The group dynamic is used to obtain insight into beliefs and attitudes of a particular group. Groups should ideally include between six and eight participants and the members should ideally be homogenous as homogeneity assists with the flow of information (de Vos et al., 2002). It is a particularly useful method of collecting data about needs assessments, for developing or refining instruments for interventions for further research, or to enrich data collected by other methods (de Vos et al., 2002, Hansen, 2006). Information is gained from the participants' common experience and is not individual-based (de Vos et al., 2002).

This insight that focus groups provide about the population group is particularly useful when a researcher is interested in the power dynamics between different actors in the population being studied (Hansen, 2006). An example of this is the power dynamics between healthcare

workers and patients. In my research project I was interested in this relationship because it affects the experience of accessing treatment at the clinic and it reveals the hidden structural violence that lies within these relationships.

By conducting focus groups the researcher obtains rich data from various perspectives. During the focus group attention must be paid to both what is said as well as how it is said and by whom (de Vos et al., 2002). Focus groups are useful for discovering new information that might be hidden, for gaining different perspectives, for gaining insight into why people behave in a certain manner; for gaining insight into the influence of group interactions and for exploring topics holistically (de Vos et al., 2002, Hansen, 2006).

In focus group discussions it is important to ensure that participants are well informed about the topic that is under discussion and they should ideally experience the particular topic during their everyday lives in order for them to provide the deep and rich information that the researcher wants (Hansen, 2006). If the participants do not share a common interest with the research topic the participants' ability to converse freely will be compromised (Bernard, 2002).

Despite the many positives of focus groups there are certain limitations to focus groups and the researcher must be aware of these. Firstly bias and influence of the researcher must be acknowledged and all attempts must be made to avoid this (Bernard, 2002). The moderator of the focus group must also be careful to avoid leading the group in a particular direction that produces biased answers (Hansen, 2006). Furthermore the effect of the group should also not be underestimated. Some participants will be more outspoken than others. This might cause the shyer participants to withdraw from the conversation or simply agree with everything that is being said (Hansen, 2006). This gives rise to the problem of individual views being

portrayed as group views where the timid participants are too afraid to voice their own view points.

In addition focus groups are limited in their ability to generalize the data gained from them to the entire population to which they belong because it is not possible to get a totally representative group (Bernard, 2002). So, while we might gain deeper insights into a particular issue, the findings might not apply to the population as a whole. There are also some physical limitations to focus groups. Groups are demanding and require ample time to prepare and conduct the interviews (Hansen, 2006). They can also become costly when the issue of reimbursement is raised or when food and drinks are provided.

For this particular research project an initial pilot focus group was held prior to the main focus groups to assist with formulating the questions for the actual groups and to assist with the formulation of my interview schedule. The pilot group consisted of 6 participants, who were female, isiZulu-speaking, and over the age of 18 years.

In total four focus groups were conducted, each comprising of 6 participants. Three of the groups consisted of females and one of the groups consisted of males. The groups were divided according to gender to facilitate the flow of the discussion and to avoid unnecessary tensions.

Participants were selected on a voluntary basis and the group sessions were conducted in the clinic where it was most convenient for the participants. The focus groups were run by a research assistant who understood the purpose of the project well. The groups were conducted in isiZulu which is the preferred language of the participants. The focus groups were audio-recorded and notes were taken by the researcher during the group session. Focus groups were used to gain a comprehensive perspective about the shared problems people encounter when they are accessing their treatment. It was useful to elicit a range of opinions

about the shared experiences of the clinic's patients and to uncover the social and cultural norms that underlie their responses and behaviours.

The data from the focus groups aided in identifying the themes relevant in developing more concrete questions for the semi-structured interviews and the questionnaires. The semi-structured interviews were used to gather more in-depth information on an individual patient level. The qualitative data was used to formulate the questionnaire and contextualize the data. The quantitative data was used as a measure to check the validity and reliability of the qualitative data collected.

4.4.3) Semi-Structured interviews

The semi-structured interview is based on an interview guide that ensures that the information that is required is collected. The use of the interview guide also assists with uniformity of the information obtained from the various participants and allows for reliable and comparable information. The interview guide offers clear instructions for the researcher to follow and is particularly helpful when there is more than one interviewer.

Ten semi-structured interviews were conducted with attendees of the clinic who were willing to discuss their thoughts and feelings with me in detail. The semi-structured interviewees consisted of four isiZulu-speaking males and six isiZulu-speaking females ranging in ages from 24 to 45. These participants were also interviewed during the focus groups. By using the same participants I was able to revisit some of their earlier comments and to explore those areas in more detail.

The semi-structured interviews were conducted in a consulting room at the clinic where it was most convenient for the patients. On average each interview lasted one hour, was audio-recorded and a research assistant was available when the participant wanted to communicate in isiZulu instead of English.

These interviews provided a deeper and more personal account of problems around access to ART. The questions for the semi-structured interviews were derived from the participant observation data, the focus group data and the literature reviewed and was used to explore in more depth and detail some of the issues raised. Participants were asked to discuss their experience colleting treatment, what difficulties they faced, if they were adherent to their treatment and what factors have affected their adherence to their treatment regimens. Besides the four categories of barriers[24] that remained a theme throughout the data collection process, other barriers to accessing ART were also explored in more detail such as the specific issues that present challenges for patients to continually access their treatment.

A particular advantage of the semi-structured interview is that the time spent on the interview is more controlled as compared to unstructured interviews (Hansen, 2006). In my particular setting this was helpful as the patients were always in a hurry to leave the clinic. Following an interview guide allowed me to be more focused on the topics that needed to be covered, although discretion was used when participants wanted to talk more about certain points.

Direct contact with participants has certain advantages. The information obtained is often detailed and can offer unique insights into the research problem. It also allows for a high degree of validity as responses can be checked for accuracy and relevance during the interview. Some participants found the experience therapeutic, although it was stressed that the purpose of the interview was for research.

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[24] The four categories of the barriers were discussed in Chapter Three: The Literature Review.

By listening to the participants' ideas and opinions some participants reported that they felt appreciated and acknowledged, and enjoyed the opportunity to talk about the issues that they faced.

Semi-structured interviews do however have some limitations. While they are useful for gathering in-depth information, obtaining that information requires skilled interaction between the researcher and the participant; it requires cooperation from the participants to dedicate their time and share their insights with the researcher (Hansen, 2006). This could prove to be a mammoth challenge if the researcher does not have good rapport with the participants.

The effect that the researcher has on the interview must also be taken into consideration. This situation is particularly important when the researcher is a healthcare provider and the participant is a patient. There is an unequal power relationship between these two actors that can potentially have an effect on the data collected (Arber, 2006). Unless there is good rapport between the healthcare researcher and the patient participants there is always the chance that the patients will tell the researcher what they think they should say (Bernard, 2002). The participant may also feel vulnerable in this situation and may participate in the research purely because of the power dynamic. The healthcare researcher must be aware of this situation and must make every effort to neutralize this dynamic.

Another important aspect to remember during the healthcare research interview is the purpose of the interview (de Vos et al., 2002). Some participants may confuse this opportunity to discuss their opinions as a counselling session. This could lead to awkward situations where the participant is revealing very sensitive information in expectation that the researcher can intervene with their problems and provide solutions, therefore it is important that the researcher make it very clear, and constantly remind the participant that the interview is for

research purposes and not for clinical reasons (de Vos et al., 2002, Hansen, 2006). As noted, participants in my study did express that they appreciated the opportunity to express their feelings and concerns, and although this is an important step in the establishment of rapport, I constantly reiterated that the information they provided was for research purposes.

Finally reliability of the participant's answers is a point of concern for any interview (Bernard, 2002). The interviewer effect, inhibitions by the participant to share sensitive information, and the context in which the data is collected make almost every interview unique (Hansen, 2006). This can make it difficult to ensure reliability of the data as each participant will add her/his own unique information.

4.4.4) Questionnaires

To increase validity and reliability of the qualitative data collected quantitative data was also collected. A simple questionnaire that covered the themes that were raised during the focus groups and semi-structured interviews were incorporated into an interviews schedule.

The questionnaires consisted of three sections that comprised of 61 items. The participants were asked about their demographic information, reasons for attending this particular clinic, time spent in the clinic, treatment regimen and date of commencement of ART, and whether they have missed any appointments. They were also asked about their own beliefs regarding the treatment and how they foresee themselves remaining on ART. Goals for taking ART were also covered as this reflects insight into their condition, and the effect of adherence counselling. Self-reported levels of adherence were also asked about since barriers to access can influence adherence.

The questions relating to the barriers that were identified in the literature as well as the data from the focus groups and interviews centred on the four categories of the barriers. Barriers were highlighted and the respondents were asked to rate the effect of the barrier on their

ability to access their treatment. Barriers were scaled form 1 to 5 where 1 equals no problem (this is not a problem for me); 2 equals a small problem (it can be a problem but I manage), 3 equals (I am neutral about this/ don't have an opinion); 4 equals a big problem (this is a problem for me); and 5 equals a very big problem (this is a big problem that can result in me not coming to the clinic). Careful note was taken of which barriers were most significant in the clinic. However, those barriers where a 5 or 'very big problem' was selected as an option, even when the percentage was low, was considered to be significant since these barriers can result in the discontinuation of ART drugs.

Questionnaires were handed out to any adult patient who consented to voluntarily participate in the questionnaire and who had been on treatment for a minimum period of one year. Participants were fully informed about the research project and its aims.

The total number of completed questionnaires returned to the researcher was 156, 82 consisted of isiZulu copies while 74 were English. More females than males responded to the questionnaires. This demographic inequality could have resulted from two separate causes. One, the clinic has a larger female population as compared to males; and two the female patients were more enthusiastic to participate in the study as compared to the males.

The questionnaire consisted of closed ended questions, Likert- scale type questions and a few open ended questions. The Likert-scale[25] questions required the patients to rate the effect of a certain barrier on their ability to access their treatment. Some open-ended questions were included to allow the patients to provide more comprehensive answers. The questions were arranged in such a way that the more easy to answer questions came first, with the more difficult or sensitive questions featuring towards the end of the questionnaire. This is in line with Behr's advice that said: "the questionnaire should start with simple factual questions

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[25] Likert-scale: This is a close ended question that requires the participant to scale their responses, usually consisting of five points (Bernard, 2006).

which can be answered without much difficulty. Complex or awkward questions should come toward the end (Behr, 1988: 157)".

The questionnaire took approximately 30 minutes to complete. The questionnaires were handed out to the patients at the beginning of their waiting time in the clinic. This was the first queue that they sat in while waiting for their clinic files. After the questionnaires were handed out the participants were instructed to either drop their completed forms in a labelled box at the entrance of the clinic or to return the questionnaire to the researcher or the research assistant. Most patients completed the questionnaire by the time that they reached the front of the queue.

The questionnaires, information sheet[26] and the consent were available in either English or isiZulu. The researcher and the isiZulu-speaking research assistant were always close at hand for those participants who had difficulty understanding certain questions or who were illiterate. Anonymity was ensured by assigning numbers to each questionnaire answered and keeping the consent separate from the questionnaire. There were no personal identifications present on the questionnaire.

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[26] Information sheet: This is mandatory for healthcare research and explains to the participant in the language of her/his choice about the study and the extent of each individual's involvement. It also covers important aspects such as confidentiality, voluntary participation and the contact details of the ethics committee that granted permission for the study to be conducted. The information sheet also provides an additional confidentiality factor by covering the questionnaire itself.

4.5)   Data Analysis

The data gathered from the qualitative methods was analysed using thematic coding. The themes were constructed around those themes identified by the literature, namely: physical, organisational, social, and economic barriers. Thematic analysis uses inductive coding[27] to analyse the qualitative data (Hansen, 2006, Bernard, 2002). The literature provides some ideas about the themes that might be elucidated from the data but the researcher largely follows a process of continually returning to the data and analysing the data to uncover further themes. This iterative process is useful for a study about access barriers as it is recognised that barriers to access are embedded within the local context and that researchers should investigate the local barriers affecting the clinic's population (UNAIDS and WHO, 2003). Coding was used to group the data into the main themes of the barriers, namely: physical, organisational, social and economic barriers. Coding of the qualitative data was done using NVIVO 10 software. In NVIVO 10, queries were run that included word frequency and coding.

Comments about the distance travelled to the hospital, transport, or physical issues with accessing the clinic were coded as physical barriers. Further comments about local clinics and the referral patterns were also included under this group. Statements mentioning the hospital and clinic, including waiting times, administration, services by health care personnel and comments about infrastructure were labelled as organisational barriers. Social barriers included any comments about the patients' own personal factors that had an influence on their ability to access the clinic. Such statements included comments about any stigma and discrimination experienced in the local community, family and treatment support, religious beliefs, traditional cultural beliefs and the patient's own belief about the concept health.

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[27] Inductive coding: Analysing qualitative data by coding for themes as they emerge (Hansen, 2006).

Economic barriers were coded by statements about any patient or organisational cost involved in accessing treatment. From the data collected only costs experienced by the patients could be evaluated. Data regarding the health system finances were gleaned from the pre-existing literature. Any answers or comments regarding financial aspects or costs were coded for. This included employment issues and time factor issues.

The recordings that were collected in isiZulu during the semi-structured interviews and focus groups were translated and transcribed into English. To check for validity and reliability the transcripts were back translated[28].

Themes that were coded for in the qualitative data were then re-worked and incorporated into a questionnaire schedule. The quantitative data was analysed using SPSS software. Basic statistical tests were performed on the quantitative data including testing for the mean, mode and median, as well as some correlation tests were done.

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[28] Back translation: This is the final step in validating the transcribed data. The translated data is re-translated into the original language in which the interview was conducted to check for accuracy.

4.6) Bias and limitations to the data

The data showed some bias towards organisational barriers more than the other barriers that were highlighted in the literature. However, with comments about the counsellors, stigma does become an important barrier, since the counsellors could have their own stigma towards the patients. However, this project did aim to investigate the barriers to accessing ART in the healthcare setting and therefore organisational barriers will be more apparent and abundant in the data than social or behavioural barriers, although these were inquired about. The focus on organisational barriers is an attempt to fill the information gap in the literature about barriers to accessing healthcare.

The conclusions from this study were largely based upon the results gleaned from the qualitative data, and as a result, is not generalizable to the general population. Generalizability is not an aim of qualitative research; instead the point of conducting qualitative research is to obtain detailed information about the research problem.

In this chapter the research methods that were used to conduct the study was discussed. The value of conducting ethnography in the healthcare setting was examined and the use of triangulation of research methods was discussed. The four different research methods, namely: participant observation, focus groups, semi-structured interviews and questionnaires were explored in detail. In the following chapter, the results from the data analysis is presented and discussed.

CHAPTER FIVE: The Physical and Organisational Barriers that Impact Upon Continuous Access To Antiretrovirals

"When we fail to listen to our patients' stories, we lose the opportunity to discover what truly ails them" (Campo, 2006: 1678)*.*

In this chapter I begin with an analysis of the main and most frequently mentioned barriers that arose from the quantitative and qualitative data analysis. These barriers to accessing health care are classified into four main categories, namely: *physical, organisation, social* and *economic barriers*. It is important to stress at the outset of this chapter that although the barriers are neatly teased out into specific categories in this thesis, as is the case in much of the literature, in reality the various categories frequently blend, transverse each other and indeed cause each other - thus producing an inter-related, fused set of barriers that individuals need to transcend in order to access ART in the public health care sector. This noted, in this chapter, I tackle the physical and organisational barriers, while in Chapter Six I turn my attention towards the social and economic barriers.

In order to set the scene, I begin the chapter with an overview of a typical day in the clinic as seen through the eyes of one of my research participants, Sandy. Sandy's story reveals many of the challenges that patients face on a monthly basis when accessing ART treatment at the clinic, and the inclusion of her experience in this chapter provides the reader with a personal feel for the patients' experiences. In addition, the portrayal of Sandy's experiences, clearly illustrates the inter-related nature of the barriers patients face as they attempt to access ART therapy at this particular clinic. The remainder of this chapter then goes on to address the physical and organisational barriers patients face in their pursuit of ART therapy at this clinic.

5.1) A Typical Day at the Clinic

Sandy has been on ART for the past two years. She was initially diagnosed with HIV when she became ill with a Tuberculosis infection and was admitted to the hospital. Sandy is 27 years old and identifies herself as an isiZulu-speaking African woman who is unmarried and has two children under the age of five. Currently she has a job as a cleaner, but the position is only temporary. She has come to the hospital today to collect her monthly supply of ART drugs.

On a typical collection day Sandy first arrives at the hospital at around 06:00am. The card office is not yet open but there is already a very long waiting line. On the side of the card office's door is a piece of paper that reads: *"Waiting time between 07:00am and 11:00am is 30 minutes. If you have waited longer than this time please inform the manager."* The paper is dirty and torn, it has clearly been stuck to the wall for some time, long forgotten and ignored by both the card office staff and the patients. Both the patients and the clerks know that the paper is merely a formality, a requirement from the hospital management, and its promise no longer holds any significance at the hospital.

At 07:00 am the long line finally begins to move and people get to sit down inside the card office. One of the clerks takes the first batch of small blue identity cards that contains a patient's name, hospital number, follow-up appointment dates and which clinic is responsible for the follow-up treatment and care. After approximately 20 minutes two clerks return each holding a stack of orange coloured files filled with papers that contain all the medical information, test results, diagnostic information and treatment since the patient first entered the healthcare service. Some files are thin and new but others are thick and slightly dirty with notes and papers spilling out of them, held together by staples or elastic bands. The clerks start calling out names and the patients who are sitting in the two front rows hastily get up

and shuffle along, desperate to collect their files and move on to the next point of service in the hospital, which is the cashier's desk.

When the patients are sent to open a hospital file at their initial visit, they are asked a series of demographic questions that are captured on the files. These details include full names of the patient, home and contact details, employment details, financial tier, and the specific hospital number allocated to the patient. The financial tier and employment details are used to classify the patients into income brackets that will determine the amount that each patient will pay for hospital services. If a patient is unemployed she/he is required to supply an affidavit indicating the status, but even the unemployed will be required to pay the basic fee of twenty rand at each contact with the hospital. For some patients the twenty rand is a significant amount to pay, and presents a major barrier to continuous access to the health care facility. The payment is accompanied by a stamp from the cash register clerk and permits the patient entry into the health care facilities where treatment and care is received.

The cards of the patients sitting in the next two rows then get taken and the clerks disappear into the filing room. After 20 minutes they reappear and their stacks of files disappear into the hands of the owners. Again the snaking line moves forward, every patient in turn filling those two front rows. Finally Sandy gets to move into the actual card office building where she can take a seat. There are four rows of chairs before her but at least now she can sit.

Eventually she reaches the front row and the clerk asks her for her blue card. Sandy's blue identity card looks slightly different from the cards of the other patients at the hospital. Her card contains two numbers, one for her hospital file and the other for her file at the ART clinic. This small difference identifies her as a patient of the ART clinic, and automatically divulges her confidential disease status. Her blue identity card gets taken by one of the clerks who once again disappear into the filing room, and once again after approximately 20

minutes reappear with piles of hospital files. Names get called out, people eagerly get up, take their files and rush off to which ever clinic in the large hospital will provide them with treatment.

Sandy's name is not called. She knows what lies ahead now. Arguments with the clerks about where she had left her file last and *'yes I did drop it in the box'* and *'yes it was returned there, I know where to drop it by now'*. Sandy's hospital file has been misplaced, or as the clerks will simply say, *'lost'*. The delay will cost Sandy another hour while she waits for another clerk to make her a duplicate file. Sandy feels terribly angry and irritated, both by the attitude of the clerks who blame the patients for losing their files, and the fact that all her medically related information is now lost.

Eventually Sandy receives her new file, a duplicate of her old file but this one is thin and clean and empty of three years' worth of medical information and test results. She heads down to the cashiers office where she pays her twenty rand and gets her stamp.

With her new file in hand Sandy is feeling less angry and heads for the ART clinic situated at the top end of the hospital. The day is already progressing and the long walk in the bright sun is making her feel hot and uncomfortable. At the end of the day after Sandy has completed her entire visit to the hospital, she would have walked approximately one kilometre within the hospital complex alone[29]. When she reaches the clinic she is confronted with the second queue of her day. She pushes her way past the over-filled passage and walks to the end of the line. At least there are enough chairs here for everyone and she gratefully sits down once again. Appreciatively she looks up at the big air-conditioner that blasts cool air onto her face.

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[29] Path distance analysis was performed using Google Earth (www.googleearth.com)

An administrative clerk, known in this particular clinic as a support services officer, walks down the passage and once again collects her blue identity card, this time to go and retrieve the clinic file that contains all her HIV related medical information and treatment scripts. The nurses follow with their register and record her name in it. Sandy knows that this wait will be a long one and she opens her bag to take out a piece of fruit. Every so often she moves up a place, inching forward to the front of this very long and slow moving line.

The crowd around her is starting to get rowdy and agitated. People begin to complain about the long wait for their clinic files. *"How much longer must we wait just to get our files?"* asks a young man sitting a couple of places ahead of Sandy. He is getting agitated and complains bitterly when the nurses walk past. His complaints are not just directed at the nurses but he also blames the new patients for holding up the queue.

Finally Sandy gets her file and moves to the nurses table. The table is large and old and on it is the clinic register that captures all the adult patients for the month. One nurse is writing in the file while the other nurse weighs Sandy on a scale. She has to take her shoes off before the weighing and now sits down on a chair to fasten the strap of her sandal. She hurries because she wants to get to the treatment room before someone can push in front of her.

In the treatment room there is a short queue and it moves rather quickly. The male nurse is very friendly and he asks Sandy, the first healthcare worker to do so, how she is feeling today. She tells him the story of her lost file and the long wait in the card office. He is empathetic and agrees with her that it is unacceptable for the hospital files to get lost, but that she should not feel too bad about it since she is not the only patient here today whose file has been lost.

From the treatment room Sandy moves to the next waiting queue. This queue is where she can sometimes wait the longest and where people complain the most. She is waiting to see an adherence counsellor. After about half an hour of waiting the line stops moving. It is tea time and all the counsellors come out of their rooms and go to the staff tea lounge where they will stay for at least thirty minutes. Now the patients are just left sitting, watching their day go by as the clock continues to tick.

At the other end of the building are the three rooms where the doctors who work purely with adult patients are located. But none of the three are currently inside their rooms. They are also waiting. *"This is absolutely ridiculous. The clinic is full and we are just standing around. It is past ten and we have hardly seen any patients. How are we supposed to function like this? We will be working until late this afternoon when the counsellors are all gone"*- says Dr Victoria, the senior doctor. The delay at the counselling office delays the whole process. In fact a delay anywhere, be it the card office or the counselling office, has a knock-on effect in this clinic where there is such strict adherence to the protocols that dictate the process of care.

Two hours pass and Sandy eventually gets her chance to enter the counsellor's room. The room is small, cramped and divided into two sections by a curtain. Behind the other curtain sits another counsellor with another patient, counting tablets. There is a desk and opposite the desk sits the counsellor. He is not friendly but also not rude. Sandy knows what is expected of her. She opens her purse, removes the old containers and hands them to the counsellor opposite her. He counts the remaining tablets and then begins to ask her a long series of questions. *"Is she coughing, or having any night sweats? What about any side-effects of the treatment?"* He further reminds her about the importance of adherence and that she must not stop taking her tablets under any circumstances. Sandy nods and agrees with him and thanks him for his advice. He writes down all that they had discussed during the session and hands her back her clinic file. In total the counselling session takes about ten minutes.

From the counselling room Sandy walks to the next queue. This is the queue for the doctors and because it is her day to see the doctor and collect treatment she will have to wait here as well. Luckily Sandy knows that it is not her date to have routine bloods taken[30] When she looks at her watch it is past 12:00am. She will have to remember to ask for a sick note from Dr V, because she will not make it to work today. Sandy is feeling worried about this, every month since she has started with these tablets she has had to take one day off from work to collect her treatment. Without the treatment she will get sick again, and there is a chance that she might die, but if this continues her job is threatened. Her manager has already issued her with a warning for taking too many sick days. He has threatened to deduct days off work from her pay from now on.

Luckily the wait for the doctor is not too long and she enters the room after the nurse had shouted: *"who is next in the line?"* The nurse is friendly and takes her file and asks her for her blue card, the one she gave to the clerks in the morning to find her hospital file. On the blue card is a collection of dates. The nurse begins to fill in the next set of empty lines for the next three months. These are her clinic visit days, her booked appointment days. To systematize things the clinic book people per day. Thus if treatment was started on a Monday then the patient will always be booked for the Monday that is twenty eight days from the current visit. It is for this reason that when the patients reach the desk where the nurses take their weight they are asked if today is their *"appointment day."* If it happens to not be the allocated appointment day, that is to say that the patient came on a different day to collect

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[30] Routine bloods: In the ART program protocol, it is mandatory that blood analysis get performed. Currently every six months liver function and kidney function tests are performed along with whole blood analysis. The CD_4 count and Viral Load is also taken for analysis.

her/his treatment, she/he is then sent to the back of the waiting line to be helped last[31]. In this situation the patients are punished for not adhering to the strict rules of the clinic.

The visit with the doctor does not take long as Sandy has no physical illness complaints and Sandy finally heads to the last queue of the day. She reaches the pharmacy queue at 13:00 pm, lunch time. Here she waits half an hour before the pharmacist returns. The queue does move rather quickly and eventually she reaches the pharmacy cubicle and collects her refilled bottles of tablets.

After collecting her treatment, Sandy walks to the entrance of the clinic to drop her files at their respective places. Before she leaves she reads another paper stuck on the clinic's wall. This one reads: *"Time for collecting treatment is 1 hour. Time for seeing the doctor and collecting 2 hours. By Order, Management"* Sandy looks down at her watch; she has spent her entire day at the hospital to collect her treatment. She is done for the day but in twenty eight days she will have to endure this process again, and after that she will have to repeat it every twenty eight days for the rest of her life.

Sandy's trip though the hospital complex is indicated in Appendix 2 and the flow and layout of the ART clinic is indicated in Appendix 3.

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[31] One male patient recalled a day when he came on an un-booked day, only to be told by the clinic nurses that it was not his day to collect and that he must return the following week.

5.2) __Physical Barriers__

5.2.1) **Transport**

In the literature, see for example Ware et al., (2013), Harris et al., (2009), Merten et al., (2010) transport is often mentioned as posing a major barrier for patients to access their ART treatment and related healthcare services. Transport at the clinic did not however present as being as big a problem as presented in the literature. This stated, problems of transport were more linked to the costs of transport involved as opposed to a physical lack of transport, something that Harris et al., (2009) also found in their research conducted in South Africa about barriers to accessing healthcare. Questionnaire respondents were asked to indicate their primary means of transportation to the clinic, and the result are shown in Figure 5.1 below.
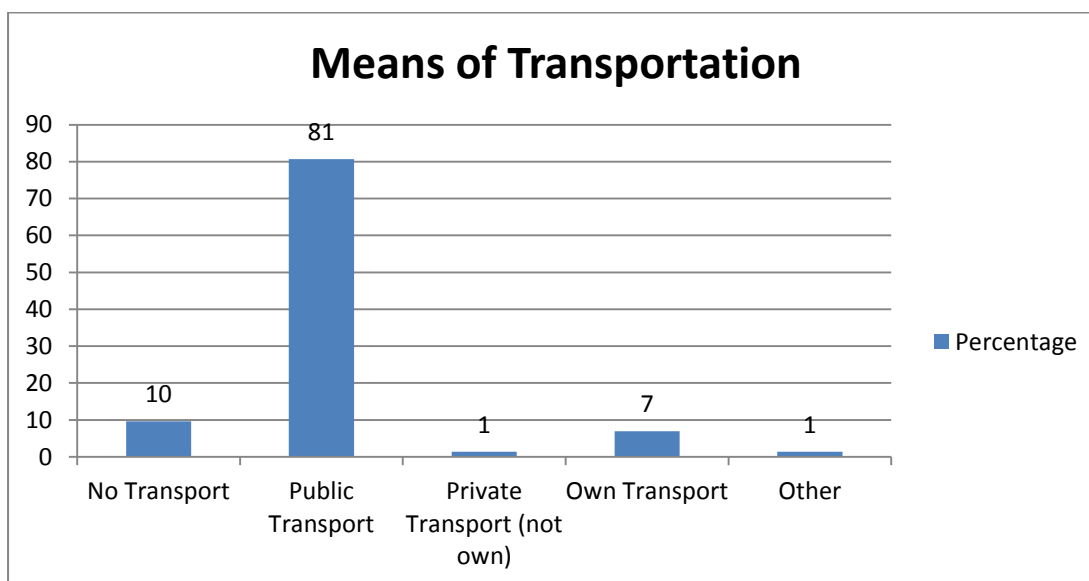
Figure 5.1: Means of Transportation

As Figure 5.1 above shows, over 80% of the questionnaire participants stated that they use public transport to get to the clinic and only 7% said that they have their own transport. In addition to this, 52% of the participants said that transport to the clinic was the most expensive cost for them to access their ART on a monthly basis. Almost half, 44%, of the

respondents said that if they don't have enough money to afford transport, they borrow money from relatives and friends to afford the transport costs to attend the clinic.

Just over half the respondents (55%) indicated that they did not consider transport to be a particular problem to accessing treatment, while 45% stated that it posed a problem of varying proportions. This is illustrated in Figure 5.2 below.
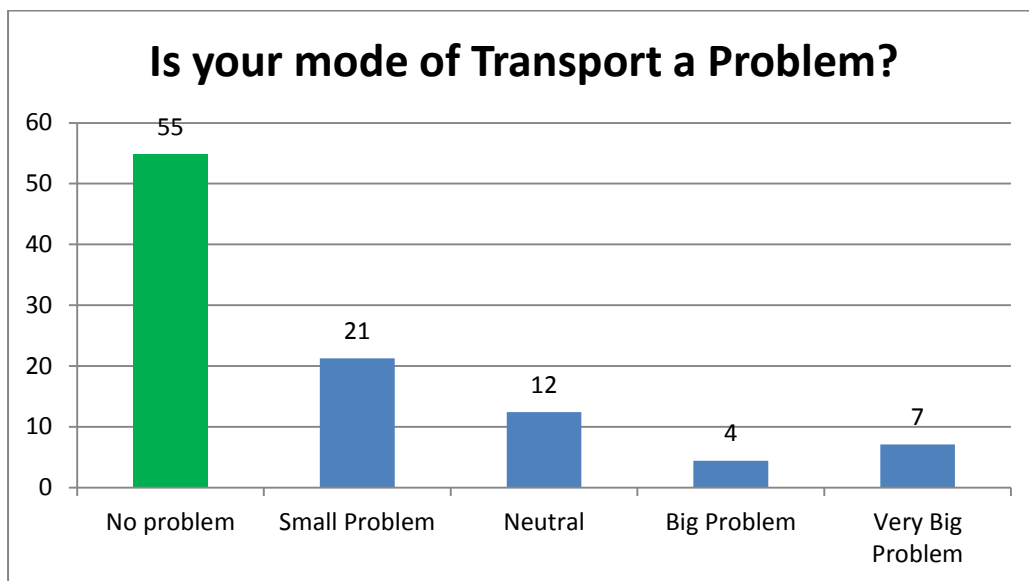
Figure 5.3: Perceived Problem of Mode of Transport

Clearly then, the participants did not perceived transport in itself to be a problem. Rather, they indicated that the *cost* of transport posed a more significant barrier. The problem of costs involved in transport to the clinic is supported by the words of the research participants. As one male research participant, Shawn, noted "*The reason [why people miss their visits] could be shortage of bus fare*". Lauren, a key research participant, added: "*for others it is not having transport money to hospital,*" to which Steven, a male participant explained: "*sometimes you have to catch a bus and you may not have money for bus fare*".

5.2.2) Distance

Another significant physical factor influencing the ability of patients to access treatment is the distance of the clinic from their homes. Respondents were asked how far the clinic was from their home. The question specifically tested the respondents' perceived view of distance, rather than absolute distance. The results of the analysis are illustrated in Figure 5.3 below; and as is evident, the majority of the patients indicated that they lived not too far from the clinic.
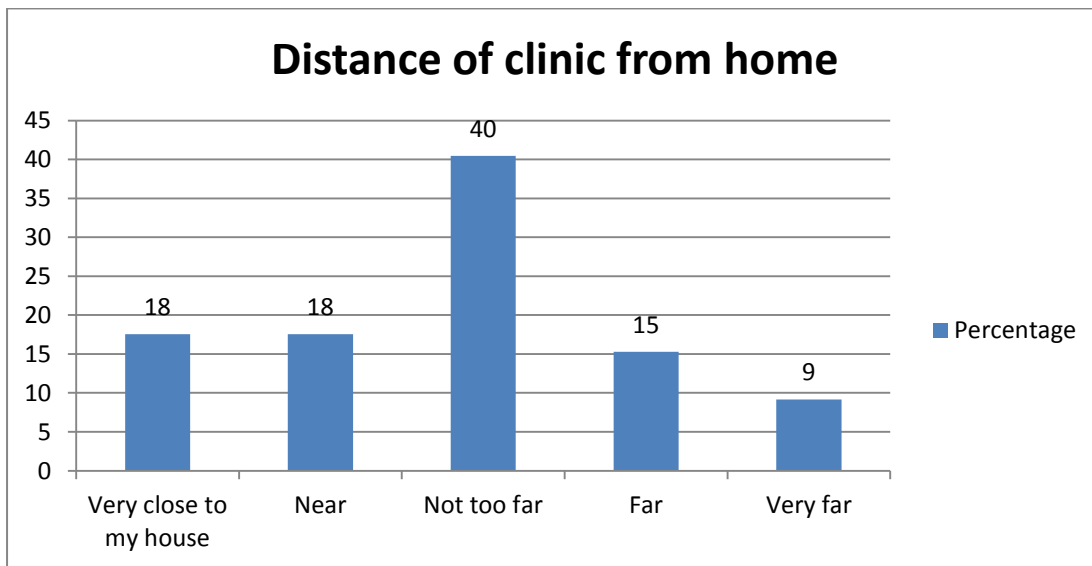
Figure 5.3: Distance of the Clinic from Home

In the literature the distance between a patient's house and the clinic was identified as a significant barrier to accessing ART. However, in this particular clinic quantitative data suggests that distance does not feature as a significant barrier. Just under half of the respondents who answered the question on the questionnaire indicated that the distance between their house and the clinic was not a problem, while just over half reported this to a problem of varying proportion. This is indicated in the Figures 5.4 and 5.5 below.
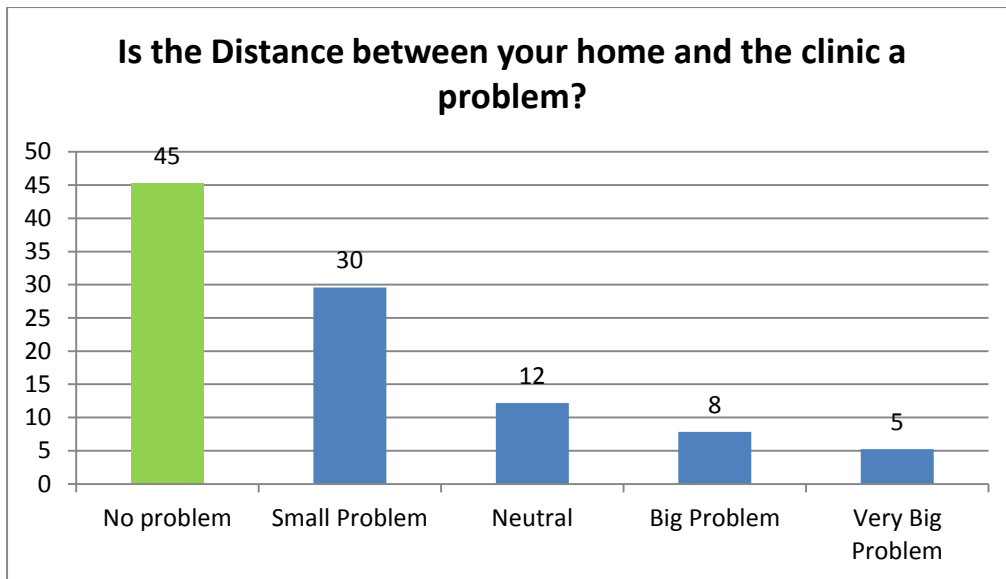
Figure 5.4: Perceived Problem of Distance between Home and Clinic
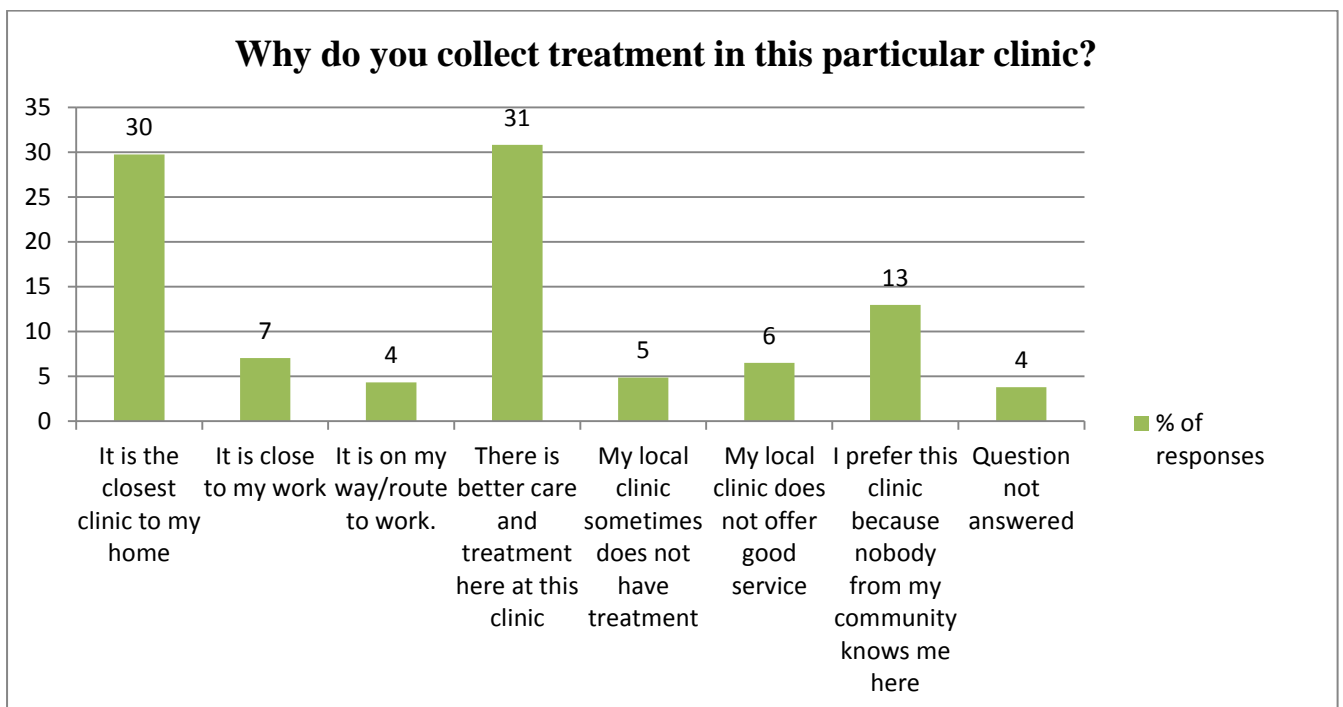
Figure 5.5 Reasons for patients using this particular clinic for treatment

One of the major motivating drivers behind the concept of primary health care is to bring

healthcare closer to where people live. Primary health care policy dictates that people should

attend their health care facilities within the area where they live. This move to bring health

care closer to people is a basic principle of primary health care and is an attempt to decrease the distance barrier between those who need medical care and the health care facility itself.

In this study, as shown above, the quantitative data revealed that distance between a patient's house and the clinic did not feature as a major barrier. However, qualitative research revealed that patients attend the clinic primarily because it is situated more closely to their place of work or because they perceive the quality of care to be better and are thus prepared to travel a distance to get to the clinic.

The clinic is situated in a large hospital, and technically should not be considered as a 'local clinic' by any of the patients. Interestingly enough however, in the questionnaire, 30% of the respondents said that it was their nearest clinic to their home. This percentage is somewhat in question. From working in the clinic, and having personally opened new files for patients initiating ART therapy, I have come to notice that many patients list a false address so as to access healthcare services at this particular hospital and clinic. These addresses usually have the same road name as the one in which the hospital is located. Since the clinic only operates during working hours, it does make it difficult for patients who are employed to collect their treatment. From the interviews and focus groups it thus became clear that the distance from work was more of an issue than having a clinic situated closer to home. This is evident in the words of the research participants.

Neville, a 50 year old male participant who has been on treatment since 2008 said: **"***No it's not nearby, just that things are much easier here",* when he was asked about the distance between his house and the clinic. These sentiments were reiterated by Neville who stated *"this Hospital is closer to my work*" and by Joseph who stated, *"this hospital is closer to my work and I am only allowed one day off per month to get to the hospital. That is why I need to*

get in and out from the hospital quick as possible so that I don't have to be delayed and request another day off from work".

It is thus clear that an anomaly exists in this case between the quantitative and the qualitative research and this highlights the importance of qualitative research endeavours. While the quantitative research reveals that patients attend the clinic due to proximity to their residences, and many indeed falsify addresses to indicate close residential proximity to the clinic, the qualitative research indicates that patients have a preference for clinics closer to their workplaces. This is significant as policy clearly dictates that patients should attend the nearest clinic to their places of residence as their first port of call in the quest for health care services, and that they should utilise these primary health care facilities for their primary healthcare needs. If the primary healthcare facility cannot provide the necessary treatment to the patient, only then should referral to a more equipped facility be validated (KZN HEALTH, 2013). However if the patient does not want to attend the local clinic then there is no alternative option available, the patients are forced to attend the clinic or stop the ART drugs. When policy conflicts with patient desires, such as the desire to attend closer to work rather than home, patients develop innovative strategies, such as falsifying addresses, so as to attend the clinic of their choice. In doing so, patients appear to be supporting the imposed policy framework, when in reality they are not.

In addition to proximity to work as a reason for attending the clinic, 31% of the patients said that they attend this clinic, because in their opinion, the quality of services provided are better than at their local clinics. The patients indicated that they are happy to travel a distance to attend this clinic because they perceive the quality of care to be better than in their local clinics. This finding is contrary to what is presented in the literature, for example Harris et al., (2009) who found that the majority of public healthcare sector users choose their facilities

due to the close proximity of the public healthcare facility to their homes. This response from the participants is significant since the patients are constrained by healthcare policy to utilize healthcare services from their local clinics, but in reality choose not to. Reasons cited for opting to use the services of clinics closer to work rather than home are numerous, and are captured in the words of the research participants.

Steven, explained "*I think it's because of the stigma around HIV. Well it's because people are trying to avoid stigmatisation. Most people take treatment however they would rather keep it to themselves which is why they travel all the way to the hospital. They feel they are somehow safe and cared for at the hospital. At the hospital doctors are always available, when one feels sick you get your treatment and you can speak to a counsellor at the same time so all that motivates us in taking our treatments. Also people are afraid they are trying avoiding isolation from negative people and to those who are not taking treatment.*"

Steven mentioned three very important reasons for why patients choose to travel the distance to attend the clinic. Firstly he mentions the stigma related to HIV healthcare, secondly, he describes that there are a range of healthcare services available at the hospital that are not available at the local clinics, and thirdly, he comments on the anonymity that the large hospital offers. It is clear that there are some advantages for attending the ART clinic that is situated at the hospital, and can explain why the patients prefer coming to this clinic.

The availability and quality of healthcare services thus plays an important role for keeping and drawing patients to this particular clinic; this is evident in the words of Neville a male participant who as explained to me during the focus group: "*this Hospital was the first hospital that provided ARV's. When the other health institutions started rolling ARVS; I was already collecting from this Hospital and I didn't want to change.*"

Lauren, a key informant explained this issue further: "*We are very satisfied with this Hospital's doctors because you get all the assistance you deserve. Especially if you have another sick problem besides HIV issue they write on your card and refer you accordingly. If it is something that the doctor is familiar with doctor simple prescribe you with medication for that problem and problem is solved. Yet at our local clinics there is no such service, doctors are not available at those clinics.'*

Veronica, also a key informant agreed with Lauren's explanation. She told me that: "*I prefer this Hospital because there is patient care. All the specialists are available everywhere you look there is a doctor to help you with your diagnosed condition. Everything is close including skin clinic. We don't mind even if we have to pay. That is why I love attending at this Hospital patient care is 100%. If you have another separate condition besides HIV problem that gets seen too and you go home smiling. Whereas at our local clinic there is no confidentiality everybody knows that you are an HIV patient and no treatment for your problems.*" Betty, a 27 year old female patient added to this "*I don't mind because here I get treated and there are always doctors available. If I have any other sicknesses the doctor would give me script and I would get treatment. Doctors and nurses are always there for us and yet at our local clinic we get treated as if being HIV positive is a punishment.*"

A female Linda, age 31 described how the availability of the ART drugs at the hospital changed her life: "*I am now relieved that we can access treatment because before people were dying like flies due to the fact that there was no education about treatment and treatment was not available at our nearest clinics. However, I wouldn't collect my treatment at our local clinic because they are always out of stock. Most local people know me so I don't want them to know about my status.*"

The hospital offers a sense of anonymity that the local clinics fail to provide. The anonymity factor is related to the healthcare and social stigma in the local communities. The aspect of anonymity was also reported in the data from the questionnaires, where 13% of the respondents reported that they chose to attend this clinic because they did not want to be seen in their local clinics collecting ART. This anonymity that the hospital unintentionally provides plays a vital role in protecting the patients from perceived harm. However as mentioned earlier, healthcare policy threatens this protection by forcing patients to attend their local clinics even if they will be subjected to social discrimination and potential physical harm due to their HIV-positive status.

Chris, a male participant explained: *"Firstly I didn't want to collect my treatment closer to home because I didn't want people to know about my status besides it is not comfortable collect HIV treatment in your area. You end up meeting up with your local neighbours whom you don't want them to know about your status because they talk too much. It is preferably to collect from this Hospital because it's away from home. Also you meet different people from all walks of lives."*

Prudence, a 24 year old female patient said *"It is better to collect at this Hospital you all join the same queue. Thereafter you have collected your card and you go to the clinic nobody worries about where you go. You don't disturb others that have other sick problems. What I have noted why people love coming here is because people are separated. No body worries about what you are here for."*

A male participant, Phil, in the focus group said of this: *"This Hospital is much private for all patients especially for HIV patient we meet with other patient at the card office to collect and pay once all that is done each one goes to different direction. None of us worries about who goes where. The people that we walk the same direction and attend the same clinic that is obvious to me that they are also on the same boat as me."*

Another participant, Roger, agreed with him: *"Yes we agree to that. A person that meets you at this Clinic is a person that is collecting treatment. At Poly clinic is not a good idea because everyone knows what you are there for and they would start talking about you."*

All these comments about not wanting to be seen in the local communities are due to poor quality service by the healthcare system, stigma and discrimination which are tantamount to structural violence. The healthcare system through insisting that patients attend clinics closest to their residences is perpetuating discrimination by inadvertently disclosing HIV positive patients' statuses and by denying patients the basic human right of *choice*.

5.3) Organisational Barriers

In order to ascertain the extent to which organisational barriers were considered a significant hindrance in accessing treatment, patients were asked about a range of organisational issues and how much of a problem these presented on a scale of 1 to 5, where 1 represented no problem and 5 represented a very big problem. The results of this are shown in Figure 5.6 and Figure 5.7 that follow. In Figure 5.6, those that indicated some kind of problem (i.e. small problem to a very big problem) were grouped and shown against those that indicated no problem, while in Figure 5.7 the extent of the problem is illustrated.

Organisational Problems
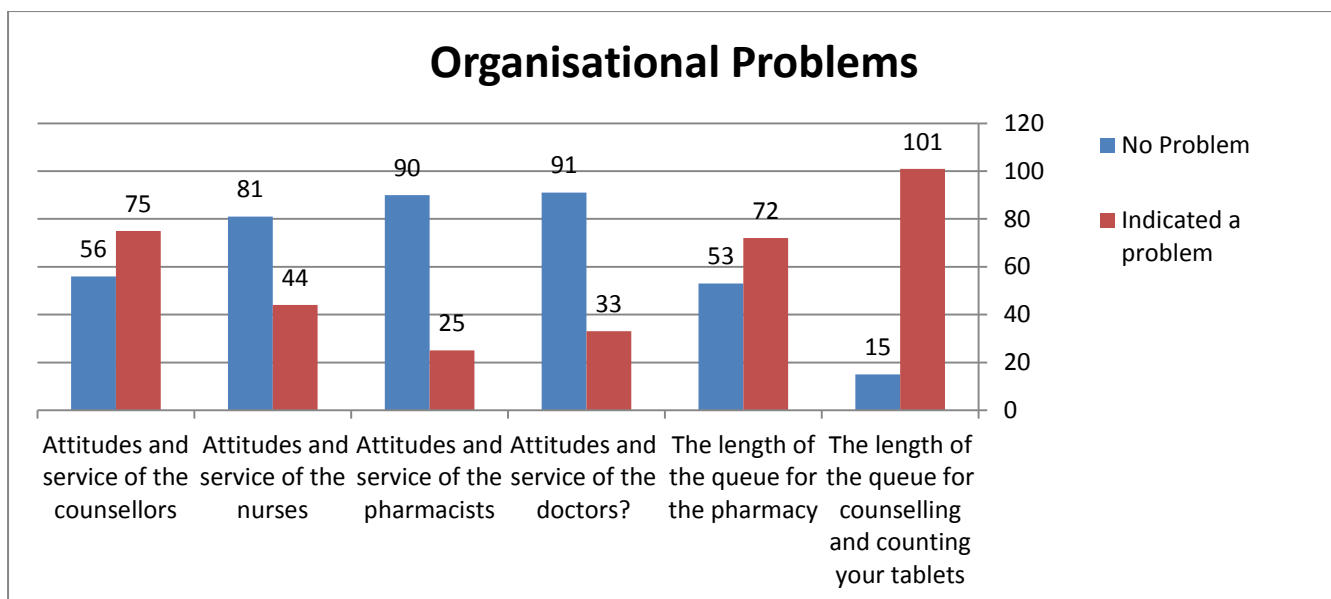
Figure 5.6: Organisational Problems
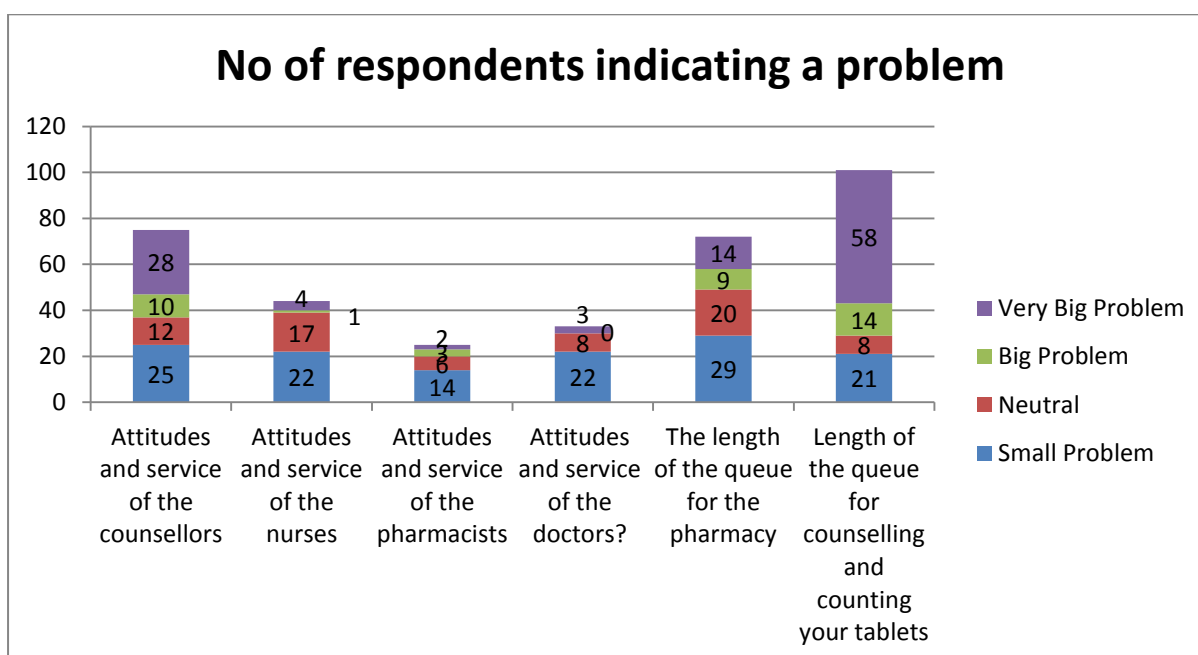
Figure 5.7: Extent of Organisational Problems

Figure 5.6 and 5.7 clearly indicate that the biggest organisational barrier experienced by respondents is the length of the queue for counselling and counting tablets, followed by the attitudes and service of the counsellors. Generally, the attitudes of the other healthcare workers (doctors, nurses and pharmacists) did not feature as a significant problem. In the following sections each of the organisational barriers are discussed in turn.

111

5.3.1) Card Office – Administration

Poor administration has serious implications for healthcare service delivery and patient satisfaction (Penchansky and Thomas, 1981). Clerks and administrators are the front line of hospitals or clinics and the patients' first encounter with the healthcare service is usually with the administrative aspect of the hospital. The quality of their services often sets the tone for the rest of a patient's visit. One of the most important functions of the administrative section is the keeping and maintaining of hospital records and files. Hospital files contain all the valuable information gathered over a period of time and documents all the points of care with

the healthcare service. The hospital file represents time, treatment, services, and money spent on the health care of a patient. It is one of the most valuable documents within the healthcare facility. This study found that more than half, 53%, of the participants' hospital files have been lost or misplaced by the card office at some point (see Figure 5.8 below).

Has your card ever been lost by hostipal clerks?

5

42

53

- Yes
- No
- Question not answered
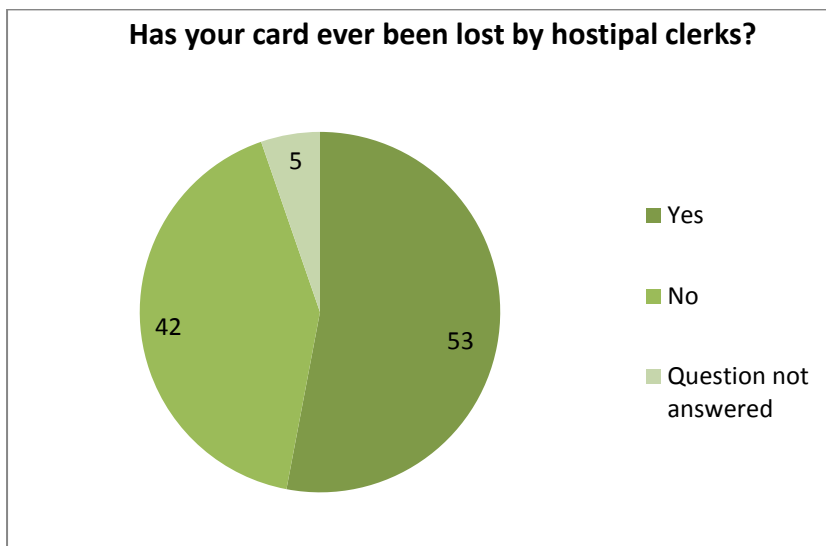
Figure 5.8: Extent of Card Loss

Besides the economic and service implications of a lost file, the issue of confidentiality is also of concern. Hospital files contain all the patient's relevant test results and summaries of consultations or admissions. A lost file compromises the patient's right to confidentiality. During a focus groups with female participants in the ART clinic, I asked how many of the

112

participants' files had been lost at the card office. All eight women replied in the affirmative. The paper-based recording and keeping of medical information thus seems to be a major problem for many people. Lauren said of the system that *"it is still very old fashion and it is an un-structured process and I hate it"*.

The lost files at the card office are a significant problem. 53% of the respondents who completed the questionnaire said that their hospital files had been lost by the card office. This has implications for the patients as well as the running of the clinic. Some participants in the focus group said that it made them so angry when their files got lost that they did not feel like returning to the clinic because they had to repeat all the tests again. The repetition of the tests is both expensive and time consuming, and one responded said that: *"losing my card (file) made me very angry. I felt so angry that I did not feel like returning to the hospital or clinic."* In addition, lost files also impacts negatively on the entire clinic and the processes involved in running the clinic. This is evident in the words of one of the doctors who deals only with adult patients, Dr Victoria said: *"as you can see, we (the doctors) are just standing around. The clinic is full and there are many patients but because of the delays in the card office we are now also delayed. Some of these patients arrived at the hospital at 04:00am this morning to stand in the queue, but no one seems to pay attention to this. It is frustrating because the patients get tired and hungry and we, the doctors, only see the patients later in the day."*

Patients' concerns over issues of lost cards are further evident in the words of Maggie, a female participant: *"How is this possible that such a thick card can go missing from card office? Why cards disappear every month? How one can explain this? This is really shocking there is no order at the card office,"* stated Gill a female participant in one of the focus groups.

Janet, another female participant shared her story about the card office losing her file: *"Our card goes missing at the card office. Previously I was pregnant and I was seen by a gynaecologist and had a miscarriage. After that I was scheduled to see a gynaecologist in Room 6; my card with my previous notes went missing. Room 6 doctor didn't have any clue of my previous history, meaning the finding from my previous miscarriage and so forth. That is really a challenge. I am now offered a duplicate card which has no previous notes regarding my previous pregnancy etc. To date my old cards have not been found."*

Another female participant, Rose, agreed with the previous comments*: "I have also experienced the same problem. Many times I have come to card office looking for my clinic card they always say that they can't find it. I would suggest that cards should be filed and sorted alphabetically. Or the other option; HIV patients should be allowed to take their cards home and return them during their appointment date, pay by the cashier and go to the clinic".*

Lauren further added to the problem of lost cards by noting that missing cards not only cause a problem in terms of valuable medical information that is lost, as well as major time delays but also exposes patients to unnecessary pathogens. This is evident in her words, *"You sit in very long lines with people coughing on you getting infected with their sicknesses. For me the process is not streamlined and not user friendly. It's an old way of doing things probably this is caused by the fact that this is a government institute."* As she explained she mentioned that because of the long wait due to a missing file they (the HIV positive patients) are exposed to a range of infectious diseases, and it presents a situation of potential harm.

Betty, 27, also complained about the delays of the card office and suggested that patients keep their files*: "Collection of card delays us a lot due to the fact that they are lost, so we would prefer to keep our cards together."* Veronica, a 29 year old female participant, also

commented on this and said that patients' files are safer at home with them: *"I would say the waiting period while collecting cards. The missing cards with all our important history. My opinion would be rather to allow us to take our cards home to be safe. Do away with duplicates they are of no use to doctors they have no previous patient notes."*

The above quotations clearly indicate that patients consider missing files to be a major problem at the clinic and that this primary concern of missing files has the opportunity of transferring into a number of other related concerns including exposure to infection because the waiting times if increased.

5.3.2) The Counsellors

The adherence counselling at the clinic was identified as a problematic area and presented the most significant barrier to accessing ART of all the service providers at the clinic. Only 11% of the respondents said that they had not experienced any problems with the counsellors in contrast to the 75% who said that the counsellors presented a major barrier for them. During the analysis of the qualitative interview transcripts, the word *counselling* was mentioned more than any other word.

A significant result from the questionnaires showed that over half of the respondents felt that the attitude of the councillors is a problem. 21% of patients scaled the problem as being catastrophic. This statistic is the most significant barrier to continuous access to ART in this particular clinic and the statistical data was corroborated by the qualitative data. The result from the quantitative data is presented in Figure 5.9 below.
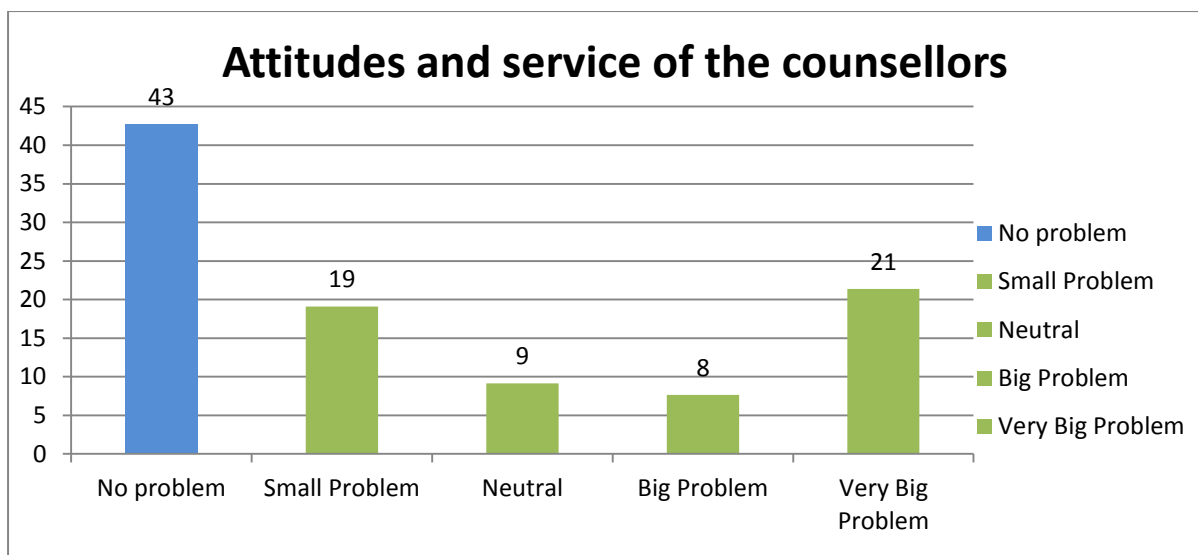
Figure 5.9: Attitudes and Service of the Counsellors

The fact that the counselling itself is the most significant barriers to accessing ART in this clinic is cause for concern and stems from the fact that policies are often misguided and out of place. The purpose of the adherence counselling is to provide a supporting service to the patients who are on life-long treatment. It is a medical intervention to ensure adherence to the ART drugs. However as was discussed earlier, biomedical interventions are not always well equipped to handle problems that are situated beyond the individual patient as the issues that are discussed with the counsellors are beyond the narrow view of the biomedical system. It is in line with this individualistic biomedical model that counselling is referred to as *adherence counselling*, because adherence focuses solely on the individual patient's ability to take treatment as prescribed. If the patient cannot comply with the strict adherence required by the ART program, then the counsellor is trained to label that patient as a '*defaulter*', despite the fact that the reasons for defaulting are often beyond the control of the individual. While the distinction between adherence and access is often overlooked in the public healthcare system, the literature too frequently confuses the situation. Ware et al., (2013) says of adherence that "since adherence means not only following dosing regimens but also being able to refill prescriptions, and since prescriptions are refilled as part of routine follow-up visits in Africa,

116

barriers to adherence and retention overlap" (Ware et al., 2009: 2). These authors further state that the term 'defaulter' is exclusively African and "imply that missed visits result from patient choice" (Ware et al., 2009: 4). However, a patient's ability to refill medications is not a matter of adherence, or at least should not be seen as one, since patients seldom miss their visits or 'default' from sheer personal choice. Instead refilling medications should be seen as part of the concept of continuous access to healthcare services. By erroneously using the term *adherence* synonymously with the concept of *access* to healthcare, discrimination and stigma is perpetuated in both the literature and the healthcare setting because most often patients are subjected to structural violence that creates the situations in which they miss their appointments. This is evident in the words of Gloria, a female research participant, who stated, *"The counsellors need more training. If one has not come on their appointment date it does not mean that they have defaulted treatment"*.

Another female participant, Doris, likewise said of this situation: *"it's a waste of time to meet with counsellors. I collect my tablets because I want to get better. They insist on counting my tablets, in their minds checking whether I have defaulted or not. For me that is a waste of time. They are also abrupt they have no time for us. In fact they need counselling themselves."* Further to this another female participant, Joyce, remarked: *"They do not even look up but just demand your pill bottle so rudely. Then if you have extra pills they will write 'defaulter' on it even though you have taken all your pills. They won't even ask why there is extra. They do not listen to us. They expect us to just sit quiet and listen to them shouting at us."*

A male participant, Jack, also commented on the attitudes and services of the counsellors, he said that: **"***Counsellors are not 100% sure about what they should do for patients. They make you feel as if you owe them something by attending at the clinic. Or by being there you irritate them somehow. I really don't like to be seen by counsellors. Yes they did help me at*

117

the beginning when I knew nothing about treatment but now I feel as if I am more professional then them".

Nelly a female patient aged 32, who has been taking ART drugs since 2009 recounts her experience of being labelled a 'd*efaulte*r' in her attempt to prevent social stigma and discrimination. *"One month I decided to put the tablets together because some tablets make lots of noise when in the container. Even in the taxi when you move your bag they make a noise. If someone knows these tablets they will know what tablets you are carrying. I showed my tablets to the counsellor and she said she will take as if I did not bring them since they are not in their container. She wrote on the card that I had defaulted and sent me to the doctor even though I had these tablets."* Nelly also felt that the counsellors needed further training in how to deal with patients, she said that: *"The counselling is so bad. Those counsellors, they need counselling themselves!"*

Regarding this matter of having to attend the adherence counselling at every monthly visit the patients have no negotiating power. They are forced to endure the protocol out of fear from being labelled a '*defaulter*' or for fear of having access to their drugs prevented because they did not follow the rules. As Mary, a female participant stated: *"They threaten us. According to my knowledge a counsellor should be someone friendly, someone you can easily talk to. The way these counsellors are they make it difficult to talk freely. We even hide some things from them,"* Another female participant, Janet, added, *"We do not talk to counsellors except when they want to know about tablets and ask you the usual questions. Other than this we do not spend time with them."* Adding to this, Sindi stated *"They do not listen, we cannot talk to them about our problems,"* while Priscilla further stressed, *"They supposed to be there for you but they don't care about us. Some of them they ignore you, continue with what they are*

busy with or play with their cell phone. Some patients they count their own tablets and sign the book and leave".

Gloria who has been on ART since 2008, told me her story about being afraid to disclose her HIV status at work and how the counsellors *'punish'* her for trying to access her treatment without following their rules. Gloria stated, *"I informed my manager that I have to collect treatment monthly. Of late she does not like the idea. At the same time I cannot disclose my status to my boss because she is the type which will tell the entire world. I reported this to the counsellors and the doctor. Sometimes I cannot make my appointment because of this. When that happens I call my child to come for my treatment but to my disappointment the counsellors refuse to give my treatment. My card is even written that "we told you that we will not give treatment to your child, come when you have time". Even when you call and say but you do know my child they tell you the same. If you have missed your appointment you get told that you defaulted even if you know that you still have enough pills. They tell you rudely that they will not help you until you go to the doctor and they throw the card at you. They tell you they can't help you if you do not want to help yourself. I tell them that I will see the doctor because they can't help me anyway. You end up being rude yourself."*

Chris, a male participant aged 39, and on ART since 2010, explained how he got into trouble with the counsellors when he attempted to prevent discrimination from some of his community members. *"One day I came without my treatment because I had gone pass somewhere and did not want that person to see my treatment. The counsellor said next time she will not give me the treatment – I asked myself what does this got to do with it because I had come on my appointment date. If you are explaining the story to a counsellor she has to understand because she is also human. There are times whereby you can't take your treatment with you for certain reasons."*

These comments highlight the discrimination that the patients are subjected to by the healthcare system. Despite the negative treatment that patients are subjected to by the counsellors, they lack negotiating power and therefore have no choice but to endure the adherence counselling to be able to access their ART drugs. If they decide that they cannot endure the counselling any longer and leave the clinic, they face a certain death. Of particular concern is that most patients consider this clinic's service to be superior to that of the local clinics and thus if they leave the clinic as a result of the negative treatment they receive, they are unlikely to seek services elsewhere.

Besides the poor services offered by the counsellors to the patients, it was suggested by some participants that the counselling was no longer required and that they thought of it as a time wasting activity. This was particularly reported by patients who had already been on ART treatment for some time, particularly over two years. Participants often mentioned that the counselling was helpful in their first year on treatment, but that after they became accustomed to taking their tablets daily the need for counselling decreased.. As Shawn told me during a group discussion: *"No, we don't want to be seen by counsellors especially we as old patients. Joining counsellor's queue is a waste of time especially if one is rushing back to work. That takes about two to three hours it is really time consuming"*.

The need for healthcare service is therefore frequently evaluated differently by the patients and the healthcare system .This difference in need perception was mentioned by both Penchansky and Thomas (1981) and Aday and Andersen (1974) in their definitions of access to healthcare and utilization of service. The changing perception of need for services must accommodate the changing perception of the patients' needs to further ensure continuation of utilization of ART services.

In addition to the problems already noted, the waiting time to be seen by the counsellors is also longer than at any other point of service in the clinic and most patients clearly view this as an unnecessary step in the process of attaining medication. This is evident in the words of Michael, a male participant, *"I have been here very early in the morning however I have spent so much time waiting to see a counsellor for nothing. Therefore I don't need them"*. Another male participant, Luke, agreed with the previous statement, he added that: *"If we could just come in the morning weigh ourselves check blood pressure and go straight to the doctor. We don't really need counsellors"*.

The adherence counselling has been implemented by healthcare policy as a strategy to ensure that patients remain on their treatment. However, as is evident from the above data and discussion, this service becomes less relevant the longer the patients remain in the system. Not only is it considered a time wasting and/or unnecessary activity but also contributes to the suffering that patients already endure in the form of perpetuating stigma and discrimination. This is a clear example of structural violence since the process is created by a social structure in the form of policy and its effects are often invisible, but leave the patients powerless.

5.3.3) Attitudes and services of the rest of the health care workers in the clinic

The pharmacists in the clinic scored the highest percentage of satisfaction with 67% of the respondents saying that they had no problem with their attitudes and service. The doctors came second with 60% and the nursing staff third with 54% of the participants saying that they had not experienced any problems with their service.

The higher scores obtained by the other healthcare professionals in the clinic might be related to the associated need that the various actors serve and fulfil. The nurses provide and administer care and treatment, while the pharmacists dispense the actual drugs. The doctors

attend to any reported illness and prescribe the required treatment regimens. The doctors play a particularly significant role in this clinic as they are often considered to be the gatekeepers of extra medical attention, such as specialised services. They are also responsible for filling in the social disability grant forms and therefore hold a particular power over those patients who seek to apply for financial assistance.

5.3.4) Monthly Visits

Monthly visits to collect ART drugs are mandated in the ART program policy with a motivation to ensure adherence[32]. This policy has caused some of the greatest upset at the clinic amongst the patients, as is presented in Figure 5.10. In the questionnaire only 35% of the respondents who answered the question regarding monthly visits said that the monthly visits were not a problem while 65% said that monthly visits do present a problem for them. A significant proportion, 20% of the respondents, reported that the monthly visits presented such a big problem for them that it could result in them not returning to the clinic or not remaining in the ART program.
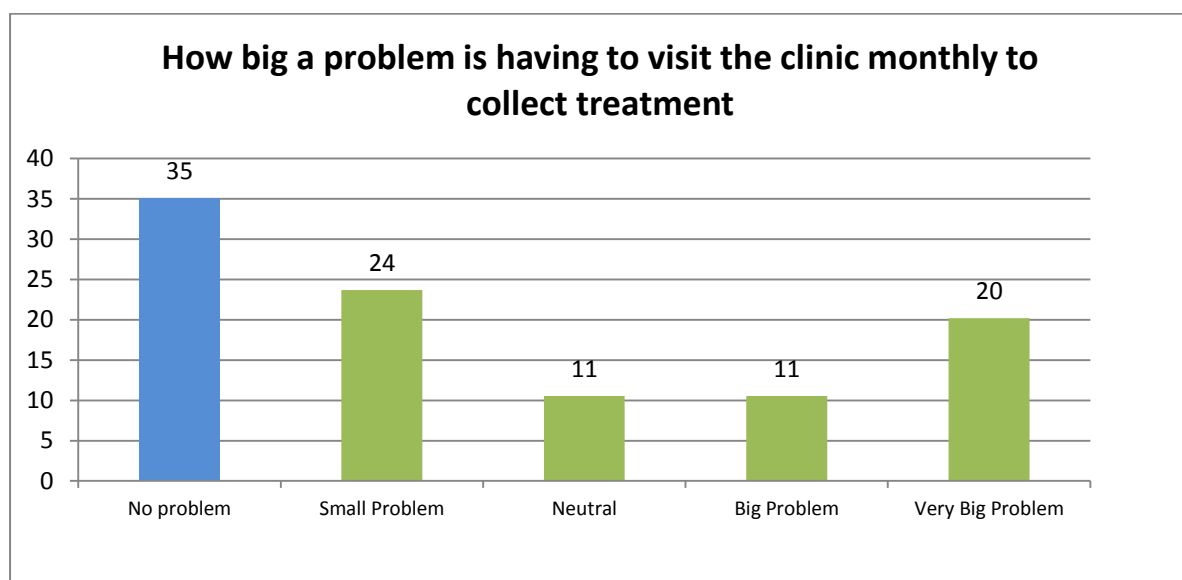
Figure 5.10: Scaling the problem of monthly visits to collect treatment.

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[32] See the 'The South African Antiretroviral Treatment Guidelines 2013'.

The problem of monthly visits was succinctly noted by research participants in the qualitative research. One female participant, Sindi, said during a focus group: *"Two months is preferable. Please don't keep us waiting just to collect treatment. You need to separate repeat and new patients so that everyone is comfortable and not delayed."* Another member of the group, Joyce added to this: *"It is really uncomfortable for me to collect treatment every month"*. Jack, a male participant simply stated that: *"Coming here is time consuming and it interrupts my work."*

The problem of monthly visits was also clearly articulated in the words of Lauren a key informant who said that*: "I hate this process, for me it is long and a tedious process. For me the process is not streamlined and it's an old way of doing things. The process takes you away from your daily life. I don't like collecting my treatment every month. I would prefer to collect my treatment every six month and six month after that I should be allowed to see the doctor and get my blood pressure checked, not to check my blood pressure every month for me that is a waste of time"*. Adding to this Lauren suggested that: *"Perhaps you should have different quadrants of patients that would identify those who need more attention. Walking patients can collect and leave. This is a suggestion to make the collection times faster. Those who are normal and healthy just there at the hospital to collect treatment should be also allowed to have their own queues"*.

Figures 5.11 and Figures 5.12 below shows the time spent per visit to collect treatment, as well as the time taken to collect treatment and see the doctor[33].

On average how much time do you spend per visit to collect treatment and to see the doctor?

	1-2 hours	3-5 hours	6-7 hours	Other
% of responses	22	49	25	4
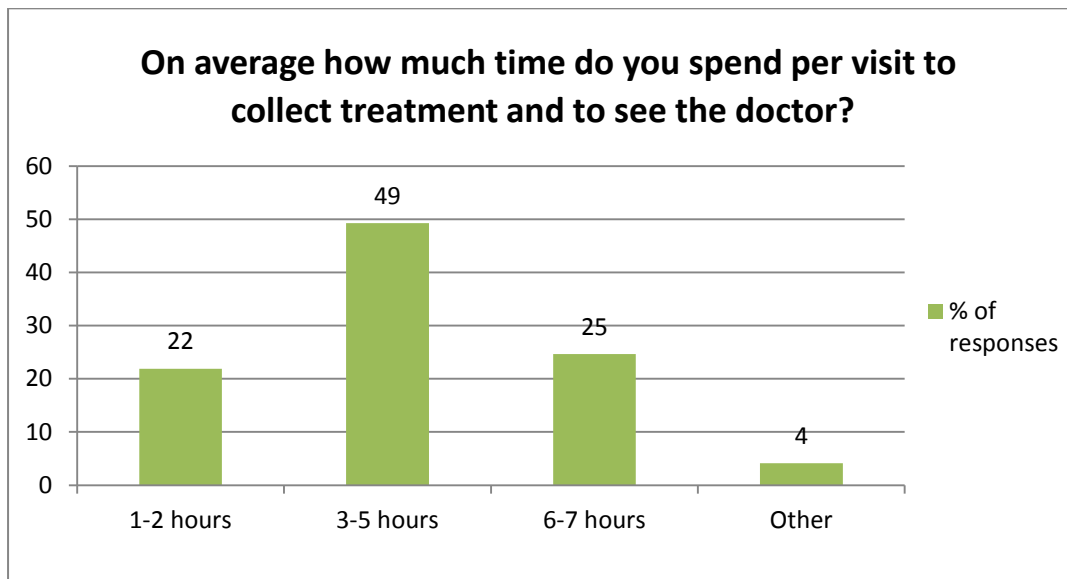
Figure 5.11: Time spent per visit including the doctor visit.

On average how much time do you spend per visit just to collect your treatment?

	1-2 hours	3-5 hours	6-7 hours	Other
% of sample	19	57	16	8
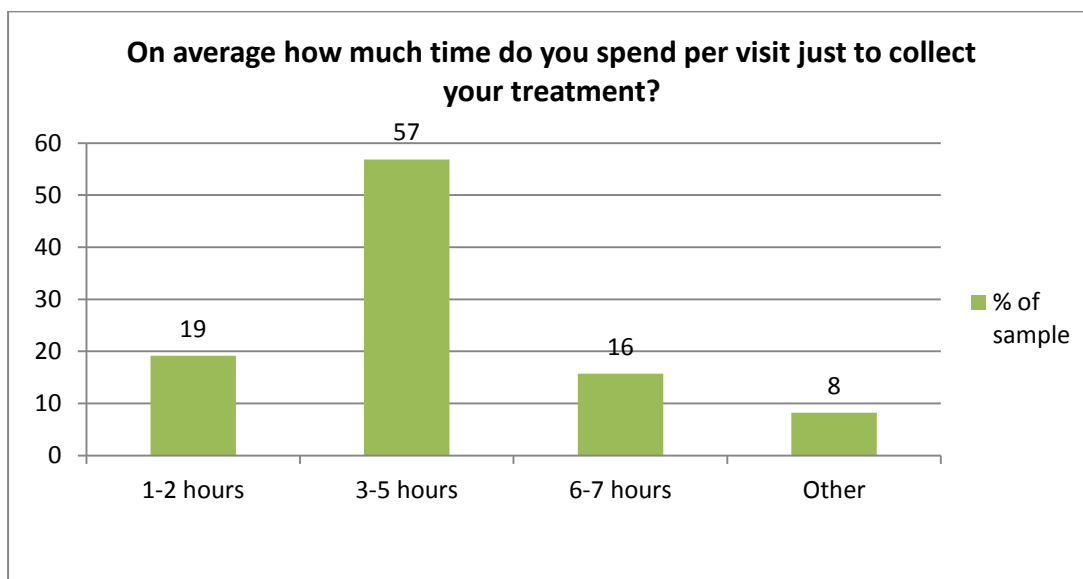
Figure 5.12: Average time spent, excluding consultation by the doctors

The majority of the patients indicated that they spend on average between three and five hours at the clinic per month to collect their treatment and see the counsellors. This time bracket remained roughly the same for visits that included being seen by a doctor. However,

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[33] Excluding those that did not answer the question or answered incorrectly

124

a significant proportion of participants (25%) reported that they spent between six and seven hours in the clinic per visit when visiting the doctor and collecting treatment.

The reported statistic that there is little difference in the time spent at the clinic when the doctor's visit is included is significant. This could result from the increased patient load in the clinic which places time pressures on the doctors to see to all their patients thus limiting contact time between doctor and patient. Penchansky and Thomas (1981) highlight that with an increase in barriers to accessing healthcare services, there is a decrease in the time spent when a patient consults the doctors, and contributes to deceasing the quality of services offered by the doctor.

While the monthly visits have been identified as a major barrier to accessing ART treatment at this clinic, the monthly visits have likewise been identified in the more recent literature as an obstacle to accessing ART drugs (see for example Wilkinson, 2013). Some interventions have been created to decrease the number of visits such as the adherence clubs that are run in the Western Cape with the help of Médecins Sans Frontières (MSF)[34]. The clinic where this research was conducted follows national policies and provincial protocols diligently. As a result there is little room for questioning whether the protocols benefit the patients in the long term, or what effect the decisions taken at policy level will have on the lives of the patients.

The ART program is expanding, and as was highlighted in the literature earlier, the government aims to double the number of people receiving ART by 2015. This in effect means that the population of the clinic will only increase. The burden on the healthcare system will also increase and the expansion will be felt by the healthcare workers, but more so by the patients who utilize the services.

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[34] *Médecins Sans Frontières* (*MSF*): "is an international, independent, medical humanitarian organisation that delivers emergency aid to people affected by armed conflict, epidemics, natural disasters and exclusion from healthcare. MSF offers assistance to people based on need, irrespective of race, religion, gender or political affiliation". For more on MSF see http://www.msf.org

The time delays created by the increased volume of patients in the clinic due to their monthly appointments is however not the only problems that the monthly visits create. One of the most significant effects of the monthly visit is the economic implications on the patients. The economic factors that result in barriers to accessing ART are further discussed in Chapter Six and demonstrate the interrelatedness of the barriers.

5.3.5) Operating times of the clinic

Operating times have been found to be a significant factor in satisfaction of services in the literature (see for example Penchansky and Thomas, 1981 and Donabedian, 1972), and can pose a major barrier to the availability dimension of accessing health care. This ART clinic operates from Monday to Friday from 07:00am to 16:00pm, and is closed on the weekends. Respondents were asked if this was considered to be a problem and the results are indicated in Figure 5.13 below.
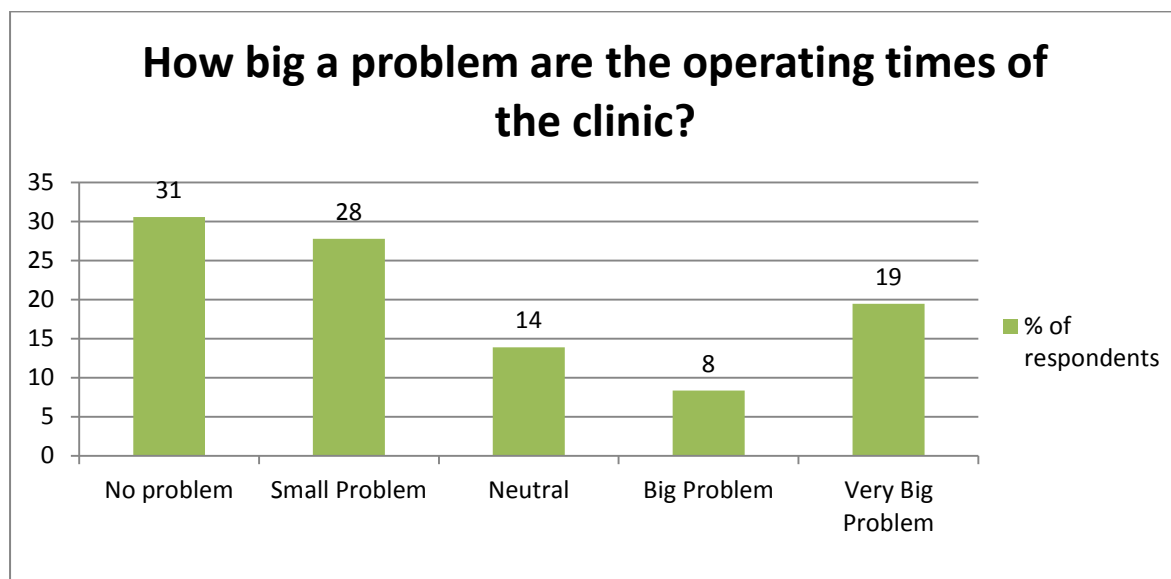
Figure 5.13: Indicating the extent of the clinic's operating hours.

According to the quantitative data, roughly a third of the participants said that the operating times of the clinic did not present a problem, while approximately two thirds said that it was a problem. Of those who listed it as a problem, 28% rated it as a small problem while 19% said

that it presented a catastrophic problem. Not surprisingly, when queried whether or not it would be easier to collect treatment on a weekend, almost half of the respondents indicated that this would be easier, as indicated in Figure 5.14 below.
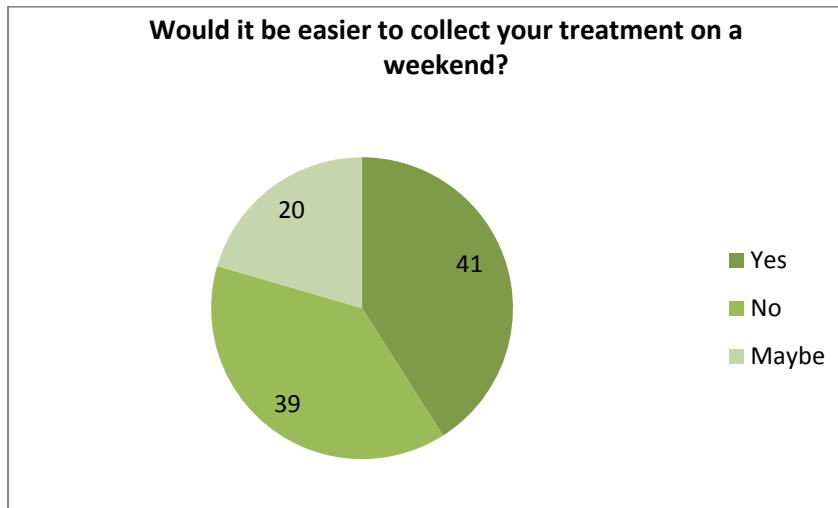
Figure 5.14: Collection over weekends

41% of the respondents said that it would be easier for them to collect their treatment over the weekends. 39% said that it would not make a difference and 20 % said that it might make things easier. These responses can be linked to the employment and unemployment of participants.

The operating times of the clinic impact the accommodative aspect of access to healthcare services. There are two main reasons why the operating times present a problem for patients. Firstly, for those who are employed, the fact that the clinic only operates during working hours has a negative impact on their employment. The second reason is stated by Michael, *"I came here at just after 13:00pm, after work. But when I got here the nurses scolded me and asked me why I came so late. They said that they will not help me on this day because it was too late and I was told to return home and come on another day. I do not understand why I get chased away when the clinic's doors only close at 16:00pm."*

127

The healthcare workers in the clinic, guided by policy and an increased demand for services, insist that the patients attend the clinic early in the morning. This places further strain on the participants, especially those who are employed. It also indicates the unaccommodating stance of the healthcare system towards the patients' needs, which in turn impacts negatively on the patients' ability to access healthcare.

In this chapter the first two categories of barriers were discussed, namely: the physical barriers that include transport and physical distance; and organisational barriers that include administrative issues, attitudes of the healthcare workers, the counsellors and counselling, and monthly visits to the clinic. Following Sandy through her day at the clinic provided a glimpse of the process involved for the patients to collect their treatment. In the next chapter I will discuss the remained two categories of barriers, namely: social and economic barriers.

CHAPTER SIX: The Social and Economic Barriers that Impact upon Continuous Access to Antiretroviral Therapy

Chapter Five outlined the physical and organisational barriers to accessing healthcare that were identified in this particular clinic through the use of both qualitative and quantitative methodology. This chapter, in turn, focuses on the barriers to accessing healthcare, but the emphasis is now placed directly upon the social and economic factors that impact upon the ability of patients to adequately access antiretroviral treatment at the clinic in question.

6.1) Social Barriers

6.1.1) Gender

As previously indicated, the majority of the respondents in this study were female, 70%, with males comprising 30% of the study population. This skewed representation was expected since it reflects the gender dynamics of the clinic's population. The ART program has a particular focus on women because females comprise more than 50% of the people living with HIV/AIDS in the world, and in sub-Saharan Africa (UNAIDS, 2012). In South Africa pregnant women were the first people to receive any form of ART drugs for the prevention of mother to child transmission. This focus on women has led to a 'feminisation' of the epidemic and in the focus of the ART program. Men have largely been excluded from the ART focus, especially in the earlier years of the program when they were not eligible to receive ART drugs (Tersbøl, 2006).

This particular clinic also commenced with the Prevention of Mother to Child Therapy (PMTCT) programme and expanded from there. However, at the outset of the ART programme it was assumed that pregnant women would attend the clinic and bring their male partners with for treatment of opportunistic infections, and that these male partners would

commence with ART therapy when the policy change allowed for it. However, in reality this did not transpire and the ART program continues to be dominated by women.

While the PMTCT program has been very successful, it is a preventative strategy that fits in well with the medical model. The reason why it has worked well under the medical model is because a drug can be prescribed that results in the prevention of HIV infection (Abdool Karim and Abdool Karim, 2010). Biomedicine is far more in control of prevention in this scenario, especially considering that most women deliver their babies in a healthcare facility (NDOH and HST, 2012). Even the latest ART policy favours the treatment of pregnant women above all other categories as the policy states that if a pregnant woman tests positive for HIV she should be commenced on triple ART on the same day as HIV diagnosis, regardless of her CD_4 count (NDOH, 2013). This policy change greatly facilitates the access of pregnant women into the ART program and this is mirrored in the clinic study population where 23% of the study population indicated that their pregnancy status was the reason why they entered the ART program.

6.1.2) Personal Health beliefs

The personal factor of forgetfulness played a significant part at the clinic in terms of both adherence and access. Forgetfulness was cited as the most common reason for having missed a dose of drugs. Forgetfulness was also identified by van Dyk (2010) as a barrier to adherence. Forgetfulness, further dealt with in Aday and Andersen's (1974) framework for understanding access to health care, demonstrates how the personal illness behaviour of the patient can affect access to health care.

A patient's own belief about the treatment and cause of disease does affect ability to access treatment and remain adherent. 93% of the respondents said that they believed that ART improved their health. 70% said that they did not believe that traditional remedies work for HIV infection; and correspondingly 91% of the respondents said that they are not taking any traditional remedies concurrently with their ART drugs.

During participant observation at the clinic I often found myself sitting alongside patients in the queue. While conducting unstructured interviews I was sitting in the queue for the pharmacy when a patient Janice began talking to me. Janice stated that every month she endures the long queues, rude staff and painful process of collecting ART drugs, but Janice does not take the tablets at home; instead she throws them away in the nearest bin outside the hospital. *"I come here every month to collect these tablets. But they have side effects; they shape your body and make you ill. I was never ill until I started with these tablets. So I now I just come here but I do not take them. The doctors made a mistake they simply did not know what else to diagnose me with so they just said HIV."*

As is evident in the above conversation, the patient's own illness belief as well as the illness beliefs of the supporting families plays a vital role in whether ART is accessed and used correctly. If people do not believe in the drugs, or do not believe they have HIV/AIDS; they will not use the drugs. Conversely, if patients believe that ART drug therapy has health benefits, as in the case of 93% of the research participants, then theoretically they will take them. This however, is not the case as a host of factors prohibit people accessing ART therapy on a continuous basis.

This noted, religious belief can also influence patients to stop taking ART. In accordance with this, Betty mentioned an experience she had had with some members of her community: "*Born again Christians they make us believe that if they pray for us you would get healed from HIV. They tell you to stop it for a while, they pray for you and see what happens after a period of 3 weeks or more after prayer. That causes lots of frictions between doctor and patient because patient end up defaulting with no proper explanation. Some patients end up back to the hospital admitted probably for a month or more.*"

Another female participant, Nelly came up to me one day at the clinic and held out a bottle of water with a sticker of a pastor printed on the label. She told me that this particular pastor was preaching that his holy water and prayer can cure HIV infection. She claimed that some of her friends, who were HIV positive had gone to his services, had consumed the water and now they are no longer HIV positive. These women had taken ART previously but have since stopped because they are now supposedly 'cured'. Nelly's concern was not unfounded. Recently a pastor in the Durban area has been reprimanded for selling his 'holy' water that he claims cures HIV infection. The local government along with the national department of health was quick to renounce his claims and reprimand the pastor for falsely leading desperate people to believe that they could be cured of infection (Peters, 2013).

Like religious beliefs, cultural beliefs and traditional medicines can also impact on access to ART drugs. Steven drew a link between traditional medications and stigma in the community: "*Some people would prefer to take traditional medicines instead of accepting that they are HIV positive, they should be on treatment. At Government hospitals treatment is reasonable, not expensive, sometime free of charge, however people would rather pay R100*

to a traditional healer for Imbiza[35]. I still feel that people from rural areas of all walks of life should be more educated about ARVs and they must stop to say they have been bewitched."

6.1.3) Disclosure and Family Support

Disclosure and non-disclosure have been identified as factors that can influence access to ART services as either a facilitator or an inhibitor to access (van Dyk, 2010). 80% of the respondents said that they had disclosed their status and use of ART to a family member, while 15% said that they had not. 5% of the respondents did not answer this question. Further to this 55% said that their treatment supporter was essential to help them access their ART on a monthly basis. The importance of a treatment supporter is indicated in the Figure 6.1 below.

What effect does a treatment supporter have on your ability to access your treatment?
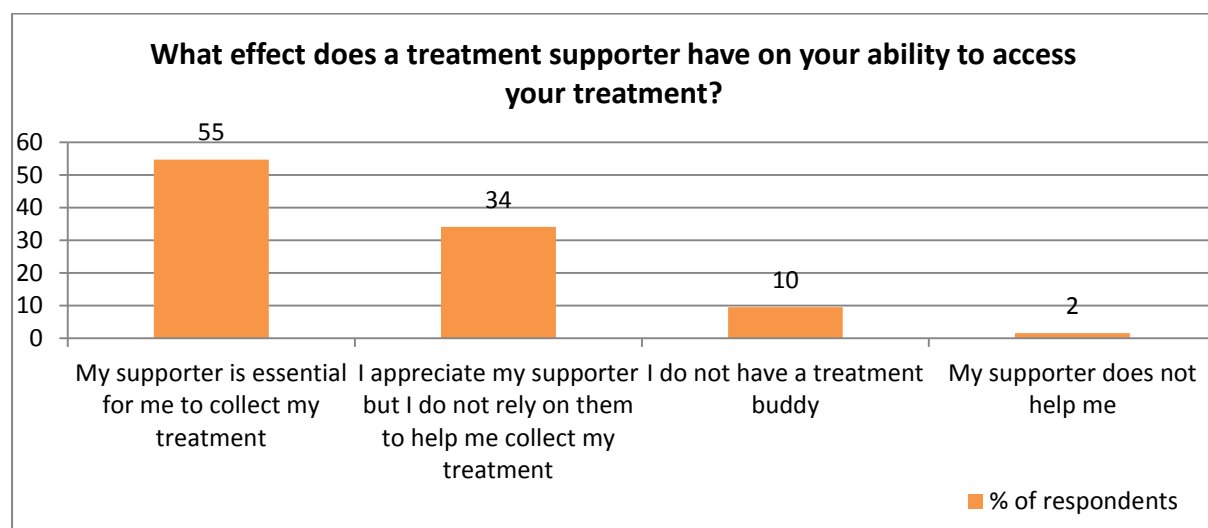
Figure 6.1: Treatment supporter

Family support, or any form of social support, is undeniably one of the most important factors for facilitating access to care and treatment. Zoe, a female participant told me that: *"I have told everyone at home and they support me. I have also disclosed to my immediate families including my children and people that I socialise with. I do take my treatment and I do receive lots of support from home."* Victor, a male patient, likewise stated: *"In my*

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[35] Imbiza: Imbiza refers to a traditional herbal drink that has medicinal properties and is made by a traditional healer (http://ndr.org.za/indigenous-knowledge/stories/182). Veronica explained that the drink is made to "clean the blood of a person".

community I am very lucky because people around there are very supportive. They support
you as long as you are aware of your status and you are taking treatment regularly. They
even advise you that there is life after HIV."

Positive social support can motivate patients to stay adherent and can simultaneously hold patients accountable. This is evident in the words of Veronica: "*My sister knows that I take ARV's. She knows what my times are, and she will always ask me if I have taken my treatment. This helps keep me motivated to know that she is also in it with me. She is my support. I can't stop anytime because she will know and ask.*"

On the flip side of the coin, however, several patients mentioned the effect that a lack of social support can have on a patient's ability to access treatment. The lack of family support can be detrimental for accessing ART. One of the male participants, Samuel, is 20 years old and is co-infected with Tuberculosis. The double burden of disease has taken its toll on the young man's body and he is thin and emaciated. Dr Victoria referred him to a dietician to assist with regaining his weight. He was commenced on ART and referred back to his local clinic for follow-up.

Three months later he returned to our clinic for a check-up. He had visibly lost weight and looked even more emaciated than he had before. At this visit Samuel came alone whereas he had previously been accompanied by one of his uncles. When asked about the nutritional supplements and porridge that the dietician had prescribed for him, as it is unusual for a patient to continue losing so much weight after three months on TB treatment, Samuel confessed the painful truth that his uncles and brother with whom he lives drink consume copious amounts of alcohol on a daily basis. He claimed that they do not bother buying any food but spend all the household money, the little that there is, on alcohol. Samuel further noted that when their money runs out they visit their friends and the drinking continues.

Samuel said that on most days he only has a slice of bread to eat in the evenings. When I probed about the supplements he had received from the dietician, he continued: *"Well, the lady had given me some milk to drink. She gave me plenty bottles of milk but then I had to take them home. Those guys that I live with, they drank all my milk before I could. They always eat all my food and I have no way of keeping it safe and from them. So now I don't have any more milk. I have an appointment with her next week again."*

When I then asked Samuel who assists him when collecting his treatment from the clinic, Samuel responded*: "No one. They just leave me on my bed. I have to get the energy somehow and walk to the clinic. The clinic is not far, but it is too far for someone who is sick like me. My chest pains when I have to walk the distance. My feet burn and is painful too."*

Samuel's story is not unusual but does capture the importance of family support for those who are ill. In Samuel's case there are numerous physical and structural barriers that create obstacles for him to access his ART, but it is his lack of family support that presents his biggest obstacle.

6.2)   Stigma

The attitudes in the local communities towards people who are HIV positive and receiving ART was furthermore identified as a major social barrier to accessing ART drugs. Participants were asked whether or not they perceive the attitudes of their community members towards people on ART to be a problem and 29% of the questionnaire participants stated that this is not a problem, but, 71% said that stigma is a problem of varying proportions. A total of 19% said stigma is a small problem, 16% were neutral, 15% said it is a big problem, and 22% identified stigma as a catastrophic problem. The results are presented in Figure 6.2 below.
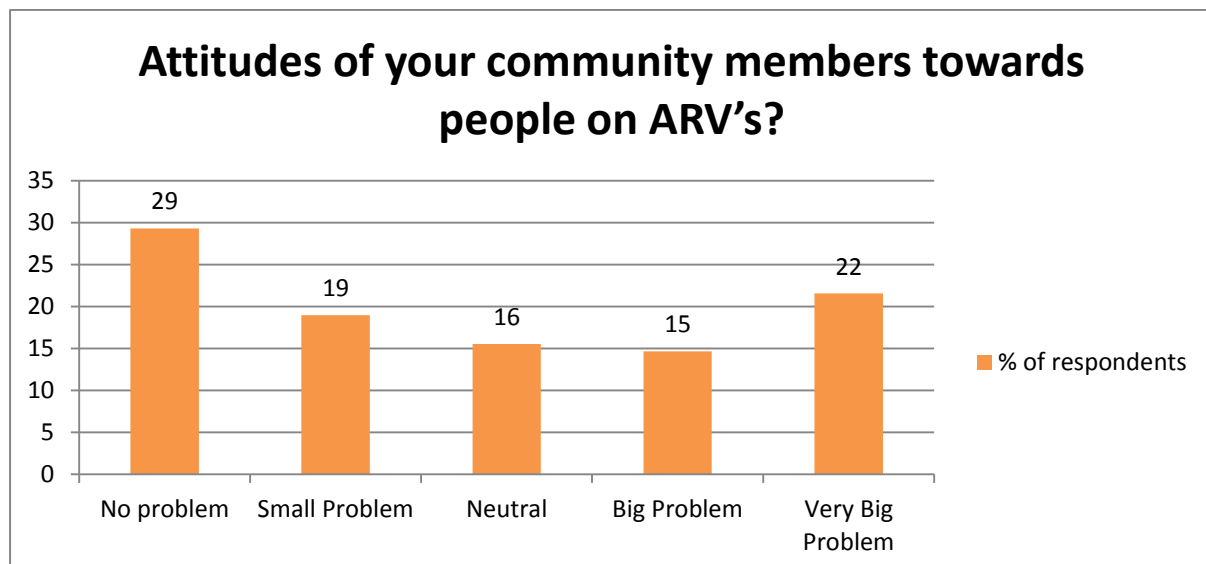
Figure 6.2: Attitudes of the community

6.2.1)   Stigma at the family level

A male participant, Roger, stated that stigma on the level of family is a major problem: "*I met a 'gogo' the other day at the clinic who is 60 years old lives in Umlazi who have been ill-treated by her mother who doesn't allow her to use her utensils, dishes etc. When they have visitors after she has eaten or used their dishes etc. she is requested to wash up everything that she has come into contact with or used just because they are afraid that she would give*

them HIV. This is very sad to find that there are still people out there who ill-treat their own family members badly just because they are HIV positive".

Another patient, Jenni, is a 26 year old female who started her ART in 2010. Jenny told me her story about accessing her ART. Since I have known Jenny she has been very enthusiastic about her treatment and improving her health. Prior to being diagnosed with HIV Jenni developed a Tuberculosis infection and was then diagnosed with HIV. Tuberculosis is the most common cause of death for patients infected with HIV and the two combined have often been referred to as the co-morbidity challenge in South Africa (NDOH and HST, 2012, Rossouw et al., 2013). In this case the TB infection provided a good ruse for Jenni to attend health care services frequently, especially since her family is very judgemental of HIV infected people and Jenni was too afraid to disclose her status to them. Jenni, like so many of the clinic attenders, is unemployed. She relies heavily on her family for social and material support.

Jenni managed to continue with her ART drugs even after her TB infection cleared two years ago. *"I just tell them that I still have the TB and that the doctor wants to check up on me because I am still very sick".* Jenny continued, *"It would be so much easier for me if I could collect maybe every three months. Then at least I would not have to borrow the money for transport every month and they would not ask all the questions about where I am going."*

The fact that Jenni was hiding her HIV status and ART from her family, ultimately affected her ability to access her treatment in the long term. According to Jenni's clinical notes and blood work she had a high level of adherence, but one day she simply stopped coming to the clinic to collect her tablets. When I contacted her to find out what had happened to her there was no response from her. Eventually I managed to get hold of her and she stated: *"My father found my ARV's. He was cleaning the house and found them under my bed. He threw them*

137

out, and then when he asked me what they were for I told him I am positive. He chased me out. I now live far away on the farm. There is no ARVs here." Her father, as a result of stigma surrounding HIV/AIDS, cut off her ability to access her treatment. Jenni is a thus a victim of various forms of structural violence. Her gender makes her vulnerable to HIV infection and her economic status contributes to her vulnerability and places her in a particularly volatile situation. Once her economic support was withdrawn her ability to continue accessing her treatment was exceedingly limited. Her suffering has been further exacerbated by the policies that drive the services in the ART clinic enforcing monthly patient visits to collect treatment. All of these larger societal forces have contributed to Jenni's discontinuation of ART treatment, indicating that on-going ART therapy is far broader than the individualistic assumptions of the biomedical paradigm and policy framework that stress adherence alone as an individual endeavour that can be simplistically equated with an individual action, devoid of the wider social and structural context and ramifications.

To the health care sector and health care providers working in the clinic Jenny just became another '*defaulter*', but her story shows the importance of family support and disclosure for continuous access to ART as well as the fact that it is imperative to look beyond individual actions when planning and implementing ART policy and programmes.

6.2.2) Community and workplace stigma

Family stigma thus clearly plays a significant role in continued access to ART therapy, but community and workplace social stigma also impacts negatively upon the continuation of ART.

This is evident in the words of Lauren who told me that: *"Communities are still very shunting about treatment and the HIV stigma and they try by all means to keep away from the HIV subject."* Chris shared this view as his reason for attending this particular ART clinic and not the one closer to his house: *"I prefer to come here because I do not know anyone here and nobody from my community is here. People talk in the communities, in the clinics out there. It is so bad in the other clinics. When you go there, everyone they will know that you have this HIV."*

An interesting observation that arose from the focus groups was that the patients felt that the healthcare sector could intervene and assist with decreasing the levels of social stigma present in their local communities. They felt that educating the communities is key to decreasing the stigma. One male participant, Micheal, reiterated: *"Communities are always negative and positive, they really have different views. Surely it is important to attend classes so that one can be educated about treatment and their status. Education is important so that you can be counselled about treatment before starting treatment. Those who discourage treatment are those who are naïve about HIV treatment."*

While stigma in the community can impact upon access to ART, stigma in the work setting can also present a barrier to accessing treatment. One of the female focus groups participants, Mary. told me that: *"It's a problem to ask for day off every month at work and they don't understand. 3 months was better. Other employers don't understand if you have HIV. The employers don't want to share the cup with you. They tell you they will call you but they don't*

because they afraid you might infect their children." The stigma tus results in fear and psychological harm, as Steven explained: *"The problems that I have experience are that it is difficult to keep asking for day off from work to since I am employed. This raises an eyebrow from my employers and at the same time you don't want to tell them about your status since you are afraid of being isolated. Therefore it would be better if we could be supplied with two months treatment."*

6.2.3) Healthcare Related Stigma

Stigma is however, not only confined to the local communities, families and workplace but is also situated within the healthcare setting itself. The literature has covered this topic extensively (see for example Holzemer et al., 2006, Sadoh et al., 2009, Parker and Aggleton, 2002). Stigma has been identified as a significant barrier to accessing ART, especially in the local clinics where confidentiality is often undermined. This is evident in the words of Veronica, Lauren and Gloria *"Local clinics don't have patient care and confidentiality. When you go collect treatment at the local clinic everybody knows that you are HIV positive,"* reported Veronica. Gloria further explained, *"At our local clinic they don't have confidentiality. After you have discussed your issue with a nurse she would simply share it with others."* Lauren further expanded on the situation in the local clinics: "*At the local clinics it is even worse because for some reasons they have new rooms painted white for TB and HIV patients. The minute you enter the gate at the local clinic you enter one of those rooms everybody already knows your diagnoses. I am not sure how the government came up with this idea of special isolated rooms for HIV patients; I really don't appreciate that. For me I think the government is promoting stigmatisation around HIV. Township clinics are painted in white to identify the HIV positive. I wouldn't want to be collecting at my local clinic. People still say you are going to die and are still gossiping about ARVs."*

Veronica explained how this stigmatisation that is caused by ill-informed healthcare policies affects access to ART. *"For some it could be the issue of collecting treatment at the local clinic, being afraid that their friends and neighbours would see them and mock them. To prevent being seen by friends and local street neighbours some would prefer not to collect treatment at all. And fear to be mocked by neighbours if treatment is collected from the local clinic."*

Lauren and Veronica's statements clearly demonstrate the disengagement between the patients and the healthcare system. Although the healthcare system is providing an essential service, they are inflicting harm on those whom they serve. It is thus clear that healthcare related stigma often forces patients to seek ART services elsewhere, which has in turn contributed to the financial burden of accessing ART drugs. The structural force of stigma becomes evident in the above mentioned data. It remains a problem for people living with HIV/AIDS, and influences other aspects such as employment and faith in the healthcare system, which further threatens the patients' ability to continually access ART drug.

6.3) Economic Barriers

6.3.1) Employment and Unemployment

Nearly half (43%) of the participants who answered the question relating to their employment indicated that they are unemployed, while 49% of the participants reported that they engage in some sort of income generating activity, be it casual work, part-time work, or full time employment. The lack of funds for the unemployed did present some problem, but most of those who responded as being unemployed said that unemployment did not hinder their ability to access treatment due to social support networks or reliance on the social disability grant. Approximately half the sample indicated that the most expensive factor in collecting

their treatment on a monthly basis was, as noted, transport. The employment/unemployment scenario is indicated in Figure 6.3 below. Despite the fact that quantitative research does not reveal a significant correlation between unemployment and ability to access ART, the qualitative research revealed underlying links between economics and access.

What is your employment situation?
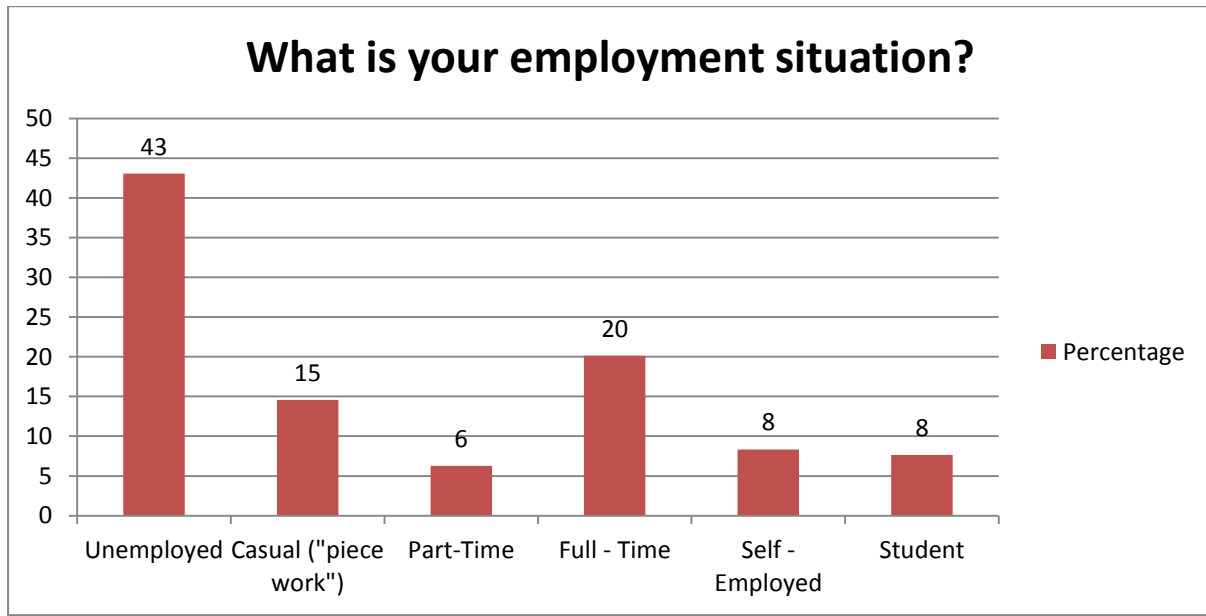
Figure 6.3: Employment

The monthly visits and the lengthy waiting times have been identified as being particularly pertinent barriers in the clinic for those who are employed. These barriers are all interrelated and quite often the one affects, or sometimes causes, the other. Being employed can be an obstacle to collecting ART drugs as patients require time off work on a monthly basis in order to access treatment. One of the reasons cited why participants are asking for a longer time between collection dates is because of the economic impact that monthly visits have on them. The monthly visits create job insecurity among those who are employed in the clinic, especially those patients who have semi-permanent jobs. Thea, a 35 year old female patient said: *"What I see as a problem is for example, I am employed on contract and my boss complains if I am not at work every month to collect treatment. When you send someone else the nurses do not like that. Even if you send your child they do not give the treatment."* A

male participant, Shawn, added: *"Sometimes I feel bad to keep asking for a day off because where I am employed I am temporary and I don't want to lose my job. Sometimes I couldn't collect because my boss did not allow me to come and collect."*

The double-edged sword between needing both treatment and employment to stay alive sometimes has devastating consequences for patients. The physical harm is as a direct result of the structural violence that is embedded within the healthcare system's policies to collect treatment every month and the employment sector's unwillingness to allow time off work to collect treatment. Many patients are in positions of employment where time off from work is not possible because the patients are lacking in skills and education and therefore are in structurally poor positions; especially those patients who hold temporary jobs. One of the female respondents in the focus group, Barbara, said the following: *"I know one case of my neighbour and she ended up dying because she could not pick up her treatment. Her boss use to give her warnings."* Another female patient, Nelly, also mentioned that it is a problem: *"Getting your treatment every two months is time saving. It is difficult for people who are employed to take off monthly as managers do not like this. Sometimes you find that you attend different clinics or different doctors in one month, managers do not like this. This may lead to patients defaulting".*

It is important to note however that it is not only under-employed or those in lower ranking employment positions that experience problems with access to ART. This is evident in the words of Shawn, a male participant: *"There is a problem that may prevent me from attending. Due to employment for example today I am going to Mpumalanga next month I will be away for the July month. It would be advisable that you give us two months treatment. I work for contactors, I travel around the world. It would be preferable if we could be allowed to be issued treatment for two months".*

After the initial interview I had with Shawn I saw him again late one afternoon at the clinic. He came over to me and asked me to help him to get a two month script. He told me: *"my boss told me that if I take another day off I will lose my job. Without my job I cannot afford to come here."* Shawn's situation is not unique. His comments however highlight that difficulty in collecting treatment while employed is not always an issue of economic powerlessness but can also be attributed to physical constraints placed on the patients but the nature of their work. This adds another dimension to the complication of being employed and having to collect treatment every month i.e. that patients may not be in the vicinity of the clinic on the day when the appointment has been allocated and there is no flexibility in the public health system for such considerations.

Like Shawn, many of the employed patients reported being faced with job loss if they continued to take their treatment. The patients are thus left to make very difficult decisions, either they can remain on their treatment and lose their jobs, or they can stop their treatment and remain employed. This quagmire experienced at the grassroots level is purely because broader level policy states that patients must attend the clinic monthly on the day that has been specified.

Employment, while necessary for sustenance, can thus create barriers to accessing ART especially at this clinic which only operates during the week days. Unemployment, likewise, although not clearly indicated in the quantitative statistics, presents a major barrier to accessing ART. Most of the patients indicated that the lack employment, and therefore money, presented some problem for them and that they had to rely on others in order to have the ability to access their treatment. This is evident in the words of Joyce, a female participant who told me: *"I would prefer to be supplied by two months treatment due to the fact that I am unemployed. I don't randomly have money to travel up and down to the hospital. Also we get odd appointments during the middle of the month. In that case I have to borrow money from*

people and I hate it. For example my next appointment is on the 19th and I won't have money.

Again I have to borrow from someone and yet if I am given 2 months' supply that would help me because I would be able to plan in advance for my next collection date".

Roger, a male participant, noted: *"My cousin who is a pastor assisted me financially to pay for my treatment the entire year."* However, constantly relying on family for support can cause strain and threaten continued access to ART, as Sarah a female participant explained: *"I have money issues, for example today I borrowed money to come here from my neighbours. Eventually you become an irritating person to your friends and families for asking for money each time you attend the clinic."*

Both employment and unemployment are thus major factors in terms of accessing ART in the present public healthcare system. This is evident in the words of a male research participant, Chris who stated: *"Companies don't have time for people who take off from work often. So when it's time for retrenchment those who have been taking off from work are the first ones who are identified for retrenchment which I think that is unfair for me and that is also discrimination and like I mentioned before also patients who are employed they are able to eat well and look after themselves those who are unemployed in most cases they default their medication because they have no food."*

Chris highlights a crucial point about the struggle within which the patients find themselves. Their lives depend on their ability to access their ART, but at the same time the process of collecting their treatment threatens their employment, which is just as crucial for them to stay alive. On the flip side of the coin, those who are unemployed frequently lack the necessary food with which to take medication and as a result become a *'defaulter'* and/or *'lost to follow-up'.*

As noted, food insecurity presents a particular problem for those who were unemployed. One female participant, Yvonne, who is 26 years old, sent me the following message: "*Hi, I'm very sorry for not come and take my medication my problem is that I can't have my pill cause it so difficult to take pill while you don't have job or food in the table it not like I don't care about my life it the situation I'm facing. Thank you very much.*" Yvonne thus had to sacrifice collecting her ART drugs because she didn't have food. Prudence, a 24 year old female participant added to the food problem: "*I guess to those who are unemployed it is difficult because the rule says you must take food before taking your tablets. What happens if you don't have food, how are you expected to take your tablets? Sometimes there is no food at home and you not sure how you can take treatment.*"

Lauren had the following to say about this: "*The other reasons could be short of food at home. One must eat before taking medication, if there is no food how can the patient not default taking their treatment? Being on chronic medication you need to up your game and eat well. Not everyone has money to buy vegetables.*" What is interesting to note in Lauren's comment is that she highlights that those patients who '*default*' on their treatment due to food shortages cannot to be blamed since they are powerless in their decision. Their powerlessness is as a result of larger economic and policy structures that perpetuate the patients' suffering by imposing strict rules in order for them to access ART. If the patients cannot manage to comply with the rules due to larger forces such as unemployment, poverty, stigma and food shortages then their access to ART is compromised.

6.3.2) Social Grants

While conducting participant observation in the clinic a female patient named Janet, called me and asked me to sit down next to her. She handed me a small piece of paper, with this message on it: *"I'm Janet from Westville. I'm 38 years old and I am not working my CD4 is 170. I'm the mother of 3 children and one I support for my brother, her mother died a long time ago and now she is 13. So, I need a favour. As a poor person I am taking my treatment difficultly the way of the situation is very bad. Yes, can't you do me a favour for the pension, because I am surviving with a grant for my 2 children and my son is 19 he won't collect a grant even I came here I borrow a bus-fare. Every day I wrote a letter to give you else can I come and see you for now I am waiting for my treatment. Thank you."*

Leclerc-Madlala (2006) examined the significance of the social disability grant within the ART setting and found that it was both a facilitator to accessing ART and also an obstacle. She also highlighted the difference in need assessment between the patient and the healthcare system that determines who is eligible for the disability grant and who is not. In line with what Leclerc-Madlala (2006) found, many of the patients who attend this clinic feel that they are eligible for the grant. During my work in the clinic I often receive requests like Janet's, and one female participant, Betty, told me: *"We would appreciate it if we could be met half way by the government. Receive some sort of food support so that while we are taking medication we would have something to eat and regain our strength."*

The participants' comments highlight the presence of structural violence embedded within the healthcare system where policy is a structural force that is created by officials who are removed from the local setting. Their detachment results in limited consideration for the everyday problems and constraints that the patients face.

In summary to this chapter it was noted that a range of barriers influence the patient's ability to continuously access their ART drugs. Many of these barriers are situated within the healthcare system itself, but others such as stigma are located in the local communities, in the patients' families and in their workplaces. What is evident from the data is that the healthcare system perpetuates the patients' suffering by enforcing policies that were created at the so-called 'centres of power' (Inda and Rosaldo, 2002), yet these are removed from the periphery where the patients are situated. The imbalance in the power dynamic further contributes to the patients suffering.

In the following chapter the effect of these barriers will discussed. In particular, the power struggle between the patients and the healthcare system will be explored, as will the patients' mechanisms of negotiation and the issue of projected violence due to structural violence.

CHAPTER SEVEN: Antiretrovirals, public health and structural violence: A melting pot of inequality

"The system reminds you how sick you are and how poor you are and how black you are".
– Lauren, female key informant

"But little concern has been shown by the South African actors about the fact that biomedical theories do not take into account the structural components of the development of the epidemic or the realities of the majority of the populations' daily lives, which are of crucial importance for grasping the gravity of the disease and its spread" (Fassin, 2007: location 457 of 5420 [Kindle version])

In Chapters Five and Six the results from the data collection tools were presented and discussed. The discussion focused predominantly on identifying the most relevant barriers and qualifying them. In this chapter I discuss how these barriers are interrelated and the effect that they have on the patients of the clinic.

7.1)   The power struggle between the patients and the healthcare system

Despite the barriers that have been addressed in Chapters Five and Six, a fair number of patients indicated that they are satisfied and happy to collect ART drugs at this particular clinic. Those who utilize the public health care system have become so accustomed to the barriers they face that these barriers have been internalised, normalised and accepted. While patients are largely satisfied with accepting poor service, what is especially worrying is that the poor service is perceived to be better than the service they receive from their local clinics.

The invisible violence and its effects are embedded within the everyday routine and procedures of the hospital and the clinic. These routines and procedures are created and instituted by health care policy, and usually by people who have very little experience or insight in the daily challenges experienced by both the patients and the health care providers who attempt to ensure that access to health care services is maintained. The patients have

come to accept that they will just have to endure these obstacles in their attempt to recover their health and reclaim their lives.

One of the most prominent inequalities within the healthcare system is the difference in the power balance between the healthcare workers and the patients. This powerlessness is recognised by some of the patients but they frequently feel unable to change their situation. As one male patient, Roger told me: "*I don't want to be punished for that just because it is not my clinic date. The staff at the clinic needs to know that they are here for us patients not to make us feel like we owe them something.*" Another male patient, Derek, added to this: "*It is important that we must be informed about new changes at the clinic. This clinic exist because of us patients.*"

According to Farmer (2004: 315) "Structural violence is both "structured and stricturing. It constricts the agency of its victims. It tightens a physical noose around their necks, and this garrotting determines the way in which resources - food, medicine, even affection – are allocated and experienced". Those who utilize the public healthcare system have constricted agency, that is to say they have very little control over their own health and decision in their own healthcare plan. They do not participate, they obey, and if they do not obey they are punished by the very system and people who are supposed to protect them in their time of vulnerability and need.

Activities such as the enforced repeated counselling are indicative of the mistrust that the public healthcare system has in the patients. The patients have to be seen every month so that they can be closely monitored. Farmer (2003) argues that this mistrust in the poorer public patients is a result of commodification of healthcare. In the private healthcare setting this scenario is the opposite. A private patient can walk into the local pharmacy where her/his repeat script is and simply collect the ART drugs, without repetitive counselling every time;

150

indicating that those who utilize private healthcare can be trusted. This is where the economic inequalities come into play and the effect of commodification of healthcare becomes evident. Private healthcare patients have to pay for their own medication and are therefore seen to be responsible and in control of their own health (Farmer, 2003). However, the public healthcare patients receive treatment for free or for a nominal sum. In turn, the patients are made to feel eternally grateful for having access to lifesaving drugs, as one doctor told a patient: *"You should be grateful that you have these tablets at all. Because there was a time when we didn't have these tablets, and they are free."* That people should be grateful for something that is a basic human right, a right to health and healthcare, is an indication of the inequality present and the power imbalance between the healthcare workers and the patients.

Fear also plays a big part in the invisibility of the violence created by the obstacles that the patients face. Patients often do not voice their concerns or criticisms because they are afraid of the health care workers who often shout at them, reprimanding them for not being *'good behaving patients'*. One male participant, Jack, said of the counselling*, "you just have to keep quiet and do what they say. If you know how to behave in the clinic there are not problems. But when you begin complaining… that is when the difficulty start".* In addition to this Neville told me: *"things are fine here in the clinic. I come early in the morning and as long as you do as they tell you and behave nicely then everything is just fine. They treat you nicely, there are no problems."* These statements might give the impression that there are no problems, that all is well. The fact that the patients have to *'behave well', 'keep quiet and do what they say'* and follow instructions without question is, in reality, where the biggest obstacle to continuous access to ART lies.

Patients are expected to simply follow instructions without much discussion or negotiation. If they do not follow the rules of the healthcare system, and dare to speak out about sub-standard services, they are treated harshly. In fact there is no room for any negotiation between the patients and the health care workers. This adds to the disempowerment of the patients which, in turn, further fuels discrimination and inequality in access to health care. One such example is that of Pamela.

Pamela is a 28 year old female patient who is unemployed. She has numerous social difficulties at home and has experienced harsh discrimination from her mother about her HIV positive status. During the first month on ART Pamela lost her only child who was a month old. Her mother consequently evicted her from her house and forced Pamela to live out on the street. Eventually, through the help of a social worker, Pamela found a place to stay with a distant relative. Throughout this trying personal period Pamela remained adherent to her ART drugs even when it was physically difficult for her to reach the hospital. As time passed Pamela settled into the routine of attending the clinic every month but struggled to find employment, which created a major stress in her life. One day Pamela was sitting in the queue to be seen by the doctors when one of the counsellors came over to her. The counsellor began reprimanding her for not attending her adherence counselling session and demanded that she return to the counselling queue. A row ensued between the counsellor and Pamela that escalated to near physical violence. The reason behind Pamela's refusal to attend the counselling is because she no longer felt that she needed it. When she refused she was reprimanded. Subsequently Pamela left the clinic and has not returned. Pamela's lack of power reflects that the unequal power relations between the healthcare staff and the patients can result in patients being lost to follow-up.

Fear is not the only motivating factor for the patients to comply with the healthcare system's rule. Most of the patients tolerate the rules and regulations, for the simple reason that *"This is our lives. We don't have a choice. We must handle these things because this is our health and our lives."* The patients taking ART for life are prisoners of this system. They have no power to negotiate their treatment plans and even less power to demand better service. They have no choice but to comply with the system because their lives depend on the lifesaving drugs. The very strict obedience to the policies and protocols laid down by the Department of Health has a direct influence on the powerlessness of the patients. They simply have to follow the rules or face the consequences of having the access to their life-saving drugs threatened.

In the literature (see for example Penchansky and Thomas 1981, Donabedian 1972, Aday and Andersen 1974) the difference in need assessment is identified as a factor that can influence access to healthcare. Patients perceive their needs for and within the healthcare system differently from how the healthcare system and healthcare workers do. This varying assessment of need is another structural driver of invisible violence within the healthcare setting.

The ART program in particular has demonstrated how influential the healthcare system's perceptions of patients' needs are and that the healthcare system's perception of needs override the very real needs of the patients. In the beginning of the ART era the healthcare system and government decided that those infected with HIV did not need ART drugs. Later, with mounting pressure from civil society and forced by law, the government and healthcare system conceded that those infected with HIV do need ART drugs. A confusing message was sent to the people living with HIV/AIDS who relied on the public healthcare sector to provide them with healthcare services. After seven years the damaging effects of those views held by government are still experienced by people in their everyday lives.

The concept of varying need is not recognised by the public healthcare system due to the fact that the ART program is situated in the biomedical system with a focus on *adherence* and not on continuous *access* to the service. For continuous access to occur all the dimensions of access to health care need to be considered, and not merely *adherence* as a catch all phrase.

The monthly visits have a domino effect on the rest of the services provided within the clinic and result in less time being available for those patients who are new to the system or who require more intense medical attention. As, Betty, a female patient said: *"We would appreciate it if you could allow us to send our relatives to collect on our behalf. Also doctor to give us a three months script so that we can collect and then after three months we can see the doctor unless if one is not feeling too well then only they can come themselves and then request to see a doctor."* As indicated, the monthly visits were found to be a significant barrier. A reason behind this is because monthly visits directly influence some of the other organisational barriers mentioned, contributing to the biggest barrier identified in this clinic, namely waiting times. Time delays were identified by Penchansky and Thomas (1981) as a factor for user satisfaction. Users decide whether their time spent waiting for healthcare services is acceptable or not. If they find that the service offered are not worth the time spent waiting for the service, they may disengage with that service (Penchansky and Thomas, 1981). Once the patients have entered into the healthcare system they no longer have control over their time, and therefore often have to choose between their health and income, for those who are employed. As Neville stated *"Sometimes it takes me about 5 hours. When it is the clinic day I just dedicate the whole day to the clinic and tell myself that the day is reserved for the clinic."* His choice reflects the structural violence that the patients are subjected to and which they accept because they feel powerless to do otherwise.

Only 10% of the participants attending this clinic said that time delays are not a problem for them while 60% reported that it does present a problem. Of those who reported waiting times to be a problem, 26% rated it as a catastrophic problem. The area where the patients felt that they wasted the most time was waiting for the adherence counselling; a service which many deemed to be irrelevant at every visit. Time delays are dependent on other areas in the hospital and clinic. A delay at the card office will impact on the time spent in the queue, so too will a delay at the counselling office cause a further delay. As was demonstrated in the observation of a day spent in the clinic, the time delay gets compounded and affects the total service of the clinic. This then and ultimately contributes to the structural violence which patients face as they are forced to be absent from work in order to access health, yet, are frequently faced by constant threats of dismissal as a result.

7.2) 'The Bad Behaviour of the Patients'

The constrained agency of the patients and the lack of negotiation between the patients and the healthcare system have, at times, led to some instances of aggression and violence in the clinic. The patients who are taking ART and utilizing public healthcare services find themselves trapped within the system. They have to take their ART to stay alive and healthy, and are largely accepting of that fact, but although they feel powerless, they are also tired of having to face the constant barriers and perpetual inequality created by the system. They thus devise many interesting ways to manipulate and 'cheat' the system.

These behaviours were noticed while I was conducting participant observation at the clinic. By engaging in what the clinic nurses refer to as *'the bad behaviour'* of the patients, the disempowered patients exert a degree of agency to recapture some form of control over their health that has now become the property of the public healthcare system.

At the clinic the patients are scolded, shouted at and threatened with the discontinuation of their treatment. They are blatantly treated like 'naughty children' for standing up against the autocratic biomedical system in which their role is limited to that of strict obedience. The first of the *'bad behaviours'* of the patients is a recurring event. Some patients have taken to throwing their tablets, or excess tablets, away into the bins situated behind the clinic building. The tablets were discovered by the cleaners who separate out the waste.

There are a number of reasons why they engaged in this sort of behaviour, depending on who you talk to. The healthcare workers in the clinic, and even some patients, say that those who throw their tablets away are '*irresponsible*' and '*ungrateful*' for the services that are available to them now. As is evident in the literature regarding the history of ART in South Africa (see for example Cullinan and Thom, 2009 and Fassin, 2007) it was a battle to get these drugs into the public healthcare system and make them available to those who need them. There are however other reasons why they would throw their tablets away and yet continue to endure the long queues in the clinic and the rude treatment from the healthcare staff. The first of these was mentioned earlier about the counsellors and their narrow focus on adherence. Some of the participants said that the counsellors are only interested in the number of tablets left in the pill containers; they are not interested in the explanations given by the patients, nor their concerns. If they have excess tablets they thus get labelled as being a '*defaulter*' very quickly.

The term *'defaulter'*, and to an extent *'adherence'*, has become a sore point for the patients and they are sensitive about being labelled as *'defaulter'*, or questioned about their adherence. There is a negative connotation attached to the term 'defaulter' and judgement is passed by the healthcare workers and by fellow patients. To avoid being labelled as a '*defaulter*' and thereby being ascribed additional stigma, some of the patients throw their tablets away in the bins. They also throw their drugs away at the clinic to uphold their social

156

image at home of being compliant. This is in keeping with what Ware et al., (2013) found in their study on disengagement from ART programs in the sub-Saharan region. Social support was identified in Ware et al., (2013) study to be important for accessing ART. Throwing tablets away in the bin could be explained as a way for the patients to regain some control over their live, while at the same time keeping a back-up plan by satisfying their social support in case they become ill again. By throwing the tablets away they are exerting some agency in the decision to take ART drugs. The patients are aware however that they are ill and will require assistance at some stage if they get ill. As a support plan they will pretend to take the tablets and attend the clinic to keep up the façade of being compliant. If they should fall ill, the blame would then not be theirs, but the ART drugs. In this way they manage to control some aspect of their health while simultaneously maintaining social support.

As the ART program expanded at this clinic the number of patients within the system also rapidly expanded. At the beginning of the program patients were referred to their local clinics if they were happy to go. However, this was quickly stopped because, as one doctor put it: *"apparently we did not follow the correct protocol, but no one even knew there was a protocol".* This measure, accompanied by the insistence by the clinic management that the patients should attend the clinic every month, resulted in the clinic becoming overpopulated. Soon overcrowding led to major problems. The delays that are caused by pre-existing barriers such as the poor administration at the card office, and the mandatory counselling at each visit has led to long delays at the clinic. These delays have resulted in frustrations growing, which one day culminated in the hidden violence escalating into physical violence.

One morning, while a nurse was giving health education to the patients in the clinic, conflict broke out. The patients became aggressive and shouted abusive words toward the staff. They demanded better quality service and insisted that the nursing staff provide the service immediately. Security was called to control the angry crowd but they were overpowered by the mass of angry patients shouting abuse at the clinic's staff.

Eventually after much talking and reprimanding by the clinic management who kept on reinforcing the hospital's policies and procedures, the patients calmed down and the clinic continued. Later I asked Veronica, who was there that day, why the patients were so angry. She told me *"some patients are unhappy about the order of flow in the clinic. They feel it is unfair that they have to wait so long just for their cards. Also they are complaining about other patients that take their hospital files home with them. When they return for their visits they get out of the same taxi. Those with their files then come straight up to the clinic while the others have to go and wait down there* (at the card office)*."*

Besides the violent outbursts other recurring behaviours have been noticed at the clinic. One of these behaviours involves the patients skipping the counselling queue and writing their own adherence results in their files. Another more serious activity involves patients signing their own medication scripts to avoid having to go to the doctor. Many of the stable[36] patients have no medical complaints, and as Lauren told me earlier, also do not see the point of visiting with the doctor when they are well. So for most the visit to the doctor involves getting their scripts signed so that they can refill their medication for the next three months before they have to see the doctor again.

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[36] Stable patients: these are patients who have been receiving ART for some time and are free of opportunistic infections or complications of ART side-effects. Their CD_4 counts have increased and are stable, and their viral load counts are below detectable limits.

Engaging in behaviours such as these, are a direct result of the consistent barriers that the patients have to endure. The clinic has specific protocols and policies that dictate the running of the clinic service and the patients simply have to comply. By engaging in these behavioural strategies they are actually communicating with the healthcare staff and services, drawing attention to the invisible violence they are made to endure every month.

The response from the clinic has simply been to label the patients as '*rude*', '*abusive*' and '*dangerous*'. They were also blamed for '*filling up the clinic*' and for the overcrowded situation. The clinic management, instead of addressing the issues of the patients, decided to punish them in the form of referring all the stable patients to their local clinics, whether they wanted to go or not. The clinic manager told me: *"none of the patients ever said that they wanted to stay here and not go back to their local clinics."* This was just simply stated as being '*policy*' and therefore devoid of considering the desperate plea of the patients for better quality services.

7.3)   Projected Violence as a result of the Structural Violence

One the most interesting observations in the clinic, and a unique barrier, was the projected violence between the patients. The atmosphere in the clinic is almost always tense, and the slightest *'misbehaviour'* can result in physical violence amongst the patients.

On several occasions I observed fighting between groups of patients, and most of the time it involved someone skipping a queue for some reason. Often it was because the older patients, who had been in the system for some time, took advantage of the newer patient's uncertainty and somehow pushed ahead of them in the line. The older patients blamed the newer patients regularly for holding up the queues because they needed more attention.

Steven explained the situation between the new patients and the old patients:

"Oh yes this [abuse and bullying] occurs regularly especially to new patients at the clinic. That is why I would prefer it if you staff can select new patients and put them separate from the older patients. In order to allow them enough time to get used to the processes such as meeting with counsellors and to follow other processes at the clinic that they are not familiar with. Patients must be treated fairly with respect. It doesn't mean that because you have been collecting your treatment for two years or more you are now the boss at the clinic. Those old patients they need to be disciplined to respect others. Especially those patients who have recently started their treatment and experiencing side effects such as black sore marks on their legs all patients need to be constantly reminded that we are all different and treatment works in different ways to different patients. All depends on our strong immune system. Please emphasise to older patients at the clinic not to mock people who are affected by obvious skin side effects they did not ask for it. Side effects must never be discussed by patients in front of other new patients.

This could frighten them to attend their clinic and also end up defaulting due to these bullies at the clinic. Sometimes they can say things they don't mean joking around HIV issues. Some people are very sensitive around the HIV issues".

While the newer patients are blamed for increasing the waiting times, others blamed sick patients for putting the stable patients at risk of infection. Chris, a male participant added to this: *"I think you need to categorise patients based on how sick they are. Sick patients should be seen monthly and given extra care. Those who are not sick and who are also not at risk should be seen separately. I think the staff should prioritise time frame of seeing very sick patients especially TB patients who are more at risk infecting others while waiting and chatting on the queue."*

Lauren added to this sentiment and highlighted the issue of threatened safety. *"While you are standing on the queues people are coughing around you bacteria all over the place we are just not safe. People that are very ill and have Tuberculosis should be provided their own queues to be seen as soon as possible and sent away. Those who are normal and healthy just there at the hospital to collect treatment should be also allowed to have their own queues".* Many of the patients who are now stable had to endure a period of serious illness. While ART does improve the immune system, HIV positive patients are more susceptible to opportunistic infections and the poor organisational arrangements within the clinic places the stable patients at risk of re-infection and create a threat to their health. Furthermore, unnecessary structural violence is evident in the long waiting times and structural confines of the clinic that exposes them to possible infection.

Perhaps the most remarkable aspect of this blaming and fighting amongst the patients is the fact that they channel their aggression more often towards each other and not the healthcare system or other barriers that create the difficulties for them to continuously access their treatment. This demonstrates the invisibility of the barriers that they face and the ubiquitous nature of the structural violence that causes the inequality which they face on a continuous, repetitive basis. It is in the repetition that the violence is lost and over looked. The patients feel powerless to voice their anger against the system so most frequently they vent their anger against those who they feel structurally able to do, namely the new and sick patients.

While there are a range of barriers that exist outside of the healthcare sector that impact upon access to life-supporting ART, the health care sector should not be one of these. Perhaps the greatest tragedy of the HIV pandemic is not that it could have been prevented all those decades ago, but that people are still dying of the disease today when effective treatment is available because their access to continuous treatment is interrupted or in some cases totally prevented.

CHAPTER EIGHT: Conclusion

8.1)   Summary of the Research

The main objective of this ethnographic research within the healthcare setting was to identify the most significant barriers to accessing ART healthcare at a public healthcare clinic in Durban, as perceived by the patients who attend the clinic on a monthly basis. The project further aimed to gain a better understanding about the structural drivers behind the barriers and how these affect the lives of the patients.

As the introduction discussed, the advent of ART drugs has provided an opportunity for those infected with HIV to regain their health. South Africa has the largest HIV epidemic in the world and as a result also has the biggest ART program. However initial access to ART was a struggle in South Africa largely as a result of poor policy. In recent years the situation has improved as a result of policy changes that have facilitated the procurement of ART drugs at a fair price and have expanded the eligibility criteria for receiving ART to the general population. However access to ART drugs requires more than the availability of the drugs and largely depends on the functioning of the public healthcare system. The success of the ART program depends on the continuous access to ART healthcare. This is crucial in the effort to reduce the devastating effect that the HIV epidemic has had on the country. However the literature, (see for example Brinkhof et al., 2008, Fox and Rosen, 2010, and Miller, 2010) reveals that nearly 30% of all those patients who initially entered the ART program have been lost to follow-up.

Healthcare facilities do not have the adequate resources to deal with this problem, and as a consequence this large group of virologically stable patients have been largely ignored by the healthcare system and literature. A reason for this can be related to the focus on adherence instead of access to ART services, in both the literature and the healthcare setting. According to the literature, sub-Saharan Africa has adherence levels to ART comparable to adherence in developed countries. However, as van Dyk (2010) points out these results are based on findings reported on research where the participants were already part of a larger trial and therefore presented artificial conditions in which adherence was augmented. Further to this, those participants who were lost to follow-up were not factored into the results, but excluded. This is a trend in quantitative research to not report the 'outliers'. The lost to follow-up patients have largely been ignored as a result, and not much is known about the reasons for discontinuation of ART, or the mortality rate associated with discontinuation of ART. Adherence results should therefore be interpreted with caution, since the reported results are based exclusively on patients who are still in the ART program. Adherence as a concept is also limiting since the focus is placed on individual behaviour that is situated in a generalized program. This has resulted in the individual patient being blamed for any non-adherence to the ART program even if their inability to access and adhere to the ART regimen is beyond their control.

This project thus focused on the concept of *access* to healthcare and explored its various dimensions. As was discussed, access to healthcare comprises of five interrelated dimensions, namely: availability, accessibility, affordability, acceptability and accommodation (Penchansky and Thomas, 1981). Contextualizing the patients' ability to remain in the ART program within the concept of access elucidates the larger structural forces that create and perpetuate the barriers that cause discontinuation to the program. This focus facilitates the understanding that discontinuation from the ART program is often due to larger structural

forces instead of individual choice. Using structural violence theory further highlights the powerlessness of the patients in their dealings with the healthcare system and the communities in which they live.

To understand the broad concept of access to healthcare an ethnographic approach was taken to conduct this research project. Ethnography provides the appropriate lens with which to study a subject more holistically and gain a deeper insight into the everyday struggle of the patients. Various methods were used to collect the data, including participant observation, focus groups, semi-structured interviews and questionnaires. The mixing of data collection methods aided in providing a broader understanding of the problem and served as a validation technique for the data acquired.

The data from the quantitative analysis revealed that organisational barriers pose greater obstacles to continuously accessing ART, with the overall waiting time being the greatest complaint. Second to this the adherence counselling services was identified as the biggest barrier to accessing ART within the clinic. The most problematic barrier outside the organisational barriers was stigma and the attitudes of community members to people living with HIV/AIDS, which was followed by economic barriers, in particular the cost of coming to the clinic that was divided between transport costs or a day off from work.

Stigma remains a problem for PLWHA as its consequential discrimination is situated in both the community and healthcare sector. Stigma in the community revealed itself to be problematic in terms of the fear associated with disclosure of HIV status and having social support to continually access and take ART. Stigma within the healthcare sector was also an important barrier that is not often discussed. Stigma in the healthcare sector was experienced on two levels. Firstly the location and layout of the local clinics identify those who are HIV positive from people suffering with other diseases and this was a motivating factor for

PLWHA to seek ART services away from their local clinics. This contributed to their financial burdens by increasing the distance to their ART facility. Secondly stigma was experienced in the form of discrimination and harsh treatment by staff. The counsellors who are supposed to provide a supporting service in enhancing adherence to the ART regimen proved to be the source of most unhappiness related to staff.

The in-depth emic perspective of the qualitative data revealed that, in line with structural violence theory, larger forces create situations which contribute to the vulnerability of the patients and further perpetuate their suffering. Their vulnerability and suffering is often overlooked as it is made invisible by the healthcare system and the policies that govern it. Most often poor policies, that were created by institutions removed from the local setting, had the most devastating effect. Most of the barriers related to the organisation can be related to policy that results in structural difficulties for the patients to access their ART drug.

As the ART program expands more patients will enter into the healthcare system. Consequently the healthcare facilities providing the care are constrained by poor policies as well as limited resources which further exacerbate the problems that patients encounter. This can sometimes lead to violent outbursts from the patients, as was demonstrated in the clinic where this study was conducted, in an attempt to reclaim their agency and regain some form of power and control over their own health.

The patients of the clinic also devised interesting methods to 'cheat' the system. While the healthcare system condemned these behaviours and even threatened criminal prosecution, little attempt was made to better understand the problems that the patients face within the ART setting.

As is evident from the data collected in this research project, the dimensions of accessing healthcare along with the associated barriers are interrelated and can impact on each other. This was seen in situations where patients who are employed are forced to decide between remaining employed or collecting ART drugs on a monthly basis. The structurally enforced organisational barrier of monthly visits and time spent in the clinic directly impacts upon the economic affordability aspect of accessing ART, without which the patients would not be able to continue to collect their ART drugs.

It is the interrelatedness of the barriers that are best explained through the concept of *access* to healthcare rather than the narrow focus on *adherence* alone that formed the central finding of this research project.

8.2) <u>Recommendations</u>

This study has found that patients often experience difficulties when they collect their ART drugs and that the increased volume of patients into the ART program has negative consequences for the healthcare facilities and also for the quality of services delivered to the patients.

Continued access to ART is vital in the combat against HIV and AIDS. In order to achieve this, better informed healthcare policies are needed that will improve the service delivery of ART drugs. Policy changes could include more rapid dispensing of the ART drugs, separate services for newly initiated patients and patients who have been in the ART program for some time, and perhaps even allowing the patients to choose the services that they feel they need per visit. Mandatory monthly visits just to collect ART drugs should also be revised as it has implication for both the patients and the healthcare system. Clinics should be given the autonomy to investigate the most relevant obstacles that their population groups experience and then create specific interventions to deal with the barriers.

Innovative programs that simplify the delivery of ART drugs are required. Lessons on simplified ART delivery can be gleaned from the private healthcare sector. Patients who attend the private healthcare sector are not constrained by structural policies. Instead, patients in the private sector are entrusted with the responsibility of their own health and therefore have easier access to ART drugs. This trust in patients must be enhanced within the public healthcare sector, where the healthcare system has far too often taken on the responsibility of patients' health instead of entrusting it to them.

Creative programs have been created elsewhere to facilitate long-term retention, such as the Adherence Clubs initiated by MSF in the Western Cape, (see Wilkinson, 2013). These strategies should be supported by policy so that collecting ART drugs is made easier for patients. These strategies also have beneficial consequences for the healthcare system, by decreasing the patient volumes and thereby reducing waiting times. This could potentially improve overall service delivery and be transferred to other primary healthcare programs where long term retention is an issue.

8.3) Areas for Further Research

More research is required into understanding the reasons why patients discontinue utilizing healthcare services, particularly within the ART setting. A broader focus on the holistic concept of access to healthcare must be a focal point in order to contextualize the barriers that patients face when they want to access treatment and care.

Another area that requires further research is to establish the timeframes of loss to follow-up. This might give more insight into the reasons why patients discontinue services and can provide an opportunity for the healthcare sector to intervene. If it is established at what points disengagement occurs, interventions can be created to prevent discontinuation from happening.

In conclusion to this research project, I found that patients who attend the public healthcare sector for ART services experience a range of obstacles that prevent them from continually accessing ART drugs, and in support of the findings in the literature, see for example Penchansky and Thomas (1981), and Donabedian (1964), patient satisfaction with the quality of service impacts on utilization. Barriers to accessing healthcare negatively impacts on patient satisfaction and consequently negatively effects continued utilization of services. Any one of the dimensions of access including, whether healthcare services are not available in terms of drugs being out of stock; or services are not accessible in terms of limited transport; or services are not affordable in terms of hidden expenses; or services are not acceptable for example the stigma that was reported in the local clinics; or services are not accommodating such as the forced monthly visits to collect treatment, present as barriers to accessing ART healthcare services and influences patient satisfaction with the service offered.

It became evident throughout this project that understanding access to healthcare in a holistic frame is fundamental to improving the quality of healthcare services in the public health sector and in eliminating the barriers within the system itself. Much depends on the patients' satisfaction with the service offered. This was made evident during the qualitative research where some participants alluded to the fact that the healthcare sector exists because of the patients. No patient should be made to feel grateful because she/he now has access to life saving ART drugs, because access to healthcare remains a **fundamental human right.**

In Reflection…

Shortly after I began my adventure into the concept of access to healthcare I had a discussion one day with a Professor of Medicine while making a cup of coffee. A very kind and inquisitive man, he asked me about my research project. I told him that I was interested in studying the barriers to accessing health care and ART drugs in our particular setting. "That is a difficult and humongous problem" he replied.

He is right; the problem is far greater than what was captured in this small project. The subject is a big one that seems to be continually misinterpreted. This further added to the length of my inquiry and complicated a complex problem even further. The patients who rely on the public healthcare system face many obstacles when they want to get treatment. My argument however, is that the healthcare sector should not be the cause of any of the obstacles that they face. That is what we can strive for because we can eliminate these barriers if we care enough to listen to our patients when they complain about us. My initial enthusiasm for this topic remains and I feel it is our duty, as scholars and healthcare providers, to challenge these difficult and complex concepts and seek solutions that will benefit those who need it the most: our patients.

APPENDICES

Appendix 1: Revised WHO Clinical Staging of HIV/AIDS for Adults and Adolescents[37]

PRIMARY HIV INFECTION
- Asymptomatic
- Acute retroviral syndrome

CLINICAL STAGE 1
- Asymptomatic
- Persistent-generalized lymphadenopathy (PGL)

CLINICAL STAGE 2
- Moderate unexplained weight loss (<10% of presumed or measured body weight)
- Recurrent respiratory tract infections (RTIs, sinusitis, bronchitis, otitis media, pharyngitis)
- Herpes zoster
- Angular cheilitis
- Recurrent oral ulcerations

CLINICAL STAGE 3
- Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations
- Severe weight loss (>10% of presumed or measured body weight)
- Unexplained chronic diarrhoea for longer than one month
- Unexplained persistent fever (intermittent or constant for longer than one month)
- Oral candidiasis
- Oral hairy leukoplakia
- Pulmonary tuberculosis (TB) diagnosed in last two years
- Severe presumed bacterial infections (e.g. pneumonia, empyema, pyomyositis, bone or joint infection, meningitis, bacteraemia)
- Acute necrotizing ulcerative stomatitis, gingivitis or periodontitis
- Conditions where confirmatory diagnostic testing is necessary
- Unexplained anaemia (<8 g/dl), and or neutropenia (<500/mm3) and or thrombocytopenia (<50 000/ mm3) for more than one month
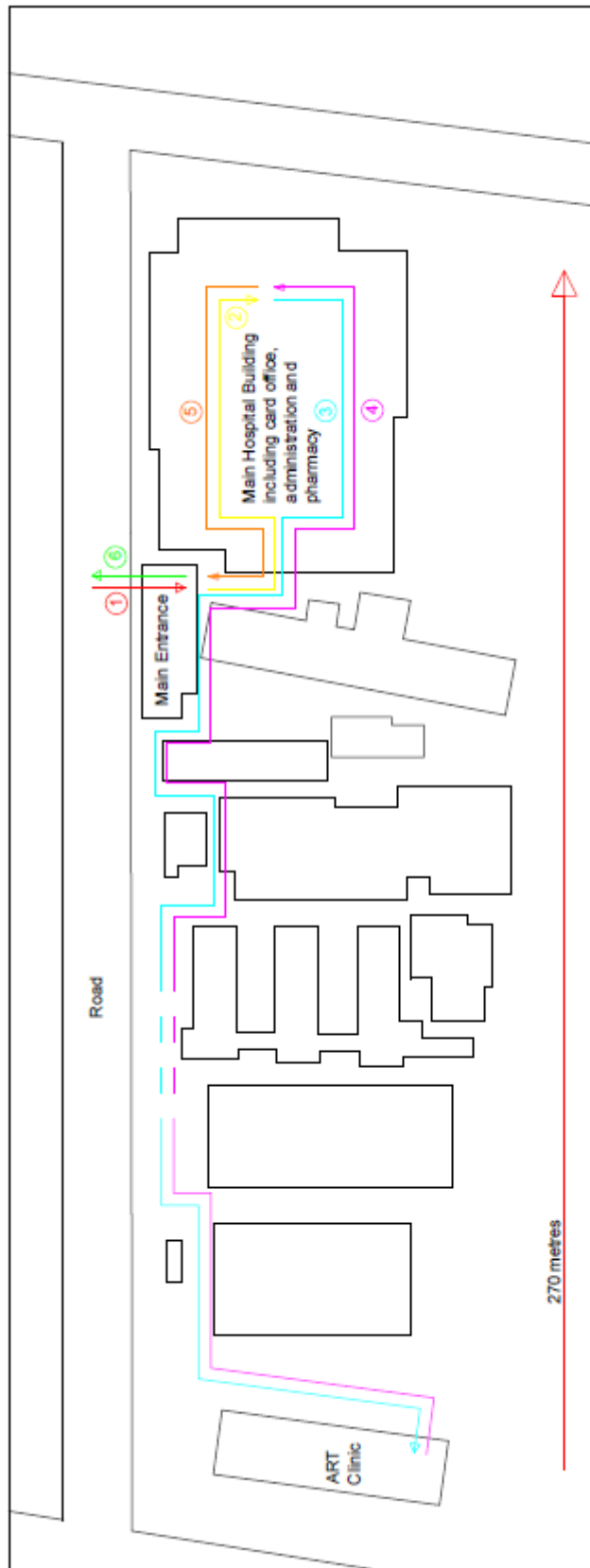
CLINICAL STAGE 4
- Conditions where a presumptive diagnosis can be made on the basis of clinical signs or simple investigations
- HIV wasting syndrome
- Pneumocystis pneumonia
- Recurrent severe or radiological bacterial pneumonia
- Chronic herpes simplex infection (orolabial, genital or anorectal of more than one month's duration)
- Oesophageal candidiasis
- Extrapulmonary TB
- Kaposi's sarcoma
- Central nervous system (CNS) toxoplasmosis
- HIV encephalopathy
- Conditions where confirmatory diagnostic testing is necessary:
- Extrapulmonary cryptococcosis including meningitis
- Disseminated non-tuberculous mycobacteria infection
- Progressive multifocal leukoencephalopathy (PML)
- Candida of trachea, bronchi or lungs
- Cryptosporidiosis
- Isosporiasis
- Visceral herpes simplex infection
- Cytomegalovirus (CMV) infection (retinitis or of an organ other than liver, spleen or lymph nodes)
- Any disseminated mycosis (e.g. histoplasmosis, coccidiomycosis, penicilliosis)
- Recurrent non-typhoidal salmonella septicaemia
- Lymphoma (cerebral or B cell non-Hodgkin)
- Invasive cervical carcinoma
- Visceral leishmaniasis

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[37] WHO Case Definitions of HIV Surveillance and Revised Clinical Staging and Immunological Classification of HIV-Related Disease In Adults and Children

Patient Flow through main hospital complex

Road

Main Hospital Building including card office, administration and pharmacy

Main Entrance

ART Clinic

270 metres

1. Patient enters the hospital complex through access gate
2. Patient proceeds to main hospital complex to pick up file
3. Patient proceeds to ART clinic

POST ART CLINIC

4. Patient proceeds back to main hospital building to return file and pick up additional treatment, if necessary
5. Patient proceeds back to main access gate
6. Patient exits main hospital complex

Internal Layout of the ART Clinic
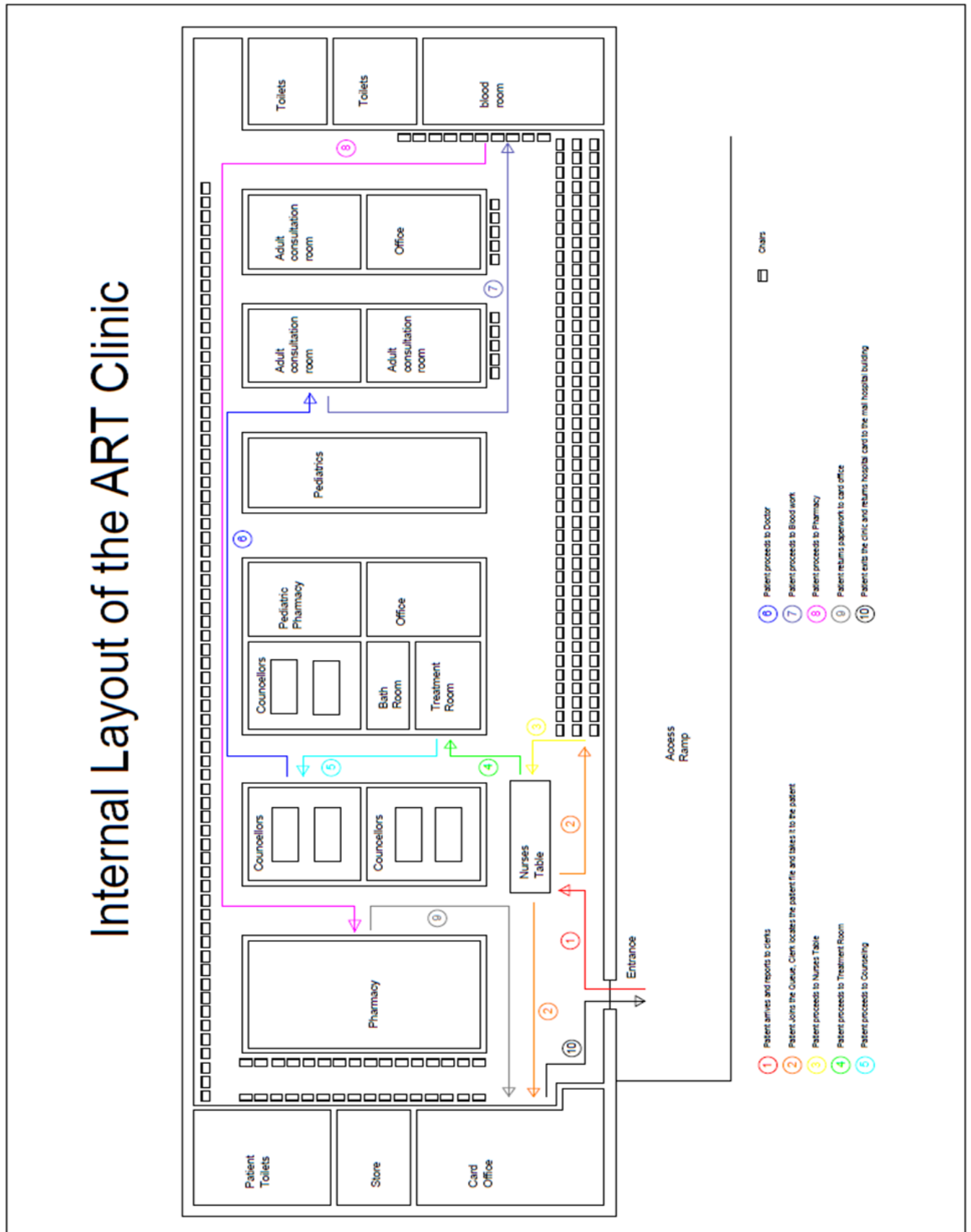
Appendix 4: Questionnaire

This questionnaire is about access to HIV-health care services and treatment. Access to care refers to the affordability, physical accessibility, acceptability, availability and the accommodative ability of the health care system to meet the needs of their clients. Please answer all the questions as best as you can. Please remember that your answers are anonymous and that there are no right or wrong answers.

Some questions will ask you to rate the answers according to how easy or difficult you find a certain factor. When you are asked to rate questions please select only one option that is most relevant for your response.

The key for the values are as follows:

Key
1= this is not a problem for me (No problem)
2= it can be a problem but I manage (Small problem)
3= I am neutral about this/ don't have an opinion (Neutral)
4= this is a problem for me (Big problem)
5= this is a big problem that can result in me not coming to the clinic. (Very big problem)

Thank you for participating.

Questions

(Start here)

1) 1) Male
   2) Female

2) **Age:**   1) 18-24
            2) 25-29
            3) 30-34
            4) 35-39
            5) Other: _____

3) **Education level:**   1) Uneducated
            2) Some primary education: _____
            3) Primary level (completed)
            4) Some Secondary: _____
            5) Secondary/ High school (completed)
            6) Current tertiary student: _____
            5) Tertiary (completed): _____
            6) Other: _____

4) **Employment:**   1) Unemployed
            2) Casual ("Piece work")
            3) Part-time

4) Full-time
5) Self-employed
6) Student

5) **Source of income:** 1) Unemployed
2) Social grant
3) Own/ employment
4) Other: _____

6) **Means of transport:** 1) No transport/ walk
2) Public transport
3) Private transport –not own
4) Own transport
5) Other: _____

7) **Date of first HIV test:** _____
8) **Date first HIV-positive result:** _____
9) **Date started on antiretroviral treatment:** _____

10) **Regimen:** 1) TDF + 3TC + EFV   TDF = Tenofovir   ABC = Abacavir
2) TDF + 3TC + NVP   3TC = Lamivudine   ddi = Didanosine
3) D4T + 3TC + EFV/NVP   EFV = Efavirenz   Lodiz = 3TC+AZT
4) AZT + 3TC + EFV/NVP   NVP = Nevirapine   d4t = Stavudine
5) TDF + 3TC/FTC + LPV/r AZT = Zidovudine
6) AZT + 3TC + LPV/r   LPV/r =Lopinavir/Ritonavir
7) Other: _____

11) **Type of visit today:** 1) Just to collect treatment.
2) To collect treatment and see the doctor.
3) Other: _____

12) **Why do you collect treatment at this particular clinic? (you can select more than one answer)**
   1) It is the closest clinic to my home.
   2) It is close to my work.
   3) It is on my way/route to work.
   4) There is better care and treatment here at this clinic
   5) My local clinic sometimes does not have treatment.
   6) My local clinic does not offer good service
   7) I prefer this clinic because nobody from my community knows me here

13) **How far is this clinic from your home?**
   1) Very close to my house
   2) Near
   3) Not too far
   4) Far
   5) Very far

14) **On average how much time do you spend per visit just to collect your treatment?**
    1) 1-2 hrs.
    2) 3-5 hrs.
    3) 6-7 hrs.
    4) Other: _____

On a scale of 1-5, one, being no problem and five being a very big problem how would you rate the following factors' effect on your ability to access your treatment?

No problem	Small problem	Neutral	Big Problem	Very-big Problem
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

15) When you are physically ill?
16) The side effects of the treatment?
17) The distance between your house and the clinic?
18) The mode of transport that you use?
19) Monthly visits to the clinic to collect your treatment?
20) The length of the waiting queue in the clinic?
21) The operating times of the clinic?

22) **On average how much time do you spend per visit to collect treatment and to see the doctor?**
    1) 1-2 hrs.
    2) 3-5 hrs.
    3) 6-7 hrs.
    4) Other: _____

23) **In your opinion please indicate why it is important for you to take your ARV's every day?**
    (You can choose more than one answer)

    1) To improve my CD4 count
    2) To decrease my viral load
    3) To prevent me from getting sick
    4) The counsellor/ doctor/ nurse told me to take it
    5) My partner/ spouse want me to take it.
    6) Other: _____

24) **Have you ever missed your appointment date to collect your treatment?**
    1) Yes
    2) No

25) **I sometimes cannot collect my treatment on my appointment date because? Please select the most appropriate answer to this question (you may choose more than one):**
    1) I always collect on my date.
    2) I was physically too ill to get to the clinic.
    3) I had to attend another clinic appointment for a co-infection that I have, e.g. TB.
    4) I had to collect treatment for my child/ relative at another clinic.

5) I had to attend a social engagement. (e.g. a family function, wedding, funeral, etc…)
6) I had no transport.
7) I had no money to come to the clinic.
8) I came earlier because my grant money would not last until my appointment date.
9) I had to work and my employer does not want me to take time off to collect my treatment.
10) I was out-of-town.
11) I feel much better now and do not see why I should collect this treatment every month.
12) I was scared a relative/ neighbour would see me come to the clinic.
13) I used too much alcohol and was unable to make it to the clinic.
14) The church/ traditional healer told me not to come for my visit to collect treatment.
15) I was in prison for a short while.
16) I did not want to sit in a long waiting queue.
17) I did not want to come to the clinic because I did not feel like it.
18) I forgot.
19) Other: _____

26) **When you cannot make it for your appointment date to collect your treatment what do you do?**
   1) I always come on my appointment date.
   2) Come on another day.
   3) Send a relative/ friend to collect treatment.
   4) Use my relative/ neighbour's treatment until I can come.
   5) Go without treatment until I can come to the clinic.
   6) Other: _____

27) **When you come on an un-booked day to collect your treatment and you are sent to the back of the queue, how do you feel?**
   1) I always come on my date so this does not affect me.
   2) I understand why I get sent to the back of the line and I am fine with this.
   3) I do not really care about this.
   4) I feel it is unfair and the clinic should be able to accommodate this.
   5) It makes me very angry so that I feel like not returning to the clinic.

28) **Would it be easier to collect your treatment on a weekend?**
   1) Yes
   2) No
   3) Maybe
   4) Other: _____

29) **The adherence counselling at every visit is intended to help you remain adherent to your treatment. What is your experience with the adherence counselling (please select one)?**
   1) I enjoy it and it helps with my adherence.
   2) I understand why I have to attend adherence counselling at every visit and do this without any complaints.
   3) It has no effect on me or my ability to access my treatment and remain adherent.

4) Makes me feel angry and irritable.
5) It is a time consuming activity without much value and makes me so angry that I do not want to return to the clinic.

30) **Has your hospital card ever been lost by the hospital clerks?**
   1) Yes
   2) No

31) **How does it make you feel when you are told that your hospital card cannot be found?**
   1) My card has never been lost.
   2) I am fine with it as long as they give me a duplicate card.
   3) I feel slightly upset.
   4) I get angry because all my information has been lost and I have to repeat tests.
   5) I get very angry and feel like not returning to the clinic to collect my treatment.

32) **How do you find the dispensing of your treatment in this clinic to be?**
   1) Very efficient and easy.
   2) Efficient
   3) Acceptable
   4) Slow
   5) Very slow and inefficient.

On a scale of 1-5, one, being no problem and five being a very big problem how would you rate the following factors' effect on your ability to access your treatment?

No problem	Small problem	Neutral	Big Problem	Very big Problem
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5
1	2	3	4	5

33) Attitudes and service of the counsellors?
34) Attitudes and service of the nurses?
35) Attitudes and service of the pharmacists?
36) Attitudes and service of the doctors?
37) The length of the queue for the pharmacy?
38) The length of the queue for counselling and counting your tablets?

39) **Why did you get an HIV test the first time?**
   1) I was sick
   2) My partner was sick
   3) I was pregnant
   4) My partner wanted me to test
   5) I wanted to know my status

40) **Do you believe that the treatment is helping you improve your health?**
   1) Yes
   2) No
   3) Unsure

41) **Do you believe that there are other remedies such as traditional herbs or rituals that can cure HIV?**
   1) Yes
   2) No
   3) Unsure

42) **Have you ever taken any traditional remedies?**
   1) Yes
   2) No
   3) Sometimes

43) **Are you currently taking traditional remedies for HIV?**
   1) Yes
   2) No
   3) Sometimes

44) **Have you disclosed your status to someone at home?**
   1) Yes
   2) No

45) **What effect does a treatment supporter have on your ability to access your treatment?**
   1) My supporter is essential for me to collect my treatment.
   2) I appreciate my supporter but I do not rely on them to help me collect my treatment.
   3) I do not have a treatment buddy.
   4) My supporter does not help me.
   5) My supporter judges me and sometimes prevents me from collecting my treatment.

46) **How important is anonymity and confidentiality to you in terms of accessing your treatment?**
   1) I do not mind being seen at the clinic collecting ARV's.
   2) It does bother me a little to be known and seen at the clinic.
   3) I am neutral about this.
   4) Anonymity is very important to me.
   5) I will not collect my treatment if I know someone from my community there and know that my confidentiality will be compromised.

On a scale of 1-5, one, being no problem and five being a very big problem how would you rate the following factors' effect on your ability to access your treatment?

	No problem	Small problem	Neutral	Big Problem	Very big Problem
47) How difficult was it for you to disclose your status at home	1	2	3	4	5
48) Attitudes of family members towards HIV-positive people?	1	2	3	4	5
49) Your own belief about the effectiveness of the ARV's?	1	2	3	4	5
50) Attitudes of your community members towards people on ARV's?	1	2	3	4	5

51) **How does taking drugs and consuming alcohol affect your ability to access you treatment?**
    1) It is not a problem for me because I do not take drugs or consume alcohol.
    2) I sometimes drink alcohol but it does not interfere with my treatment.
    3) I drink quite a bit of alcohol and it sometimes makes me forget to take my treatment or come for my appointment to collect.
    4) I spend all my money on drugs and alcohol and cannot afford to come to the clinic at those times.

52) **What is the most expensive thing for you to collect your treatment every month?**
    1) Transport
    2) Hospital fees
    3) It costs a day off at work
    4) Other:_____

53) **If you do not have enough money for transport to the clinic what do you do?**
    1) I always have enough money.
    2) I walk, so transport money is not a problem for me.
    3) I borrow money from my relative/friends/neighbours.
    4) I do not come to the clinic that month for my appointment.
    Other: _____

54) **How does unemployment affect your ability to collect your treatment?**
    1) I am employed/ earn some money.
    2) Not a problem, I have good social support.
    3) It is a small problem but I manage.
    4) This is a big problem because I cannot afford the transport to the clinic every month.
    5) It is a catastrophic problem that presents a big challenge for me, resulting in me not being able to come to the clinic some months.
    6) Other:_____

55) **How does being employed create a barrier for you to access your treatment?**
    1) It does not affect me, I am unemployed.
    2) It is not a problem being employed and having to collect my treatment.
    3) I have to take a day off work to collect my treatment.
    4) Coming every month to collect my treatment is threatening my job security but I can still collect my treatment even without employment so I am not very worried.
    5) Coming every month to collect my treatment is threatening my job security, and without my job I cannot afford to come to the clinic to collect my treatment.
    6) Other:_____

56) **Do you receive a social grant/ disability grant?**
    1) Yes
    2) No

57) **If yes, in what way does the grant enable you to collect your treatment?**
    1) I do not receive a grant.
    2) The money helps with the costs of collecting every month but it is only temporary until I am better and can return to work.

3) The grant is my main source of income and if it ends I will find it very difficult to come to the clinic.
4) It is my only income. If it ends I will not be able to collect my treatment anymore.
5) Other:_____

On a scale of 1-5, one, being no problem and five being a very big problem how would you rate the following factors' effect on your ability to access your treatment?

58) The costs involved too come to the clinic every month?

59) The costs involved in obtaining hospital service?

No problem	Small problem	Neutral	Big Problem	Very big Problem
1	2	3	4	5
1	2	3	4	5

60) **How do you feel about taking ARV's for the rest of your life?**

1) I am happy and will take it for as long as I have too.
2) I see the benefit because it has helped me to get better.
3) My health has improved but the tablets have side-effects and that makes me feel sad.
4) Taking tablets of the rest of my life is going to be difficult, I do not know if I can manage it for the rest of my life.
5) Other: _____

61) **Have you ever skipped a dose or defaulted on your treatment, even if it was just for a day?**
    1) Yes
    2) No
    If yes, for how long did you not take your treatment? _____
    If yes, please indicate your reason or reasons:

1) I forgot
2) I ran out of tablets before my next visit.
3) I was at work and left my treatment at home.
4) I was on a family/ social outing and left my treatment at home.
5) I was in prison and did not have my treatment with me.
6) I was afraid someone from my community will see me drink my tablets.
7) I have another illness and all the tablets are just too many to take.
8) I had bad side-effects and felt too ill to take the treatment.
9) I do not have enough food at home to eat and take my treatment every day.
10) I do not have clean water at home to take my treatment.
11) Someone at my church/ traditional healer told me to stop taking my treatment.
12) I did not feel like taking my treatment.

The End
Thank you for participating.

Bibliography

ABDOOL KARIM, S. S. & ABDOOL KARIM, Q. 2010. *HIV/AIDS in South Africa,* Cambridge, New York, Melbourne, Madrid, Cape Town, Singapore, Sao Paulo, Dubai, Tokyo, Cambridge University Press.

ABDOOL KARIM, S. S., ABDOOL KARIM, Q. & BAXTER, C. 2010. Overview of the book. *In:* KARIM, S. S. A. & KARIM, Q. A. (eds.) *HIV/AIDS in South Africa.* Cambridge University Press.

ADAY, L. A. & ANDERSEN, R. 1974. A framework for the study of access to medical care. *Health Serv Res,* 9**,** 208-20.

ADAY, L. A. & ANDERSEN, R. M. 1981. Equity of Access to Medical Care: A Conceptual and Empirical Overview. *Medical Care,* 19**,** 4-27.

ANDERSEN, R. M. 1995. Revisiting the Behavioural Model and Access to Medical Care: Does it Matter? *Journal of Health and Social Behaviour* [Online], 36. [Accessed 27/06/2013].

ANYINAM, C. 1987. Availability, accessibility, acceptability, and adaptibility: Four attributes of African ethno-medicine. *Social Science & Medicine,* 25**,** 803-811.

ARBER, A. 2006. Reflexivity: A challenge for the researcher as practioner? *Journal of Research in Nursing* [Online], 11. [Accessed 03 April 2013].

BARNETT, T. & WHITESIDE, A. 2006. *AIDS in the Twenty-First Century: Disease and Globalization,* New York, Hampshire, PALGRAVE MACMILLAN.

BASHSHUR, R. L., HOMAN, R. K. & SMITH, D. G. 1994. Beyond the Uninsured: Problems in Access to Care. *Medical Care* [Online], 32. Available: http://www.jstor.org/stable/3765875 [Accessed 30/06/2013].

BEAUCHAMP, T. L. & CHILDRESS, J. F. 1994. *Principles of Biomedical Ethics,* Oxford, Oxford University Press.

BEHR, A. 1988. *Empirical Research Methods for the Social Sciences,* Durban, Butterworths.

BERNARD, H. R. 2002. *Research Methods in Anthropology: Qualitative and Quantitative Approaches,* Oxford, California, Alta Mira Press.

BOLER, T. & ARCHER, D. 2008. *The Policitcs of Prevention: A Global Crisis in AIDS and Education,* London, Pluto Press.

BRINKHOF, M. W. G., PUJADES-RODRIGUEZ, M. & EGGER, M. 2009. Mortality of Patients Lost to Follow-Up in Antiretroviral Treatment Programmes in Resource-Limited Settings: Systematic Review and Meta-Analysis. *PLoS ONE* [Online], 4. Available: http://dx.doi.org/10.1371%2Fjournal.pone.0005790 [Accessed 02/07/2013].

CAMPO, R. 2006. "Anecdotal Evidence": Why Narratives Matter to Medical Practice. *PLoS Med* [Online], 3. Available: http://dx.doi.org/10.1371%2Fjournal.pmed.0030423 [Accessed 08/08/2012].

CLARK, R. & COFFEE, N. 2011. Why measuring accessibility is important for public health: a review from the Cardiac ARIA project. *Public Health Bulletin of South Australia* [Online], 8.

DE VOS, A., STRYDOM, H., FOUCHE, C. & DELPORT, C. 2002. *Research at Grass Roots: For the social sciences and human services professions,* Pretoria, Van Schaik.

DENNILL, K., KING, L. & SWANEPOEL, T. 1999. *Aspects of Primary Health Care: Community Health Care in Southern Africa,* Cape Town, Oxford University Press.

DILTS, A. 2012. Revisiting Johan Galtung's Concept of Structural Violence. *New Political Science,* 34**,** 191-194.

DONABEDIAN, A. 1972. Models for Organizing the Delivery of Personal Health Services and Criteria for Evaluating Them. *The Milbank Memorial Fund Quarterly* [Online], 50. Available: http://www.jstor.org/stable/3349436 [Accessed 21/10/2013].

EPSTEIN, H. 2007. *The Invisible Cure: Africa, the West and the Fight against AIDS,* London, New York, PENGUIN BOOKS.

FARMER, P. 2001

Infections and Inequalities: The Modern Plagues [Kindle version 3.4]. Berkeley Los Angeles London: University of California Press.

FARMER, P. 2003. Pathologies of Power: Health, Human Rights, and the new war on the Poor. Berkeley Los Angeles London: University of California Press.

FARMER, P., NIZEYE, B., STULAC, S. & KESHAVJEE, S. 2006. Structural Violence and Clinical Medicine. *PLoS Med* [Online], 3. Available: http://dx.doi.org/10.1371%2Fjournal.pmed.0030449 [Accessed 01/07/2011].

FASSIN, D. 2007. When bodies remember: Experiences and Politics of AIDS in South Africa [Kindle version 3.4]. Berkeley Los Angeles London: University of California Press.

FETTERMAN, D. M. 1989. *Ethnography: Step by Step,* Newbury Park, London, New Delhi, SAGE Publications Ltd.

FOUCAULT, M. 1963. The Birth of the Clinic [Kindle version 3.4]. *In:* LAIGN, R. D. (ed.) Taylor & Francis e-Library 2003 ed.: Routledge Taylor & Francis Group.

FOX, M. P. & ROSEN, S. 2010. Patient retention in antiretroviral therapy programs up to three years on treatment in sub-Saharan Africa, 2007–2009: systematic review. *Tropical Medicine & International Health,* 15**,** 1-15.

FRIED, J., HARRIS, B. & EYLES, J. 2012. Hopes interrupted: accessing and experiences of antiretroviral therapy in South Africa. *Sexually Transmitted Infections,* 88**,** 147-151.

GALTUNG, J. 1969. Violence, peace, and peace research. *Journal of peace research,* 6**,** 167-191.

GARI, S., DOIG-ACUNA, C., SMAIL, T., MALUNGO, J., MARTIN-HILBER, A. & MERTEN, S. 2013. Access to HIV/AIDS care: a systematic review of socio-cultural determinants in low and high income countries. *BMC Health Services Research,* 13**,** 198.

GOVENDER, P. 2009. Love, courage, insubordination and HIV/AIDS denialism. *In:* CULLINAN, K. & THOM, A. (eds.) *The Virus, Vitamins and Vegetables: The South African HIV/AIDS Mystery.* Auckland Park: Jacana Media (Pty) Ltd.

GREENHALGH, T. 2010. *How to Read a Paper: the basics of evidence-based medicine,* West Sussex, Wiley-Blackwell.

GULLIFORD, M., FIGUEROA-MUNOZ, J., MORGAN, M., HUGHES, D., GIBSON, B., BEECH, R. & HUDSON, M. 2002. What does 'access to health care' mean? *Journal of Health Services Research & Policy,* 7**,** 186-188.

HANSEN, E. C. 2006. Successful Qualitative Health Research: A Practical Introduction [eBook version]. Australia: Allen and Unwin.

HARDON, A., HODGKIN, C. & LAIGN, R. 2006. From access to adherence: The challenges of antiretroviral treatment. Geneva: WHO, University of Amsterdam, Royal Tropical Institute.

HARRIS, B., GOUDGE, J., ATAGUBA, J. E., MCINTYRE, D., NXUMALO, N., JIKWANA, S. & CHERSICH, M. 2011. Inequities in access to health care in South Africa. *Journal of Public Health Policy,* 32**,** S102-S123.

HENDERSON, P. C. 2011. *AIDS, Intimacy and Care in Rural KwaZulu-Natal: A Kinship of Bones,* Amsterdam, Amsterdam University Press.

HOLZEMER, W. L., UYS, L., MAKOAE, L., STEWART, A., PHETLHU, R., DLAMINI, P. S., GREEFF, M., KOHI, T. W., CHIRWA, M., CUCA, Y. & NAIDOO, J. 2006. A conceptual model of HIV/AIDS stigma from five African countries. *Journal of Advanced Nursing,* 58**,** 541-551.

HUMAN, O. 2011. The Rings Around Jonathan's Eyes: HIV/AIDS Medicine at the Margins of Administration. *MEDICAL ANTHROPOLOGY,* 30**,** 222-239.

HUNTER, M. 2010. *Love in the time of AIDS: Gender, Inequality and Rights in South Africa,* Scottsville, University of KwaZulu Natal Press.

IGE, S. & QUINLAN, T. 2012. *African REsponses to HIV/AIDS: Between Speech and Action,* KwaZulu Natal, University of KwaZulu Natal Press.

INDA, J. X. & ROSALDO, R. 2002. *The Anthropology of Globalization,* Oxford, Blackwell Publishers.

JONES, P. S. 2010. Mind the gap: Access to ARV medication, rights and the politics of scale in South Africa. *Social Science & Medicine,* 74**,** 28-35.

KZNHEALTH 2003. A Framework for a Referral System for Health Service Delivery in KwaZulu Natal.

KZNHEALTH 2010. Strategic Plan for KwaZulu Natal Health 2010-2014. *In:* HEALTH, K. N. D. O. (ed.).

LECLERC-MADLALA, S. 2006. 'We will eat when I get the grant': negotiating AIDS, poverty and antiretroviral treatment in South Africa. *African Journal of AIDS Research* [Online], 5. [Accessed 21 October 2011].

LECLERC-MADLALA, S. 2009. Cultural scripts for multiple and concurrent partnerships in southern Africa: why HIV prevention needs anthropology. *Sexual Health,* 6**,** 103-110.

MAGULA, N. 2006. *Adherence to HAART in the First Year of the Rollout Program at King Edward VIII Hospital, KwaZulu-Natal, South Africa. .* Master of Science in Clinical Research, TUFTS University.

MCLAUGHLIN, C. G. & WYSZEWIANSKI, L. 2002. Access to care: remembering old lessons. *Health Serv Res* [Online], 37. [Accessed Dec].

MERTEN, S., KENTER, E., MCKENZIE, O., MUSHEKE, M., NTALASHA, H. & MARTIN-HILBER, A. 2010. Patient-reported barriers and drivers of adherence to antiretrovirals in sub-Saharan Africa: a meta-ethnography. *Tropical Medicine & International Health,* 15**,** 16-33.

MILLER, C. M., KETLHAPILE, M., RYBASACK-SMITH, H. & ROSEN, S. 2010. Why are antiretroviral treatment patients lost to follow-up? A qualitative study from South Africa. *Tropical Medicine & International Health,* 15**,** 48-54.

MUKHERJEE, J. S., IVERS, L., LEANDRE, F., FARMER, P. & BEHFOROUZ, H. 2006. Antiretroviral Therapy in Resource-Poor Settings: Decreasing Barriers to Access and Promoting Adherence. *Journal of Acquired Immune Deficiency Syndrome,* 43**,** 123-126.

MURRAY, L., SEMRAU, K., MCCURLEY, E., THEA, D. M., SCOTT, N., MWIYA, M., KANKASA, C., BASS, J. & BOLTON, P. 2009. Barriers to acceptance and adherence of antiretroviral therpay in urban Zambian women: a qualitative study. *AIDS care,* 21**,** 78-86.

MYER, L. 2010. Barrier Methods. *In:* ABDOOL KARIM, S. S. & ABDOOL KARIM, Q. (eds.) *HIV/AIDS in South Africa.* 2nd ed. Cambridge, New York,Cape Town: CAMBRIDGE UNIVERSITY PRESS.

NDOH 2011a. Government Gazette No. 35423 National Health Act, 2003 Policy on National Health Insurance. *In:* HEALTH, N. D. O. (ed.). Pretoria.

NDOH 2011b. National Health Insurance: Healthcare for all South Africans. *In:* HEALTH, N. D. O. (ed.). Pretoria: DOH.

NDOH 2012. Global AIDS Response Progress Report 2012 Republic of South Africa. *In:* DEPARTMENT OF HEALTH, N. (ed.).

NDOH 2013. The South African Antiretroviral Treatment Guidelines 2013. National Department of Health Republic of South Africa.

NDOH & HST 2012. The National Health Care Facilities Baseline Audit: National Summary Report 2012. *In:* TRUST, H. S. (ed.). Westville: Health Systems Trust.

OLDSTONE, M. B. A. 2010. *Viruses, Plagues, and History: Past, Present, and Future*, Oxford University Press.

OLIVER, A. & MOSSIALOS, E. 2004. Equity of access to health care: outlining the foundations for action. *J Epidemiol Community Health,* 58**,** 655-8.

PARKER, R. & AGGLETON, P. 2002. HIV/AIDS-related Stigma and Discrimination: A Conceptual Framework and an Agenda for Action. Horizons Program.

PARSONS, T. 1951. *The Social System,* London, The Free Press of Glencoe.

PAUL FARMER 2004. An Anthropology of Structural Violence. *Current Anthropology,* 45**,** 305-325.

PENCHANSKY, R. & THOMAS, J. W. 1981. The Concept of Access: Definition and Relationship to Consumer Satisfaction. *Medical Care,* 19**,** 127-140.

PETERS, S. 2013. *KZN to intensify 'Aids cures' fight* [Online]. Available: www.iol.co.za/news/south-africa/kwazulu-natal/kzn-to-intensify-aids-cure-fight-1.1606617#.

 [Accessed 13 November 2013 2013].

POOL, R. & GEISSLER, W. 2005. *Medical Anthropology,* New York, Berkshire, Open University Press.

POOL, R. & GEISSLER, W. 2011. Situating sickness and health. *In:* BLACK, N. & RAINE, R. (eds.) *Medical Anthropology.* Berkshire, New York: Open University Press.

POSSE, M., MEHEUS, F., VAN ASTEN, H., VAN DER VEN, A. & BALTUSSEN, R. 2008. Barriers to Access to antiretroviral treatment in developing countries: a review. *Tropical Medicine and International Health,* 13**,** 904-913.

REDA, A. A. & BIADGILIGN, S. 2011. Determinants of Adherence to Antiretroviral Therapy among HIV-Infected Patients in Africa. *AIDS Research and Treatment,* 2012.

ROSSOUW, T., LESSELLS, R. J. & DE OLIVEIRA, T. 2013. *HIV & TB Drug Resistance & Clinical Management Case Book,* Cape, South African Medical Research Council.

SADOH, A. E., SADOH, W. E., FAWOLE, A. O., OLADIMEJI, A. & SOTILOYE, O. 2009. Attitude of health care workers to patients and colleagues infected with the human immunodeficiency virus. *Journal of Social Aspects of HIV/AIDS,* 6**,** 17-23.

SAHRC 2009. Public Inquiry: Access to Health Care Services. *In:* COMMISSION, S. A. H. R. (ed.). South African Human Rights Commision.

SAVAGE, J. 2006. Ethnographic Evidence: The value of applied ethnography in healthcare. *Journal of Research in Nursing,* 11**,** 383-393.

SCHEPER-HUGHES, N. 1992. Death Without Weeping: The Violence of Everyday Life in Brazil. Berkeley, Los Angeles, London: Univeristy of California Press.

SCHEPER-HUGHES, N. 2004. Parts unknown: Undercover ethnography of the organs-trafficking underworld. *Ethnography,* 5**,** 29-73.

SCHWARTLANDER, B., GRUBB, I. & PERRIENS, J. 2006. The 10-year struglle to provide antiretroviral treatment to people with HIV in the developing world. *The Lancet,* 368**,** 541-546.

SHILTS, R. 1987. *And the Band Played On: Politics, People, and the AIDS Epidemic,* New York St Martin's Press.

STEINBERG, J. 2008. *Three Letter Plague: A young man's Journey through a Great Epidemic,* Johannesburg, Cape Town, Jonathan Ball Publishers.

STOTT, K., MICHEL, J. & DE OLIVEIRA, T. 2013. Principles of HIV drug resistance for clinical management in South Africa. *HIV Nursing Matters,* 4**,** 24-30.

TERSBØL, B. P. 2006. 'I just ended up here, no job and no health…' — men's outlook on life in the context of economic hardship and HIV/AIDS in Namibia. *SAHARA-J: Journal of Social Aspects of HIV/AIDS,* 3**,** 403-416.

THURMOND, V. A. 2001. The Point of Triangulation. *Journal of Nursing Scholarship,* 33**,** 253-258.

TIMSIT, J.-F. 2005. Open the intensive care unit doors to HIV-infected patients with sepsis. *Critical Care,* 9**,** 629 - 630.

UN 2013. The Millenium Development Goals Report 2013. *In:* NATIONS, U. (ed.). New York: United Nations.

UNAIDS 2003. Handbook on access to HIV/AIDS-related treatment. *UNAIDS,* 1**,** 1-130.

UNAIDS 2010. Towards Universal Access: Progress report 2010. Geneva: UNAIDS.

UNAIDS 2012. UNAIDS Global Report 2012: Together we will end AIDS.

UNAIDS 2013. TREATMENT 2015. Geneva: Joint United Nations Programme on HIV/AIDS.

UNAIDS & WHO 2003. Handbook on Access to HIV/AIDS-related treatment. Geneva: UNAIDS, WHO, International HIV/AIDS Alliance

UNAIDS & WHO 2011. The Treatment 2.0 Framework for Action: Catalysing the next phase of treatment, care and support. *In:* WHO, U. (ed.). Geneva: WHO,UNAIDS.

UNAIDS, WHO & UNICEF 2011. Global HIV/AIDS Response: Epidemic update and health sector progress towards Universal Access. Geneva: WHO, UNAIDS, unicef.

VAN DYK, A. C. 2010. Treatment adherence following national antiretroviral rollout in South Africa. *African Journal of AIDS Research,* 9**,** 235-247.

VAN DYK, A. C. 2012. *HIV/AIDS Education, Care and Counselling: A Multidisciplinary Approach,* Cape Town, Pearson Education South Africa.

VAN STADEN, S. J. & DU TOIT, D. A. 2003. *Nursing Sociology,* Pretoria, Van Schaik Publishers.

WARE, N. C., IDOKO, J., KAAYA, S., BIRARO, I. A., WYATT, M. A., AGBAJI, O., CHALAMILLA, G. & BANGSBERG, D. R. 2009. Explaining Adherence Success in Sub-Saharan Africa: An Ethnographic Study. *PLoS Med,* 6**,** e1000011.

WARE, N. C., WYATT, M. A., GENG, E. H., KAAYA, S. F., AGBAJI, O. O., MUYINDIKE, W. R., CHALAMILLA, G. & AGABA, P. A. 2013. Toward an Understanding of Disengagement from HIV Treatment and Care in Sub-Saharan Africa: A Qualitative Study. *PLoS Med,* 10**,** e1001369.

WHO 2003. Adherence to long-term therpies: evidence for action. Geneva.

WHO 2007. WHO Case Definitions of HIV Surveillance and Revised Clinical Staging and Immunological Classification of HIV-Related Disease In Adults and Children.

WHO 2011. Global health sector strategy on HIV/AIDS 2011-2015. *In:* ORGANISATION, W. H. (ed.). Geneva.

WHO 2013. Consolidated Guidelines on The Use of Antiretroviral Drugs for Treating and Preventing HIV Infection. Geneva: World Health Organisation.

WHO, UNAIDS & UNDP 2010. Using TRIPS flexibilities to improve access to HIV treatment. Joint United Nations Programme on HIV/AIDS.

WILKINSON, L. S. 2013. ART adherence clubs: A long-term retention strategy for clinically stable patients receiving antiretroviral treatment. . *South African Journal of HIV Medicine,* 14**,** 48-50.

WILLIS, E. M. 2010. The Problem of Time in Ethnographic Health Care Research. 20. [Accessed 31 Jan 2013].

WOOD, R. 2010. Antiretroviral Therapy. *In:* ABDOOL-KARIM, S. S. & ABDOOL-KARIM, Q. (eds.) *HIV/AIDS in South Africa.* 2nd ed. Cambridge: CAMBRIDGE UNIVERSITY PRESS.

ZELNICK, J. & O'DONNELL, M. 2005. The Impact of the HIV/AIDS Epidemic on Hospital Nurses in KwaZulu Natal, Sout Africa: Nurses' Perspectives and Implications for Health Policy. *Journal of Public Health Policy,* 26**,** 168-185.