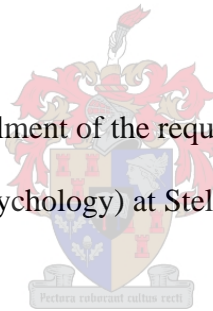


**Identifying structural barriers to antiretroviral therapy adherence**

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Thesis presented in fulfilment of the requirements for the degree of  
Master of Arts (Psychology) at Stellenbosch University



Supervisor: Professor SA Kagee

March 2011

## DECLARATION

By submitting this thesis electronically, I declare that the entirety of the work contained therein is my own, original work, that I'm the authorship owner thereof and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

.....

J.H. Vermeulen

.....

Date

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## SUMMARY

The topic of antiretroviral adherence remains a subject of continued importance, as it is associated with positive health outcomes amongst patients attending public healthcare facilities. Available literature on adherence behaviour mainly focuses on the psychological and behavioural barriers, while overlooking the multitude of structural barriers within the patient's environment affecting the patient's adherence to antiretroviral treatment and care. The present study provides a unique perspective on adherence behaviour amongst persons living with HIV and receiving antiretroviral treatment, as it identifies important structural barriers to clinical attendance and pill-taking.

The sample for this study were selected from patients attending an infectious diseases clinic at a major peri-urban secondary hospital and receiving antiretroviral therapy, nurses and doctors providing health services to patients, and patient advocates providing psychosocial support to patients under the auspices of a local non-governmental organisation. The participants included in this study were selected by means of convenience sampling to participate either in semi structured interviews or focus group discussions. Participants were assured of the confidentiality of the process and their anonymity in both cases. Both semi structured interviews and focus groups were digitally recorded and transcribed after which transcriptions were entered into Atlas.ti for textual analysis. Transcriptions were thematically analysed according to the perceptions of various participants. The main themes that emerged from the present study included individual barriers, poverty-related barriers, institution-related barriers, and social and community-related barriers.

The results of the present study were triangulated by considering the concurrences and discrepancies between the patients, clinicians and patient advocates on the main, and subthemes. These themes were then discussed according to Bronfenbrenner's (1972) Ecological Systems Theory, which divided the main themes identified according to the

different systems operating within the patient's environment, i.e. the micro-, exo-, and macrosystem. The microsystem included both individual psychological and behavioural barriers and poverty-related barriers. Institutional barriers were considered within the exo-system of the patient's ecological environment. And the social and community-related barriers were considered within the macrosystem of the patient's ecological environment.

The significance of this study lies in the identification of adherence behaviour as the product of the patient's environment through the examination of triangulated data. Future research may include effective ways in which patients can be assisted in developing the necessary skills to cope with their environment and to enhance social support. The development of strategies to support newly-enrolled patients also still needs investigation.

## OPSOMMING

Volgehoue antiretrovirale behandeling bly 'n onderwerp van voortdurende belang omdat dit geassosieer word met positiewe gesondheidsuitkomste onder pasiënte wat van openbare gesondheidsfasiliteite gebruik maak. Beskikbare literatuur oor volhoudings gedrag fokus grootliks op sielkundige en gedragshindernisse, terwyl veelvuldige strukturele hindernisse binne die pasiënt se omgewing steeds misgekyk word. Dié studie bied 'n unieke perspektief op volhoudingsgedrag onder MIV-positiewe pasiënte wat tans antiretrovirale terapie ontvang, aangesien dit belangrike strukturele hindernisse tot kliniek bywoning en die neem van medikasie identifiseer.

Dié steekproef sluit pasiënte in wat tans antiretrovirale terapie by 'n aansteeklike siektes-kliniek by 'n peri-stedelike sekondêre hospitaal ontvang. Dit sluit ook dokters en verpleegsters in wat gesondheidsdienste aan dié pasiënte verskaf, en pasiënt-advokate wat psigo-sosiale ondersteuning aan pasiënte verskaf onder die vaandel van 'n plaaslike nie-regerings organisasie. Dié deelnemers is deur middel van gerieflikheidssteekproef geselekteer om aan semi-gestruktureerde onderhoude of fokusgroepbesprekings deel te neem. Deelnemers van albei groepe is van hul anonimiteit en die vertroulikheid van die proses verseker. Beide die semi-gestruktureerde onderhoude en die fokusgroepbesprekings is digitaal opgeneem en transkripsies is daarvan gemaak, waarna die transkripsies in Atlas.ti gelaai is vir tekstuele analise. Transkripsies is tematies geanaliseer volgens die persepsies van die verskeie deelnemers. Die hooftemas wat na vore gekom het, sluit in individuele hindernisse, armoedeverwante hindernisse, institusieverwante hindernisse asook sosiale en gemeenskapsverwante hindernisse.

Resultate van dié studie is getrianguleer deur die verskille en ooreenkomste te vind tussen pasiënte, klinici en pasiënt-advokate oor die hoof- en subtemas. Die hooftemas is toe volgens Bronfenbrenner (1972) se Ekologiese Sisteemeteorie verdeel in die verskillende

sisteme teenwoordig in die pasiënt se omgewing, naamlik die mikro-, ekso-, en makrosisteme. Die mikrosisteme het individuele sielkundige en gedragshindernisse asook die armoede- en gesondheidsverwante hindernisse ingesluit. Institusie- en sosiale hindernisse is binne die eksosisteme van die pasiënt se ekologiese omgewing beskou en sosiale en gemeenskapsverwante hindernisse is beskou binne die makrosisteme van die pasiënt se ekologiese omgewing.

Die belang van dié studie lê in die identifisering van volhoudingsgedrag as produk van die pasiënt se omgewing, soos beskou deur die Ekologiese Sisteemteorie. Toekomstige navorsing kan fokus op effektiewe maniere waarop pasiënte bygestaan kan word om die nodige vaardighede te ontwikkel om hul omgewing beter te kan hanteer en beskikbare sosiale ondersteuning te kan verbeter. Die ontwikkeling van strategieë om nuwe pasiënte by te staan, benodig ook verdere navorsing.

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Nadia Vermeulen

22 October 2010



## **DEDICATION**

I dedicate this thesis to all my friends at K.C. who has provided me with support, and has taught me the ability to persevere against all odds.



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## CHAPTER ONE: INTRODUCTION

### 1.1 Introduction and rationale for the present study

The Human Immunodeficiency Virus (HIV) has emerged as a pandemic with an impending catastrophic impact on human societies worldwide (Burden of Disease Research Unit, 2007). Globally the number of HIV infections have risen from 8 million in 1990 to 33.2 million in 2007 (Department of Health South Africa, 2007; UNAIDS, 2007). In South Africa alone, there is currently 5.7 million people living with HIV (UNAIDS, 2007), accounting for nearly 11% of the population (Burden of Disease Research Unit, 2007), making South Africa home to the largest population of people living with HIV in the world. HIV accounts for nearly 1,400 new infections per day in this region and it is estimated that HIV will also account for 75% of premature deaths by 2010 (Burden of Disease Research Unit, 2007).

The commencement of antiretroviral therapy (ART) in the early 1990's, brought the hope that this therapy would serve as a cure for HIV. It was, however, soon realized that this was an improbable goal, not likely to be realized, since it would require HIV-infected individuals to adhere to long term antiretroviral therapy, as they would have to receive ART for many years, if not life (Finzi et al., 1999; Ware, Wyatt, & Tugenberg, 2006). Adherence to ART regimens are vital for the individual patient and for the general public since non-adherence can result in drug-resistant strains being easily transmitted from one individual to another (Roberts & Mann, 2000). Yet, non-adherence to medical treatment still continues to be a challenge (Stone et al., 2001).

Poor treatment adherence is currently the most important barrier to effective ART treatment (Stone et al., 2001). Consistent and near perfect adherence to antiretroviral therapy regimens is needed to attain the maximum benefit from these potentially effective treatments (Kalichman et al., 2001). Antiretroviral therapy, however, is an unforgiving drug, as clinical studies have shown that a particularly high level of adherence (90%-95% or greater) is

required for an improved virological outcome, a greater increase in CD4+ lymphocyte count, and a lower hospitalization rate among individuals infected with HIV (Chesney, Morin & Sherr, 2000; Forgarty et al., 2002; Paterson et al., 2000). The likelihood of sustaining therapy over a longer period of time has also been associated with patients who show higher levels of adherence (Bangsberg et al., 2003). Poor adherence to ART, on the other hand, is the most likely cause for therapeutic failure, associated with virologic failure, immunologic failure, and clinical progression of the disease (Carpenter et al., 2000; Department of Health and Human Services, 2008).

Reasons for poor adherence to ART have frequently been documented in the literature. According to the literature those reasons have most recurrently been associated exclusively with individual psychological and behavioural barriers relating to specific patient and regimen characteristics (Forgarty et al., 2002; Ware et al., 2006). These barriers commonly include forgetfulness (Schuman et al., 2001), pill burden (Berg, Michelson, & Safren, 2007), side-effects (Davies et al., 2006), beliefs and perceptions about treatment regimens, substance abuse (García & Côté, 2003), literacy and self-efficacy (Wolf et al., 2007), and emotional distress (Penna & Treisman, 2005).

Little emphasis has been placed on the structural barriers to ART treatment, factors that patients may have little control over (García & Côté, 2003). Adherence behaviours related to social, economic, political and cultural domains, which collectively make up social structures, and how they act as barriers, have greatly been ignored until recently (Shriver, Everett, & Stephen, 2000). Research should therefore examine how the environment affects patients' adherence behaviour to the same extent as how individual psychological and behavioural factors affect patients' adherence behaviour (Sumartojo, 2000).

## 1.2 Need for the present study

The prevalence of HIV among South Africans remains at a very high level. Currently 5.2 million of South Africa's population are infected with HIV, adding to a prevalence rate of 10.6% (Shisana et al., 2009). When excluding HIV-infected children under the age of 2 years, the prevalence rate of HIV rises to 10.9% (Shisana et al., 2009). The prevalence rate differs between the nine provinces, ranging from 6.6% in the Eastern Cape to 14.9% in the Western Cape in 2008, for the age group of 2+ years (Shisana et al., 2009). Within the same year the Western Cape showed a prevalence rate of 10.7% for the same age group (Shisana et al., 2009).

South Africa is currently the country with the largest number of HIV and AIDS-infected individuals enrolled in antiretroviral therapy in the world (National Department of Health, 2007). The local AIDS and Demographic model (ASSA, 2003) projects that in 2009 (mid year) 583,264 adults and 68,505 children will be receiving antiretroviral therapy in South Africa (Nicolay & Kotzé, 2008). It is also projected that 470,379 adults and 26,391 children with AIDS are not on antiretroviral therapy, contributing to the 1,148,539 HIV-infected individuals currently eligible for antiretroviral therapy (Nicolay & Kotzé, 2008). April 2004 saw the initiation of the national rollout programme in South Africa, with demonstration projects being launched in Khayelitsha in 2001 and in Gugulethu in 2002 (Boulle et al., 2008).

HIV-infected individuals participating in the Khayelitsha demonstration project demonstrated high levels of adherence to antiretroviral therapy, as they sustained the suppression of viral replication, with a reduced risk of developing resistance (Medicénes Sans Frontières South Africa, 2003). The demonstration project launched reported that 90.6% of adults achieved virological suppression within six months after initiation of antiretroviral

therapy, and only 1.3% of individuals were reported to be on second-line regimens by the end of 2005 (Boulle et al., 2008).

This demonstration project firmly required potential candidates to undergo an assessment of clinical and social conditions, as well as their expected ability to adhere to antiretroviral treatment (Medicénes Sans Frontirés South Africa, 2003). Candidates' ability to adhere to antiretroviral therapy was assessed according to their adherence to co-trimoxazole prophylaxis and tuberculosis treatments, their ability to attend regular clinic visits and the prerequisite of having disclosed their status to at least one other person (Medicénes Sans Frontirés South Africa, 2003).

After the candidates had been enrolled in the demonstration project, they were provided with support materials, such as pill boxes and drug identification charts, daily schedules, diaries, educational materials explaining the risks and benefits of antiretroviral therapy (Medicénes Sans Frontirés South Africa, 2003). They were also required to have a treatment assistant, and received peer support through support groups hosted by the clinic twice monthly. There they could discuss barriers to adherence, adverse effects, and psychosocial problems (Medecins Sans Frontieres South Africa, 2003).

In the national rollout, the criteria by which candidates were selected for antiretroviral therapy changed, as the distribution of antiretroviral therapy became more widespread than the Khyalitsha demonstration project. Many of the patients receiving antiretroviral therapy did not have access to the same amount of social, psychological and material support, as the candidates of the demonstration project. The same level of adherence could therefore not be expected from the national rollout patients. Adherence in this group was likely to be much lower.

### **1.3 Aims of the present study**

The first aim of the present study was to determine the difficulties patients experience in adhering to treatment and care and the factors involved making it difficult for patients to take their medication. The second aim was to gain insight into what doctors and nurses perceived to be barriers to patients' adherence to care and their perception of factors that seem to play a role in patients' ability to adhere to medication. The third aim was to uncover the perceptions of patient advocates around the issue of patients' adherence to care and their adherence to medication.

In addressing the above mentioned aims, it was possible to: (a) identify a triangular view of the barriers patients face in attending clinic appointments and taking their medication; that is from the perspective of patients, clinicians (doctors and nurses) and patient advocates, (b) to discuss these barriers through a theoretical framework, which included the Bronfenbrenner's (1972) Ecological Systems Theory.

### **1.4 Overview of chapters**

Chapter 2 provides an overview of the HIV pandemic, incidence and prevalence of the HIV pandemic, antiretroviral therapy, adherence to antiretroviral therapy, individual barriers to antiretroviral therapy, structural barriers to antiretroviral therapy, and a theoretical framework. Chapter 3 describes the method that was used for the present study, including the research design, the selection of participants, data analysis and ethical considerations. Chapter 4 includes the findings of the present study. In chapter five the results are discussed and explained by incorporating theory with the findings, the implications of the findings of the present study as well as the implications for future research are discussed.

## **CHAPTER TWO: REVIEW OF THE LITERATURE**

### **2.1 HIV pandemic**

AIDS was first identified as a new pandemic in 1981 (Turkoski, 2006). It took an additional two years to isolate and pinpoint the HIV to be the forerunner to AIDS (Turkoski, 2006).

Unknown 28 years ago, HIV-related causes have already contributed to a human toll of 25 million deaths worldwide, since the beginning of the pandemic (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2008; World Health Organization, 2007).

In 2000 HIV overtook tuberculosis (TB) as the world's leading infectious cause of adult deaths (Farmer et al., 2001). The HIV and AIDS pandemic has proved to be a global pandemic, which continues to be a problem of unprecedented dimensions (WHO, 2007) and a critical challenge to health (Department of Health South Africa, 2007). HIV infection and AIDS-related conditions have become more important than ever before (Department of Health, South Africa, 2007). The total number of infections has increased from around 8 million in 1990 to virtually 40 million today, and increasing (Department of Health South Africa, 2007). As the pandemic developed, a growing number of people are reaching advanced stages of HIV infection (Antiretroviral therapy coverage among people with advanced HIV infections (percentage), 2008), reducing life expectancy by more than 20 years (WHO, 2007). The estimated number of people newly infected with HIV each year continue to exceed the increase in the number of people receiving antiretroviral drugs 2.5 to 1 (Joint United Nations Programme on HIV/AIDS (UNAIDS), 2008; WHO, 2007).

### **2.2 Incidence and prevalence of HIV**

Globally statistics of people living with HIV, indicate that in 2007 there were over 32.3 million people living with HIV worldwide, and 2.5 million of those being new infections within this period. This infection rate indicates that 8,600 individuals were infected with HIV per day (Dorrington, Bradshaw, Johnson & Budlender, 2004). In the same year, it was

estimated that 2.7 million people worldwide died because of AIDS, with more than 5,700 individuals dying of AIDS daily, mainly due to poor access to HIV treatment and prevention services (Dorrington et al., 2004).

Sub-Saharan Africa is the most seriously affected by the HIV epidemic (Joint United Nations Programme on HIV and AIDS [UNAIDS], 2008; World Health Organization [WHO], 2007). This region accounts for more than a third (32%) of new HIV infections globally in 2007, as well as 76% of AIDS-related deaths (Dorrington et al., 2004). AIDS, therefore, remains the leading cause of death in this region.

In South Africa the demographic impact of HIV is even greater (Dorrington et al., 2004). The Joint United Nations Programme on HIV and AIDS Organization (2008) declared South Africa to be the country with the largest number of HIV infections in the world. It was estimated that in 2004 more than 5 million of the total South African population of 46 million were HIV positive, with a daily infection rate of 1,400 individuals (Burden of Disease Research Unit, 2007). HIV and AIDS were also the main cause of death in this region (UNAIDS, 2007). The World Health Organization estimated that 1.8 million South Africans had died from AIDS-related diseases since the start of the pandemic (WHO, 2007), killing 336,000 between mid-2005 and mid-2006 alone (Dorrington, Johnson, Bradshaw & Daniel, 2006). HIV/AIDS accounted for 47% of deaths in 2006, which, without an intervention strategy, would account for 75% of premature mortality by 2010 (Burden of Disease Research Unit, 2007). In reality the pandemic was taking a bigger toll than shown by statistics. Causes of death statistics significantly underestimated the number of AIDS deaths, due to stigma associated with HIV and AIDS. Details completed on the death certificate tended to focus on opportunistic infections or mechanisms of death rather than providing the underlying cause (Dorrington, Bourne, Bradshaw, Laubscher & Timacus, 2001).



### **2.3 Antiretroviral therapy**

Antiretroviral therapy is the main type of treatment for HIV and AIDS (Introduction to HIV and AIDS treatment, 2008). The objective of antiretroviral therapy was to treat the illness and lessen the concentration of viral load in the blood, or if possible, to maintain it at an undetectable level, thereby slowing the evolution of the illness (Gallant, 2000). The greatest aim of antiretroviral therapy is to improve the length and quality of the lives of patients living with HIV or AIDS (García & Côte, 2003), and to provide infected individuals with control over the damage HIV causes to their immune system (Kalichman, 1998).

These early antiretroviral therapies presented problems, as these therapies were not convenient as potent combination therapies expected infected individuals to take more than one drug (Introduction to HIV and AIDS treatment, 2008). This could entail taking up to 20 pills per day (Gulick, 2006). These regimens which involved several medications not only included complicated schedules which usually divided every 8 hours in a fasting state (Gulick, 2006), but also included dietary restrictions (Safren, Radomsky, Otto & Solomon, 2002; Weiss et al., 2003; Yeni et al., 2002). Over time the complexity of antiretroviral treatment had been reported to lead to poor adherence (Bova, 2000).

Strategies for antiretroviral therapy are now more successful than those formerly available (Centers for Disease Control and Prevention, 1998). Triple-combination therapies introduced a dramatic decrease in the incidence of new opportunistic infections, as well as a reduction in hospitalisations (Powderly, Landay & Lederman, 1998), and AIDS-related deaths in persons with AIDS and those in the intermediate stage of HIV (Hoggs et al., 1998; Yeni et al., 2002).

Taking highly active antiretroviral treatment will be a lifelong requirement (Bova, 2000) as the dynamic and chronic nature of HIV necessitates these potent and continuous therapies for the duration of viral replicative capability (Wainberg & Friedland, 1998).

Patients should know that the first regimen more often than not presents the best chance of a simple regimen with long term treatment success and prevention of drug resistance

(Department of Health and Human Services, 2008). The durability of the first regimen first and foremost is associated with adherence, tolerability and convenience (Yeni et al., 2002).

### **2.3.1 Antiretroviral medications**

#### **2.3.1.1 Combination antiretroviral therapy.**

Combinations of various antiretroviral drugs need to be taken at the same time. If a single drug out of these combinations were to be taken on its own, HIV would quickly become resistant to it and the drug will not be effective any longer (Introduction to HIV and AIDS treatment, 2008). The combination of several antiretroviral drugs into one treatment regimen to be taken at the same time immensely decreases the rate at which resistance would develop, increasing the success of these antiretroviral combinations in the long run (Introduction to HIV and AIDS treatment, 2008). Antiretroviral therapy regimens thus consist of a combination of three drugs, which include two Nucleoside/Nucleotide Transcriptase inhibitors (NRTIs) plus one Non-Nucleocide Reverse Transcriptase Inhibitor (NNRTI) (WHO, 2006).

##### **2.3.1.1.1 Nucleoside/Neocleotide Transcriptase Inhibitors (NRTIs).**

NRTIs are known to interfere with the action of an HIV protein called reverse transcriptase, which is needed for the HIV virus to make new copies of itself (Introduction to HIV and AIDS treatment, 2008). NRTIs are also the backbone of antiretroviral therapy combinations, and should be used with a companion NNRTI (WHO, 2006). List of Nucleoside/Neocleotide Transcripase Inhibitors (NRTIs) indicated in Table 1.

Table 1

*Nucleoside/Nucleotide Reverse Transcriptase Inhibitors (NRTIs)*

Abbreviation	Generic name	Food restrictions	Description of drug
3TC	Lamivudine	Take with or without food	Lamivudine (3TC) is vital to all first-line ARV regimens in resource limited countries. It has been proved safe, has a favourable toxicity profile, relatively cheap to produce and widely available.
ABC	Abacavir	Take with or without food	Abacavir (ABC), the use is generally reserved to second-line regimens. It provides an effective backbone for the use of NNRTIs or as part of triple nucleoside regimen. ABC is associated with severe hypersensitivity reaction to 2-5% of patients who receive the drug.
AZT or ZDV	Zidovudine	Take with or after food	Zidovudine (AZT) is included as
d4T	Stavudine	Take with or without food	Stavudine (d4T) is recognized as a life saving drug that has played a crucial role in ART rollout because of its availability in FDC's, the low cost of FDC and the clinical efficacy of regimens recommended. FDC is also preferred over AZT because of the requirement for limited or no laboratory monitoring. d4t may be used as substitute for AZT if intolerance occurs and TDF and ABC are unavailable.
FTC	Emtricitabine	Take with or without food	Emtricitabine (FTC) is a new NRTI that has recently been included in the WHO's recommended first-line regimens. FTC is an equivalent alternative to 3TC, and it shares the same efficacy against HIV

Table 1 *Continued*

Abbreviation	Generic name	Food restrictions	Description of drug
TDF	Tenofovir	Take with or without food	Tenofovir (TDF) is included as preferred first-line NRTI because of efficacy, ease of use and safety profile. TDF has a long half life and can be used as once-daily regimens. Availability of TDF in resource limited settings is currently limited but it is hoped that it will become more available at reduced costs.

*Note:* From “Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents,” by Department of Health and Human Services, 2008, Retrieved from <http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>. And “Antiretroviral therapy for HIV infection in adults and children: Recommendations for public health,” by the World Health Organization, 2006. WHO Library Cataloguing in-Publication Data.

### **2.3.1.1.2 Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs).**

NNRTIs are vigorous drugs, and an important antiretroviral class, to be combined with two NRTIs in first-line therapy, and assist the construction of a rather simple initial regimen (WHO, 2006). The NNRTIs act by stopping HIV from replicating within cells by inhibiting the reverse transcriptase protein (Introduction to HIV and AIDS treatment, 2008). The NNRTIs efavirenz (EFV) and Nevirapine (NVP) are well-known for clinical efficacy when administered in the proper combination regimen (WHO, 2006). List of Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) indicated in Table 2.

Table 2

*Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs):*

Abbreviation	Generic name	Food restrictions	Description of drug
EFV	Efavirenz	Take on an empty stomach	Efavirenz (EFV) can be used once daily and is generally well tolerated. EFV should be avoided in patients with a history of psychiatric illnesses, when there is a potential for pregnancy and during the first trimester of pregnancy.
NVP	Nevirapine	Take with or without food	Nevirapine (NVP) is widely available and is less costly than EFV. The initiation of NVP at the same time as other new drugs that can also cause rash should be avoided where possible.

*Note:* From “Panel on Antiretroviral Guidelines for Adults and Adolescents. Guidelines for the use of antiretroviral agents in HIV-1-infected adults and adolescents,” by Department of Health and Human Services, 2008, Retrieved from <http://www.aidsinfo.nih.gov/ContentFiles/AdultandAdolescentGL.pdf>. And “Antiretroviral therapy for HIV infection in adults and children: Recommendations for public health,” by the World Health Organization. 2006. WHO Library Cataloguing in-Publication Data.

**2.3.1.2 First-line regimens.**

First-line drugs for adults and adolescents infected with HIV include a preferential two NRTIs/NNRTI approach, which includes two NRTIs of either (1) Zidovudine (AZT) or Stavudine (d4T); or (2) Tenofovir (TDF) or Abacavir (ABC); plus either (3) Lamivudine (3TC) or Emtricitabine (FTC) to be grouped with one NNRTI consisting of either (4) Efavirenz (EFV) or Nevirapine (NVP) (WHO, 2006).

The choice of which antiretroviral drug to be included in first-line regimens depends on several factors, including (1) the price and availability of antiretroviral drugs, (2) the number of pills needed to be taken, (3) the side-effects of the various antiretroviral drugs, (4) the laboratory monitoring requirements associated with the various antiretroviral drugs, and

(5) whether there are co-blister packs or fixed dose combinations available (Introduction to HIV and AIDS treatment, 2008).

### **2.3.1.3 Second-line regimens.**

It was recommended that patients who show virological failure, indicated by resistance to a specific combination, or patients whose side-effects are particularly bad, be switched to second-line antiretroviral therapy regimen (Introduction to HIV and AIDS treatment, 2008; Provincial Government of the Western Cape, 2004).

Second-line antiretroviral regimens include a minimum of three new drugs, of which one drug is from a new class, in order to increase the likelihood of treatment success (Introduction to HIV and AIDS treatment, 2008). In the case of second-line antiretroviral regimens triple NRTIs can be considered as an alternative to first-line antiretroviral therapy regimens. Where NNRTIs provide additional complications protease inhibitors (PI) can be introduced to this regimen (WHO, 2006).

### **2.3.2 Improved health outcomes due to antiretroviral therapy.**

The development of combination antiretroviral therapy with protease inhibitors contributed to a radical transformation of the disease. HIV/AIDS, sometimes a riotous terminal illness, which included several opportunistic infections, has become a fairly reversible and controllable chronic condition for a considerable amount of people living with HIV and AIDS, especially those having access to treatment (Bova, 2000; Nischal, Khopkar & Saple, 2005; UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, 2008), even when administered at a late stage. The decrease in the incidence of death from AIDS and the increased number of people living with HIV/AIDS can be directly ascribed to the improvement and widespread use of antiretroviral medication, particularly protease inhibitors (Centers for Disease Control and Prevention, 2001a). It was estimated that without

antiretroviral therapy 495,000 infected individuals would die due to AIDS-related deaths in South Africa by the year 2010 (Dorrington et al., 2004).

## **2.4 Adherence to antiretroviral therapy**

Adherence not only entails taking antiretroviral drugs exactly as prescribed (Continuing antiretroviral treatment, 2008), but literature also defines adherence to treatment as the match between the patient's behaviour and healthcare advice (Haynes, Sackett & Taylor, 1980), or as the reflection of the patient's desire to participate actively in the treatment regimen and the patient's collaboration with a healthcare professional.

### **2.4.1 Non-adherence is a challenge**

Non-adherence had been a predicament for as long as remedies had been prescribed (Chesney, 2006). The increase in chronic illness, accompanied by long-term therapies, resulted in the recognition that patient non-adherence was an omnipresent and costly problem (Chesney, 2006).

Notwithstanding the advances that had been made in adherence research, non-adherence rates continued nearly unaffected during the last decade of the previous century (Burke, Dunbar-Jacob, & Hill., 1997). The lack of strict adherence to antiretroviral therapy was a persistent problem and one of the key challenges to AIDS care worldwide (Van Dulmen et al., 2007; Weiser et al., 2003). Because treatment resistant strains emerge after even a brief lapse in therapy, non-adherence presents a serious concern.

### **2.4.2 The importance of adhering to antiretroviral therapy**

The dawn of antiretroviral therapy meant a second chance at life for patients living with HIV and AIDS (Ware et al., 2006). Recognizing the promise of a second chance meant that HIV-infected individuals may have to receive therapy for many years, if not life (Finzi et al., 1999; Ware et al., 2006), and entails a commitment from the patient as well as the healthcare team (Department of Health and Human Services, 2008).

Medication adherence and regular clinic attendance are essentially vital for successful treatment outcomes, functional recovery (Continuing antiretroviral treatment, 2008; Maskew, MacPhail, Menezes & Rubel, 2007; Paterson et al., 2000; Wagner & Rabkin, 2000) and to attain successful and prolonged viral load suppression in plasma (Bangsberg et al., 2000; Bangsberg et al., 2003; Haubrich, 1999). Adherence has shown to be the main determinant of the biological outcome measures of HIV (Mannheimer et al., 2005). The significance of optimal adherence stems from the fatal consequences that occur otherwise, both in treatment efficacy and the development of resistance (Moralejo, Ines, Marcos, Fuertes & Luna, 2006).

Individuals with high levels of adherence not only sustained therapy over a longer period of time (Bangsberg et al., 2003) but also achieved the greatest virological and immunological gains (Mannheimer et al., 2005) and slowed progression to AIDS (Bangsberg et al., 2000). Therapeutic gain was not achieved by patients who had not properly adhered to their antiretroviral regimens (Davies et al., 2006; Wainberg & Friedland, 1998). A considerable amount of patients did not receive the maximum benefits from medical treatment, resulting in poor health outcomes, lower quality of life and increased health costs (Burke & Ockene, 2001). Even short term non-adherence (as little as one week) could result in treatment failure (Vanhove, Schapiro, Winters, Merigan & Blanschke, 1996).

The majority of patients benefit from antiretroviral therapy (Department of Health and Human Services, 2008). The likelihood of the success of antiretroviral therapy, however, is directly related to the level of adherence and commitment to the therapy (García & Côte, 2003; Montaner, Hogg, Raboud, Harrigan & O'Shaughnessy, 1998; Vanhove et al., 1996). Low adherence or even partial adherence to prescribed antiretroviral medication is possibly the key cause of therapeutic failure (Carpenter et al., 2000; Deeks, Smith, Holodniy, & Kahn, 1997; Liu et al., 2001; Stone et al., 2001), with treatment failure in approximately half the patients it has been prescribed to (Valdez et al., 1999).



### 2.4.3 Methods for assessing adherence

Antiretroviral adherence is important for treatment outcome, but determining adherence continues to be a complicated and demanding task (Plipat et al., 2007). While adherence is vital to treatment response, it has been found repeatedly that healthcare workers are meagre predictors of their patients' adherence to therapy (Bangsberg et al., 2002; Paterson et al., 2000). The measurement of adherence to therapy represents a challenge, and there is less agreement on the best strategy for assessing antiretroviral therapy adherence, as there is no 'gold standard' of measurement (Chesney, 2006; Simoni et al., 2006). An ideal assessment measure would be reliable, valid, logistically practical, and would have low participant and staff burden (Simoni et al., 2006). There is no single optimal assessment strategy for all situations, even in developed countries (Chesney, 2006). There are many validated tools and strategies to choose from (Department of Health and Human Services, 2008). Each of these approaches has its strengths and weaknesses.

Simoni et al. (2006) suggested that adherence to antiretroviral therapy could be measured by direct and indirect methods. Direct methods would consist of a biological analysis of active drug metabolite or other markers in a patient's blood, urine or other bodily fluids to verify active drug ingestion of antiretroviral drugs. Indirect methods, on the other hand, would not measure the presence of antiretroviral drugs in the individual, but rather include methods such as self reporting calendars and record of missed doses (Chesney, 2006; Ickovics, 1997; Plipat et al., 2007), clinical assessments, medical chart reviews, clinical attendance, pharmacy refill records (Bangsberg et al., 2002; Cramer, Mattson, Prevey, Scheyer & Ouellette, 1989; Kagee, 2004; Simoni et al., 2006), electronic drug monitoring (Chesney et al., 2000; Wagner & Rabkin, 2000; Waterhouse, Calzone, Mele & Brenner, 1993) and therapeutic impact data such as immunological and virological data as indicated by HIV-1 RNA viral load and CD4 count (Plipat et al., 2007; Simoni et al., 2006).

#### **2.4.4 Adherence rates**

Despite the wide recognition it enjoys as vital to treatment success, rates of adherence to antiretroviral therapy have commonly been suboptimal (Reynolds, 2004). Expected adherence among patients with chronic conditions such as diabetes, arthritis, cardiovascular disease and HIV (Chesney et al., 1999; Osterberg & Blaschke, 2005), have been found to be particularly low when compared to those with acute conditions, such as flu and appendicitis. Van Dulmen et al. (2007) found that treatment adherence among patients with chronic conditions dropped most dramatically after six months of treatment.

Poor adherence is a widespread problem, with as many as two thirds of patients adhering to less than 90% of their prescribed doses (Bangsberg & Moss, 1999). The rate of non-adherence to antiretroviral therapy is estimated to range between 50% and 70% (Chesney et al., 2000; Weiser et al., 2003), in patients taking their antiretroviral medication in accordance to dosage, time and dietary restrictions (Reynolds, 2004). Poor adherence is associated with poor medical outcomes as measured by viral load or CD4 count (Bangsberg et al., 2000). Dangers of non-adherence may even be greater for patients who take simplified regimens as compared to more complex ones (Roberts & Mann, 2000).

Within other therapeutic areas such as diabetes or hypertension, the consumption of 80% of prescribed doses is believed to be adequate, but is associated with a 50% failure rate in antiretroviral therapy (Paterson et al., 2000). Intake of less than 80% of antiretroviral medication is not sufficient to demonstrate viral and immunological suppression after six months of therapy (Haubrich, 1999).

Non-adherence rates to HIV therapy are similar to those in other illnesses. However in HIV, near perfect adherence to complicated antiretroviral therapy is necessary to obtain successful treatment outcomes (Chesney et al., 2000; Sackett & Haynes, 1979). The success of antiretroviral therapy largely depends on the patient's ability to fully adhere to treatment

(Kalichman, Catz, & Ramachandran, 1999). Full adherence to antiretroviral therapy is considered to be an adherence level of more than or equal to 95%. This level is necessary to sustain total suppression of the virus and prevent the development of resistance to the therapy (Chesney et al., 2000; Gulick, 2006; Kitahata et al., 2004; Nischal et al., 2005; Paterson et al., 2000; Plipat et al., 2007). Patients with levels of 95% or higher had superior virological outcome, a greater increase in CD4 lymphocyte count, lower hospitalization rate than those with lower levels of adherence (Paterson et al., 2000). However, adherence rates to treatment and to medical recommendations are rarely that high (Darnell, Murry, Martz & Weinberger, 1986).

#### **2.4.5 The consequence of poor adherence**

##### **2.4.5.1 Quality of life, morbidity and mortality.**

Patients who are non-adherent to antiretroviral therapy regularly demonstrate negative health outcomes which may impact not only on their morbidity and mortality, but also on their quality of life (Dick, Schoeman, Mohammed & Lombard, 1996; Lange, 2003; Ledergerber et al., 1999). Adherence to antiretroviral regimens allow for the level of HIV in an infected person's blood to remain suppressed, and for CD4 counts to remain at a high level. These can greatly improve the quality of life (Turkoski, 2006). Antiretroviral therapy can also prolong the infected patient's life, as patients with a high level of adherence sustained therapy over a longer period of time than those with a low level of adherence (Bangsberg et al., 2003; García & Côte, 2003).

##### **2.4.5.2 Mutation of the virus and the development of resistance.**

As adherence decreases, failure rates sharply increases with the dose-response effect (Ickovics & Meade, 2002). The lack of strict adherence results in inadequate dosage, which allows for HIV to rapidly mutate and form new variants of the virus (Kalichman et al., 1999). This may then contribute to resistance to a particular treatment regimen. Patients who miss as

few as 5% of their scheduled doses of antiretroviral medication demonstrated major setbacks (Paterson et al., 2000). This 5% non-adherence rate can rapidly lead to virus mutation, resistance to current medication and the development of medication resistant strains of the virus (Mellors, Riley, & Erlen, 1997).

Once resistance to one particular antiretroviral therapy has occurred, it may be necessary for patients to resort to second-line drugs (Kalichman, 1998). Second-line antiretroviral medications may prove to be problematic, as they're not available in generic drugs and cost approximately \$1500 per patient per year in comparison to first-line generic antiretroviral regimens priced at \$150 per person per year (Mukherjee, Ivers, Leandre & Farmer, 2006).

#### **2.4.5.3 Development of opportunistic infections.**

Patients infected with HIV are at risk of developing opportunistic infections which might include *Pneumocystis carinii* pneumonia, cytomegalovirus retinitis, various oral diseases and complications, changes in bone mass, and increased risk for bone diseases, cervical cancer, kaposi sarcoma, toxoplasmosis, tuberculosis, nontuberculosis mycobacterial disease, esophageal candidiasis and non-hodgkin lymphoma (Ledergerber et al., 1999; UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, 2008). The use of antiretroviral therapy is crucial to successfully control opportunistic infections, because it contributes to the recovery of the immune function by halting virus induced immunologic damage (Powderly et al., 1998), which considerably lessen the risk of suffering from opportunistic illnesses (Heiden et al., 2007). AIDS-related opportunistic illnesses continue to occur due to poor adherence (Michelet, 1998). When patients do not properly adhere to their antiretroviral therapy regimen, it leads to a less durable regimen which contributes to an increase in the incidence of opportunistic infections among HIV-infected individuals (Glor & Smith, 2005).

#### **2.4.5.4 The importance of adhering to antiretroviral therapy for public health.**

Adherence to antiretroviral regimens is essential, not only for the health of the individual patients, but also for the public as a whole (Roberts & Mann, 2000). The problem is of significant clinical importance at both individual and collective level, given the transmission of multidrug-resistant strains into the community, may reduce the advances made in antiretroviral therapy (Chesney, 2006; Imrie, Beveridge, Genn, Vizzard & Cooper, 1997; Moralejo et al., 2006; Wainberg & Friedland, 1998). Patients with suboptimal adherence to antiretroviral therapy and poor adherence to the use of safer sex practices, such as the use of condoms, may infect others with their own antiretroviral drug-resistant strain virus (Paterson et al., 2000). Proper adherence to antiretroviral therapy have shown success in reducing the viral load in an infected individuals' blood and genital secretions, this implies that successful antiretroviral therapy have the potential to decrease the possibility of transmission of the HI-virus to others (Wainberg & Friedland, 1998).

#### **2.5 Individual barriers to antiretroviral adherence**

Prevalence and consequences of poor adherence to HIV medication have frequently been acknowledged in literature (Altice & Friedland, 1998; Forgarty et al., 2002; Murri et al., 2000). Reasons that may add to non-adherence are abundant and may vary depending on population and setting (UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, 2008). The reasons involve far more than simply failing to take medication (Chesney, 2006) but also include factors such as sleeping through scheduled dosage times, patient and regimen characteristics, such as adverse side-effects (Davies et al., 2006), relationship with healthcare providers (Rabkin & Chesney, 1999), beliefs in the drugs' effectiveness.

Research on barriers to treatment adherence has almost exclusively focused on individual psychological and behavioural barriers (Kagee, 2004), such as stigma, fear of

disclosure (Ware et al., 2006), beliefs and perceptions about self-efficacy, perceptions about illness and social support (García & Côte, 2003). Substance abuse and emotional distress can also diminish adherence to medical regimens such as antiretroviral therapy (Kalichman et al., 1999).

Demands for adherence may not always be perceived by patients as the highest priority, and often compete with those factors created by other life stressors such as poverty, homelessness and even discrimination (Remien, Hirky, Johnson, Weinhardt & Le, 2003). Understanding these reasons is essential to develop interventions that will improve adherence to therapeutic regimens among people living with HIV/AIDS (García & Côte, 2003)

### **2.5.1 Regimen characteristics.**

#### **2.5.1.1 Forgetfulness.**

Forgetting is the main reason patients give for missing their dosages (Chesney, 1997; Chesney et al., 1999), especially when patients are asymptomatic (Kagee, 2004). Other reasons connected to forgetfulness include explanations of “was busy”, or “was away from home” (Reynolds, 2004). Although forgetfulness is cited as the primary reason for non-adherence, non-adherence involves far more than simply forgetting to take medication (Chesney, 1997).

#### **2.5.1.2 Pill burden.**

Even though antiretroviral treatment provides benefits, it is often complicated and challenging, which can make extraordinary demands on individuals infected with HIV, as patients need to take pills for an indefinite period of time (Gordillo, Del Amo, Soriano & Gonzalez-Lahoz, 1999; Roberts & Mann, 2000). Previous studies done on HIV-infected patients and patients with other chronic diseases indicated that the rate of adherence is likely to decrease as the the number of medications, the frequency of dosages, and the increasing complexity and duration of the treatment increase (Berg et al., 2007; Samet et al., 1992). The

interaction among medications, and between food and medication may easily lead to confusion, also contribute to non-adherence (Haynes, 1979; Moyer et al., 1999; Nischal et al., 2005; White, 2005). The size of pills has also been reported to be an issue (Starting antiretroviral treatment, 2008). It has been reported across a variety of medical disorders and diseases, such as hypertension, diabetes, and vascular disorders that less frequent dosage results in better adherence (Van Dulmen et al., 2007).

### **2.5.1.3 Side-effects.**

Often experiencing side-effects makes it hard for patients to adhere to antiretroviral therapy (Chesney, 1997; Continuing antiretroviral therapy, 2008; Wall et al., 1995). The link between side-effects and non-adherence seems to be one of which HIV positive people are aware of, with side-effects being cited time after time as a reason for non-adherence (Chesney et al., 2000). Up to half of patients on antiretroviral therapy may encounter the unpleasant effects of medication (Felley et al., 2001). The truth is that many patients may face the downsides of therapy, long before they see the benefits if they ever do (Glor & Smith, 2005; Walsh, Horne, Dalton, Burgess & Gazzard, 2001).

The downside of antiretroviral therapy vary according to regimens, and may include nausea, fatigue (Continuing antiretroviral therapy, 2008), chronic diarrhea, abnormal fat distribution, weight changes, anemia, peripheral neuropathy (Bova, 2000), hypersensitivity, lactic acidosis, increased blood lipids, bleeding events, lipodystrophy and pancreatitis (UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, 2008). Side-effects from HIV treatment impact not only a patient's adherence to therapy, but also impact on the quality of the life of the patient (Johnson & Neilands, 2007). Side-effects may also be viewed as controllable, that is that one has the power to stop medications and consequently eliminate the side-effects of antiretroviral therapy (Johnson & Neilands, 2007).

## **2.5.2 Patient characteristics**

### **2.5.2.1 Demographic characteristics.**

In general sociodemographic factors do not seem to predict behaviour related to adherence, even though some studies found that male sex, white ethnicity, older age, higher income and higher education and literacy correlated with better adherence (Icovics & Meade, 2002).

Some studies confirmed race and ethnic background to be associated with treatment adherence (Kalichman et al., 1999; Metha, Moore, & Graham, 1997). Although ethnicity appears to be important in predicting HIV treatment adherence, the mechanisms that account for these differences are unknown (Kalichman et al., 1999).

### **2.5.2.2 Emotional distress.**

Poor adherence has been related to unsuccessful life events, depression, depressive symptoms, emotional upset (Catz, Kelly, Bogart, Benotsch & McAuliffe, 2000; Sarna et al., 2008; Sullivan, Dukes, Harris & Dittus, 1995), anxiety, hopelessness, and other patient factors related to decreased adherence including dementia, psychosis, and personality factors (Penna & Treisman, 2005). HIV positive people with relatively high levels of depression and low sense of social support were less likely to follow medication and health advice, and to keep appointments than people with a high sense of social support (García & Côte, 2003). Emotional and cognitive disturbances that occur as part of the depressive symptom picture may inhibit the patient's ability to concentrate and to remember important details, such as the recommended time of day or the sequence of administering the medications (Kagee, 2004). Depression can reduce the motivation to seek healthcare, impare adherence to prescribed treatment, decreased quality of life, and increased mortality (Cook et al., 2004).

### **2.5.2.3 Health literacy.**

Knowledge of medication instructions is certainly a requirement for adherence (Weiss et al., 2003). A higher level of adherence is related to sufficient knowledge of treatment, and the



costs of poor adherence (Schuman et al., 2001). Knowledge may also encourage the development of adherence-related skills that may increase motivation, or it may be that knowledge is a substitute for motivation. A person, who makes the effort to learn about an illness, will also make the effort to control it (Weiss et al., 2003).

#### **2.5.2.4 Patients' beliefs.**

Attitudes and beliefs about the normative behaviour have also been shown to play a role in adherence (Kagee, Le Roux & Dick, 2007). A greater belief in one's ability to adhere to antiretroviral therapy and the confidence in its benefits were associated with higher quality of health and health functioning (Reynolds, 2004). Positive beliefs that antiretroviral regimen would prolong life or improve the RNA level are associated with improved adherence (Paterson et al., 2000).

#### **2.5.2.5 Patient literacy and self-efficacy.**

Low literacy and low self-efficacy are factors associated with poor adherence to antiretroviral treatment (Kalichaman et al., 1999; Schuman et al., 2001). In general, patients with low literacy have less knowledge of the management and treatment of their chronic diseases and have poor disease outcomes (Hope, Wu, Tu, Young & Murray, 2004). The ability to read and comprehend medical instructions play an important role in treatment adherence (Kalichman et al., 1999), as patients with low literacy have the highest rate of non-adherence. Wolf et al. (2007) found that patients with marginal literacy skills were least likely to self-report missing any dosages of antiretroviral therapy. Poor patient literacy was associated with a more than three times greater likelihood of missed doses, as these patients were 3.3 times more likely to be non-adherent to their antiretroviral regimen (Wolf et al., 2007). Higher levels of literacy was associated with a more than 95% adherence rate (64% of those who adhered had an education level equal or above ninth grade, versus a 40% who had an education level below ninth grade) (Graham, Bennett, Holmes & Gross, 2007). Certain individual characteristics of

people with low literacy may create obstacles for direct patient-physician communication and, in turn, increase the likelihood of embracing mistaken beliefs (Wolf et al., 2005). An example of this is incorrect perceptions of the goals of HIV medications (Kalichman et al., 2001).

In addition to the likelihood of poorer knowledge of HIV treatment, patients reported lower self-efficacy for taking medication as prescribed (Wolf et al., 2007). Self-efficacy refers to individuals' own perceived ability to perform specified behaviours or sets of behaviour (Wolf, et al., 2007), and is associated with higher antiretroviral therapy adherence (García & Côte, 2003; Reynolds, Testa, Su, Chesney & Robbins, 2003). If low literacy were a significant risk factor for improper adherence to medication, then self-efficacy mediated the relationship between the two (Wolf et al., 2007). Self-efficacy, but not knowledge, mediated the impact of low literacy to medication adherence (Wolf et al., 2007). Self-efficacy relating to the managing of medication may explain why many lower literate patients may not adhere to their antiretroviral therapy (Wolf et al., 2007). Self-efficacy has previously been investigated in a variety of contexts; it was repeatedly found to be a measure to predict the likelihood of initiating communication (Makoul & Roloff, 1998), and the likelihood of adjusting to illness and treatment (Forsyth & Carey, 1998). Self-efficacy was also found to contribute to individuals' confidence about the benefits of antiretroviral therapy and to adhere to it (Reynolds, 2004).

#### **2.5.2.6 Relationship with healthcare provider.**

A supportive relationship with healthcare providers is as imperative as the decision to begin with antiretroviral therapy (Trzynka & Erlen, 2004). Trust and collaboration between the patient and the healthcare provider positively reinforce the patient's adherence to medication (Catz et al., 2000). Research suggests that only 50% of professional advice is likely to be taken by patients (WHO, 2001). Poor patient adherence to medical treatment and advice has

wide-ranging consequences that include medical and psychological complications, associated with the disease, which compromise the patient's quality of life and also cause a waste of healthcare resources (Cleemput & Kesteloot, 2002).

#### **2.5.2.7 Social Support.**

Social support has proved to be a strong predictor of medical adherence (Reynolds, 2004; Simoni et al., 2006; Williams & Bond, 2002). Social support can be defined as encouragement from family and friends for patients to co-operate with the prescriptions of health professionals (WHO, 2001). Social support comes from many sources such as the provider-patient relationship, family, significant others, peers and networks within the community (Trzynka & Erlen, 2004). Social support can be directly enhanced by providing reinforcements or reminders, or indirectly by enhancing patient motivation or mitigating the negative effects of other stressful events (Singh, Berman, Swindells, Mohr & Squire, 1999).

#### **2.5.2.8 Stigma.**

AIDS-related stigma is a major barrier to HIV treatment. HIV is a stigmatizing disease (Davies et al., 2006). Stigmatizing attitudes to HIV and those most at risk of HIV infection derive from the fear of infection and a negative value based on assumptions about people living with HIV. These factors fuel prejudice and discrimination (UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, 2008). The public and private nature of pill-taking behaviour has also created a new domain for adherence barriers (Davies et al., 2006).

#### **2.5.2.9 Substance abuse.**

Alcohol and drug abuse have frequently been reported to have a relationship with not only risky behaviours and exposure to HIV, but have also been associated with poor adherence and poor appointment keeping (Trzynka & Erlen, 2004). The abuse of substances also influences the effectiveness of antiretroviral therapy, not only by affecting the adherence to

regimen, but also through an independent mechanism (Garcia & Cote, 2003). Alcohol consumption has also been shown to have a direct effect on HIV progression (Parsons, Rosof, & Mustanski, 2008). Better adherence was associated with recent abstinence from a moderate to high-risk level of alcohol use (Parsons et al., 2008).

## **2.6 Structural barriers to antiretroviral adherence**

Biomedical and behavioural research have dealt primarily with HIV at the level of the individual, but reasons for non-adherence are complex involving more than the patient's characteristics and attitudes (Sumartojo, 2000). Literature suggests there is more to antiretroviral therapy adherence than simply remembering to take medications, but it is rather a complex issue, involving social, cultural, economic and personality factors as well (Chesney, 2006).

Because there are multiple levels of causation research on antiretroviral adherence needs to target various levels, including individuals and their environments. Many view behaviour as personally motivated or exclusively resulting from a person's conscious decisions (Sumartojo, 2000). By solely looking at the individual psychological and behavioural barriers, adherence knowledge or motivation is explained without addressing the root or the context that contributes to poor adherence. The role of the environment is often overlooked (O'Leary & Martins, 2000).

These factors have different names in literature, such as environmental, structural, societal, political, and contextual factors, often reflecting the disciplines of the writers (Sumartojo, 2000). HIV-related structural barriers are defined as the barriers to, or facilitators of an individual's adherence behaviour, which may relate to economic, social, political, organizational or other aspects of an individual's environment (Sumartojo, 2000).

Little emphasis has been placed on the structural barriers or structural facilitators to treatment adherence which individuals may have little direct control over (Garcia & Cote,

2003). Sumartojo (2000) suggested that research should focus on the environment, to the same extent as research had, until recently, focused on individual and psychological factors. Demands for adherence often compete with other life stressors, such as poverty, and is therefore not always perceived by patients as the highest priority (Remien et al., 2003).

Parker and Easton (2000) suggested that most research on structural factors could be grouped into a smaller number of analytically distinct but interconnected categories such as economic (under)development and poverty, migration, seasonal work, and social disruption. Kagee et al. (2010) also suggested that structural barriers could be grouped into categories, but divided into more detailed sub-categories namely, poverty-related structural barriers, institution-related factors, and social and community-related barriers. According to these authors poverty-related structural barriers would include poverty, transport, and food insecurity, lost wages, disability grants and migration. Institution-related factors would include barriers related to the healthcare facility, overburdened healthcare facilities, and clinicians as well as medical resources available to patients. Lastly, social and community-related barriers would include stigma, disclosure, religion, culture, substance abuse programmes, and social resources.

Poverty-related factors are outside an individual's control. In the South African context these factors include lack of transport, lack of food security, out-of-pocket fees associated with travelling, as well as factors related to healthcare institutions and to social and community-related barriers (Sumartojo, 2000). These poverty-related factors are more significant barriers to the adherence to long-term antiretroviral therapy than patients' individual behaviour (Mukherjee et al., 2006).

## **2.7 Theories to understand adherence**

According to Eccles, Grimshaw, Walker, Johnson and Pitts (2005) theory provides a “coherent and non-contradictory set of statements, concepts or ideas, organizes, predicts and

explains phenomena, events, and behaviour”. Although theory played an important part in explaining adherence behaviours, existing theory has primarily been developed from individual psychological and behavioural research into social and cognitive theories (Kagee, 2008; Remien et al., 2006). These theories include the Health Belief Model, Theory of Reasoned Action, and Theory of Planned Behaviour.

### **2.7.1 Health Belief Model**

The Health Belief Model was proposed by Rosenstock in 1966 (Rosenstock, Strecher, Becker, 1988). The basic components of this model attributes adherence to two variables: (1) the value patients place on a particular goal; and (2) the patient’s estimate of the likelihood that a certain action will contribute to a particular goal (Mainman & Becker, 1974). When these variables are conceptualized within the context of adherence behaviour, the associations are: (1) the desire to achieve good or better health; and (2) the belief that adherence will improve the patient’s health (Janz & Becker, 1984). Furthermore, the Health Belief Model also theorizes that patients are more likely to adhere to treatment under conditions which include: (1) them at least possessing some health knowledge and being motivated to stay healthy; (2) them clearly perceiving HIV as a serious medical and health problem; (3) them being convinced that ARV treatment is effective, meaning that it is possible for them to obtain control over the disease at an acceptable cost and that the cost does not outweigh the benefits; and (4) the presence of an internal or external stimulus referred to as a “cue to action”, which would include barriers that prohibit the patient from adhering to ARV treatment (Ilongo, 2004). Thus, the Health Belief Model proposes that if the patient was presented with the facts and alternatives surrounding ARV treatment, the patient would adhere (Kagee, 2008).

### **2.7.2 Theory of Reasoned Action and Theory of Planned Behaviour**

The Theory of Reasoned Action was first introduced by Ajzen and Fishbein (1980) and assumed that the patient's intent to perform a given health behaviour was influenced firstly, by their attitude towards a given action; and was based upon their positive or negative beliefs and evaluation of the outcome of the given action (Munro, 2007). Secondly, the decision to perform given health behaviour was also based upon the subjective norms or perceived expectations of important others and the motivation for the patient to comply with others' wishes (Munro, 2007). Self-efficacy is a third influencing factor, i.e. the patient's sense of self control and perception of their ability to perform a given health action (Spring, 2008). Thus, the Theory of Reasoned Action assumes that adherence behaviour is under the volitional control of the patient, and intention to be adherent is the single best indicator of their motivational readiness to act (Prochaska & Velicer, 1997; Sutton, 1997).

The Theory of Reasoned Action was renamed by Ajzen (1985) as the Theory of Planned Behaviour adding the concept of perceived control over opportunities, resources and skills necessary to perform particular health behaviours. This concept of perceived behavioural control is similar to the concept of self-efficacy as proposed by the Theory of Planned Behaviour, which, instead of only focusing on the perception of control over personal capabilities, also includes external circumstances (Munro, 2007).

### **2.7.3 Social Action Theory**

Although the previous theories mainly described adherence in terms of social cognitive theory, Ewart's (1991) Social Action Theory touches on social context when understanding adherence as a health behaviour. According Johnson et al. (2003) and Gore-Felton et al. (2005) this theory proposes that health behaviours result from the interaction between three domains: (1) the self-regulation capabilities of the patient such as the adherence self-efficacy and treatment expectations; (2) responses to internal affective states that influence the self-

regulation process, such as depression, anxiety and positive affect; and (3) the larger environmental context, which include socio-demographic and treatment variables. Thus, this theory ascribes patients' ability to be adherent to ARV treatment to their ability to change behaviours that endanger their health. This ability to change behaviour is influenced by the patient's self-change processes (cognitive capability, information processing, self-efficacy, outcome expectancies, social skills, self-regulation skills, rewards). It is also influenced by contextual factors such as environmental factors and social interactions that encourage or discourage the change process (Ewart, 1991).

## **2.8 Theoretical framework for this study**

While the previously mentioned social and cognitive theories were mainly based upon individual psychological and behavioural barriers and explained adherence behaviour accordingly, the present study will explain adherence according to an ecological perspective as such a theory posits multiple levels of influence and reciprocal causation (Chisholm et al., 2007). A theory such as Bronfenbrenner's (1972) Ecological Systems Theory thus has the potential to illustrate how structural factors may act as barriers or facilitators to individual adherence behaviour. Ecological Systems Theory (Bronfenbrenner, 1975), suggests that behaviour is shaped by three levels of environmental influences, namely the intermediate environment such as the family in which a person operates, social institutions such as the healthcare system, transportation system, local economy, and the larger social and community context in which people live (Bronfenbrenner, 1975).

## **2.9 Conclusion**

The present chapter indicated the scale of the HIV and AIDS pandemic on a global as well as a local level. The importance of ART regimens and the importance of precise adherence to ART have also been stressed, since non-adherence to ART impacted on both individuals and their communities. However, to date adherence behaviour was mainly addressed in the



context of individual psychological and behavioural barriers, with very little focus on the barriers present within the patient's context or environment.

In the next chapter the following will be reported on: the method of collecting the data on the structural barriers to ART adherence, recruitment of participants, informed consent procedures, data analysis and ethical approval.

## CHAPTER THREE: METHOD

In the present study a qualitative research design was used.

### 3.1 Participants

By means of convenience sampling, a total of 26 participants were recruited to participate in the study. The sample comprised four groups, namely, patient advocates (n=10), patients (n=10), doctors (n=3) and nurses (n=3).

For the patients to be eligible to take part in the study, they had to (1) have a formal clinical diagnosis of HIV, (2) be enrolled in the antiretroviral treatment programme offered at Helderberg Hospital.

Healthcare workers (nurses and doctors) enrolled in the study were employed at Helderberg Hospital and working at the Infectious Diseases Clinic with HIV patients enrolled in the ART programme. Patient advocates were employed by the Phillippi Trust, a local non-governmental organization (NGO) that provides HIV positive patients with psycho-social support.

#### 3.1.1 Recruitment of the participants

##### 3.1.1.1 Patient advocates.

Patient advocates were recruited from Phillip Trust, an NGO in Somerset West that provides psycho-social assistance to HIV-infected individuals in the local community. Two groups consisting of five participants each were recruited to take part in focus groups. One of the research team members contacted the head of the Phillippi Trust who then arranged for participants to take part in the focus groups.

##### 3.1.1.2 Patients.

Patients were recruited through the Phillippi Trust to take part in semi-structured interviews. Patients were contacted by the patient advocates at the Phillippi Trust, informed about the

study and invited to participate. Appointments were made with patients who agreed to participate in the study and meetings with them were held at the Phillipi Trust offices.

### **3.1.1.3 Healthcare workers.**

Healthcare workers were recruited to take part in semi-structured interviews. This group consisted of registered nurses and medical doctors from the Helderberg Hospital. The healthcare workers were identified by the Head of the Infectious Diseases Clinic at Helderberg Hospital. After they were identified as viable candidates for the study, they were approached by one of the research team members, and were presented with the option to take part in the semi-structured interviews, or to decline if they so wished.

### **3.1.2 Informed consent procedures**

The nature of the study was explained to all three groups of participants in a private room, either at the Infectious Diseases Clinic at Helderberg Hospital, or at the Phillipi Trust offices in Somerset West. All the participants were approached as prospective candidates, and invited to take part in this study. In this private room they were informed that: (1) their participation was entirely voluntary, that they could decline if they so wished, and that they had the right to withdraw from the study at any time; (2) that there were no foreseeable risks involved in participating in this study; (3) that they would not directly benefit from this study, but would receive a R50 grocery voucher and R20 for transportation, as appreciation for their participation in the project. Patient advocates were also provided with R20 as contribution towards their transportation fees; (4) All participants were informed that their input would be entirely confidential, and that the research team were the only ones who would have access to the interview material; (5) Patients were also informed of their anonymity once the data was processed, and that their names would not be made public in any way; (6) Their responsibility would be to take part in a semi-structured interview or focus group in the case of patient advocates, and that they would be encouraged to elaborate on their responses; (8) It was also

explained to them that there would be absolutely no consequences should they wish not to participate; (9) Lastly, they were informed about the intended use of a tape recorder to record the interviews or focus groups, in order for data to be transcribed and analysed.

After the above was explained to them, they were asked to verbally confirm their participation. Once they confirmed that they wished to participate in the study, they were asked to sign an informed-consent form, indicating that they understood what had been explained to them, and that they formally acknowledge their participation.

After the interviews or the focus groups, patients were presented with the opportunity to ask any questions they might have. Patients were then presented with a R50 grocery voucher and a R20 contribution towards their travelling expenses, as an expression of gratitude. Patient advocates were also presented with a R20 contribution towards their travelling expenses.

### **3.2 Data collection methods**

Data was collected through semi-structured interviews conducted with patients and healthcare givers, as well as two focus group discussions conducted with patient advocates. The semi-structured interviews involving patients were conducted at the Phillippi Trust offices, while interviews involving doctors and nurses were conducted at Helderberg Hospital, both locations in the vicinity of Somerset West. The semi-structured interviews were carried out by a research team, consisting of a project supervisor, two honours students from the Department of Psychology at Stellenbosch University, and the principal researcher. The interviews lasted an hour on average, and were recorded on tape, for the purposes of transcription and analysis of the data obtained.

The focus group discussions involving patient advocates from the Phillippi Trust were conducted at Stellenbosch University. The focus groups were lead by the project supervisor. Both focus groups lasted an hour, and were also recorded on tape, for the purposes of

transcription and analysis of the data obtained. Interview schedules are presented in Appendix A and B.

### **3.3 Data analysis**

The semi-structured interviews and focus group discussions were recorded digitally, with the consent of the participants. These digital recordings were then transcribed in a Microsoft Word document. The transcriptions were then saved in a plain text format in order to be entered into the Atlas.ti programme, which assisted with the thematic analysis of the transcriptions.

A codebook was constructed in order to code transcriptions accurately. Transcriptions from patient interviews (n = 2), doctors (n = 1), nurses (n = 1), and FGD with patient advocates (n = 1) were used to create the codebook. The transcriptions were examined for codes that arose within the transcriptions. According to these codes, the codebook was established, consisting of the code, the definition of the code, as well as an example of a quotation matching the definition of the code. See Appendix C, D and E for the codebooks.

Initially the transcriptions were divided into three groups, namely patients, patient advocates and clinicians, which consisted of the doctors and nurses. Each of these categories was coded according to two to three main headings, which has taken a similar format in the three categories. (1) Patients were coded in terms of two main headings of patient individual factors (PIF), and patient identified structural barriers (PISB). (2) Patient advocates were coded in terms of three main headings of patient advocate experiences (PAE), patient advocate-identified individual factors (PAIIF), and patient advocate-identified structural barriers (PAISB). (3) Lastly, the clinicians were also coded in terms of three main headings, consisting of clinician experiences (CE), clinician-identified individual factors (CIIF), and clinician-identified structural barriers (CISB). Underneath each main heading, the transcriptions were finally coded according to the sub-themes that had arisen in the

transcriptions. After coding each category individually, families were made of themes relating to one another, with the assistance of Atlas.ti. Networks were then established making a clear distinction between the different main headings and sub-themes that arose from the transcriptions. After the completion of families and networks, it was possible to do a codes output table and a quotations output table. The codes output table indicated the frequency the different codes had arisen in the different transcriptions, as well as the sum total of the frequency between all transcriptions. The quotations output table illustrated the quotations underneath each code individually.

After the completion of the coding, the codebook was revised to ensure conceptual clarity, by making certain that all the codes, definitions and quotations correlate with each other as closely as possible. The quotations output table was then used to check the quotations against the codebook, to ensure they all satisfy the criteria set by the codebook.

The three categories were then collapsed into one document, and coded again with the assistance of the codebook. Families were then established according to similar themes that had arisen in the transcriptions. Networks were established for a second time to make a clear distinction between the different main headings and sub-themes that arose from the transcriptions. The barriers identified through the coding of the transcriptions were then discussed in terms of General Systems Theory in Chapter 5.

### **3.4 Ethical approval**

The ethical approval needed to conduct this study was obtained from the Committee for Human Research at Stellenbosch University, the Western Cape Department of Health, the superintendent of Helderberg Hospital, and the director of the Infectious Diseases Clinic at Helderberg Hospital. Ethical approval is presented in Appendix F and G.

## CHAPTER FOUR: RESULTS

Patient advocates and clinicians readily responded to the request to participate in the focus group discussions and semi-structured interviews respectively. None who was approached turned down the opportunity to participate in the study. At the onset, some patients appeared reluctant to participate in the study, as they thought it would take up their time and that they would be late for their transportation. This obstacle was overcome by asking patient advocates to schedule appointments with patients and accompany them to interviews. Patient advocates and clinicians keenly shared their perceptions about the barriers patients experienced in taking their ART. Patients on the other hand appeared to need more prompts and cues during the semi-structured interviews to share the difficulties they experienced in adhering to their medication and care. Codenames were used to ensure the anonymity of the participants.

The following themes emerged from the interviews with patients, clinicians and focus group discussions with patient advocates: (1) individual barriers, (2) poverty-related barriers, (3) institution-related barriers, and (4) social and community-related barriers. Within these four themes, sub-themes were also identified. All the themes and sub-themes will be discussed in this chapter. Table of themes was attached in Appendix H.

### **4.1 Individual barriers to ART adherence**

Focus group discussions with patient advocates, and semi-structured interviews conducted with patients and clinicians recognized five individual barriers that related to patients' adherence behaviour. These barriers were: (1) forgetfulness, (2) health literacy, (3) literacy, (4) medication, and (5) mental health.

### 4.1.1 Forgetfulness

Forgetfulness as a barrier to ARV treatment adherence was associated with patients' inability to remember not only to take their medication, but also to do so at a scheduled time and according to prescribed directions.

*Clinicians.* Forgetfulness as a barrier to adherent behaviour was identified by two of the nurses from the sample. Sisters Kabini and Kekaba, both registered nurses at the Infectious Diseases Clinic indicated that patients would often go without their medications for days due to their forgetfulness to take it or to obtain it from the hospital pharmacy during scheduled clinic visits. According to sisters Kabini and Kekaba, respectively:

*... some said they will, they forgot their tablets here then they just go without tablets.*

*... people are tending to forget. We are human beings and we tend to forget.*

*Discrepancies.* It was clear that for the nurses, the patients' forgetfulness was a salient theme. However, patient advocates and the patients themselves did not indicate forgetfulness as a barrier to adherent behaviour. The effect of forgetfulness identified by the nurses was concerned with actual pill-taking behaviour, and did not extend to the patient's ability to remember to attend scheduled clinic visits.

### 4.1.2 Health literacy

Health literacy was associated with patients' ability to understand information related to HIV and ART, and their ability to make decisions around adherence to ART treatment and care. These decisions were based on information and perceptions of the patients.

*Patient Advocates.* Patient advocates from both focus group discussions testified to patients' lack of knowledge and misguided perceptions about HIV and ART. The patient advocates indicated that these misguided perceptions caused patients significant distress. Misguided perceptions reported by the patient advocates included the perception that TB



would develop into HIV, or that they would definitely contract TB when they had been diagnosed as HIV positive, and that this would lead to an inevitable death.

The patient advocates from both focus group discussions also indicated that patients displayed misguided perceptions and knowledge about ART and the use thereof. Many patients were under the impression that they should not take their medication on an empty stomach. And, although it was recommended that some should be taken after meals, it was preferred that patients take their medication on an empty stomach rather than skipping doses when they did not have any food. Some patients were considered to be ignorant about the importance of taking ARVs, as they were unaware of the indefinite duration of treatment and possible side-effects associated with ART. A patient advocate quoted one of her patients:

*I'm here because the doctor said to me my CD4 count is very low. I need to come but as soon as my immune system is strong, I stop the medication.*

*Clinicians.* Doctor Periam, a doctor from the United Kingdom, and Dr Smith, the head of the Infectious Diseases Clinic at Helderberg Hospital indicated that patients may not always understand fully how their medication should be taken. This lack of understanding often occurred despite being counselled in their home language. Dr Smith is quoted:

*I think...um...the issues are from a practical point of view, some of the issues may...may be that they don't understand a hundred percent how to take them, even though they do get counselled in their own language.*

*Concurrences and discrepancies.* Patient advocates and clinicians associated health literacy with adherent behaviour. However, these respondents provided different reasons for its importance. Both patient advocates and clinicians related health literacy to the patient's ability to understand how to take ART, but patient advocates identified the patient's knowledge and perceptions of HIV and ARTs as an additional barrier to ART adherence. Clinicians on the other hand regarded patients' health literacy to be related to their level of

education. Misguided knowledge and perceptions around HIV and ARVs reinforced the crucial role of patient advocates and clinicians in providing patients with the correct guidelines and information around the disease and treatment thereof.

#### **4.1.3 Literacy**

Literacy as barrier to ART adherence was associated with their ability to correctly read or comprehend the medical instructions of their prescriptions. Barriers associated with literacy were also associated with the importance of literate friends or family members.

*Clinicians.* From the experience of Dr Smith and Sister Kekana low literacy often acted as a barrier to ART adherence. Sister Kekana stressed the importance of patients' ability to read their prescriptions in the absence of a literate friend or family member. It was often necessary for patients to revert back to the instructions of their prescriptions, as with certain medications such as NVPs the instructions did not remain the same for the duration of the prescription. She also indicated that barriers associated with literacy were intensified amongst patients who had missed their scheduled clinic visits, as these visits provided clinicians with the opportunity to remind them of any changes in prescriptions.

*Discrepancies.* The effect of literacy on the patient's adherence to ART was clearly indicated by clinicians. However, patient advocates and the patients did not express any difficulties in understanding the instructions set out by ART prescriptions.

#### **4.1.4 Medication**

Experiences with ART medication, and the consumption thereof were associated with the characteristics of the medication. It was also related to the patient's experience of taking the medication.

*Patient Advocates.* Patient advocates from the first focus group discussion stated that patients experienced discomfort and unpleasantness when taking ART medication. Side-effects and physical characteristics of tablets, such as the size of the tablets, were seen as

contributing to these negative experiences. Patient advocates emphasized the importance of educating patients about the possible side-effects before initiating treatment.

*Patients.* Three of the patients included in this sample stated that they have experienced one or more side-effects associated with ART medications. These side-effects were reported to have been worse after the initiation of ART, or when taken on an empty stomach. Patients reported nausea, vomiting, drowsiness and hypersomnia as some of the side-effects they experienced. Gerome, described his experience of taking ARV medication:

*When I take the pills on an empty stomach, then I am like a drunken person. I can't take the medication on an empty stomach; the pills make me sleep a lot.*

*Clinicians.* All of the doctors indicated that patients experienced discomfort or unpleasantness associated with characteristics such as size, thickness and volume of tablets. However, the doctors disagreed on the effect this discomfort, unpleasantness and experience of side-effects had on the patient's pill-taking behaviour. Dr Periam did not consider side-effects to be a significant barrier to ART adherence, as the community from which the patients came were seen to be fairly resilient. Dr Smith on the other hand believed that ARVs did impede on the patient's willingness to adhere to ART.

*... taking their pills, especially in the beginning, they may have side-effects that make them nauseous or make them start vomiting, they feel dizzy and they may not have been adequately prepared for those side-effects...um...and that may lead them to not take their pills.*

*Concurrences and discrepancies.* Patient advocates, patients and clinicians agreed that the experience of side-effects and consumption of ART medication to be unpleasant. There was however a disagreement between clinicians about how these negative experiences affected patients' pill-taking behaviour. There was concurrence between patient advocates and clinicians, but not between patients on the effect the physical characteristics had on the

experience of consuming. The patients were the only group from the sample to stress the effect of taking medication on an empty stomach.

#### **4.1.5 Mental health**

Patient's mental health was associated with the effect psychological well-being had on their ability to adhere to their ART. Additionally, the role of mental health on adherent behaviour was also associated with having received treatment for these conditions.

*Patients.* From the entire sample, a single patient identified mental health to have been a barrier to ART medication adherence. Priscilla, a mother of one, often experienced episodes of depression. She had received treatment for this condition. She explained how her mental health contributed to her non-adherence to ARVs:

*When one feels de-motivated, you aren't in the mood for anything, you don't want anyone around you, and then at that stage I am not in the mood to take my medication.*

*Discrepancies.* Even though mental health was not mentioned by patient advocates or clinicians as barrier to ARV adherence, the quotation provided by Priscilla indicated the need for other aspects of the patient's health to be considered when treating a person infected with HIV. These aspects of health should include mental health as a barrier to ART adherence.

## **4.2 Poverty-related barriers**

Insufficient financial resources was a reality for the patients included in this sample. Day-to-day living was a challenge for most. Although patients were provided with free ARV medications and services at the Infectious Diseases Clinic, their finances, or the lack thereof, appeared to be a significant barrier to their ability to adhere to ARV treatment and care.

During this study several barriers to ART adherence were identified, which directly or indirectly related to the patient's financial situation. The poverty-related barriers identified

were: (1) employment, (2) migration, (3) disability grants, (4) transportation, (5) living arrangements, (6) reminder tools, and (7) transportation.

#### **4.2.1 Employment**

Employment was associated with the effect treatment and scheduled clinic appointments had on the patient's occupational circumstances and income. In addition, adherence also had an effect on their occupational circumstances.

*Patients.* The effect of ART on the patient's ability to participate in physical employment and to generate an income, was identified by two of the patients. The need to participate in these activities was described by Gerome:

*...I can't, I can't work in that heat. I wanted to go and to also make my contribution to our household, that we can at least have an income...*

The inability to participate in demanding work-related activities, which was possible prior to the initiation of ART, did not directly impact on ARV adherence. However, the lack of financial income indirectly impacted on patients' ability to adhere to ARV treatment and care. This was owing to patients not being able to afford transport and food, and could also be associated with aspects such as disability grants and living arrangements.

Shaamiela, a mother of one, described how her employment impacted on her ability to adhere to scheduled clinic visits in the past. Employment made it difficult at times to organize the necessary leave in order to attend her scheduled clinic visits.

*Clinicians.* Dr Periam and sister Bekaka identified scheduled clinic visits to impede on the patient's ability to attend work, as these scheduled clinic visits often required that patients regularly take a full day's leave. This was especially problematic when treatment was initiated as patients were required to attend scheduled clinic visits once a week or once every two weeks. Patients were often not prepared to disclose their HIV status to their employers which made it more difficult for them to explain to employers why they had to take leave on

such a regular basis. Sister Bekaka testified to one or two patients being dismissed by their employer, due to their inability to get the necessary leave to attend scheduled clinic visits. Patients consequently had to miss work on a regular basis. Missing a full day's work often meant that patients had to forgo a day's pay, even though they had a medical certificate. This meant that attending scheduled clinic visit often had an additional financial strain on patients, in addition to the expenses associated with travelling to the clinic. Dr Periam stated:

*If you don't pitch, you don't get paid if you don't work. So...that has got a financial effect to get here.*

Three of the clinicians also identified that routines associated with shift work imposed on adherence to medication. Working irregular shifts often contributed to the patient's inability to remember to take their medication or to do so at a set time. Sister Bekaka stated:

*The different shifts that people work...sometimes they work day-shift for a week, and then night-shift for a week and with the switch it is difficult for them, so they don't drink their medication. They don't take their medication at regular times.*

Although non-adherence was mostly attributed to forgetfulness associated with shift-work, clinicians indicated that some patients intentionally chose not to take their medication while they were at work. The decision not to adhere to ARV medication often stemmed from not wanting to make an issue of taking their tablets.

*Concurrences and discrepancies.* Aspects surrounding employment as barrier to ARV treatment and care were identified by patients and clinicians. Patient advocates did not reveal any problems surrounding the issue. While patients mostly showed a greater concern for the indirect effect ARVs had on their ability to generate an income, clinicians were more concerned with the direct effect attending scheduled clinic visits had on their motivation to adhere to ARVs and to attend scheduled clinic visits.

### 4.2.2 Migration

Non-adherence to ARV care was also associated with resettlement or the passage through provinces due to employment opportunities, holidays and significant events outside the area of the clinic where patients received ART. Significant events specifically included funerals and religious holidays.

*Clinicians.* Four clinicians from the sample associated migration with the patient's non-adherence to ART care. The clinicians stressed the importance of patients seeking out treatment in the event of migration. However, the clinicians indicated that this was often not the case. Dr Nkwali attributed reasons for non-adherence to patients not being aware of where they should seek treatment, or to the fact that many tend to put ARV treatment on the "backburner" until they have found employment. She also indicated that patients did not consider treatment to be a priority especially when they felt asymptomatic. Dr Periam added that patients often chose not to seek treatment when visiting friends or relatives, since patients perceived that they had to disclose their HIV positive status if they wanted to go for treatment in that area.

In addition to the importance of obtaining treatment during temporary or permanent migration, it was also important that migrant patients had to obtain transfer letters when doing so. Sisters Kekana and Kabini stressed the significance of patients being transferred out to other clinics, to ensure that staff at those facilities "had something on paper" when treating patients. Clinicians felt that the inability to obtain a transfer letter in itself acted as a barrier to acquire the proper ARV treatment.

*Discrepancies.* The effect of both temporary and permanent migration on the patient's ability to adhere to ARV treatment was a prominent concern amongst clinicians. It was however not a concern amongst patients or patient advocates. The reason for the clinicians' concern might be associated with their experience of patients returning to their local clinics,

and migrant patients arriving days or even weeks late for their scheduled clinic visits, which consequently resulted in inadequate adherence to care.

### 4.2.3 Disability grants

The majority of the patients included in this sample either had already applied for a disability grant, or were in the process of applying for it or were already receiving a disability grant.

Patients were considered as dependent upon disability grants as their primary source of income and to maintain their daily living, which subsequently enabled adherent behaviour.

However, disability grants were also identified as a barrier to ARV adherence, as it did not motivate patients to attain better health. Getting better often meant that they would forgo their primary source of income as they would not requalify for a grant.

*Patient advocates.* Patient advocates from both focus group discussions expressed that patients experienced difficulties in obtaining a disability grant, due to complications in the administration. Patient advocates from the second focus group discussions perceived disability grants to be an enabler of ART adherence, as it mostly formed an essential part of the patient's income, which enabled them to purchase food to take their tablets with.

Although disability grants contributed to adherent behaviour, it was also a barrier to ARV adherence since patients stopped taking ARVs to have their grants continued. A patient advocate from the first focus group discussions stated:

*The other thing I experienced, I don't know if I'm right or wrong is HIV positive people they make the HIV the government's responsibility, because they want to get their grant, because if you are HIV positive you get the grant for the six months so when you are better you don't want to take the medication because of that, because of the grant.*

*Patients.* Difficulties in obtaining a disability grant were expressed by one of the patients. Jacobus indicated that these difficulties were directly attributed to paperwork being



lost by the doctors and the lack of feedback on the progress of applications. Even though some of the patients included in this sample indicated that they were already receiving disability grants, their ability to cover all their expenses was still difficult. Priscilla was one of the patients who still struggled to sustain her daily-living.

*...it is actually a problem, sometimes there isn't any food. It is a struggle. The grant we receive is not always...it does not always cover everything.*

Priscilla also indicated that she knew of patients receiving disability grants who intentionally did not take their medication, or spent the grant they received inappropriately. She stated:

*That people that receive the grant. They do not take their medication. They drink, they buy wine with the money.*

*Clinicians.* Dr Periam and Dr Smith indicated that patients often held a misconception around the continuation of their disability grant. These misconceptions contributed to non-adherence to ARV medication among patients. Both clinicians indicated that patients were often unaware that grants were only temporary, and that they often showed an entitlement to money from the government because they were HIV positive. Dr Nkwali indicated that patients often did not requalify for a disability grant once they were well enough, which subsequently meant that they had to return to work to generate an income. Some of these patients expressed anger towards her because she could not ethically recommend their grants to be continued. She also indicated that patients had threatened to stop their medication as blackmail in an attempt to have their grants continued. However she did not report any patients actually stopping their ARV medication. She stated:

*And you want them to...to continue with their medication. So sometimes they can use it as blackmail, to say that, if you don't give it to me, I am going to stop my medication.*

Sister Bekaka testified to patients actually having stopped their medication when their CD4 count exceeded 500cells/mm<sup>3</sup>. These patients did so in an attempt to requalify for a disability grant after their six months duration elapsed, to generate some sort of income.

*...we found out a while back that patients who had taken their medication regularly grants got stopped after six months as their CD4 count exceeded 500, and they did not work, because it is difficult to get a job again when you have lost or left it. They would then stop their medication so that they would become ill again, and their CD4 count would stop so they would get a grant again.*

*Concurrences and discrepancies.* Difficulties in obtaining government grants were expressed by both the patient advocates and the patients. Disability grants as a motivation to discontinue treatment was a salient barrier raised by the patient advocates, patients, and the clinicians. Clinicians recalled some patients threatening to discontinue their ARV, but none actually doing so, while the patient advocates and patients indicated that patients really did do it. Clinicians, but not the patient advocates or patients, experienced patients illustrating misguided perceptions about the disability grants. A sense of entitlement and the belief of an indefinite grant were common concerns. A patient indicated that to her knowledge, patients who received the grants often abused it, rather than used it for appropriate or necessary causes.

#### **4.2.4 Food insecurity**

Precise adherence to ART medications not only required strict adherence to treatment and care but also required patients to adhere to dietary restrictions. However, clinicians indicated that in the event of food insecurity, taking ARVs on an empty stomach to be preferred to not taking it at all. However, hunger exacerbated the likelihood of patients experiencing side-effects.

*Patient advocates.* Food insecurity as barrier to ARV adherence was emphasized by both focus group discussions. It often happened that patients did not have any food when it was time to take their pills. Patient advocates indicated that it was possible to take the ARVs on an empty stomach, but it was not advised for all the medications patients received.

A patient advocate from the first focus group discussions indicated that certain community resources were available to patients experiencing food insecurity. However they often did not solve the problem of food insecurity completely, as resources such as soup kitchens provided patients with only one meal. Although this enabled them to take one dose of their ARVs on a full stomach they still did not have food at home to take the second dose with.

*Patients.* The majority of the patients included in the sample perceived it as important to take their ARV on a full stomach. However, food insecurity meant that this was not always possible. Six of the patients from the sample regarded food insecurity as a barrier to their ARV adherence. Andrew, a 32 year old divorced man described the severity of the problem:

*Sometimes when there is nothing, then I get water, just to fill me up, so I can take my medication.*

Patients also indicated that they had to go to great lengths to take their ARVs on a full stomach. They often had to make debt, or ask family or neighbours for something to eat when they had nothing in the house. Other times they would just go days without eating.

*Clinicians.* Dr Nkwali indicated that she had come in contact with a patient who indicated food insecurity to be a problem when she had to take her ARVs. According to Dr Periam food insecurity contributed to the patient's reluctance to take medication.

*They don't want to take their medicine without food, so they don't take it.*

*Concurrences and discrepancies.* Food insecurity as barrier to ARV adherence was indicated by patient advocates, patients and clinicians. Patient advocates indicated that

despite the assistance of community programmes such as soup kitchens, patients were often left with limited solutions, as they still battled with food insecurity at home. Patients indicated the amount of effort it takes to take their medication. Both clinicians and patients associated food insecurity with patients' reluctance to take their medication.

#### **4.2.5 Living arrangements**

Most of the patients attending the Infectious Diseases Clinic or Helderberg Hospital resided in either a rural or semirural community. Patients often shared accommodation with relatives or friends. The effect of their financial situation often left them with no alternative.

*Patients.* One of the patients indicated that his living arrangements affected his ability to adhere to his ARV medication, and that he had stopped his ARV treatment once before. Due to his financial situation he had to share his accommodation with four relatives, which consequently lead to a lack of privacy. Since privacy was a luxury he could not afford, his living arrangements made it difficult for him to take his medication in private. Winston described what his living arrangements was like.

*We are at the moment five who live together in a bungalow, in a structure, it is a wooden structure. It is rather small and there is only one big bed in the room in the bungalow, and we all sleep on it.*

*Clinicians.* Dr Nksosi indicated that the patient's ARV adherence may have a lot to do with their living arrangements, due to the close proximity patients lived in with others and that patients were often left with no privacy. She stated:

*It might also have a lot to do with the fact that everyone is just so...living so close together, that they are almost just like in each others' space kind of thing.*

Dr Smith on the other hand associated the patient's living arrangements with the changing of routine, which often impeded on their ability to remember taking their medication.

*A lack of routine, or a change in routine, is a huge...I find is a huge thing.*

*Um...weekends, unexpected visitors or unexpected things happening, they lose their routine, and then they...then they forget to take their pill.*

*Concurrences and discrepancies.* The lack of privacy as a result of a crowded living situation was a barrier to ARV adherence. This was mentioned by both clinicians and one patient. One clinician also attributed the lack of routine to patients' living arrangements which often made them forget to take their medication. However, neither patient advocates nor the other patients regarded living arrangements as a barrier to ARV adherence.

#### **4.2.6 Reminder tools**

Part of adequate adherence to ART is the importance of taking medication according to a structured timeline. Depending on the patient's particular regimen, prescriptions mostly indicated that ARVs be taken 12 hours apart.

*Clinicians.* The lack of reminder tools as a barrier to precise ARV adherence was only raised by Dr Smith. She was concerned that patients who lived in poverty often did not have the resources to purchase the basic tools to indicated time, such as watches, cell phones, televisions, or radios. The lack of such reminder tools acted as a barrier to precise adherence, since patients had no way of telling what time they should take their scheduled doses of ARV medication.

*Discrepancies.* Although patients from this sample lived in a state of poverty, neither the patient advocates nor the patients indicated that the lack of reminder tools was a problem in adhering to specific timelines when taking ARV medication.

#### **4.2.7 Transportation**

In addition to adherence to medication, the adherence to care was of equal importance. Due to the financial stance of patients, the access to private transportation was most often

restricted. Patients either had to rely on public transportation or travel by foot to attend scheduled clinic visits.

*Patient advocates.* During both focus group discussions with patient advocates patients' inability to afford public transportation to the clinic was identified as a barrier to care adherence. Patient advocates from the second focus group discussion indicated that due to the patient's inability to afford transportation to get to the clinic, patients often had no other option but to travel long distances by foot. Due to natural elements this journey was often physically daunting and worsened by the physical state of their bodies. When patients had to weigh up walking to the clinic with attending scheduled clinic visits, they often decided not to attend. A patient advocate stated:

*Sometimes they, they got a problem because they don't want to walk and they decide, no I'm going stay home, I'm not going to the, to the doctor.*

*Patients.* Six of the patients reported not having the resources to travel to the clinic by taxi, even an amount of R7 was more than they could afford. Matthew, who had stopped treatment once before, indicated that he discontinued his medication because he did not have travel fare to get to the clinic.

*Because I did not have money for transport each month that is why I stopped my medication.*

Six of the patients also indicated that because they did not have the funds to travel to the clinic by taxi, they had to travel to the clinic either hitch-hiking or on foot; sometimes walking up to three hours one way. Travelling by foot not only consumed a significant amount of time but also meant that patients had to start walking as early as four o'clock in the morning to be able to get to the clinic on time. Shaamiela indicated that she had to allow for additional time to walk to the clinic, because she had to take her young son to the clinic with her, and that the pace they walked at was determined by him. Gerome on the other hand

indicated that he had to pray for a safe journey, as travelling by foot meant that he had to pass through rough neighbourhoods in the dark to get to the clinic. In the event that patients were able to travel to the clinic by taxi, they were still required to travel to the clinic by foot from the taxi rank in town, since the taxis did not travel all the way to the clinic.

*Clinicians.* All the clinicians identified transport to be a barrier to adherence to care. Sister Kekaba contributed the patient's inability to adhere to care to the lack of necessary funds to make use of public transport. The costly nature of taking a taxi to the clinic were emphasised by Dr Periam. She indicated that trips to the clinic often meant having to take more than one taxi, and therefore patients had to get up early to get to the clinic on time. Dr Nkwali and sister Kabini indicated that patients who were not able to afford public transportation had no other option but to walk to the clinic to attend scheduled clinic visits. Sister Bekaka mentioned that patients, who were able to afford a taxi, still had to travel from the taxi rank to the clinic by foot, because the clinic was not part of the taxi routes. Dr Smith indicated that the location of the clinic contributed to extra strain on the patient's ability to get to the clinic, as many of these clinics were not located within the patient's community. Dr Periam and sister Kabini pointed out that strikes and riots by taxi owners, which often lasted days, impacted on patients' ability to get to the clinic on a set date.

*Concurrences and discrepancies.* Patient advocates, patients and clinicians indicated that patients' inability to afford transport impacted on their adherence to care. They have all indicated that patients who did not have the funds to travel by public transport had to do so by foot. Patient advocates and patients indicated that due to having to walk to the clinic patients often chose to discontinue ARV medication and care. Patient advocates described the daunting effect of having to travel by foot, while patients described the effect of having to travel with a child and being concerned for their safety while travelling through rough

neighbourhoods. Clinicians on the other hand also associated the location of the clinic outside the patient's community and the effects of taxi riots and strikes as barriers linked to transport.

### **4.3 Institution-related barriers**

Institution-related barriers were associated with the: (1) healthcare system; (2) healthcare facility, and (3) the staff employed at the healthcare facility.

#### **4.3.1 Healthcare system**

Barriers related to the healthcare system were those barriers which patients did not have direct control over. Difficulties associated with the healthcare system were: (1) the patient's access to the healthcare system, and (2) the open access of ART.

##### **4.3.1.1 Patients' access to healthcare system.**

*Clinicians.* Difficulties patients had in accessing the healthcare system were associated with the patient's ability to adhere to ARV treatment and care. Dr Smith indicated that patients might not find it particularly easy to access the healthcare system, and even when they managed to access the healthcare system, there was the possibility that they could be subjected to a rather unpleasant experience.

*Discrepancies.* Although Dr Smith indicated that patients might find it difficult to access the healthcare system, she did not express what exactly these difficulties were. Neither the patient advocates nor the patients directly identified any difficulty in accessing the healthcare system. Patients did however concur with Dr Smith on having encountered an unpleasant experience after they had accessed the healthcare system. These unpleasant experiences were however related to the healthcare facility rather than the healthcare system per se.

##### **4.3.1.2 Open access of ART in the healthcare system.**

The open access of ART in the healthcare system was associated with the present availability of ARV drugs in comparison to the restricted availability during the years of rollout



programmes. During the rollout programmes, such as the Khayelitsha Programme, candidates for ART were subjected to the strict assessment of clinical and social conditions. Regular clinic attendance was used as a tool to assess the patient's ability to adhere to ART. Programmes like the Khayelitsha Programme consequently showed high adherence rates due to patients being strictly selected for ART. However, in recent years ARV medication had become more widespread, going beyond the chosen few of the national rollout programme. Although there was still a criterion on which the selection of patients was based, some of the strict selection criteria of the rollout programme had fallen away.

*Clinicians.* Dr Smith identified the implications of allowing open access to ART to patients as a barrier to ART adherence. Lower rates of adherence were reported among patients who had open access to ART when compared to those of the national rollout programme. She also indicated that clinicians had a more accurate picture of how it was to treat patients with ARVs since patients were being treated for longer periods of time.

*...obviously we are less selective, and we have more of an issue with adherence, people are falling off the programme, people being in ARV for longer, the side-effects are starting to manifest. One gets more of a realistic picture of what it is like to treat patients with ARVs really.*

*Discrepancies* Patient advocates, patients and clinicians did not implicate the effect of open access on ART as a hindrance to patients' adherence to ART. This issue could be more apparent to Dr Smith as she had been involved with ART since it became available.

#### **4.3.2 Healthcare facility**

Barriers related to the healthcare facility were associated specifically with the Infectious Diseases Clinic and the Helderberg Hospital to which the former was connected. The barriers related to the healthcare facility were identified as: (1) administration and protocol followed

by staff, (2) language in which patients were attended to, (3) waiting times, (4) overcrowding, and (5) privacy.

#### **4.3.2.1 Administration and protocol followed by staff.**

Difficulties relating to the administration and the protocol followed by staff included the organization and management of patient files and medication. These difficulties were also associated with adherence checks at these facilities.

*Clinicians.* The record keeping of patient files at the hospital was indicated as a concern by sister Kekana. The concern was however not related to the Infectious Diseases Clinic, but rather to the hospital where patients were admitted for in-patient treatment. She was alarmed by the fact that during the patient's admittance to the hospital, their original files from the Infectious Diseases Clinic could often not be found, or that the hospital did not transfer the files from the Infectious Diseases Clinic to the wards. As a result, duplicate files were often opened for these patients. This procedure resulted in the absence of original notes concerning the patient's condition and the treatment they received as out-patient at the Infectious Diseases Clinic. She also indicated that hospital staff was often unaware of the patient's HIV status, which consequently left many patients without ARVs for the duration of their hospital stay. She was quoted as saying:

*Sometimes the patient's HIV diagnosis is looked over, they do not know if he is on treatment or not, and sometimes the patient will lay for days, two three days without medication. Then I will find out when I go and work in the ward. I will go and have a look.*

The concerns on the protocol hospital staff followed with regard to the patient's medication were also raised by sister Kekana. On admittance to hospital, patients often brought their own medication with, but staff would frequently not write down the particular information on the patient's chart. Subsequently clinicians at this facility had no knowledge of whether the

patients had taken their medications or not, and whether they had done so as prescribed. This also complicated the staff's ability to do pill counts or to assess the patients' adherence.

*Discrepancies.* Patients and other clinicians didn't raise any concerns about the administration of the healthcare facility or the protocol the staff followed in admitting in-patients. Sister Kekana was able to identify this barrier due to her experience in working in the wards. The lack of concern amongst clinicians about the administration and protocol of the hospital could be because all the clinicians included in this sample were employed at the Infectious Diseases Clinic, and patients' original files and notes on their treatment were freely accessible to them, since this was where patients received out-patient treatment. Ensuring that patients received their medication and adherence checks was an integral part of the clinicians' job at the Infectious Diseases Clinic.

#### **4.3.2.2 Language in which patients were attended to.**

Language as barrier to ART stemmed from the diverse population the Infectious Diseases Clinic provided services to. Patients were mostly Afrikaans-, English- and Xhosa-speaking, while the majority of the clinicians employed at the Infectious Diseases Clinic were proficient in either Afrikaans or English or they were bilingual. The barriers to ART adherence were associated with the inability or difficulties clinicians had in communicating with patients.

*Clinicians.* Difficulties or the inability to communicate with patients were mostly reported in the interactions with Xhosa-speaking patients. Dr Smith indicated that although she did not speak a fluent Xhosa, she was able to obtain a basic medical history from Xhosa-speaking patients. She and Dr Periam indicated that they occasionally had to make use of a translator when dealing with these patients. When they were not able to attend to these patients themselves, they were able to refer the patients to one particular doctor on the staff, who was a Xhosa.

The ability of clinicians to communicate or understand Afrikaans- or English-speaking patients was not raised as a general concern. Dr Periam reported a difficulty in communicating with Afrikaans-speaking patients but this was not a great concern since most of the staff at the Infectious Diseases Clinic could speak both Afrikaans and English.

The impact of language on the clinician's ability to communicate especially with Xhosa-speaking patients created a possible barrier to adherence as it was considered important to gain an understanding of underlying psycho-social issues to adequately treat ARV patients. Dr Smith stated:

*...you don't get the nuances or the complicated stories, especially the psycho-social issues that get lost completely.*

The inability to get the necessary information from patients was also reported to have added to the frustration the clinicians experienced when treating patients.

*Discrepancies.* Although the clinicians reported some degree of difficulty in communicating with patients and obtaining a comprehensive medical history and psycho-social background in order to adequately treat patients, patient advocates and the patients themselves did not express any concerns about their ability to communicate with clinicians or any impact of a language difficulty on the treatment they received.

#### **4.3.2.3 Overcrowding.**

In South Africa, a large number of patients seek out ART at public healthcare facilities, as financial hardship did not allow for the necessary resources to access private healthcare. As a result public healthcare facilities were most often overstretched in their capacity to accommodate everyone who needed ART.

*Patient advocates.* The experience of congestion at the Infectious Diseases Clinic was expressed by patient advocates from the first focus group discussion. They also mentioned

that patients often had an “uncomfortable” experience when they attended this facility. Patients often did not “feel welcome” due to the overstretched capacity of the facility.

*Patients.* Three of the patients indicated that overcrowding at the facility caused them inconvenience, often as a result of the influx of patients from other clinics. This resulted in extended waiting times and the lack of privacy when being attended to.

*Clinicians.* Dr Smith indicated that the Infectious Diseases Clinic was not able to keep up with the growth in patients seeking ART at that facility, especially with the influx of patients from the Eastern Cape. She also expressed her concern for the overstretched capacity of the hospital when patients required in-patient treatment. The hospital had a 100% bed occupancy rate, and patients were often not able to get a bed for days. She also indicated that when patients were required to stay at the hospital they would often have to get onto a trolley. If the trolleys were full they would have to get onto a mattress on the floor. When the mattresses were full, the patients often ended up on a blanket on the floor.

*Concurrences and discrepancies.* Both patient advocates and patients were concerned with the patients’ experiences when attending the Infectious Diseases Clinic. Patients and clinicians attributed the overstretched capacity in part to an influx from patients from other regions or clinics. One of the clinicians identified the effect an overstretched capacity had on in-patient treatment at the hospital. The patients have attributed the origin of other institution-related barriers to the overcrowding at the facility.

#### **4.3.2.4 Waiting times.**

*Patient advocates.* The return of patients to the Infectious Diseases Clinic was indicated to be inevitable for some of the patients, as they might not be able to attend to everything in one day due to waiting times. Return was often necessary to have their prescriptions filled.

*Patients.* Seven of the patients from this sample expressed a degree of inconvenience due to lengthy waiting periods when being attended to by the nurses or doctors, and having their prescriptions filled at the pharmacy. Gerald stated:

*I get here at six thirty, and then there are already a lot of people. Then I have to wait, and then I have to see the doctor. I only see the doctor past eleven or past twelve.*

The importance of arriving early in the morning on the date of scheduled clinic visits was also emphasized by the patients, some having arrived at five or six in the morning to be able to go home early in the afternoon. Although they arrived early in the morning their visit could still be a lengthy one. Straight-forward activities, such as being weighed or to have blood pressure taken, in addition to waiting for the doctor, counsellor or at the pharmacy, were all considered to be time consuming activities.

*Clinicians.* The three doctors regarded the patient's visit to the clinic to be a lengthy one, which could often be a "whole day thing". Patients did not particularly like coming to the clinic, because the wait was not "so nice". According to Dr Periam

*...they will first wait for the sisters, and get their pill counts, and then if they need to see the doctor, they will wait for the doctor, and wait at the pharmacy. By that time, they have waited and waited and waited for hours.*

Dr Smith pointed out that the patients may have to wait wherever they choose to access the healthcare system, as it might be overcrowded, but patients receive a good service and generally get everything attended to.

*Concurrences and discrepancies.* Patients and clinicians indicated that patients experienced prolonged waiting times at the healthcare facility. Having to wait long was inconvenient for patients as it had an effect on the time they had to arrive at the clinic and the time they were able to leave. The patient advocates added that the result of the waiting times

had an effect on patients having to return to the clinic to conclude aspects of treatment that were not previously attended to, such as having their prescriptions refilled

#### **4.3.2.5 Privacy.**

Due to congestion at the Infectious Diseases Clinic, the lack of privacy was inevitable. Private consultation rooms were not available for patients when being attended to by the nurses or counsellors. More than one patient at a time received treatment in one room.

*Patient advocates.* The first focus group discussion identified uncomfortable experiences during scheduled clinic visits. These experiences were attributed to the lack of privacy patients experienced when being attended to by nurses or counsellors at the facility. Patient advocates also indicated that the lack of privacy at the facility contributed to the patients' unwillingness to attend their scheduled clinic visits.

*Clinicians.* Dr Nkwali and sister Kekana thought that the lack of privacy at the facility made it difficult for patients to share any concerns, problems or difficulties in adhering to ARV treatment or care. Dr Nkwali mentioned the following:

*And some may not even be able to comfortably say what their problem is, there is just no privacy.*

*Concurrences and discrepancies.* There was a discrepancy between what patient advocates and clinicians perceived the influence of the lack of privacy had on patients' adherence to ART. Patient advocates considered the lack of privacy to have an effect on the patient's motivation to attend scheduled clinic visits, while the clinicians were concerned that patients were not able to discuss any obstacles they experienced in adhering to ART. Patient advocates and clinicians, however, agreed about the lack of privacy at the facility, but patients themselves did not show any concerns about the lack of privacy at the healthcare facility.

#### 4.3.2.6 Patients' experiences of staff at the healthcare facility.

*Patient advocates.* Patients' negative experiences with staff in charge of ARV patients were a concern indicated by patient advocates from both focus group discussions. Hostility, unkindness, and a lack of empathy from staff members were reported by these participants. Patient advocates attributed these negative attitudes to certain biases staff members held about patients' race or social class. One of the patients mentioned:

*...those coming from a good home, and they are white and rich haughty people, they are treated properly. But we underprivileged, we are treated hard for no reason, to say it straight, we are spoken to rudely.*

The above mentioned quotation emphasized why patient advocates thought that the underprivileged patients attending the healthcare facility were treated differently than the patients perceived to be of a "higher" social standing.

Patient advocates also attributed the ill-treatment of patients to the patients' punctuality in attending scheduled clinic visits. Being late for appointments, missing appointments completely, or attending appointments on dates other than scheduled were also seen as a cause of negative interactions. Patients who frequently abused alcohol or substances were also reported to be more likely to have experienced negative interactions with staff.

*Patients.* Three of the patients from the sample testified to have had a negative experience with staff members. They however attributed being ill-treated to their lack of punctuality with scheduled clinic visits. Winston explained one of his negative encounters with staff.

*I stay away for a day or two, and then I think I will be ok, it can do no harm. When I get there the next day they kick, rant and rave.*

*Clinicians.* Five of the clinicians from the sample indicated patients' negative experiences with staff to be an issue. Dr Smith stated:



*And I think you see...you see it often that the staff get short with the patient; say they come late to the clinic...*

Knowledge of staff members being short-tempered or raising their voices at patients was admitted by Dr Smith and sister Kabini. These occurrences were attributed to patients being seen as “not playing the game”. Patients perceived as “not playing the game” was not punctual with their scheduled clinic visits. This lack of punctuality caused disruption in the flow of proceedings in the clinic which consequently added to the clinician’s workload. These clinicians furthermore attributed the staff’s short-temperedness to stress created by the workload of the clinicians at the healthcare facility. Attending to large volumes of patients often also required having to work through lunch breaks.

Dr Smith and sister Kabini revealed that the negative experiences patients had with staff contributed to the patients’ unwillingness to attend certain clinics. In some cases patients often chose to stay home, even though their condition warranted treatment or in-patient treatment.

*Concurrences and discrepancies.* Patient advocates, patients and clinicians concurred about negative interactions or experiences patients had with staff at the healthcare facility. Participants agreed on some of the causes of these negative interactions or experiences and differed on others. Patients’ punctuality with their scheduled clinic visits was indicated as a contributing factor by the patient advocates, patients and clinicians. Patient advocates also attributed these negative interactions or experiences to biases staff held about patients’ race, social class and substance abuse. Clinicians furthermore indicated working conditions of the staff to be part of the reason for negative interactions. However, only clinicians indicated that some patients chose not to adhere to their scheduled clinic visits or in-patient treatment due to the negative interactions with staff.

### **4.3.3 Staff at the healthcare facility**

Institution-related barriers associated with the staff at the facility were mainly identified by the clinicians, and the concerns raised were: (1) experiences of staff working with patients receiving ART, (2) burnout, (3) the lack of resources to provide staff with psychological assistance, and (4) health literacy of staff. Although these barriers were not directly associated with the patients' adherence to care, it impacted on the quality of treatment the patients received when attending the healthcare facility.

#### **4.3.3.1 Experiences of staff in working with patients receiving ART.**

Three of the clinicians from this sample expressed having experienced certain feelings and emotions when treating ART patients. The large number of patients, the observation of these patients, and their dealings with and the treatment of these patients were seen as contributors to these feelings and emotions. Feelings of being “scared”, “frightened”, “disconcerted” and being “overwhelmed” in reaction to these situations were described by Dr Nkwali and Dr Smith who stated:

*...but the sheer numbers are overwhelming and the pressure...the pressure never lets up, and the clinic always grows and continues to get bigger.*

The sense of “helplessness”, “hopelessness”, and “disempowerment” was also attributed to these circumstances. These feelings were provoked by the perceived inability to change the social circumstances of the patients, such as the community the patients came from, drug abuse and depression.

Dr Smith described the stressful and demanding nature of dealing with patients who were once well and then became ill and required in-patient treatment. She indicated that the patient's inability to adhere to scheduled clinic visits also contributed to feelings of “frustration” amongst staff.

#### **4.3.3.2 Burnout.**

The burnout of staff was associated with being overworked and the emotional toll taken by treating ART patients. Dr Smith was the only clinician to indicate the issue of burnout amongst staff. This could possibly be because as head of the Infectious Diseases Clinic, she was the one to speak to staff members who showed signs of burnout, while informally attempting to assist in dealing with the situation.

#### **4.3.3.3 The lack of psychological support for the staff.**

Although the clinicians indicated that they experienced a range of feelings and emotions when treating ARV patients, Dr Smith indicated that the staff did not have any automatic psychological support to deal with these feelings and emotions. A social worker was assigned to the hospital, but she was not directly affiliated with the Infectious Diseases Clinic, and mainly assisted with difficult grant applications. Psychologists, or anyone with skills to provide support, were not available to refer staff to. The issue of burnout was a matter mainly treated in-house through a once-a-week meeting where the improvement of the hospital was discussed. This often resulted in a forum where staff members aired their frustrations.

Although these meetings provided the staff with an opportunity to air their frustrations, the meetings were not done on a professional basis with the assistance of a mediator. These meetings, however, enabled Dr Smith to pick up on some of the issues the staff battled with.

#### **4.3.3.4 Health literacy of staff.**

Staff's insufficient knowledge relating to the treatment of patients infected with HIV and AIDS was only raised by sister Kekana. The insufficient knowledge of staff was mainly associated with a barrier that had been experienced in the past. Past knowledge was the cause of fear amongst staff, as "everyone knew it was a disease, and that's where it stopped". She also indicated that staff in the hospital was more likely than those in the Infectious Diseases Clinic to have insufficient knowledge about the disease and treatment. However, she also

indicated that since the courses they had attended they had better understanding about the disease and treatment and that the sisters saw the patients in a different light.

#### **4.4 Social and community-related barriers**

Social and community-related barriers to ART adherence were associated with the collective beliefs or perceptions of the ART patient's community, as well as the resources available in the community in which these patients resided. The barriers that were identified were: (1) stigma and disclosure, (2) patient advocates' access to patients, (3) religion, (4) substance abuse (5) culture, and (4) treatment support programmes.

##### **4.4.1 Stigma and disclosure**

Stigma and the patient's willingness to disclose to friends or family were negatively associated with adherence behaviour, because of the perceived effect it would have on how their communities would treat patients.

*Patient advocates.* The association between stigma and disclosure and patient's adherence to ART were highlighted by patient advocates from both focus group discussions. The patient's willingness to disclose to family and friends was coupled with the fear of being stigmatized. These fears included being rejected, their family being ashamed of them, or a fear of what their community would have to say. The need to secretly take their tablets, collecting them from their clinic, or not wanting to see a doctor, was often fuelled by stigma. A patient advocate from the second focus group discussion said:

*He told me that he is shy, he did not want to talk, because he was afraid that everyone would reject him. It made that he did not want to collect his medication from the clinic, or go to the doctor, because he did not want to disclose.*

The set up at the facility was also considered to be a stigmatizing agent. A patient advocate indicated how just being referred to a certain room in the clinic for ARV treatment "automatically" identified patients as being HIV positive.

*Patients.* Patients described the effect stigma had on how they felt about themselves. Andrew revealed that due to the stigma associated with being HIV positive, patients were often “considered to be less, not like a complete person”, like “someone who was inferior to others”. Stigma due to being HIV positive contributed to a fear of how their community would react towards the patients. Margaret was worried that her community would laugh at her if they found out that she was HIV positive. Mitch indicated that he was aware of patients being verbally assaulted in the streets for being HIV positive.

Patients indicated a reluctance to disclose their HIV status to family and friends. Both Winston and Andrew indicated their reluctance, because the news of their status would travel through their neighbourhoods or communities. Winston described the result of disclosing.

*The neighbourhood is so small that it would go around everywhere, it is not only the nearby proximity, and it doesn't matter where the people live. If a small fire is started then the whole field catches fire, the way that they go about.*

Two of the patients indicated that their reluctance to disclose their HIV positive status was exacerbated by friends or families who abused alcohol, since being intoxicated had an effect on their talkative nature. Some of the patients stated that their inability to disclose their HIV-positive status required them to take their medication when no one else was around. to the need of having to take their medication when no one was around.

*Clinicians.* Dr Nkwali and Dr Periam both indicated the significant amount of stigma associated with being HIV positive. When compared to having other illnesses patients infected with HIV were considered to be more prone to stigmatization by their communities. This was seen to have originated from misguided perceptions communities held around HIV. Many of these perceptions associated with being HIV positive were still attributed to the “promiscuous nature” of patients.

Dr Nkwali and Dr Smith indicated that patients generally did not refuse care because of the fear of communities acting violently towards them, but rather because of the fear of being laughed at, talked about, or being stigmatized due to their HIV positive status. This fear was considered to contribute to the patient's refusal of home-based care or visits by patient advocates when their condition warranted it. The stigma which fuelled this refusal was often associated with the possibility of being identified as HIV positive or because they knew the person who was providing them with the service. According to Dr Nkwali

*...they might need home-based care, they are terminally ill, and they still don't want it, because they are still scared that people are going to talk about them. Although we do explain the confidentiality issues, they still see the stigma around HIV as being bad in their communities.*

Dr Nkwali and Dr Smith indicated that patients often demonstrated a reluctance to attend scheduled clinic visits at certain clinics in the fear of knowing other patients, or staff employed at the clinic. This situation often contributed to patients seeking services at clinics outside their immediate area, in an attempt not to be identified as being infected with HIV.

Sister Bokaka stated:

*A lot of the patients refuse to go there, because they know the people who work there, they know the patients who come there.*

The effect of stigma on the patient's willingness to adhere to ARV drugs was also emphasised. Dr Periam indicated that some patients refused to take their tablets in the presence of others, because they did not want to reveal that they were HIV positive.

The clinic was also identified as a prime stigmatizing agent by one of the clinicians, although the clinic did not intentionally create a stigmatizing environment. Sister Kekaba described an incident where a box containing patient cards was accidentally changed from the Infectious Diseases Clinic to the ARV clinic. This situation resulted in angered patients who

became verbally abusive towards staff, because they were under the impression that they would be identified as being HIV positive.

*Concurrences and discrepancies:* Patient advocates, patients and clinicians concurred that patients demonstrated a reluctance to disclose due to fear instilled by stigma. Patients were the only participants who expressed how being stigmatized made them feel about themselves. They expressed a real fear that their HIV positive status would spread through their communities should they disclose, especially should they disclose to an intoxicated relative or friend.

The patient advocates and clinicians emphasized the effect of stigma on the patient's adherence to ARV treatment and care. Not having disclosed meant that they needed to take their tablets secretly. They also concurred about the role of the clinic as a stigmatizing agent. Clinicians were the only participants to indicate that stigma contributed to patients seeking treatment in areas where they did not know patients or staff.

#### **4.4.2 Patient advocates' access to patients**

Home visits by patient advocates provided patients with assistance with difficulties they experienced in adhering to ART. Difficulty to get access to patients acted as a barrier to patients' adherence, as patients often did not receive the additional assistance from the patient advocates.

*Patient advocates.* Concern about the inability to access patients due to the communities the patients resided in was raised by patient advocates from both focus group discussions. Patient advocates indicated a fear for their safety when entering some of the patients' communities. One of the patient advocates said:

*It is your greatest fear when you work in the field. And where you enter, in our area there is a lot of squatter camps, and it is dangerous, but we have to go through there,*

*because at the end of the day our patients remain important, so we have to go there every day.*

This patient advocate referred to the physical characteristics of the patients' communities, the lack of protection, and often the type of client they had to visit. The risky nature of visiting patients was particularly applicable to those patients who were addicted to drugs.

*Clinicians.* The difficulties patient advocates experienced in accessing their clients were a concern raised by one of the clinicians. Dr Smith attributed these difficulties to the inability to physically contact the patients. Patient advocates often had to return several times to a patient's home due to patients not being at home at the time of the visit. Patients often missed a couple of visits before difficulties they experienced in adhering to ART were attended to.

*Concurrences and discrepancies.* Patient advocates and one of the clinicians concurred that patient advocates found it difficult to access patients at their homes. The reasons for these difficulties were however attributed to different circumstances. While the patient advocates emphasised the characteristics of patients and their environment as well as their own experiences in having to travel through those communities, the clinician attributed difficulties to patients not being accessible or available. Although there was a discrepancy in the reasons for the difficulties given by the patient advocates and clinicians, all the reasons resulted in patients not receiving the essential support with their adherence.

#### **4.4.3 Religion**

The role of religion on patients' ART adherence was associated with influence of religious beliefs and values of a religious institution on the patients' willingness to take their ART medication.

*Patient advocates.* The non-adherence or discontinuation of medication due to religious beliefs or church dogma was recognized by patient advocates from the first focus



group discussions. Some of the patients believed that due to their faith in God, it was not necessary for them to take their ARV medication. A particular religious institution was specifically identified as one that had instructed patients not to take their ARV medication. The reason for these instructions was that the “cure” for their condition was provided by their faith and a healing prayer. By taking ARV medication, patients challenged the way of God and they were ill because of their disobedience to God. A patient advocate from this group said:

*If you believe that you went out for prayer and you got your healing prayer there's no need to doubt God, so you better not take you medication.*

*Patients.* The patients from this sample did not indicate that their religious beliefs or the religious institution of the church acted as a barrier to their ARV adherence. Some of the patients who were affiliated with one specific religious institutions indicated that they received messages encouraging them to take their ARV medication.

*Clinicians.* The influence of religious beliefs or institutions on the patients' ART was only mentioned by one clinician. Sister Kekaba indicated that she had treated a patient, who insisted on being retested because he believed that he was “cured” by the healing prayer he received. This patient felt severely dejected when he was informed that his second test was positive.

*Concurrences and discrepancies.* Patient advocates and clinicians agreed that the influence of religious beliefs or religious institutions impacted on patients' beliefs around the necessity of taking ARV medication and subsequently also impacted on their HIV positive status. They also agreed that patients believed that when they received a healing prayer they would be “cured” of HIV and that adherence to ARV would be disobedience to God. There was however a distinct discrepancy between the messages patients received surrounding ART adherence, and those reported by the clinicians and patient advocates.

#### 4.4.4 Substance abuse

The effect of substance abuse, and more specifically alcohol abuse, on ART adherence could be considered within both the individual and a social and community-related context. The lack of alcohol treatment programmes in this particular community prevented patients to adequately adhere to ARV medication.

*Patient advocates.* Patient advocates from both focus group discussions mainly attributed patients' non-adherence associated with substance abuse to individual barriers. They identified substance abuse as contributing to patients often forgetting to take their ARV medications when intoxicated. According to a patient advocate from the second focus group discussions

*You have to take it twice a day, twelve hours apart. Maybe you have to take your medication in the morning, now you take it. When you get up, you are sober, you drink your medication. As the day progress, you start to drink. Tonight you have to...especially if you are drunk, then you are not going to take it because you are under the influence of alcohol*

The patient advocates from the focus group discussions testified to being aware of patients who consume alcohol. It was however difficult for them to see the reasons why patients abused alcohol.

*Patients.* The effect of alcohol abuse on patient's non-adherence to ARV medication was indicated by Priscilla, one of the patients.

*I also drank and I forgot to take my treatment, I didn't worry. Look, when a person drank, you don't worry.*

Several patients from the sample admitted to having abused alcohol in the past. However, none of the patients interviewed perceived terminating their alcohol consumption to be a problem. The consumption of alcohol was also not considered to have an effect on their ART

adherence. The achievement of sober habits was attributed to personal achievement, rather than to the assistance of social networks or treatment support programmes.

*Clinicians.* Four of the clinicians attributed non-adherence and default of ART to substance abuse. The effect of being intoxicated often caused patients to forget to take their ARV medication, or it contributed to their reluctance to take their medication while drinking.

Clinicians also indicated that it is necessary for patients to adequately address the reasons why they were abusing alcohol. Dr Smith suggested that even though patients may want to stop drinking, the treatment programmes were often inadequate in helping them to do so. The treatment programmes available within the patients' communities such as AA and AlAnon, were often not ideal as they generally did not accommodate Xhosa-speaking patients.

*Concurrences and discrepancies.* The effect of substance abuse on the patient's ability to adequately adhere to ART was raised by both the patient advocates and the clinicians. However, only one patient attributed substance abuse to non-adherence. The rest of the patients denied that substance abuse had an effect on their adherence. The availability of treatment programmes to assist all patients to stop drinking was deemed necessary by both patient advocates and clinicians. Patients on the other hand indicated that they either had stopped or could stop drinking by themselves without outside assistance.

#### **4.4.5 Culture and tradition**

The influence of culture and tradition on patients' ability to adhere to ART could be considered as a mutual influence; the influence of cultural beliefs, practices and traditions on adherence, and the influence of adhering to ART on cultural beliefs, practices and traditions.

*Patient advocates.* The role of cultural beliefs, practices and traditions on the patient's adherence to ART, and the effects of ART on cultural beliefs, practices and traditions were identified by patient advocates from both focus group discussions. Although both groups

discussed the role of traditional medications in ART adherence, they differed about how traditional medication contributed or influenced ART adherence. The first focus group discussion indicated that traditional medication was not an issue of concern to their patients' ART adherence. They were not concerned because the Helderberg Hospital mainly provided treatment to the coloured community, rather than the black community where traditional medicine was regarded as playing a more prominent role. However, the second focus group discussion indicated that some patients treated at the clinic believed in the effect of traditional medicine, and that the ARVs would not be effective. The patient advocates from this focus group discussion nevertheless concurred with the first focus group discussion on race being a contributing factor to patients' use of traditional medication. According to patient advocates from this group some of the patients who started ART indicated that they were not taking traditional medications. After baseline blood works were done, however, the opposite would happen eventually.

*Clinicians.* Patients' beliefs surrounding the efficacy of ART were identified by one of the clinicians. These beliefs were associated with patients' race or cultural background. Dr Nkwali mentioned that patients from a coloured background were more likely to believe in the efficacy of ART, than patients from a Xhosa background. Coloured patients also showed a greater sense of eagerness to initiate ART. Xhosa patients showed grave concern about stigma in their communities, and the effect home visits from patient advocates and hospices would have on them. They demonstrated a greater reluctance to take their ARV medication due to these reasons.

The influence of patients' cultural background was also identified as having an effect on their ability to disclose their HIV positive status to family. The inability to disclose was closely associated with their expected cultural roles or traditional roles. These roles were often more problematic for female patients. Sister Kekana explained a situation she

frequently came in contact with in her dealings with patients. Pregnant mothers who had started on AZT and NVP were often expected to breastfeed their newborn infants, as bottle feeding was not an acceptable practice in their culture. Having received ARV treatment therefore made it difficult for these mothers to explain why they could not breastfeed their babies.

*Concurrences and discrepancies.* Patient advocates and clinicians agreed that the patient's cultural background acted as a barrier to ART adherence; however, there were some discrepancies in the opinions about which aspects of ART it had an effect on. Patient advocates were concerned that the patient's cultural background contributed to the use of traditional medicine in conjunction with their ART. Patients were dishonest about the use of traditional medicine since ART should not be initiated while patients were using traditional medicine. Clinicians on the other hand attributed patients' cultural background to their willingness to take their ARV medication and the patient's perceived efficacy of these medications. The clinicians also indicated that treatment often impeded on the patient's cultural and traditional beliefs and practices as it required doing what was expected of them. This often contributed to the patient's reluctance to disclose to family. Patients themselves did not indicate the traditions of their culture as having an effect on their treatment or ability to adhere to medication.

#### **4.4.6 Support**

##### **4.4.6.1 Social support.**

The actual or perceived support patients received from their social networks, such as family, friends or neighbours was identified as an important enabler of ART adherence. Social support enabled patients to adequately adhere to their medication, to do so on time, and boosted patients' confidence and trust in the treatment.

*Patient Advocates.* Patient advocates from both focus group discussions considered patients who did not have any social support to be more likely to struggle with ART adherence. Support from social networks contributed to adherence by reminding patients to take their ARV medication, to do so at scheduled times and ensuring they “stick” to their ARV medication. A patient advocate from the second focus group discussion mentioned that reminding patients of the consequences of not properly adhering to ARV medication was also an essential part of social support.

*You need to have someone who is going to remind you, remember you need to take this for the rest of your life, if you don't take this understand you're not going to be okay. But if you're alone sometimes you determined to deny it.*

*Patients.* The facilitating effect of social support on the patient's ability to adhere to ART was raised by six of the patients from the sample. Patients indicated that their family often reminded them to take their ARV medication; they were even reminded by their young children. Encouragement to boost their moral and to collect their ART medication from the clinic was also reported by patients. Margaret said she was woken up by family in the mornings to be able to take her medication on time. Gerome described the social support he received from his family.

*My mother tells me to drink my pills, and then she tells me 'hey hey it is five to seven, take your pills and two slices of bread and drink them'. I have a good understanding with my family...*

*Clinicians.* The importance of having social support and the negative effect of the absence of social support on patients' ability to adhere to ART were reported by two of the clinicians. Dr Smith indicated that patients who had a good treatment supporter, social support or a good family structure “really managed to take their pills”.

*I think it depends on the family structure and the support structure of the patient.*

*If...if there is really a good support...someone who really cares for that patient, they will somehow make them swallow their pills.*

The need for social support to vulnerable populations, such as the elderly or illiterate, was especially emphasised by sister Kekana. She also described how the lack of social support to vulnerable populations impact on their ability to adhere to their medication.

*They can't read, they're forgetful, they...they need to have that patient person with them to tell them here is your tablets, and come drink you tablets, and make sure that they drink it, don't put it at the bed side or at the table when they have breakfast, or whatsoever they need to make sure that the patient take it.*

These people lack support systems at home, probably because care givers got tired of staying at home looking after them, and decided to look for a job, leaving these patients with no one to look after them.

*Concurrences and discrepancies.* The importance of the involvement and support from social networks in ART adherence was emphasised by patient advocates, patients, and clinicians. Reminding patients about the implications of non-adherence was also considered a vital aspect of social support by the patient advocates. The negative effect of not having social support was expressed by patient advocates, while clinicians added that the effect was intensified amongst vulnerable populations. Although patient advocates and clinicians regarded the lack of social support as an important aspect, patients did not mention how the lack of social support impacted on their ability to adhere to their ARVs.

#### **4.4.6.2 Financial support.**

The financial support patients received from family, friends or neighbours was not only associated with money, but also physical support. This type of support included goods which particularly enabled patients to adequately adhere to treatment and care.

*Patients.* The importance of financial or physical support as an enabler to adhere to ART medication and care was raised by four of the patients from the sample. Financial support from relatives or neighbours enabled patients to take their ARV medications with food, or to travel to the clinic to attend their scheduled clinic visits. Patricia described the effect financial support from a family member had on her ability to adhere to her scheduled clinic visits.

*My mother spoke with me; she was able to help me at that moment. Because yesterday I was at the clinic, I took the taxi, she gave me the money, thirty rand, and I got to the clinic.*

Similarly, Shaamiela described how the financial or physical support she received from her family assisted her in taking her medication.

*There was a time I did not have food in my house, and I had to take my pills, then I couldn't. But if I didn't have, I could always go and ask my family next door, in order for me to just take my pills.*

*Discrepancies.* Although financial or physical support was a salient issue amongst patients, patient advocates and clinicians did not indicate the importance of obtaining this type of support from social networks. The reason why this was identified by patients could possibly be attributed to the fact that the conditions that necessitated physical or financial support concerned basic aspects of their everyday life such as food and transport. The basic needs created the need for obtaining financial or physical support.

#### **4.4.7 Treatment support programmes**

Treatment support programmes included the Treatment Action Campaign (TAC). The TAC was identified as a civil society force which aimed to provide comprehensive healthcare services to individuals infected with HIV.



*Patient advocates.* The direct effect of the TAC as an enabler of patients' adherence to ART was not identified. Patient advocates from the first focus group discussions indicated the indirect effect it had on patients' ability to adhere, by getting the patients to disclose their status. The approach of the TAC was regarded as a "militant way" of getting patients to disclose their status publicly. Patient advocates did not present other influences of the TAC.

*Discrepancies.* The indirect effect of the TAC on disclosure was only identified by the first focus group. Neither the second focus group discussion, nor patients and clinicians indicated treatment support programmes to have a direct or indirect effect on the patient's ability to adhere to ARV treatment and care.

#### **4.5 Conclusion**

Through focus group discussions with patient advocates and semi-structured interviews with patients and clinicians a range of barriers and facilitators to patients' ART adherence were identified. The main barriers and facilitators were related to individual barriers, poverty-related barriers, institution-related barriers, and social and community-related barriers. There were certain concurrences but also discrepancies between the patient advocates, patients and clinicians included in this sample about which of these barriers contributed to patients' adherence or non-adherence to ART, how they contributed and why. These concurrences and discrepancies contributed to a unique view of the subject matter of adherence as they represented a triangular view of: (1) difficulties patients experienced in adhering to treatment and care, (2) what the doctors and nurses perceived the difficulties were that patients experienced in adhering to treatment and care, and (3) what the patient advocates perceived the difficulties to be. The collection of data from focus group discussion with patient advocates allowed for systematically and simultaneously getting patient advocates' perceptions related to patients' adherence to ART. Semi-structured interviews with clinicians and patients allowed the flexibility to explore themes that arose during these interviews. The

analysis and discussion which follows in Chapter 5 will consider the results of the study within the framework of Bronfenbrenner's (1972) Ecological Systems Theory.

## CHAPTER FIVE: DISCUSSION

### 5.1 Adherence behaviours as the product of the patient's environment

The influence of the environment on health and illness has been known since the time of Hippocrates (Taylor, Repetti, & Seeman, 1997). Yet, predominant conventional theories such as the biomedical model still regard adherence behaviour as being influenced only by biological and psychological factors (O'Leary & Martins, 2000). Most psychological and medical research does not incorporate environmental factors in understanding adherence behaviour (Munro, Lewin, Swart, & Volmink, 2007; Williams & Patterson, 1996).

The data presented in the previous chapter however indicate that adherence behaviours are more complex than suggested by biological and psychological barriers such as forgetfulness, mental health, health literacy and barriers associated with medication regimens. This complexity brings into focus the need to consider the patient's environment either as a facilitator or as a barrier to adherent behaviour. Adherent behaviour may thus be better explained by Kurt Lewin's classical equation  $B = f(PE)$  (Lewin, 1935, p. 73) as the product of the interplay between the patient and the environment.

Bronfenbrenner's (1972) Ecological Systems Theory provided a multilevelled conceptual framework within which the complex adherence behaviours associated with the individual barriers, poverty-related barriers, institution-related barriers, and social and community-related barriers could be broken down to the level of the patients' environment in which they originated. This conceptual framework also provided some insight into how these structural barriers either restricted or facilitated adherence behaviours. Such an approach is often overlooked by conventional biological and psychological research (Cox & Meade, 1975; Lambert & McKeivitt, 2002; Van der Geest & Hardon, 2006).

## **5.2 Bronfenbrenner's (1972) Ecological Systems Theory**

The Ecological Systems Theory extends beyond conventional research theory which mainly focuses on the individual, to a theory which, apart from individual barriers, addressed the patient's adherence in a global context (Coday et al., 2002; DiClemente, Crosby, & Kegler, 2002). The use of the Ecological Systems Theory as a multi-levelled framework made it possible to consider the patient's environment as a complex conceptual map of the influences on adherence behaviours (Reppucci, Mulvey, & Kastner, 1983).

This conceptual map considered adherence behaviours situated within the patient's environment as a "set of nested structures" where one structure was fitted within the others like "Russian dolls" (Bronfenbrenner; 1979). As represented by the modified Ecological Systems Theory (included in Appendix I) the various systems operating within the patient's ecological environment include the individual as its own system as well as the micro-, exo- and macrosystem, and will be discussed accordingly.

### **5.2.1 The individual as a system**

According to Potgieter (1998), the individual patient could be regarded as a complete system which consisted of various emotional, cognitive and behavioural sub-systems. These sub-systems were considered as individual psychological and behavioural barriers by both conventional research as well as the present study. Although the identification of these barriers may not have been the primary aim of the present study it was still included in the modified Ecological Systems theory as it was considered an important contributor to the context of barriers within the patient's environment.

Previous research regarding individual barriers to adherence was included, and the findings of the present study largely coincided with findings of previous research, such as: (1) Chesney (1997) and Chesney et al. (1999) on forgetfulness amongst patients; and (2) Gordillo et al. (1999) and Roberts and Mann (2000) on the problem of pill-burden to ART adherence.

The data obtained also agreed with studies done by: (3) Weiss et al. (2003) on health literacy; (4) Kalichman et al. (1999) and Schuman et al. (2001) on the effect of illiteracy on adherence; and (5) Catz et al. (1998) and Punjari et al. (2008) on the role of mental health in determining adherence.

### **5.2.2 Microsystem**

Bronfenbrenner (1979) identified the microsystem as any context where a person has immediate experience and personal interaction with others. Interpersonal relationships within this setting include those with family, friends or neighbours within the patient's immediate environment. According to the modified Ecological Systems Theory this microsystem included: (1) barriers associated with stigma and disclosure, and (2) the facilitative effect of tangible social support on adherence behaviour.

#### **5.2.2.1 Stigma and disclosure.**

As suggested by the modified Ecological Systems Theory, stigma could be located within both the micro- and macrosystem. It was essential to consider stigma and disclosure within both these systems in order to understand how it functioned as a barrier to adherence. While the macrosystem was more concerned with the origin of stigma, the microsystem considered the effect thereof on the patient's interactions with individuals within their microsystem.

The present study found that patients feared disclosure of their HIV positive status to others within their environment for several reasons. In keeping with the findings of Maskew et al. (2007) the present study found patients to be reluctant to disclose that they are HIV positive to employers for the fear of being dismissed. This reluctance to disclose their HIV positive status not only restricted their ability to obtain the necessary leave to adhere to scheduled clinic visits, but also affected their pill-taking behaviour. Similar to Davies et al. (2006) respondents indicated that due to the fear of their HIV positive status being discovered patients often hid medication bottles, and subsequently forgot to take their medication.

Additionally, both Hardon et al. (2006) and the present study found that patients would deliberately skip doses when privacy was not available at the scheduled dosing time. The present study also found that patients chose not to disclose their HIV positive status to certain friends due to the fact that these friends frequently abused alcohol. Patients indicated that disclosing to these friends would mean that the news of their HIV positive status would spread through their community like a wildfire.

In agreement with Liu et al. (2006) the present study found that patients refused in-patient treatment as well as home-based care when terminally ill. They also refused to receive home visits from patient advocates, in fear of inappropriate disclosure of their HIV positive status. Patients associated inappropriate disclosure with their social network discovering their HIV positive status through services provided at home, or at the public healthcare facilities. Thus, patients' adherence to ART care was compromised by their fear of having to deal with stigma when accessing certain healthcare resources within their environment.

#### **5.2.2.2 Social and tangible support.**

The modified Ecological Systems Theory located social and tangible support within the microsystem of the patient's environment. The reason for this was that social networks within their environment were found to be responsible for the facilitation of their adherence behaviours. Similar to Catz et al. (2003) the present study found that encouraging patients to co-operate with the prescriptions of clinicians facilitated adherence behaviours.

In agreement with Singh et al. (1999) the present study found that family members and neighbours were typically the ones who either directly or indirectly reinforced adherent behaviours. Respondents indicated that direct reinforcement included reminding patients to take their medications at specific times and according to the instructions of their physicians. While indirect reinforcement included boosting the patient's moral or their motivation to take ARVs, as well as reminding patients of the implications of non-adherence.

Waddell and Messeri (2006) ascribed the importance of social support to: (1) an enhanced access to resources; (2) an enhanced immune response; (3) the improvement in health-related behaviours; and the (4) improvement in mental and physical health by reducing levels of stress or buffering patients from stressors that diminish health and well-being (Turner & Turner, 1999). Additionally Ennett, Bailey, and Dederman (1999) and Resnick et al. (1997) indicated that social support (5) reduced risk behaviours and increased emotional bonding through the provision of information and advice, and positive peer influence.

Similar to the findings of Waddell and Messeri (2006), the present study also found that social support enhanced the patient's access to other resources. Despite coming from a context of poverty, social networks also contributed to adherent behaviour amongst patients through donating financial or tangible resources to patients. These resources included food to take their medication with, or money to acquire either food or transportation. These resources were considered as having a grave effect on adherence to ART treatment and care.

### **5.2.3 Exo-system**

The exo-system was the second system in Bronfenbrenner's (1979) multi-levelled Ecological Systems Theory. Visser (2006) described this system as the organizational level of the patient's ecological environment. This system included the relationship between two or more settings in the patient's ecological environment of which one setting did not include the patient, but rather the patient's immediate environment.

As indicated in the modified Ecological Systems Theory this system included institutional barriers, which were divided into three sub-barriers namely: (1) the public healthcare system; (2) the specific medical resources available to the patients at the Infectious Diseases Clinic and Helderberg Hospital; and (3) staff as a medical resource available to the patients.

### **5.2.3.1 Healthcare system.**

#### **5.2.3.1.1 Inclusion criteria of patients to ART programmes.**

As indicated by the modified Ecological Systems Theory the first institution-related sub-barrier ascribed the lack of strict adherence to the shift in the criteria for inclusion of patients to ART programmes. Dr Smith referred to this shift in the inclusion criteria as the “open access” to ART treatment. Concerns surrounding the “open access” to ART treatment were associated with the introduction of more lenient inclusion criteria by the National Department of Health in 2004 and then again in 2010, when compared to those first introduced by rollout programmes such as the Khayelitsha Project in 2003.

Rollout programmes such as the Khayelitsha Project (2003) presented above average adherence amongst patients due to the strict inclusion criteria of these programmes. Patients were considered for ART according to: (1) a biological criteria of WHO stage III and IV (WHO stage criteria indicated in Appendix J) and a CD4 count of  $<200\text{cells}/\text{mm}^3$ ; (2) regularity, where patients had to attend HIV clinics for at least three months being on time for the last four visits; (3) meeting social and adherence criteria, including the evaluation of home environment, disclosure, family support and a treatment supporter. After having met these criteria patients were only selected by a community selection committee (Médecins Sans Frontières South Africa, 2003).

After the introduction of the Standardized National Eligibility Criteria for Starting Regimens for Adults and Adolescents in 2004 patients were now considered for enrolment based upon a biological criteria of: (1) CD4 count of  $<200\text{cells}/\text{mm}^3$  irrespective of stage or (2) WHO stage IV AIDS-defining illness, irrespective of CD4 count and (3) patient’s expressed willingness and readiness to take ART adherently (Provincial Administration Western Cape, 2004). These guidelines included psycho-social considerations of: (1) demonstrated reliability, like having attended three or more scheduled clinic visits; (2) no



active alcohol or substance abuse; (3) no untreated active depression; (4) recommended disclosure or member of support group; (5) insight, demonstrated by acceptance of status, the consequences of infection and the role of treatment before commencing ART. However they were psycho-social considerations and did not serve as an exclusion criteria (Provincial Administration Western Cape, 2004). These considerations meant that more HIV positive patients were now able to access ART, but since the removal of the strict inclusion criteria adherence rates showed a significant decline.

A further concern was associated with the possibility of an ever greater decline in adherence due to the introduction of a new Standardized National Eligibility Criteria for Starting Regimens for Adults and Adolescents in 2010. Even though these new guidelines were introduced after the data was collected, these guidelines contributed to an even greater “open access” to ART, as they completely excluded the psycho-social considerations of the 2004 guidelines, and lowered the biological criteria. Eligibility for ART now solely depended upon either: (1) CD4 count  $<200\text{cells/mm}^3$  irrespective of clinical stage, (2) CD4  $<350\text{cells/mm}^3$  in patients with TB/HIV or pregnant women, (3) WHO stage IV irrespective of CD4 count, (4) MDR/XDR-TB (National Department of Health, 2010). Not only did the “open access treatment” raise concerns about the patient’s ability to adhere to ART, but also that the large number of patients now eligible for ART would contribute to an even greater patient load on an already overstretched public healthcare facility.

#### **5.2.3.2 Public healthcare facility.**

The second aspect associated with institutional barriers as indicated by the modified Ecological Systems Theory was related to the healthcare facility. The public healthcare facility in the present study was represented by the medical resources available at the Infectious Diseases Clinic and Helderberg Hospital, and the role it played as either facilitators or barriers to patients’ adherence to ART treatment and care.

#### **5.2.3.2.1 Healthcare facility and the protocol staff followed when treating patients.**

In keeping with the findings of Maskew et al. (2007) the present study showed the importance of efficient administration of paper files at the public healthcare facility, to be able to provide patients with the essential treatment and assist them with adherent behaviours. In addition to the findings of Maskew et al. (2007) the present study also found that missing crucial information on patients' treatment was often the result of lost or duplicated files. The importance of original patient files was stressed as duplicate files often did not contain information such as contact details, treatment history, past clinic visits and blood tests were not recorded in those files. Therefore, in the absence of original patient files, it was also difficult for clinicians to keep track of each individual patient's progress.

The absence of this information was considered to have compromised the quality of care patients received at these facilities. In 2004 the National Department of Health announced the development of a health information system. This system was designed to alleviate the operability in admissions, discharges and transfers, as well as maintenance of full patient records. However the implementation of such a system has yet to be realised.

Apart from administrative difficulties, clinicians indicated that due to protocol followed by hospital staff when admitting patients the patients' ability to adhere to ART treatment was gravely compromised when receiving in-patient treatment. The mismanagement of patients' ARV medication meant that patients often went without ART for several days. In addition to that patients often spent whole days without receiving routine monitoring of their condition during their hospital stay. The above mentioned conditions experienced by patients in public healthcare facilities strongly contradict an environment where adherence should be facilitated and ensured.

#### **5.2.3.2.2 Overcrowding, waiting times and privacy.**

In a context of limited financial resources private healthcare was a commodity patients could not afford. With even more patients becoming eligible for ART due to the open access to treatment, the demand for already limited public healthcare resources to accommodate patients was greatly restricted. These demands for public healthcare not only lead to a shift in infrastructure but also impacted on personnel and financial resources at the Infectious Diseases Clinic and Helderberg Hospital. Though more patients had access to treatment, they were now also exposed to conditions which impinged on their motivation to adhere to ART care.

Despite limited literature on the barriers associated with public healthcare, respondents indicated that the large numbers of patients now utilizing public healthcare resources meant that patients had to wait for extended periods of time before being attended to by doctors, nurses, and counsellor as well as having their prescriptions filled at the hospital pharmacy. This demand contributed to the lack of privacy when being attended to, as the overstretched capacity meant that multiple patients were attended to at the same time. The overstretched capacity of the Infectious Diseases Clinic to accommodate out-patients extended to the hospital where patients were admitted for in-patient treatment. A 100% bed occupancy rate was not uncommon for these facilities and patients often ended up on the floor when waiting for a bed to become available. This overstretched capacity therefore negatively impacted on the quality care available to the patient.

Not only did overcrowded public healthcare facilities compromise the quality of care available to the patients, but these experiences with facilities also obstructed the patient's willingness to endure these circumstances when attending scheduled clinic appointments. Facing these overcrowded circumstances not only contributed to lengthy clinic visits and a lack of privacy, but also meant that patients had to leave as early as four o'clock in the

morning to get ahead of other patients to be able to leave the facility at a reasonable time in the afternoon.

Having to leave in the early hours of the morning introduced a new set of barriers to ART adherence, as patients feared for their safety when having to travel through certain communities in the dark. Based on crime statistics of the South African Police Service (2010) Western Cape patients had to travel through communities where 2,274 counts of murder, 1,707 counts of attempted murder, 34,410 counts of assault, and 12,543 counts of robbery with aggravated circumstances, have been reported within the past year. When considering the level of crime within the patients' environment their hesitation to attend scheduled clinic appointments cannot be ignored

#### **5.2.3.2.3 Language.**

Limited language resources further impeded patient care. Afrikaans- and English-speaking patients could comfortably address their concerns in consultation. However Xhosa-speaking patients often had difficulty in communicating not only clinical concerns but deeper issues that were often lost in translation. This inability stemmed from staff mainly being Afrikaans- or English-speaking, with only one doctor being Xhosa-speaking, and another being able to take a basic medical history in Xhosa. Subsequently Xhosa-speaking patients were either referred to the Xhosa-speaking doctor, or had to use an interpreter.

Swartz (1998) indicated that at an interpersonal level the use of an interpreter during consultation introduced a third person to a situation mainly designed for two. Subsequently such a situation carried certain risks regarding confidentiality and the inappropriate disclosure of a patient's HIV positive status. It was suggested that the use of an interpreter should be avoided where possible. The clinician's ability to adequately address adherence problems when using an interpreter could be greatly compromised as patients might be less forthcoming through a third party, especially when the patient knew the interpreter (South

African HIV Clinicians Society, 2007). Dr Smith emphasized the importance of good communication between patient and clinician in addressing problems surrounding adherence. This is imperative as an understanding of the patient's psycho-social issues enabled staff to adequately address any difficulties the patients experienced with their adherence.

Swartz (1998) indicated that the reasons for using an interpreter were related to the institution and its needs. The lack of Xhosa-speaking staff at the healthcare facility, as well as the absence of "official" interpreter positions raised the question of equal care for all patients. Both the present study and Swartz (1998) found that in hospitals without official interpreters cleaners or family members should be used as interpreters.

Although there were no official interpreter positions at the Infectious Diseases Clinic the South African HIV Clinicians Society (2007) recommended that independent interpreters be trained on issues of confidentiality to be prepared for such a position. They would then have the ability to obtain vital information from patients and make it easier to reveal issues regarding their adherence within an environment where they felt comfortable.

#### **5.2.3.2.4 Patients' relationship with healthcare workers.**

As indicated by the modified Ecological Systems Theory patients' relationship with their healthcare workers was considered within the exo-system of their environment. This relationship was considered important since the staff were found to be a valuable medical resource available to patients at the Infectious Diseases Clinic.

The Department of Health (2003) and Tzynka and Erlen (2004) considered a trusting and supportive relationship between patients and healthcare workers to be indispensable and an important facilitator of better adherent behaviour amongst patients. The importance of such a relationship was also stressed by Catz et al. (1998) who indicated that any interaction with a patient provided the clinicians with an opportunity to reinforce adherent behaviour. Additionally, a supportive and non-judgemental environment has the potential to enable

patients to honestly discuss and address any problems with their adherence (Department of Health, 2003).

Even though literature such as Catz et al. (2000), Murphy, Roberts, Martin, Marelich and Hoffman (2000) and Murphy, Roberts, Hoffman, Monalina and Lu (2003) indicated that trusting and supportive relationships enabled adherent behaviour, the present study found that negative interactions with healthcare workers had the ability to act as a barrier. Respondents indicated that patients' relationships with healthcare workers were influenced by negative interactions, which subsequently impeded on their willingness to adhere to ART care. Patients took responsibility for these negative experiences and the short-temperedness of staff, as they attributed these to their lack of punctuality with scheduled clinic appointments. Clinicians on the other hand attributed these negative experiences to nature and workload associated with their jobs. Whether experiences were deemed positive or negative, it had a definite effect on patients' willingness to attend scheduled clinic appointments.

### **5.2.3.3 Healthcare workers at the IDC.**

#### **5.2.3.3.1 Experiences, burnout and lack of resources.**

The third aspect of institutional barriers as indicated by the modified Ecological Systems Theory in Appendix I was associated with the clinicians as a medical resource available to the patients seeking ART treatment. Attending to the acute needs of the ART patients they treat on a daily basis, the needs of the clinicians were often overlooked (National Department of Health, 2004). Clinicians encountered large numbers of patients in limited resource settings. They were often burdened with a severe workload and consequently faced burnout. However, the availability of services to address the psychological implications associated with such circumstances was not addressed adequately.

The Department of Health (2003) announced the development of staff support programmes at healthcare facilities. These programmes included the provision of time and

structured staff support programmes for debriefing and grief management associated with the loss of patients, especially those well-known to staff. Although clinicians indicated a great need for such a programme, still no resources or professional services were available to them, which resulted in these matters being dealt with informally.

Addressing the psychological needs of the clinician should be considered a priority, as their well-being contributed to the “type” and quality of medical resources available to ART patients. The importance of addressing these needs have already been indicated by the patient–healthcare provider relationships, and its effects on patients’ willingness to adhere to scheduled clinic appointments.

#### **5.2.3.3.2 Staff health literacy.**

The lack of adequate health literacy amongst staff in the past served as a barrier to ART treatment. In the years before the widespread knowledge of HIV and AIDS, some clinicians reported not knowing more than HIV being a disease, or the special challenges associated with treating ART patients. However, the National Department of Health indicated that from 2003 onwards, healthcare workers had to receive specific training regarding ART treatment and adherence and that the training should be updated periodically (Department of Health, 2003). Such educational courses and the progress made in ART contributed to better health literacy amongst staff, translating into better care and assistance with adherence amongst patients.

#### **5.2.4 Macrosystem**

The third system of Bronfenbrenner’s (1972) Ecological Systems Theory included the macrosystem. This system was considered the “blue print” of the patient’s specific society, culture and sub-culture (Bronfenbrenner, 1994). As indicated by the modified Ecological Systems Theory, adherence behaviours within this system were understood by: (1) poverty-related barriers associated with a specific economic system; (2) social and community-related

barriers related to wider systems of ideology operative within the patient's society, and (3) the availability of social resources within their communities.

#### **5.2.4.1 The influence of poverty on ART adherence to treatment and care.**

Bronfenbrenner (1979) located the origin of poverty-related barriers within the macrosystem of the patient's environment, as the effect of poverty was a function of a specific economic system. According to the Gini coefficient, a commonly used measure of social inequality, South Africa was classified within the category of "very high levels of social inequality" with a score of 0.578 (United Nations, 2009), along with countries such as Haiti or Brazil. This number was based on a score of which the value 1.00 represented a situation of perfect equality and 0.00 a situation of perfect inequality. In other words a country with a Gini coefficient of 0.00 wealth was divided equally amongst everyone, and a Gini coefficient of 1.00 represented a situation where only one person had all the wealth and everyone else had nothing (United Nations; 2009).

A level of very high social inequality inevitably contributed towards an environment with limited financial resources. Similar to Hicks et al. (2007), Tegger et al. (2008) and Ware et al. (2009), the present study found that even though these patients received free ARVs, their limited financial resources still negatively impacted on their ability to adhere to ART treatment and care. The effect of limited financial resources on patients' adherence behaviour was found to be similar to that in a study conducted by Nguyen and Stovel in Botswana (2004). The present study found that the limited resources associated with poverty affected the patient's ability to afford basic commodities such as food, "reminder tools" and transport which could facilitate better adhere to ART treatment and care. Poverty limited the patient's adherence by impeding on the ability to expend. Adequate adherence also impacted on their vocational abilities and interfered with their current working conditions.



#### **5.2.4.2 Restricted vocational abilities and conditions of employment.**

South Africa has an official unemployment rate of 25.3%. Speculations are that this rate could actually be as high as 30% (Statistics South Africa; 2010). With 4.3 million unemployed South Africans, concerns about patients' ability to remain part of an economically viable workforce continue to be legitimate. Patients taking part in this study were concerned that due to the physical effect ART had on their body they would not be able to perform previously feasible tasks and be able to generate a sufficient income. It is evident from the perspective of patients that the inability to generate a sufficient income posed a barrier to ART treatment and care.

As in the study of Weiser et al. (2003) clinicians indicated that in some cases the nature of patients' employment conditions negatively impacted on their adherence, particularly the lack of health benefits. Furthermore the timely nature of scheduled clinic appointments, the frequency of these visits, and especially when treatment was initiated, meant that patients had to forgo a day's pay each time they had to attend the clinic. Failure to disclose their HIV status to their employers further restricted patients' ability to attend the clinic. In the context of widespread unemployment rates, many patients were reluctant to risk taking leave for scheduled clinic appointments as they did not want to risk possible dismissal.

Clinicians also reported that patients who worked shifts were continually burdened by having to remember to take their medication, and by being confronted by their inability to take their medications in private without being questioned by colleagues. The nature of working irregular shifts and facing possible exposure therefore contributed to non-adherent behaviour.

#### **5.2.4.3 Disability grants.**

With the unemployment rate speculated to be as high as 30%, being HIV positive in itself became a source of income amongst patients (Nattrass, 2006). Qualifying for a disability

grant also meant that patients became reliant upon disability benefits as their primary source of income. Disability grants facilitated better adherence amongst patients by alleviating poverty (Lund, 1999), however it also became a barrier to adherence and good health.

Disability grants were indicated as difficult to obtain, and being HIV positive alone did not automatically qualify a patient to receive a grant. In addition to the administrative difficulties patients experienced in applying for a disability grant, patients had to qualify for the biological criterion of a CD4 count of  $<200\text{cells}/\text{mm}^3$ . This biological criterion meant that patients had to be ill enough to meet the criteria for an AIDS diagnosis to be able to obtain a disability grant of R1010, in 2009 (Nattrass, 2006; South African Social Security Agency, 2009).

In agreement with Ravallion (2003) the present study found that patients did not perceive the amount of R1010 to be sufficient to support day-to-day living. However, based upon the international poverty line of R9.10 (\$1.25) per patient per day the World Bank (2010) indicated that people should be able to meet their most basic needs on the amount of R430.70 (\$60) per month. Keeping in mind the high unemployment rate these disability grants were often the single source of household income for patients. TB studies conducted in the Western Cape Nattrass (2006), found that when a disability grant was regarded as a source of income it compromised the patient's need or motivation to maintain adherent behaviour and good health. Patients therefore compromised their adherent behaviour by deliberately forgoing ART in an attempt to maintain a CD4 count below  $200\text{cells}/\text{mm}^3$ . In doing so, these patients would become eligible to apply for an extension of their grant. Clinicians furthermore indicated that even though patients became non-adherent to ART, there were also times when patients used the threat of non-adherence in an attempt to have their disability grant continued.

The effect of disability grants on adherence behaviour however still remains controversial. Despite this controversy the present study, in agreement with Natras (2006), concluded that patients obtained access to a disability grants through an act of desperation. These acts of desperation compromised patients' health, as they limit much needed healthcare in order to be able to afford basic commodities

#### **5.2.4.4 Food insecurity as a function of poverty.**

Food insecurity was considered a macrosystem barrier to ART adherence. The inability to afford certain foods is associated with high levels of poverty. Available literature on food insecurity, such as studies done by Baylies (2002), De Waal (2002) and Du Guerny (2002), associated an increased level of food insecurity with the HIV positive patient's inability to adhere to special diets. However, the present study found that food insecurity resulted in an inability to afford even the most basic foods.

In keeping with the findings of Ware et al. (2009) the present study found that in most cases patients made use of available social resources within their environment when experiencing food insecurity. These social resources included soup kitchens or obtaining food from family members or neighbours to take their medication with. There were however times when patients simply did not have a choice but to "do without" when their social resources were exhausted. The inability to purchase these most basic foods made patients reluctant to take their ART medication. They would often dismiss the clinician's recommendations, to take ART medication on an empty stomach rather than skipping doses completely, as the hunger-induced side-effects of the treatment were too difficult to overcome.

Marson and De Cock (2004) stressed the importance of food security, as hungry or undernourished patients found it difficult or sometimes impossible to adhere to complex ART regimens. Being well-nourished was essential to the survival and functional recovery of the

patient while on ART (Ware et al., 2009), and medications were considered to be more effective when patients were well nourished.

#### **5.2.4.5 Living arrangements as a function of poverty.**

Limited financial resources restricted patients' options regarding their living arrangements. Moralejo et al. (2006) found barriers related to living conditions, to be associated with the type of relationship the patient had with the person they lived with. The present study, however, found that these barriers were rather associated with an overcrowded living situation. Such a living situation had a negative impact on the patient's willingness to take ART medication in the presence of others. Such living arrangements also meant an environment with regularly disrupted daily routines, which subsequently contributed to forgetfulness when taking ART medication.

#### **5.2.4.6 Reminder tools as a function of poverty.**

As indicated by the Modified Ecological Systems Theory, the absence of reminder tools within the patients' environment was ascribed to poverty. This came as clinicians associated the lack of these reminder tools with the patient's restricted ability to purchase items such as watches, cell phones or television sets to assist them with precise adherence to the scheduled dosing times. In agreement with Golin et al. (2002) the clinicians confirmed that patients who used more adherence aids had been more likely to be adherent. Supported by Golin et al. (2002), clinicians stressed the importance of reminder tools. However, neither the patient advocates nor the patients showed any concerns about the patient being able to afford reminder tools.

#### **5.2.4.7 Transportation as a function of poverty.**

As indicated by the Modified Ecological Systems Theory, the present study found the inability to afford transportation to be a function of poverty. It was found that public transportation was an expenditure most patients struggled to afford, which confirmed the

findings of Mukerjee et al. (2006). Similar to studies conducted in Nigeria and Tanzania this study found that obtaining money for transportation to attend scheduled clinic visits was rarely as easy as “dipping into a ready supply of cash” (Ware et al., 2009). For patients who were seeking out-patient treatment, an amount as little as R7 was more than some could afford. In the absence of financial resources for transportations, patients either did not adhere to their scheduled clinic appointments, or they travelled to the clinic by foot. Some hitch-hiked, sometimes travelling up to three hours at a time, while enduring harsh elements.

Patients who were able to afford public transportation faced additional barriers in adhering to scheduled clinic appointments, such as a poor public transportation system in the area of the Infectious Diseases Clinic. Taxi routes were itinerant to the Somerset West CBD and the patients who were able to afford public transportation were still required to complete the rest of their journey by foot. Additionally, taxi strikes negatively impacted on the patients’ ability to get to the Infectious Diseases Clinic on time. Subsequently patients were often left without transportation for several days at a time. The public transportation system also left patients without alternative means of transportation, such as buses. Maintaining scheduled clinic appointments were directly related to the patient’s ability to remain adherent to ART (Stout, Leon, & Niccolai, 2004).

#### **5.2.4.8 Migration.**

The present study, in agreement with studies by Lima et al. (2009) found migration amongst HIV positive patients to be a common occurrence. The decision to migrate was most often associated with patients’ socio-economic status and resulted from the inability to generate an income within their present environment (Lima et al., 2009). Consequently, during permanent migration the patient’s need to seek out ART treatment and care was often outweighed by the need to obtain employment, or to acquire some sort of income, especially when the migrant patient was asymptomatic.

Additionally respondents indicated that adherence was also compromised by insufficient knowledge as to where they could seek out ART treatment and care within their new environment. Respondents furthermore associated non-adherent behaviour with certain beliefs around having to disclose their HIV positive status to their family before being able to access ART treatment and care. “Having to disclose” often outweighed the perceived need or importance of accessing much needed care.

Respondents indicated temporary migration to have a negative effect on adherent behaviours amongst patients. Similar to permanent migration, temporary migration resulted in patients from other regions of the country resettling in the Western Cape in search of employment, often leaving their families behind. Returning to those regions during holidays or for specific events such as funerals was identified as a barrier to adherent behaviour. During both permanent and temporary migration patients travelled without a sufficient supply of ART medication. Despite not having a sufficient supply of ART medication, migrant patients still chose not to seek ART care in the area where they had settled, and subsequently went without it.

Clinicians expressed grave concern about both permanent and temporary migration, as in both cases patients often travelled without the necessary transfer letters. The lack of this necessary documentation compromised the quality of care amongst migrant patients accessing treatment at other public health facilities. Clinicians at those facilities were required to treat patients without the necessary information on their medical history, blood tests or current treatments.

### **5.2.5 The effect of social and community-related barriers on adherence**

The effect of social and community-related barriers present within the macrosystem was associated with the barriers posed by wider systems of ideology within the patient’s society or community (Bronfenbrenner, 1994). Within this system adherent behaviour was facilitated

or restricted by the beliefs, knowledge, attitudes and values of the patient's society or community. As suggested by the modified Ecological Systems Theory barriers associated with the patient's particular society or community included: (1) stigma associated with HIV and AIDS; (2) attitudes and values of religious standings or institutions; and (3) cultural values and practices.

#### **5.2.5.1 Stigma and disclosure.**

Though the effect of stigma and disclosure was previously noted as a microsystem barrier due to its effect on the patient's interaction with others, it was also deemed a macrosystem barrier since stigma was considered to have originated within this system. The origin of stigma was derived from two sources, the first being the fear of contagion, and secondly from the negatively based assumption about people living with HIV (UNAIDS/WHO Working Group on Global HIV/AIDS and STI Surveillance, 2008). Like Ritamaki et al. (2006) the present study attributed negatively based assumptions to stigma which included the attitude of the community towards and understanding of HIV and HIV positive individuals.

Goffman (1963) associated stigma with the shared meanings or schemas of the patient's community. The present study indicated that stigma associated with being HIV positive to have evolved from the faulty schemas or beliefs of the community around the transmission of HIV. Patients indicated that stigma resulted in being treated differently by their social networks or communities. Patients also indicated that their decision to disclose their HIV status to others was greatly influenced by their fear that they would become a source of ridicule in their communities or, what Goffman (1963) referred to as "being inferior".

The collective beliefs, values and attitudes of the patients' community not only played a part in their decision to disclose their HIV positive status to others, but also contributed to the reluctance amongst patients to utilize the medical resources within their communities. In

accordance with Liu et al. (2006) this reluctance was illustrated by the patient's refusal to attend healthcare facilities, utilize home-based care when terminally ill, or to receive visits from patient advocates to assist with difficulties in adherence. However, in agreement with the findings of Reis et al. (2005), the healthcare facility itself was also a prime stigmatizing agent, and contributed to an already reluctant patient's unwillingness to attend scheduled clinic visits.

Studies such as Ritamaki et al. (2006) suggested that the negative effect of stigma on adherence behaviours could be addressed within the exo-system of the patient's environment. Ritamaki et al. (2006) concluded that this could be done by doctors at public healthcare facilities attending to stigma-related issues when counselling patients prior to their ART initiation.

#### **5.2.5.2 Religion.**

Based on patient advocates' reports rather than patients' reports it was found that the beliefs and values of a specific religious institution prevented patients to adhere to ART. When patients affiliated with this religious institution chose to receive a healing prayer, their adherent behaviours were considered as deviant from God's will, because their adherent behaviour would then "indicate" that they did not believe in God. It was believed that these healing prayers served as a cure for their HIV or AIDS. Although this specific religious institution placed great restrictions upon adherent behaviour, patients affiliated with other religious institutions only indicated to have received facilitative messages from their various religious affiliations.

#### **5.2.5.3 Cultural and traditional background of patients.**

The role of cultural and traditional background had a dual effect on the ART adherence behaviours amongst patients. Firstly, the collective beliefs, practices and traditions impeded on patients' willingness to adhere to their ART medications. Studies conducted amongst



African American and ethnic minorities indicated adherence amongst these groups to be poorer than Caucasian participants (Metha et al., 1997). Reasons for these differences could however not be found (Kalichman, 1999).

The present study on the other hand did not consider race alone when determining adherent behaviour, but also considered the collective beliefs, practices and traditions of racial groups. These collective beliefs, practices and traditions were largely associated with the beliefs or perceptions of the effectiveness of ART, which subsequently contributed to their willingness to adhere. Cultural practices also had some bearing on whether patients took traditional medications in conjunction with their ART regimens.

The second finding related to cultural and traditional background was the effect of ART on cultural expectations. The study presented the example of a black mother who could not breastfeed her infant due to the risk associated with ART. Bottle-feeding an infant was frowned upon by her culture. Additionally, such cultural expectations meant that patients had to disclose their HIV status as an explanation why they could not conform to cultural practices.

#### **5.2.5.4 Resources available to patients within their communities.**

As indicated by the modified Ecological Systems Theory, the third system operating within the macrosystem identified barriers associated with the availability of certain resources within the patient's community. The resources identified were: (1) the patient advocates' access to patients and (2) the availability of substance abuse programmes.

##### **5.2.5.4.1 Patient advocates' access to patients.**

Patient advocates proved to be a valuable resource within the patient's community, as they assisted patients with any difficulties in their adherence, as well as serving as a link between the clinic and the community. However, the enabling effect of patient advocates as a social resource was often limited by the physical structures of the communities the patients resided

in. Respondents indicated that the neighbourhoods within the patient's community and certain townships instilled a fear amongst patient advocates when they had to do home visits. This fear was partly fuelled by certain groups of people residing in the area, such as those abusing substances. Respondents indicated that the characteristics of the neighbourhood often made it difficult to contact patients, therefore patient advocates often had to return several times to the patient's residence.

#### **5.2.5.4.2 Substance abuse.**

The importance of substance abuse as a barrier to ART treatment and care has changed over the last seven years. In 2003 during the Khayelitsha Project, substance abuse excluded patients from the rollout programmes. In 2004 the Standardized National Eligibility Criteria for Starting Regimens for Adults and Adolescents, substance abuse was a consideration when ART was initiated. However, since the new guidelines for initiating ART, substance abuse has not been a consideration for selecting patients for ART.

Substance abuse however remained of great importance to clinicians and researchers as it was still considered to be a barrier to ART adherence (Garcia & Cote, 2003; Parsons et al., 2008; Trzynka & Erlen, 2004). Literature on this subject of substance abuse locate non-adherent behaviour within individual-system of the patient's environment, as it mainly explained non-adherence as the result of substance-induced forgetfulness (Trzynka & Erlen, 2004).

The present study on the other hand identified substance abuse as a macrosystem barrier to adherence, since the select resources available within the patients' communities limited their ability to address substance abuse through treatment support programmes. This was especially limited amongst certain language groups. Clinicians indicated that the lack of treatment programmes amongst Xhosa-speaking patients was of particular concern. Clinicians also indicated that patients could greatly benefit from the establishment of such

programmes within their communities to further facilitate adherence. Patients themselves did not feel that substance abuse was a problem or that it interfered with their adherence, despite having admitted to substance abuse prior to initiating ART.

### **5.3 Conclusion**

Upon examination of the data included in the previous chapter several barriers to adherence as a product of the patient's environment were identified. The examination of adherence behaviours moved beyond the conventional individual psychological and behavioural research on this matter. However the present study did not disregard these barriers, but rather included them into the patient's multi-structural environment, which proved the importance of also considering poverty-, institutional-, and community-related barriers to ART adherence. Although these barriers were analytically distinct, the various systems in the patient's environment were interrelated. The need for interventions were emphasised by research, as the change in any of the systems would subsequently lead to distinct change in the patient's adherence behaviour.

### **5.4 Significance of study**

The present study presented an original perspective on ART adherence behaviour. Through the triangulation of the perspectives of patients, clinicians (doctors and nurses) and patient advocates this study was able to identify structural barriers through using a specific framework. This framework considered ART adherence as a product of the patient's environment, as well as the interplay between the systems operating within this environment. By including different groups of respondents it was also possible to identify the different systems within the patient's environment, and how these systems contributed to non-adherence. Lastly, considering the patient's environment as barrier to or facilitator of the patient's adherence, several original barriers were identified, which were not yet identified in other studies on ART adherence.

### **5.5 Limitations of study**

A limitation posed by this study could be attributed to the data collection stage. The presence of two to four interviewers, may have affected the responses obtained from patients included in the sample. Patients were reassured that their responses would be kept confidential and anonymous. However the number of interviewers present may have contributed to discomfort amongst patients when sharing information on sensitive issues. The number of interviewers may also have contributed to patients not being as forthcoming as they possibly would have been in a one-on-one situation. This possible discomfort may have been intensified by the difference in race and social class of the respondents and the interviewers.

### **5.6 Suggestions for future research**

The present study did not present immediate solutions to the barriers to ART adherence within the patient's environment. However, it provided a solid foundation for research to address how patients could be assisted in developing the necessary skills to cope with their environment more effectively in order to improve adherence behaviours.

An investigation into how the new inclusion criteria could be considered in determining how adherence behaviours amongst HIV positive patients were affected. By doing so strategies could be developed to support newly enrolled patients to adhere to ART treatment and care.

Effective ways of enhancing social support from the patient's social networks should also be explored, as they provide a rich source of social and tangible support. This could be done by examining ways of how disclosure could be enhanced or how social networks could be included in the treatment programmes to improve patients' ability to adhere. Lastly, the present study also invited the investigation of the political factors operating within the patient's environment, as no political barriers to ART adherence were reported by the respondents.

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## **APPENDIX A**

### **INTERVIEW SCHEDULE: CLINICIANS**

1. What is your position? (Clinician, nurse, doctor)
2. Please tell me about your experience in treating AIDS patients. (Probe: What is it like for you)
3. What do you think are patient's experiences of the healthcare system in general?
4. What do you think is the hardest part for patients in taking their medication?
5. What do you think is the patient's experience of the clinic in particular?
6. How would you describe your patient's relationship with you?
7. What do you think are patient's main problems that make it difficult for them to attend clinic appointments?
8. Are there any aspects of the clinic, the way things are set up or organized, that you think make it difficult for patients to come for their appointments?
9. What aspects about the clinic or the healthcare system do you think can be changed to make it easier for patients to come for their appointments?
10. If these changes were made, can you tell me how it would be different or better for patients in terms of attending clinic appointments?



## APPENDIX B

### INTERVIEW SCHEDULE: PATIENTS

1. What do you see as the most important factors that act as barriers to your attending your clinic appointments as you are required to?

*Potential probes:*

a. Do you generally think you attend your appointments the way you are expected to?

b. Why do you think you don't attend your appointments the way you are expected to?

c. Tell me about the difficulties you face in your life that make it difficult to attend the clinic regularly?

2. We are interested in the kinds of things you think would stop you from attending your appointments regularly. Can you think of all the things in your life that you think make it difficult for you to attend the clinic?

3. Please tell me about your experience with the medicine you are taking? What is it like?

4. What is your experience of the healthcare system in general?

5. What is your experience with the clinic in particular?

6. How would you describe your relationship with your doctor or nurse?

7. What are the main problems that you have in your life that make it difficult for you to attend your clinic appointments?

8. Are there any aspects of the clinic, the way things are set up or organized, that make it difficult for you to come for appointments?

9. What aspects about the clinic or the healthcare system can be changed to make it easier for you to come for your appointments?

10. If these changes were made (mention the suggestions the patient gave in above), can you tell me how it would be different or better for you in terms of attending clinic appointments?

11. Is there anything that we haven't talked about that you want to say about any of these issues?

**APPENDIX C**  
**CODEBOOK FOR CLINICIANS**

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*Codebook for Clinicians*

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Code	Definition	Example of quotation
CE	The clinician's experience, or feelings and emotions related to treating patients on antiretroviral therapy.	<p>“...we look at the actual absolute numbers...the numbers...that need to be on treatment...uhm...it can be very overwhelming...”</p> <p>“...if you just look at the numbers, I think the numbers are overwhelming.”</p> <p>“...one often feels very helpless, in terms of improving social circumstances. I mean the whole thing around adherence...”</p>
CIIF	Clinicians' identification of individual behavioural and psychological factors related to the patients' treatment adherence.	

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CIIF – Forgetfulness	Individual factor related to the patients' forgetfulness in taking medication.	“...omdat people are tending to forget. We are human beings and we are we tend to forget...”
CIIF – Health literacy	Individual factor related to the patients knowledge and information pertaining to HIV/AIDS and antiretroviral therapy.	“...some of the issues may...may be that they understand a 100% how to take them, even though they do get counselled in their own language...”
CIIF – Literacy	Individual factor related to the patients' level of education.	“They may not be...may not be literate.”
CIIF – Medication characteristics	Difficulties experienced in the actual taking of medication.	“The volume of the pills. That is the biggest barrier...”
CIIF – Side-effects	Individual factor related to the side-effects patients experience in taking antiretroviral medication.	“Then the other issues than taking their pills, especially in the beginning, they may have side-effects that make them nauseous or make them start vomiting, they feel dizzy and

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB	Clinician identification of structural barriers.	they may not have been adequately prepared for those side-effects..."
CISB – Access to mental healthcare	Patients' ability to access adequate mental health services.	<p>"I think that, on the whole, they would probably find it a difficult system to access.</p> <p>Um...um...first of all...um...the clinics, and generally the casualty, or generally where ever they access the healthcare system they have to wait and it is overcrowded..."</p>
CISB – Burnout	Burnout relating to overworked healthcare professionals.	<p>"...I think...I think...burnout is an issue. And also seeing your patients die, who are doing well, or have put so much effort into,</p>

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB – Clinic – Administration	Administration relating to the organization or management of patient files and medication, and the taking of medication.	<p>and then they don't do well...and I think that is also hard.”</p> <p>“...cause what happen in the hospital is there's a problem with the files. Files have been duplicated and stuff so the original notes is not in there to say that the patient is known with us and that the patient is positive and is on this treatment.”</p>
CISB – Clinic - Overcrowding	Volumes and numbers of patients seeking treatment at clinic.	<p>“Basically...um...the beds are always full. We have a 100% bed occupancy. So you have to wait for a discharge before you can admit a patient. So they all go to casualty, and if they are sick enough to stay there they get onto a trolley. If the trolleys</p>

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB – Clinic - Privacy	Issues related to privacy due to a lack of resources.	are full they get onto a mattress on the floor. If the mattresses are full, they sometimes end up with a blanket on the floor.”
CISB – Clinic - Privacy	Issues related to privacy due to a lack of resources.	“...with privacy sometimes in that corner where they do the pill counts and the adherence check, because there is some patients that are chronic when they come for the pill count, before they...they or if...if...if they have problems and they need to see the doctor then the sister would have to find out, is there a problem that needs to be seen by the doctor
CISB – Clinic - Waiting	Amount of time elapsed before treatment is provided to patient.	“That it is a very long visit to the doctor (laugh) in one day. I mean, some people wake up at four to come to the clinic, and

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB - Difficulty accessing healthcare system	Difficulties patients' experience in attaining access to healthcare system.	they only leave at four in the evening.”
CISB - Disability grant – Misconceptions	Patients fail to understand the purpose of the grant.	“...he disability grant issue is a huge issue...um...because patients initially aren't often aware of the fact that it is a temporary grant.”
CISB – Disability grant – Patient factor	Factors affecting a criterion specified attainment and use disability grant by patients.	And I have met a couple of patients they have ones, because it is a short term thing for most until they get reassessed at what ever level intervals, if they are better and they don't have any other conditions going on, they won't requalify.”



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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB - Disability grant – Poverty	Poverty-related issues associated with attainment of a disability grant.	“...but a problem lots of the patients have is that they have been sick, been out of the labour market or they may have never been employed. Um...they might look after kids who are HIV positive, and now their grant get stopped, or can't reapply again. And they...the patients find it very frustrating, because there obviously isn't an income support for them...”
CISB – Disclosure	Difficulties patients have in revealing status to others.	“...non-disclosure at the home or the workplace is an issue, because they hide their tablets, they may not have them in their face right there, and that may lead to them forgetting to take their doses

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB - Employment	The effect of being HIV positive, and the implications of adhering to treatment on patients' employment.	“Um...I think it's...um...it interferes with their ability to work that is quite an important thing. They don't want to tell their employers they are HIV positive...um...so, equally their employers get sick of them, especially in the beginning where they come in once a week, once in every two weeks.”
CISB - Employment – Routine	Lack of routine due to employment, resulting in missed dosages.	“People who work shifts, it can be a problem...it could be a big problem...because they need to take to take their medication at eight o'clock, they don't want to make an issue of leaving work, or taking some tablets, and getting questioned about it. They

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB - Experiences with healthcare professionals	Interactions experienced between patients and healthcare professionals.	<p>might not remember to take their tablets with them...um...they have left them at home.</p> <p>They...that kind of...um...their lifestyle doesn't fit in with being home for both those doses that could be a problem."</p>
CISB - Healthcare facility - Lack of counsellors	Lack of counsellors for debriefing healthcare workers involved with treating HIV patients	<p>"We don't have a social...we have a social worker attached to the hospital and not of the ARV team, she doesn't play a big role</p>

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB - Healthcare facility - limited resources	Lack of resources that limit adequate treatment of patients within the healthcare facility.	except for maybe difficult grants or something. We don't have a psychologist, access to psychologist...
CISB - Health literacy – Staff	Staffs' insufficient knowledge related to the treatment of HIV/AIDS patients.	“And we as the sisters, you've seen that little corner in which we were the other day, and we have to see two patients at a time. Two sisters and a nurse in that corner works in doing the weights and the temperatures and stuff.”
CISB - Lack of routine	The change in patient's daily routine that disrupts the patients'	“...weekends, unexpected visitors or unexpected things

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
	ability to take medication on time.	happening, they lose their routine, and then they...then they forget to take their pill..."
CISB – Language	Difficulties experienced by clinicians or patients' in communicating or understanding one another.	<p>“But you don’t get the nuances or the complicated stories, especially the psycho-social issues that get lost completely...”</p> <p>“...a lot of thing are lost in translation.”</p>
CISB - Lay counsellors - ineffective training	Informal training prohibits proper counselling of patients.	<p>“We have the councillors, who are more lay counsellors, and they often do not have the skills to deal with...(inaudible speech) they don’t really have the skills to deal with...um...many of the psycho-social issues...”</p>
CISB – Living arrangements	Discomfort patients experience related to living conditions.	<p>“It might also have a lot to do with the fact that everyone is just so...living so close together, that</p>

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB – Migration	Failure to seek out medical care in areas outside their local clinic.	<p>they are almost just like in each others' space kind of thing.”</p> <p>“Or some patients have moved from another province to another province. And they are informed that they need to be transformed out. But then they just get that break where they stop, or they are moving over. They just don't seek help at...at the next stop. Or maybe they didn't know. It all just stops, for no apparent reason.”</p>
CISB - Migration - Transfer letters	Failure to attain transfer letter when areas outside their local clinic.	<p>“...without having their treatment is another issue for patients non adherent raak mense want hulle trek weg trek van een gebied na 'n ander gebied toe, verstaan,then hulle kom nie om te kom vra vir a</p>

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB - Open access to treatment	The open selection criteria of patients of patients receiving	<p>transfer letter nie. Hulle gaan.”net, cause they don’t know they could do that come andask for a transfer letter. Hulle gaan net na daai area toe, dan gaan meld hulle by die kliniek en dan bel die kliniek daarvan af om te se sister hier het so an so meneer opgedaag, hy se hy is a pasient by hulle klinieken hy se hy’s op die an die behandeling hy’t die potjies gebring daar van die hospital, en a good thing- that he did cause the files number stays the same, so then we fax the stuff to them at the clinic there</p> <p>“Because we had initially had...had funding from ARC,</p>

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB - Patient advocates - Lack	Difficulties patient advocates experience in getting hold of	<p>which is a NGO, and you were only allowed to treat parents and we very very limited. And, all those patients did very well, because we were very highly selective. Now there is more open...pretty open access, and...uhm...obviously we are less selective, and we have more of an issue with adherence, people falling off the program, people having, as...as they are on ARVs for longer, the side-effects are starting to manifest, and...um...one gets more of a realistic picture of what it is like to treat patients with ARVs really.”</p> <p>“We find it frequently that they go there a few times and the</p>



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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
of access to patients	patients.	patients aren't at home and they miss quite a few...quite a few visits"
CISB – Poverty – Finances	Patient's financial situation due to poverty.	"Some patients just don't have money."
CISB – Poverty – Food insecurity	Poverty-related factors resulting in limited availability of food, in order to medication.	"And there was another lady as well who came in and said that she didn't have food for three days either. And it was very difficult for her to take...to take her medication."
CISB - Poverty - Reminder tools	The lack of tools to aid patient in remembering to take medication, due to poverty.	"The there are people who don't have clocks don't have alarms no nothing. Maybe they have a radio at a certain time of the day that news count up, and ok that's the time that I must take my tablets.

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB - Poverty – Transport	Difficulties patients experiences in getting to the clinic due to the lack of financial resources.	But what if the battery is flat?  What if there’s no power? How do they go about remembering the time?”
CISB - Staff protocol	Ineffective ways of managing the treatment of patients.	“... lots of the ARV clinics that are not in the patients’ community, so there are transport issues, and that is a great barrier to care.”  “ It is still very...HIV care, and especially antiretroviral, is still very separate. They are...um...they are seen separate and different and lots of the medical staff don’t want to get involved, and therefore don’t, you know...people get their averted, and that is there, and you have to go there, and I don’t want to get involved...”

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB – Religion	Beliefs and practices' effect on the patients' adherence to treatment.	<p>“The church does have an influence, cause I had this patient...um...who came to me”</p> <p>doctor saw him, doctor told him that there it was and she asked me in to do a finger prick so that he can see both the test that was he said to me, sister I come today to have a test, an HIV test, and I asked him why? You are mos positive..why do you want.. said cause I’m not positive, I was prayed for and I believe I am no more positive. So I said to him ok, we gonna do the test again and give him a date to come back for the results, and when he came back I said to him, umm doctor...I made a little</p>

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB – Stigma	Bias or discrimination experienced or perceived by patients due to their HIV status.	<p data-bbox="963 501 1394 1048">note for doctor not note actually I told her that I just like to not that the patient believed that he’s HIV positive free and required a test to be done and so when done and the test that was done now afterwards is the same. So then he, but he was so so depressed.”</p> <p data-bbox="963 1144 1394 1323">“But I think stigma, to me stigma is the biggest...the biggest issue.”</p> <p data-bbox="963 1397 1394 1724">“...the stigma patients, people, patients experience in the clinics. They do not want to be identified as being HIV positive.”</p>

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
CISB - Substance abuse	The misuse of certain substances that interferes with the patient's ability to adequately adhere to treatment regimen.	"... You know the patient cant stop drinking that it probably will affect their adherence."
CISB - Substance abuse - lack of treatment programme	Lack of proper treatment programmes for patients who abuse certain substances.	"...it very frustrating...um... because there aren't particularly good programs, even if the patients want want to stop, there aren't particular programmes."
CISB - Support – Social	Perceived or actual support attained through social networks.	"...as long as they have a good patient treatment supporter, someone of the family who really cares for them, they seem to really manage to take their pills."
CISB - Tradition	Traditional practices and beliefs effect on patients' adherence to treatment.	"Well the culture is, especially when a girl is pregnant and she found out that she's positive, ,

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
		<p>and her CD4 is below 200 and she has start using the AZT and the Niverapine and then go on full HAART after some time then they need to (sneeze, sneeze) disclose their problem. And that is a problem for them really cause when they are among their fathers and parent and have this child is now born then they, how do they present themselves bottle feeding the child...cause it's not in their culture. Their culture relies that every mother breast feed their children. How do you explain to your mum, that I can't breast feed ...well enough stuffed breast with milk in it and you can't breast feed your child. How do you</p>

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*Codebook for Clinicians (continued)*


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Code	Definition	Example of quotation
		explain it? How do you go around that? I've had this problem with patients all the time..."
CISB – Transport – Distance	Difficulties patients experience in getting to the clinic due to the distance they need to travel.	“For some it could be the distance.”
CISB - Transport – Riots	Instability and reliability of the public transport system on the patient's ability to get to the clinic.	“...die taxi's riot en hulle kan nie vervoer om hie uit te kom nie, soos nou onlangs almal se verskoning was, en die volgende dag toe's die hele lot hier , en...sommige...”

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**APPENDIX D**  
**CODEBOOK PATIENTS**

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*Codebook for Patients*

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Code	Definition	Example of quotation
PIF	Individual factors affecting patients	
PIF - Emotional wellbeing	The contribution of patients' emotional wellbeing to their ability to adhere to their medication.	“ Daar is baie tye agterna wat ek ook besef dit is, ek moet my medikasie drink. As mens so musmoedig voel, jy voel jy is so lus vir niks nie, jy wil niemand rondom jou hê nie, dan voel jy net op daai stadium, ek is nie lus om my medikasie te drink nie...”
PIF– Medication	Patients' experience with medication	“Vanaf ek die eerste keer op die medikasie gegaan het, dit het my net baie laat slaai. Ek het net baie lomerig gevoel, maar toe ek nou nader aan verder begin drink toe begin dit nou met my begin werk.”



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*Codebook for Patients (Continued)*


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Code	Definition	Example of quotation
PSB	Structural barriers identified by patients	
PSB - Access to mental health services	Difficulties patients' experience in accessing services related to mental health.	“...Ja, hulle stuur vir jou Denova toe, daai is ‘n plek waar hulle vir jou uit droog om vir jou te help...die dokter wou nou vir my gestuur het, toe sê ek ek wil nie gaan nie...”
PSB - Clinic – Overcrowding	Volumes and numbers of patients seeking treatment at clinic.	“Ja, dit is, dit is 'n bietjie van 'n probleem ja, dit is um, ek meen dit is 'n, daar is te veel mense daarso, dit is 'n, hulle moet natuurlik ook almal kans gee, daar is partykere wat jy drie, vier ure sit en dan vat hulle net jou gewig, ek meen dis, dis, dis um..”
PSB - Clinic – Waiting	Amount of time elapsed before treatment is provided to patient.	“...daar is te veel mense daarso, dit is 'n, hulle moet natuurlik ook almal kans gee, daar is partykere wat jy drie, vier ure sit en dan vat hulle net jou gewig...”

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*Codebook for Patients (Continued)*


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Code	Definition	Example of quotation
PSB – Clinic – Waiting – Food	Lack of food when attending clinic	“...as jy nie geld in jou sak het nie of kos saam neem nie, dan raak jy maar honger daar en dit is nie lekker om so heeldag te sit nie...”
PSB – Disability grant - Difficulties	Problems patients may experience when applying for disability grant	“...toe sê hulle vir my dat my papiere daar weg geraak het, by die hospitaal, nou moet ek weer aansoek doen...”
PSB - Disability grant - Patient factor	Factors affecting a criterion specified attainment and use of disability grant by patients	“...daai mense wat kry die grant, hulle drink nie hulle medikasie nie, hulle drink, hulle koop wyn daarvan...”
PSB - Disability grant – Poverty	Poverty-related issues associated with attainment of a disability grant.	“Dis nie altyd wat die disability alles dek nie. Ons kan nie met daai R900 alles cover nie, want dis klomp dinge wat ons moet doen met daai R960.”
PSB – Employment – Capability	The effect of physical wellbeing on employment capabilities	“...omdat ek in so 'n toestand is, daai warmte, ek kan nie, ek kan nie in daai warmte gaan werk nie. Ek

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*Codebook for Patients (Continued)*


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Code	Definition	Example of quotation
		wou graag gegaan het, en ook maar my bydra gedoen het vir die huis, dat ons dam 'n onkomste kry, maar ek kan nie in daai warmte gaan pars nie.”
PSB - Experiences with healthcare professionals	The nature of interactions experienced between patients and healthcare professionals	“Ek sal sê, baie susters wat nors is, hulle attitude is nie lekker nie...”
PSB – Mobility (Migration)	Factors relating to the movement of patients from one place to another, due to socio-economic circumstances.	“...ek het ‘n begrafnis en volgende week, dat hulle dit vir my uitstel tot volgende week...hulle het ingestem...”
PSB - Poverty - Food insecurity	Poverty-related factors resulting in limited availability of food.	“Vir my is dit nie eintlik, dit is eintlik 'n probleem, partykeer is daar nie eintlik kos nie. Dis eintlik 'n struggling. Ja, en hierdie geld wat ek nou kry is maar basies net vir die huur en die elektrisiteit, dan is daar

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*Codebook for Patients (Continued)*


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Code	Definition	Example of quotation
		miskien nou honderd rand oor vir kos...”
PSB – Poverty – Housing	The effect of poverty on housing conditions	“...dit verg biekie baie stabiele huisvesting...”
PSB – Stigma – Disclosure	The effect of stigma on the patients’ ability to disclose	“Ek weet nie, miskien sal hulle miskien nou wil vra, hoe en waar en wat, ek is nog nie seker nie, ek voel ek is nog nie reg om vir hulle te sê nie.”
PSB - Substance abuse	The misuse of certain substances that interferes with the patients’ ability to adequately adhere to treatment regimen.	“Ek het ook gedrink, ek het ook gedrink en vergeet van my behandeling, ek het nie geworry nie.”
PSB - Poverty – Transport	Difficulties patients experiences in getting to the clinic due to the lack of financial resources.	“Om by die hospitaal uit te kom nie, want ons ry per taxi. Soos ek reeds voorheen gesê het, met die dissability moet ek baie dinge dek en dan is daar nie partykeers geld vir die taxi nie.”

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*Codebook for Patients (Continued)*


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Code	Definition	Example of quotation
PSB - Support – Financial	Necessary financial support from social networks in order to obtain access to treatment	“Wat ek daar in kan sit, my ma het saam met my gepraat, sy is instaat om my nou te help, want ek was gister by die hospitaal, ek het met die taxi gery. Sy het vir my geld gegee, ‘n dertig rand, en ek het daar uit gekom, en hulle is instaat om vir my te ondersteun...”
PSB - Support – Social	Perceived or actual support attained through social networks.	“Mense wat groter as ek is, ouer as ek, wat ek al vertel het, wat ek in my vertrouwe kan neem, wat nie vir my sal skel teen die pad nie, of wat sal sê, het jy gehoor Patricia het HIV, of het julle gesien sy hou vir haar kwaai, sy het daai siekte. O, nee, nee glad nie, dit is mense wat saam met my die pad stap, wat vir my ondersteun. As ek so mismoedig voel, dan kan ek na hulle toe gaan en dan kan hulle weer vir my opbeur, weer mooi met my praat,

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*Codebook for Patients (Continued)*


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Code	Definition	Example of quotation
		goeie woordjie en so aan. Wat my hand vat en wat lief is vir my, nie mense wat vir my seer maak en afkraak nie...”
PSB – Stigma	Bias or discrimination experienced or perceived by patients due to their HIV status.	“...as jy HIV positief is, jy is 'n minder, jy is nie 'n volle persoon nie, jy is 'n minderwaardige persoon.”
PSB - Transport – Distance	Difficulties patients experience in getting to the clinic safely due to the distance needed to travelled.	“...en ek moet in die oggende, dan stap ek van die huis af, ek stap four o' clock van die huis af, dan kom ek mooi, half sewe dan kom ek hier bo by die dokter...”
PSB – Transport – Taxi’s – Routes	The effect of routes taxi’s travel on the patients’ ability to access care	“...ek dink nie die taxi ry daai, daai roete nie...”
PSB – Work – Leave	The effect of employment conditions or	“gewoontlik dan moet...toe ek nog gewerk het, dan is ek altyd as ek vir

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*Codebook for Patients (Continued)*

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Code	Definition	Example of quotation
	responsibilities on a patients' ability to access care.	die afspraak gaan vir die kliniek of so, het ek altyd gevra of ek die dag kan af kry en dan gaan ek nou die dag soon toe.”

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**APPENDIX E**  
**CODEBOOK PATIENT ADVOCATES**

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*Codebook for Patients Advocates*

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Code	Definition	Example of quotation
PAISF	Individual factors as identified by patient advocates	
PAISF – Dislike of medication	Patient advocate’s identification of patients’ dislike of the medication	“Yeah and also something that now comes to my mind, it’s simply not nice to take medication.”
PAISF - Medication characteristics	Difficulties experienced in the actual taking of medication.	“I mean some of those tablets are so big.
PAISB	Structural barriers as identified by patient advocates	
PAISB – Lack of access to mental health services, due to limited resources	Difficulties patients' experience in accessing services related to mental	“Maybe they do, because most of them are people who use alcohol and drugs. It’s a



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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
	health due to limited resources.	very big problem, I mean, every Monday with our meeting, that would be the main problem... (speech in background) ...yes, substance abuse, yes but, then we don't have the resources where you can actually send the people, but you can't even send them, because if they don't have to go, how will you get them there. So, it's a problem that it seems that there's no solution..."
PAISB - Access of patient advocates to patients – Safety	Threatening circumstances experienced by patient advocates when accessing patients in certain areas	“Dit is jou grootste vrees as jy in die veld werk. En waar jy ingaan, daar by ons is daar baie plakkers kampe, en dis gevaarlik, maar ons moet daar deur gaan, want op die einde van die dag is ons

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
PAISB – Clinic – Hospital - Administration	Difficulties with clinic and hospital administration when it comes to admitting of patients.	kliente die belangrikste, so ons moet daar deurgaan, elke dag.”  “ARV pasiënte word nie dadelik gehaal van die ambulance om vir hulle op, of ‘n mens kan nie vir hulle dadelik opneem. Hulle moet eerste na die dag hospitaal toe gaan om die folder te sien, om die folder te kry om op te gaan hospitaal toe...”
PAISB - Clinic – Overcrowding	Volumes and numbers of patients seeking treatment at clinic.	“... but at the moment their space... their very cramped.”
PAISB - Clinic – Privacy	Issues related to privacy due to a lack of resources.	“There is not enough rooms to see the counsellor in private. So that’s also very uncomfortable for most of them...”

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
PAISB – Clinic - Waiting	Amount of time elapsed before treatment is provided to patient.	“...but sometimes they sit in the queue, and they will have to wait until four for an appointment.”
PAISB - Clinic structure – Discomfort	Patients' experiences of clinic due to unaccommodating clinical structure.	“I think they do not feel unwelcome, but at the moment their space... their very cramped. So it's a very uncomfortable experience. There is not enough rooms to see the counsellor in private. So that's also very uncomfortable for most of them...”
PAISB – Denial	The non-acceptance of the patients' HIV status contributes to patients' non-adherence to antiretroviral therapy.	“Party mense is in denial. Die pille is daar, hulle sien pille daar, maar hulle is nog al die tyd in denial. Hulle weet die dokter het nou gesê hulle is positive, die pille,

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
PAISB – Disability grant – Difficulties administration	Difficulties patients experience in attaining a disability grant, and its effect on adherence to medication.	<p>moet nog gedrink word maar iets in hulle brein sê vir hulle hulle is nog nie positive nie, that’s why, gaan ek nie die pille gebruik nie.”</p> <p>“...baie van die mense het aansoek gedoen vir ‘n disability grant...um...dit vat ‘n tyd want jy kry nou ‘n datum dan gee hulle vir jou drie dan moet jy weer na die dokter toe gaan en die dokter het nie reg ingevul nie dan moet daai mense weer vir so ‘n maand of so wag vir ‘n appointment met ‘n dokter...um... toe het ons besluit, toe het ek vir hulle gesê ‘n mens kan klein begin want kyk daai mense gaan nou vir hulle medikasie nou,</p>

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
		<p>hulle is nou committed hulle gaan nou hulle medikasie drink, maar jy kan iemand ook nie nou, jy gee solank die pille, drink die pille en jy weet daar is niks wat daai persoon kan eet nie.”</p>
PAISB - Disability grant - patient factor	Factors affecting a criterion specified attainment and use of disability grant by patients	<p>“I don’t know if I’m right or wrong is HIV positive people they make the HIV the government responsibility, because they want to get their grant, because if you are HIV positive you get mos the grant for the six months so when you are better you don’t want to take the medication because of that, because of the grant.”</p>

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
PAISB - Experiences with healthcare professionals – Negative	Negative interactions experienced between patients and healthcare professionals.	<p>“Hostility from the staff. They would er...let me also say maybe unkindness and impatience from the nursing staff...”</p> <p>“Nurses, nurses yes, and they’re very impatient when they do not do as they are told. So I think that for them is a very uncomfortable place to be.”</p>
PAISB - Health literacy	Factors related to the patients knowledge, understanding and information pertaining to HIV/AIDS and antiretroviral therapy.	<p>“...somyds, um, gebeur dit dat hulle verstaan nie lekker waarom HIV gaan nie, en ek is nogal bly dat ons daar is om vir hulle die regte riglyne te gee oor HIV, en somtyds het mense baie verkeerde aspekte oor HIV, ne. Want as die mense praat oor HIV dan</p>

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
PAISF – Implementation of treatment support programmes	Patients’ experience as identified by patient advocates in the implementation of treatment support programmes	<p>sal ek daar staan om te luister  waar kom hulle aan hulle  kennis wat hulle het...”</p> <p>“Treatment Action Campaign, the people that you worked with, has this, almost, militant way of getting their people to disclose, and that for us we’ve experienced it with one of our counsellors who has (?),disclose publicly, but then they accepted it, personally, and that was quite some...”</p>
PAISB - Non-disclosure	Difficulties patients have in revealing status to others.	<p>“So dit het ‘n hele, die feit dat hulle nie hulle status bekend maak nie, they don’t disclose, dit het another effect on their body, it puts</p>

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
		<p>more stress on the, more strain, and even that makes them even go quicker to you know to the stage of full blown AIDS and that and also how they take the medication, and the root would I agree with (name) that they don't want to be rejected, because when you work with..."</p>
PAISB – Poverty – Disability grant	The effect of not having a disability grant on patients' ability sustain day to day living.	<p>"...it's not very nice to see that kind of thing because you go to the clinic, some of them are very hungry, they don't get disability grants."</p>
PAISB - Poverty - Food insecurity	Poverty-related factors resulting in limited availability of food.	<p>"I had a client, we have a client, and we go and visit him, his mother always say, but their not working, and all</p>



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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
PAISB – Poverty – Transport	The effect of poverty on patients' ability to adhere to treatment visits.	<p>the children is now HIV positive. So the one they go to the soup kitchen, now only in the mornings they have the soup kitchen, and what do they do maybe if you have to take the tablets at night, where do they get food?"</p> <p>“Die taxi’s is daar maar die taxi’s is... kyk net, van my af tot in die dorp is die taxi klaar vir jou R6, maar jy wat nou ook nie... unemployed is en jy werk nie, jy’t nie geld nie en jy is klaar ‘n moeder en al die, hoe gaan jy daar uitkom, om in die dorp te kom? In baie van ons gevalle is daar ‘n probleem saam met ons, maar jy ka nook nie, maar die mense wil net daar</p>

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
PAISB – Religion	Beliefs and practices' effect on the patients' adherence to treatment.	<p>uitkom vir hulle appointments. Even die hospitaal daar van die village af, die taxi ry nie hospitaal toe nie, die taxi ry nie uit ons community uit hospitaal toe nie, daai mense moet stap van Gardens af regop om by die hospitaal uit te kom...”</p> <p>“...van ‘n godsdienstige oopkunt af, hulle medikasie sal los dat hulle glo die Here het vir hulle gesê, en daai mense het baie sterk invloed op hulle kerkmense, dat jy dit nie hoef te drink nie.”</p>

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
PAISB - Substance abuse	The misuse of certain substances that interferes with the patients' ability to adequately adhere to treatment regimen.	<p>“...die Universal Church, hulle is baie daarop dat as jy geneesing by hulle gekry het maak dit dat jy nie jou medikasie kan neem nie.”</p> <p>“I know about...how many patient, two patients, or three patients is still struggling with drinking, with going to the point where they want to put them on the ARVs, because their struggling with alcohol...”</p>
PAISB - Support – Social	Perceived or actual support attained through social networks.	<p>“We, they had to bring the family, and just the impact knowing the person, because sometimes they come with the person to the ARV site not knowing that the person is HIV positive, not knowing</p>

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
PAISB – Stigma	Bias or discrimination experienced or perceived by patients due to their HIV status.	<p>what it’s all about. So only that they may find out that the person is about to you know prepare to go on ARVs, and with a family that also has this fear of what is the community going to say, what are the other family members gonna say about it.”</p> <p>“...stigma, because some people know that we’re working in this field.”</p> <p>“So if your very near with those people, or seen with them, then it simply means that they’re also positive. So that might be the reason...”</p>
PAISB – Stigma – Disclosure	The effect of stigma on patients’ ability to disclose to others.	“...baie van hulle is afraid to disclose to their families, um... because now, in some

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
PAISB – Tradition and culture	Traditional practices and beliefs effect on patients' adherence to treatment.	<p>of the communities now you are HIV and they don't want to be involve with you, dis amper hulle is doodskaam vir die mense, in jou eie familie wil hulle nie disclose nie..."</p> <p>"For instance, you know it, the people are very different race, some of them they do live internationally (...um...) because most of them they know if you tell the doctor that you're use it , the doctor is not going to give you antiretrovirals and they sommer said no I'm not taking any traditional medication and that will come out four months down the line after you started the ARVs because you're going</p>

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
		<p>to start ARVs and then  you're not going to stop  taking medication and when  you go back for the baseline  blood it will eventually  show.”</p>
PAISB - Transport – Distance	Difficulties patients experience in getting to the clinic due to the distance needed to travelled.	“Daar was een pasient by my, sy het haar ARVs gekry, en dan het sy nie geld gehad om huistoe te gaan nie.”
PAISB – Transport – Taxi’s routes	Difficulties patients’ experience in getting to the clinic due to taxi routes that do not include the clinic in their travel schedule.	“‘n Uur van die taxi rank tot by die hospitaal, so ‘n uur, dit vat so ‘n halfuur om te loop (...ja dis baie vêr... ). Dis hoekom die volk, die mense as hulle swak is dan... hulle het nie taxi geld nie (Is daar taxi’s wat ry hospitaal toe?) Daar is nie taxi’s wat ry nie, daar het altyd vantevore

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*Codebook for Patients Advocates (continued)*


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Code	Definition	Example of quotation
		<p data-bbox="1013 436 1396 851">‘n bus gestaan wat elf uur ry, twee uur ry, wat ons op hospitaal wat die buste nog daar gewees het maar nou dat daar nie meer buste is nie ry die taxi’s nie soontoe nie.’</p> <p data-bbox="1013 907 1396 1391">“Busse wat hospitaal toe gegaan het dan het die mense noe gegaan, okay, vanoggend sewe uur is daar ‘n buste hospitaal toe, hulle gaat nou hulle pille haal, hul medikasie haal.”</p>

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## APPENDIX F

## ETHICAL APPROVAL: HUMAN RESEARCH COMMITTEE



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY  
jou kennisvennoot • your knowledge partner

19 December 2008

Prof SA Kagee  
Dept of Psychology

Dear Prof Kagee

**RESEARCH PROJECT :** "UNDERSTANDING THE BARRIERS TO ANTIRETROVIRAL THERAPY ADHERENCE AMONG PATIENTS LIVING WITH HIV: A QUALITATIVE INQUIRY"

**PROJECT NUMBER :** N08/12/354

A review panel considered the application for interim approval and registration of the abovementioned project on behalf of the Committee for Human Research.

In principle the panel is in agreement with the project, but requested that you should attend to the following matter(s) before the project could be approved:

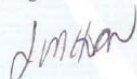
1. With regard to the patient information leaflet and informed consent documents:
  - 1.1 The informed consent process needs to be explained in more detail. Who will be responsible for recruiting patients and obtaining informed consent?

On receipt of the additional information/corrected document(s) the application will be reconsidered. **Please HIGHLIGHT or use the TRACK CHANGES function to indicate ALL the corrections/amendments clearly in order to allow rapid scrutiny and appraisal.**

**Please quote the abovementioned project number in ALL correspondence henceforth.**

For standard CHR forms and documents please visit: [www.sun.ac.za/knowledgepartner/committees\\_CHR.htm](http://www.sun.ac.za/knowledgepartner/committees_CHR.htm)

Kind Regards

  
PP  
Prof PJT de Villiers  
Chairperson: Committee for Human Research  
RESEARCH DEVELOPMENT AND SUPPORT (TYGERBERG)  
Tel: +27 21 938 9207 / E-mail: mertrude@sun.ac.za

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Fakulteit Gesondheidswetenskappe • Faculty of Health Sciences



Verbind tot Optimale Gesondheid • Committed to Optimal Health  
Afdeling Navorsingsontwikkeling en -steun • Research Development and Support Division  
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E-pos/E-mail: rdsinfo@sun.ac.za



## APPENDIX G

## ETHICAL APPROVAL: WESTERN CAPE DEPARTMENT OF HEALTH

21/01/2009 10:14 0214839895

FINANCE

PAGE 01/01



Verwysing  
Reference  
Isalathiso 19/18/RP03/2009

Navrae  
Enquiries  
Imbuzo Dr I. Govender

Telefoon  
Telephone  
Ifowuni 021 483 8558

Departement van Gesondheid  
Department of Health  
ISebe lezeMpilo

Professor A. Kagee  
Department of Psychology  
Stellenbosch University  
Private Bag X1  
Matieland  
7602

FAX: 021 8083584

Dear Prof Kagee

**ART adherence among patients living with HIV**

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that your research proposal has been approved however the department would like to raise a few points of interest:

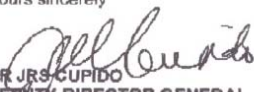
- 1) Your proposal does not make any mention of the interviews with Patient Advocates from the Phillipi trust which is stated in Annexure 2 of the Provincial documents. Kindly provide clarity on this point.
- 2) There are currently many research studies and interventions seeking to identify and overcome barriers to adherence and it would be useful to understand what new knowledge you wish to elicit as this is not clear from your protocol.

Please contact the following member of staff to assist you with access to the facility:

- 1) Dr E. Erasmus at [erasmu@pgwc.gov.za](mailto:erasmu@pgwc.gov.za) Tel: 021 8054704 (SMS: Helderberg Hospital)

We look forward to hearing from you when your research has been completed.

Yours sincerely

  
DR JRS CUPIDO  
DEPUTY-DIRECTOR GENERAL  
DISTRICT HEALTH SERVICES AND PROGRAMMES

DATE: 19/01/2009

CC: MS B. SMUTS  
DR V. ZWEIGENTHAL

D: HIV/AIDS/TB DIRECTORATE

Dorpstraat 4  
Postbus 2060  
KAAPSTAD  
8000

4 Dorp Street  
PO Box 2060  
CAPE TOWN  
8000

## APPENDIX H

### THEMES

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*1. Individual barriers*

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Sub themes

Codes included in the sub-theme

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*(a) Health Literacy*

CIIF-Health literacy; PAIIF-Health literacy.

*(b) Literacy*

CIIF-Literacy.

*(c) Medication*

CIIF-Medication-Characteristics; CIIF-Medication-Side-effects; PAIIF-dislike of medication; PAIIF- medication characteristics; PIF-Medication.

*(d) Mental health*

PIF-Emotional well-being.

*(e) Forgetfulness*

CIIF-Forgetfulness.

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## 2. Poverty-related barriers

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Sub themes	Codes included in the sub-theme
<i>(a) Employment</i>	CISB-Employment; CISB-Employment-Routine; PSB-Employment-Capabilities; PSB-Employment-Leave.
<i>(b) Migration</i>	CISB-Migration; CISB-Migration-Transfer letters.
<i>(c) Disability grants</i>	CISB-Disability grants-Poverty; CISB-Disability grants-Misconceptions; CISB-Disability grants-Patient factor; PAISB-Disability grants Difficulties-Administration; PAISB-Disability grants-Patient factor; PAISB-Poverty-Disability grants; PSB-Disability grants-Poverty; PSB-Disability grants-Difficulties; PSB-Disability grants-Patient factor.
<i>(d) Food_insecurity</i>	CISB-Poverty-Food insecurity; PAISB-Poverty-Food insecurity; PSB-Poverty-Food insecurity.
<i>(e) Living arrangements</i>	CISB-Lack of routine; CISB-Living arrangements; PSB-Poverty-Housing.
<i>(f) Reminder tools</i>	CISB-Reminder tools.

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*Poverty-related barriers (continued)*

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## Sub themes

## Codes included in the sub-theme

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*(g) Transport*

CISB-Poverty-Transport; CISB-Transport distance;  
CISB-Transport-Taxi's-Riots; PAISB-Poverty-Transport;  
PAISB-Transport-Distance; PAISB-Transport-Taxi's-  
Routes; PSB-Poverty-Transport; PSB-Transport-  
Distance; PSB-Transport-Taxi's-Routes.

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### 3. Institution-related barriers

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Sub themes	Codes included in the sub-theme
<i>(a) Access to healthcare system</i>	CISB-Access to healthcare system.
<i>(b) Open access to treatment</i>	CISB-Open access to treatment.
<i>(c) Administration and staff protocol</i>	CISB-Clinic-Administration; CISB-Staff protocol.
<i>(d) Language patients are attended to</i>	CISB-Language.
<i>(e) Overcrowding</i>	CISB-Clinic-Overcrowding; PAISB-Clinic-Overcrowding; PSB-Clinic-Overcrowding.
<i>(f) Waiting</i>	CISB-Clinic-Waiting; PAISB-Clinic-Waiting; PSB-Clinic-Waiting.
<i>(g) Lack of privacy</i>	CISB-Clinic-Privacy.
<i>(h) Patient's experiences with staff</i>	CISB-Experiences with healthcare workers; PAISB-Experiences with healthcare workers; PSB-Experiences with healthcare providers.

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*Institution-related barriers (Continued)*

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Sub themes	Codes included in the sub-theme
<i>(i) Experiences of staff in treating patients with ART</i>	CE.
<i>(j) Burnout</i>	CISB-Burnout.
<i>(k) Lack of resources</i>	CISB-Healthcare facility-Limited resources.
<i>(l) Staff's health literacy</i>	CISB-Health literacy-Staff

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#### 4. Social- and community-related barriers

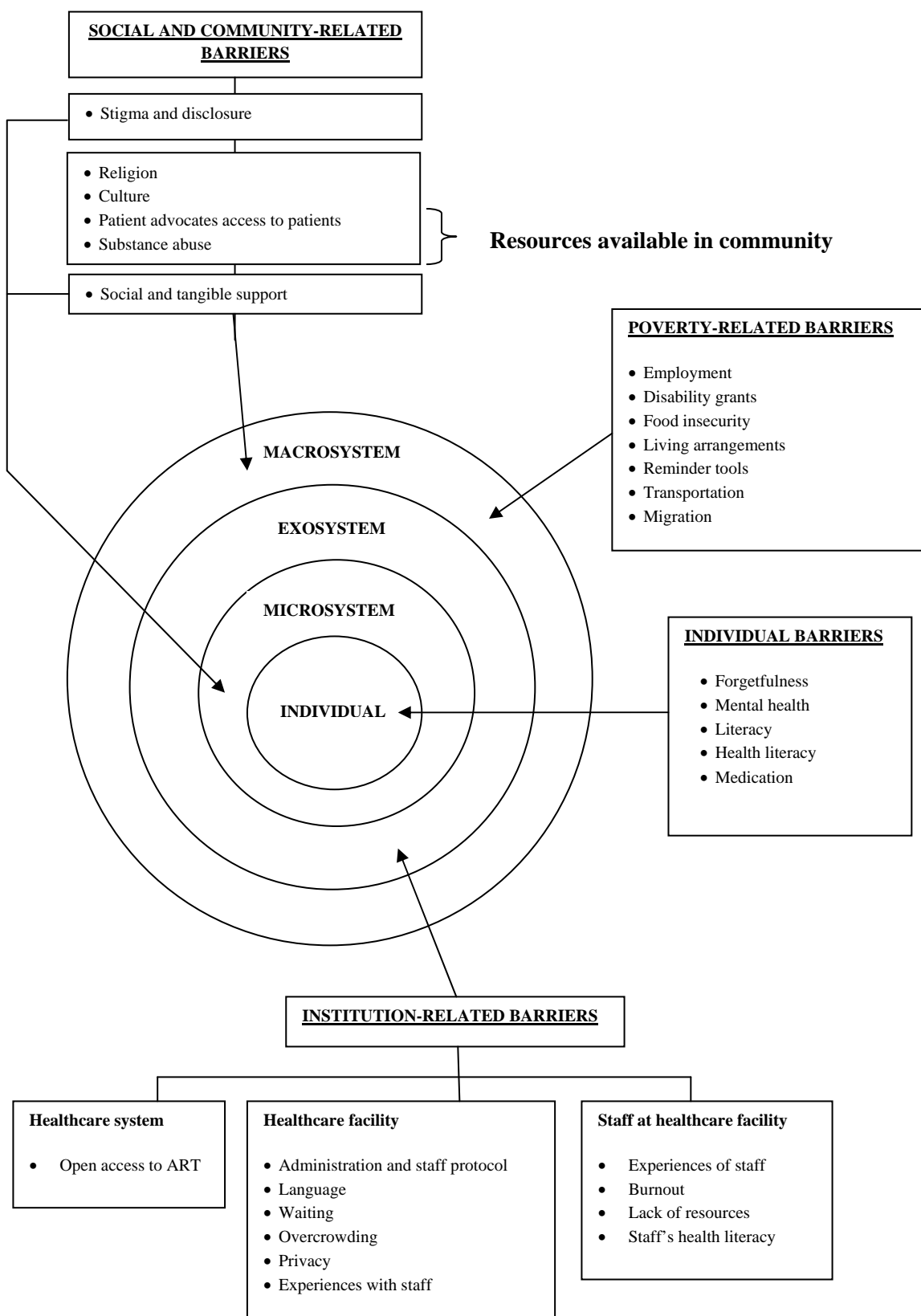
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Sub themes	Codes included in the sub-theme
<i>(a) Stigma</i>	CISB-Stigma; PAISB-Stigma; PSB-Stigma.
<i>(b) Disclosure</i>	CISB-Disclosure; CISB-Stigma disclosure; PAISB-Stigma-Disclosure; PSB-Stigma-Disclosure.
<i>(c) PAs access to patients</i>	CISB-Patient advocates-Lack of access to patients; PAISB-Access of patient advocates to patients-Safety.
<i>(d) Religion</i>	CISB-Religion; PAISB-Religion.
<i>(e) Tradition and culture</i>	CISB-Tradition and culture.
<i>(f) Substance abuse</i>	CISB-Substance abuse; CISB-Substance abuse-Lack of treatment programmes; PAISB-Substance abuse; PSB-Substance abuse.
<i>(g) Support</i>	CISB-Support-Social; PAISB-Support-Social; PSB-Support-Financial; PSB-Support-Social.
<i>(h) Treatment support programmes</i>	PAISB-Implementation of treatment support programmes.

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APPENDIX I

MODIFIED ECOLOGICAL SYSTEMS THEORY





**APPENDIX J**  
**WHO CLINICAL STAGING**

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*WHO Clinical Staging*

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Clinical Stage	Symptoms
Clinical Stage 1	<ul style="list-style-type: none"> <li>• Asymptomatic</li> <li>• Persistent generalized lymphadenopathy</li> <li>• Unexplained persistent hepatosplenomegaly</li> <li>• Papular pruritic eruptions</li> <li>• Extensive wart virus infection</li> <li>• Extensive molluscum contagiosum</li> <li>• Fungal nail infections</li> <li>• Recurrent oral ulcerations</li> <li>• Unexplained persistent parotid enlargement</li> <li>• Lineal gingival erythema</li> <li>• Herpes zoster</li> </ul>
Clinical Stage 2	<ul style="list-style-type: none"> <li>• Recurrent or chronic upper respiratory tract infections (otitis media, otorrhoea, sinusitis or tonsillitis)</li> <li>• Unexplained moderate malnutrition not adequately responding to standard therapy</li> <li>• Unexplained persistent diarrhoea (14 days or more)</li> <li>• Unexplained persistent fever (above 37.5°C intermittent or constant for longer than one month)</li> </ul>
Clinical Stage 3	<ul style="list-style-type: none"> <li>• Persistent oral candidiasis (after first 6–8 weeks of life)</li> <li>• Oral hairy leukoplakia</li> </ul>

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*WHO Clinical Staging (continued)*


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Clinical Stage	Symptoms
	<ul style="list-style-type: none"> <li>• Acute necrotizing ulcerative gingivitis or periodontitis</li> <li>• Lymph node tuberculosis</li> <li>• Pulmonary tuberculosis</li> <li>• Severe recurrent bacterial pneumonia</li> <li>• Symptomatic lymphoid interstitial pneumonitis</li> <li>• Chronic HIV-associated lung disease including bronchiectasis</li> <li>• Unexplained anaemia (&lt; 8 g/dL), neutropaenia (&lt; 0.5 × 10<sup>9</sup> per litre)</li> <li>• And/or chronic thrombocytopenia (&lt; 50 × 10<sup>9</sup> per litre)</li> <li>• Unexplained severe wasting, stunting or severe malnutrition not responding to standard therapy</li> <li>• Pneumocystis pneumonia</li> <li>• Recurrent severe bacterial infections (such as empyema, pyomyositis, bone or joint infection or meningitis but excluding pneumonia)</li> <li>• Chronic herpes simplex infection (orolabial or cutaneous of more than one month's duration or visceral at any site)</li> <li>• Extrapulmonary tuberculosis</li> <li>• Kaposi sarcoma</li> <li>• Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs)</li> </ul>
Clinical Stage 4	<ul style="list-style-type: none"> <li>• Central nervous system toxoplasmosis (after one month of life)</li> <li>• HIV encephalopathy</li> </ul>

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*WHO Clinical Staging (continued)*


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**Clinical Stage**
**Symptoms**


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- Cytomegalovirus infection: retinitis or cytomegalovirus infection affecting another organ, with onset at age older than one month
  - Extrapulmonary cryptococcosis (including meningitis)
  - Disseminated endemic mycosis (extrapulmonary histoplasmosis, coccidiomycosis)
  - Chronic cryptosporidiosis
  - Chronic isosporiasis 42
  - Disseminated non-tuberculous mycobacterial infection
  - Cerebral or B-cell non-Hodgkin lymphoma
  - Progressive multifocal leukoencephalopathy
  - Symptomatic HIV-associated nephropathy or HIV-associated cardiomyopathy
  - HIV-associated rectovaginal fistula
- 

Note: *Department of Health (2010)*