# The development of a scale to assess structural barriers to adherence to antiretroviral therapy

by
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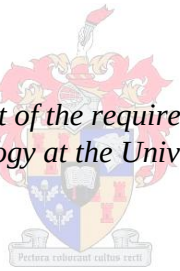

*Thesis presented in fulfilment of the requirements for the degree Master of Science in Psychology at the University of Stellenbosch*

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December 2011

## DECLARATION

I, the undersigned, hereby declare that the work contained in this thesis is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

…… ……

Signature Date

## ABSTRACT

As the only effective treatment for HIV/AIDS, adherence to antiretroviral therapy (ART) is critical for successful treatment outcomes. Despite its open availability since the national rollout in 2004, adherence to ART has remained sub-optimal and the number of individuals shifted to the more expensive second-line therapy on steady increase. The literature reports more commonly on individual, psychological, and behavioural barriers to treatment. However, there has been a vast interest in the structural barriers that prohibit adherence to ART. In previous research, my colleagues and I identified the following structural barriers to treatment adherence: stigma-related barriers, the disincentives associated with disability grants, poor relationships with clinic staff, lack of privacy at clinics for counselling and treatment, transport difficulties in travelling to the clinic, long patient waiting times, food insecurity, substance abuse and the absence of substance abuse programmes, and migration. The data were arrived at by means of triangulated qualitative interviews obtained from patients, patient advocates, doctors, and nurses. Together, these qualitative data formed phase 1 of this study. The next step or phase 2, in this research was to develop a valid and reliable quantitative instrument based on these qualitative data.

Therefore the primary aim of the study presented in this thesis was to identify the underlying factor structure of four scales aimed at measuring adherence at two levels namely, adherence to clinic attendance, and adherence to pill-taking. After sampling a group of almost 300 persons living with HIV (PLWH) four valid and reliable scales assessing structural barriers to adherence to ART were derived at with Cronbach alpha coefficients ranging from 0.87 to 0.91. For each scale, a general or higher order factor was determined by means of hierarchical

transformation suggesting that the items on each of the scales were dominated by a single underlying factor.

The findings of this research suggest that it is possible to assess the structural barriers to adherence that PLWH face on a daily basis. With a proper means, such as these scales, to assess structural barriers to adherence to ART clinicians may be able to identify patients who are likely to default and provide adequate attention to the most distressing barriers.

*Keywords*: Antiretroviral therapy, structural barriers, adherence, HIV/AIDS

## OPSOMMING

Antiretrovirale terapie (ART) is die enigste effektiewe behandeling teen MIV/Vigs.Behandeling met hierdie terapie kan slegs suksesvol voltooi word indien die medikasie ononderbroke en gereeld geneem word. Alhoewel medikasie vrylik beskikbaar was sedertdien die nasionale bekendstelling in2004, het die aantal individue watna duurder tweede lyn terapie oorgegaan het toegeneem. Die volhoubaarheid van ART was dus nie optimaal nie. Dit kan toegeskryf word aan individuele -, sielkundige - en gedragstruikelblokke tydens behandeling wat tans baie aandag geniet in die literatuur.Om by te voeg, strukturele hindernisse tot ARTgeniet ook tans baie aandag. Met hierdie as agtergrond, was die primêre doel van die studie om die onderliggende faktor struktuur van vier skale wat strukturele hindernisse tot ART op twee vlakke meet, naamlik getroue kliniek bywoning en neem van medikasie,te indentifiseer.

Ons het met vorige navorsing die volgende strukturele hindernissetot ART geidentifiseer: stigma-verwante hindernisse, hindernisse wat verband hou met ongeskiktheidstoelaes, swak verhoudings met kliniek personeel, die gebrek aan privaatheid by klinieke in terme van berading en behandeling, vervoerprobleme, lang wagtyevir pasiënte, voedselonsekerheid, dwelmmisbruik en die afwesigheid van middelmisbruik-programme, asook migrasie. Data aangaande bogenoemde strukturele hindernisse is ingesamel deur middel van kwalitatiewe onderhoude met pasiënte, pasiënt-advokate, dokters en verpleegsters (fase 1). Gedurende fase 2 van hierdie studie is„n geldige en betroubare kwantitatiewe instrument op grond van hierdie kwalitatiewe data ontwikkel.

„n Steekproef van ongeveer 300 MIV-geinfekteerde individuehet deelgeneem. Vier geldige en betroubare skale is ontwikkel ten opsigte van die assessering van strukturele hindernisse in terme van gereelde gebruik van antiretrivale middels, met Cronbach alpha

koëffisiënte tussen 0.87 en 0.91.Vir elke skaal is 'n algemene of hoër-orde faktor bepaal deur middel van hiërargiese transformasie wat daarop dui dat die items op elk van die skale gekenmerk is deur ‚n enkele onderliggende faktor.

Ons bevindinge dui daarop dat dit moontlik is om die strukturele hindernisse wat MIV individue daagliks tot ART ondervind te meet. Met die gebruik van hierdie skale sal klinicidus in staat wees om pasiënte te identifiseer wat moontlik van ART sal afwyk of die terapie sal staak met die klem op mees onstellende hindernisse.

*Sleutel woorde*: Antiretroviraleterapie, strukturele hindernisse, volhoubaarheid, MIV / Vigs

## ACKNOWLEDGEMENTS

With this thesis I would like to acknowledge the following people:

Firstly, to my supervisor Professor Ashraf Kagee, thank you for your continued support and guidance, for understanding and providing me with much needed motivation to continue reading and writing even when life seemed to want to counteract this at every stage. I am very grateful to have had you as my supervisor.

Secondly, I would like to acknowledge Professor Deon de Bruin whose statistical expertise guided my analysis. Thank you.

Thirdly, I would like to acknowledge the staff from the Philippi Trust whom without I would not have been able to complete this thesis successfully. To Erika and Rozete, thank you for the time and effort that went into recruitment and the completion of the questionnaires. To Rozete, thank you for assisting me by allowing the patient advocates to help with recruitment as well. To all the patient advocates that went out of their way to help me recruit participants for the study, I thank you whole-heartedly.

Fourthly, to my family, mom, dad, Danie, oupa and Louis, thank you for your support through every day of this process. To my friends, Chantal and Andrea, all I can say is- where would I be without the two of you?

Lastly, to Marienna Le Roux and Cecile Joubert from the Psychology department, thank you for your support and guidance.

Bronwynè Jo'sean Coetzee

July 2011

## DEDICATION

I dedicate my thesis to my mother. Mom, I love you and I thank you for each and every opportunity that you have provided me with. I hope one day that I can repay you.

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# CHAPTER 1

# INTRODUCTION

## 1.1 Introduction and rationale for the present study

The success of antiretroviral therapy (ART) in treating HIV-AIDS has rendered the disease as no longer life-threatening but a chronic and manageable condition (Nischal, Khopkar, & Saple, 2005). However, adherence to ART remains an obstacle to treatment success (Mills et al., 2006). Adherence to ART is obstructed by numerous psychological, individual, and structural barriers. The aim of this study was to use previously determined structural barriers to adherence to ART, and develop an appropriate tool with which to assess such barriers.

### 1.1.1 HIV/AIDS: Global figures.

At present, the HIV/AIDS epidemic has spread to almost 60 million people worldwide, with an estimated 25 million having died from HIV-related causes (Joint United Nations Programme on HIV/AIDS [UNAIDS], 2010 ). An estimated 33.4 million people were living with HIV in 2008, of which 430 000 were children born with HIV. The number of individuals newly affected by HIV continues to dominate the actual numbers on treatment. According to UNAIDS (2010) five people are infected with HIV for every two that have just started treatment. By the end of 2008, more than 4 million people living in low and middle income countries had access to HIV treatment. However, global coverage continues to remain low with only 42% of the global total having had access to treatment in 2008(UNAIDS, 2010).

### 1.1.2 HIV/AIDS: Sub-Saharan Africa.

Sub-Saharan Africa remains the region most affected, accounting for 67% of the global population living with HIV (UNAIDS, 2010). Approximately 1.9 million new HIV infections occurred in this region during 2008, bringing the total up to 22.4 million persons living with HIV

(PLWH) in Sub-Saharan Africa. Despite stabilization of the epidemic over most of Sub-Saharan Africa, Southern Africa still bears a disproportionate share of the global total infected and living with HIV. In almost all of the nine countries in Southern Africa, the adult HIV prevalence is greater than 10% (UNAIDS, 2010).

#### 1.1.3 HIV/AIDS: South Africa.

In 2009 an estimated 5.7 million people were living with HIV in South Africa, making it the largest population of PLWH worldwide (UNAIDS, 2010). Despite a decline in the rate of new infections (Adult HIV prevalence decreased from 5.8% in 2001 to 5.2 % in 2008), the number of PLWH increased in 2008(UNAIDS, 2010).

### 1.2 Stages of Infection

Persons living with HIV usually endure a number of stages of infection. The World Health Organization (WHO) describes four stages of infection (World Health Organization [WHO], 2010). Individuals in WHO stages one and two are fairly asymptomatic. Persons in WHO stage three experience weight-loss, diarrhoea, and relatively severe oral infections. Persons in WHO stage four suffer from full-blown AIDS. Individuals in stage four are estimated to die within a year or two if they are not receiving antiretroviral therapy (ART) (Dorrington, Johnson, Bradshaw,& Daniel, 2006).

### 1.3 Antiretroviral therapy (ART)

HIV/AIDS is eventually fatal without treatment (Dorrington et al., 2006). In 2008, 44% of the population in need of antiretroviral treatment had access to it. Despite the vast improvement since the 2% coverage only five years prior, the national rollout has yet to reach all in need. ART has substantially improved health outcomes, as HIV/AIDS is now far from a terminal illness and rather a manageable chronic illness (Nischal et al., 2005). According to the

WHO (2010) patients adhering fully to ART are less likely to transmit the disease to sexual partners. However, patients with unrecognized HIV illness and infection contribute greatly to the on-going sexual transmission. Approximately 495 000 individuals are expected to die due to AIDS related death by the end of 2010 in South Africa, without ART (Dorrington, Bradshaw, Johnson, & Budlender, 2004). ART thereby has the potential to control and decrease AIDS related morbidity and mortality (Centre for Disease Control and Prevention [CDC], 2001). However, advances in treatment rely on adequate adherence as well as sufficient access to treatment.

The overarching goals of antiretroviral therapy are aimed at reducing patient morbidity and mortality (Garcia & Cote, 2003). With proper use of the medication patients should experience fewer HIV related illnesses. Patients' CD4 counts should gradually rise and remain above 200 copies/ml, which is the baseline count. The viral load in the patient's blood should become nigh undetectable (< 400 copies/ml) and continue to remain undetectable whilst on ARV therapy.

**1.4 Barriers to adherence**

A considerable amount of research has been focused on individual-level barriers to adherence to ART. In particular focus has been given to depression (Seldjeski, Delahanty, & Bogart, 2005), health literacy, forgetfulness (Mills et al., 2006), substance abuse (Kalichman, Rompa et al., 2001; Weiser et al., 2003; Gordillo, Del Amo, & Soriano, 1999), low self-efficacy (Berg, Michelson & Safren, 2007), fear of disclosure (Ware, Wyatt & Tugenberg, 2006) and emotional distress (Kalichman, Ramachandran & Catz, 1999).

Despite a steadily emerging literature, structural barriers to adherence have received much less attention. Shriver, Everett and Morin (2000) have described structural factors as broad

based forms of social construction which include legal, political and environmental factors acting as barriers or facilitators to peoples actions. Various authors have categorized these barriers differently. Kagee, Remien, Berkman, Hoffman, Campos and Swartz (2010) divide structural barriers into three main groups namely, (1) institution-related factors, (2) poverty-related factors and (3) culturally and politically-related factors. Mills et al. (2006) group these barriers into (1) patient related factors, (2) beliefs about medication, and (4) daily schedules.

Structural barriers to a large extent impede patient adherence, as these barriers cause obstructions to patients' daily routines. Studies that prompted this research, conducted by Coetzee, Kagee and Vermeulen (2011), Kagee and Delport (2010), and Nothling (2009) identified structural barriers to adherence from the perspectives of three key stakeholders. Health care workers (doctors and nurses), patients, and patient advocates were asked to provide their insights into the possible barriers patients may face when it came to (a) attending clinic appointments and (b) the actual taking of their medication. The studies were qualitative in nature and the results showed that patients face an array of debilitating structural barriers that include: waiting times at the hospital which interferes with working hours, overcrowding at the clinic, language barriers with clinicians, lack of counsellors especially skilled counsellors, stigma, non-disclosure, interference with daily routines, transport difficulties, migration, disability grants that served as disincentives, psychosocial issues that include substance abuse and a lack of support programs for this, food insecurity and a lack of privacy. These studies collectively formed Phase 1 of this research and the basis on which the scales (Phase 2) were developed.

Phase 2 of this research has attempted to quantify these issues by means of scale development. Ideally, the scales will provide clinicians with a tool to allow for early identification of barriers that may impede adherence in new enrollers of ART. Early detection

will provide an opportunity to limit the number of patients that drop out of care or progress to second or third line treatment.

### 1.5 Motivation for the present study

An emerging literature including the data collected from Phase 1 of this study, suggests that structural barriers greatly impede adherence. However, no attempt has been made thus far to measure these barriers in a clinical setting. With the overwhelming numbers of patients seeking treatment at public health hospitals, it has become vital to ensure that those who are already on treatment remain on treatment. The knowledge gained on structural barriers that impede adherence served as a guide to develop an instrument to determine what barriers patients face that result in poor adherence rates. With a proper means to assess the salience of these barriers, clinicians will be able to identify those barriers which create the greatest obstacle to care.

### 1.6 Aims and objectives

The aim of the present study was to identify the underlying factor structures of a series of scales assessing structural barriers to ART as identified in Phase 1 of the research. Phase 1 of the study has already been conducted and involved in depth qualitative interviews with key stakeholders. Several barriers were identified. Phase 2 was therefore aimed at quantifying these findings by developing a valid and reliable psychometric instrument that can be used by clinicians to measure the most salient of these barriers, and identify those patients who face multiple structural barriers to adherence.

### 1.7 Overview of chapters

Chapter 2 provides an overview of the current literature regarding antiretroviral therapy, adherence, and measuring adherence to ART. Furthermore, the review identifies both individual and structural barriers to adherence. Finally, the conceptual framework within which the study is

thought to exist is explained. Chapter 3 describes the methodology that was followed in the present study, including the research design, the selection of participants, data collection, and the data analysis procedure. Chapter 4 discusses the results found in the present study. Chapter 5 involves a discussion of the results, including the implications of the present study's findings and directions for future practice and research.

# CHAPTER 2

# LITERATURE REVIEW

## 2.1 Antiretroviral Therapy (ART)

Since the introduction of antiretroviral's (ARVs) in the 1990's, treatment and care for PLWH has completely revolutionized (Hardon et al., 2006). The latest indicators of patients on treatment in South Africa shows that 919, 923 people were receiving ART by the end of November 2009 (UNGASS, 2010). This number excludes the additional 51, 633 people receiving treatment from private clinics and NGO's. This number is substantially larger than the 140, 000 persons that were estimated to be on treatment only three years prior (Dorrington et al., 2006). The majority of these patients remain on first-line therapy. However, the numbers failing at first line treatment are of concern. Médecins Sans Frontières (MSF, 2010) found that 14% of the patients supported by the HIV/AIDS programme they helped initiate in Khayelitsha (a township in the Western Cape) in 2005 had to be moved to second-line therapy after only five years on treatment. Second-line therapy is far more expensive than first line and particular concern has been raised to developing resistance to second-line regimens in third world countries, especially since monitoring of patient viral loads is either sub-standard or absent (Fox, Ive, Long, Maskew & Sanne, 2010).

## 2.2 Antiretroviral Regimens

Early enrolment into ART is critical for receiving the most out of treatment and to reduce complications. Mortality rates range between 3% -26% amongst adult PLWH during the first year of ART, with most deaths occurring within the first few months (WHO, 2010).Antiretroviral therapy guidelines have changed somewhat since those recommended by

the WHO in 2006. The 2010 edition of the ART guidelines as described by the WHO recommends that two key changes be made:

1. Commencement of treatment.

In the 2006 guidelines, patients with a CD4 count < 200 cell/mm3 were started on treatment. In the 2010 ART guidelines, all patients (including pregnant women and adolescents) with a CD4 < 350 cells/$mm^3$ are recommended to start treatment immediately. If CD4 count testing is not available, those with a WHO clinical stage of three or four are intended to start treatment as well (WHO, 2010).

2. Calls to reduce the use of Stavudine (d4T).

Fifty-six percent of ART regimens continue to use Stavudine (d4T), especially in resource-limited settings as alternatives such as Zidovudine (AZT) and Tenofovir disoproxil fumarate (TDF) remain more expensive. It is recommended strongly by the WHO that d4T be progressively phased out of HIV regimens (WHO, 2010). Recent studies (e.g. Kline et al., 2008) have shown that prolonged exposure to d4T has severe side effects. Disfiguring, and toxic side effects such as lipodystrophy, peripheral neuropathy, and lactic acidosis have been identified and are painful as well as life threatening to PLWH (WHO, 2010). The following two regimens exist for newly infected (naïve) patients.

### 2.2.1 First-line Therapy – Schedule One.

The following regimen differs for pregnant women who are HIV positive, as well as for those individuals with either a TB (tuberculosis) or HBV (hepatitis B virus) co-infection. Unless contraindicated, all patients commence therapy on:

1. Zidovudine (AZT); 300 mg every 12 hours **or**Tenofovir disoproxil fumarate(TDF) with
2. Lamivudine (3TC); 150 mg every 12 hours **or**Emtricitabine (FTC) and
3. Efavirenz (EFV); 600 mg at night (or 400 mg if < 40 kg) or Nevirapine (NVP); 200 mg daily for 2 weeks, followed by 200 mg every 12 hours.

### 2.2.2 Second-line Therapy –Schedule Two.

Patients who do not follow treatment as prescribed, and consequently continue to fail virologically may ultimately be changed to second line therapy, or schedule two treatment (WHO, 2010). Patients commence schedule two as follows:

If either Stavudine (d4T) or Zidovudine (AZT) have been used in first line therapy then use:

TDF with 3TC (or FTC) with ATV/r or LPV/r.

If TDF had been used in first-line therapy then use:

AZT with 3TC (or FTC) with ATV/r or LPV/r (Lopinavir/ritonavir).

## 2.3 Adherence to ART

Adherence to antiretroviral therapy is currently the greatest predicator of treatment success for people who are able to access the drugs (Mills et al., 2006). However, adherence to ART remains a key challenge to HIV/AIDS care worldwide (Van Dulmen et al., 2007; Weiser et al., 2003).

Schonnesson, Diamond, Ross, Williams, and Bratt (2006) define adherence in terms of dose adherence, schedule adherence and dietary adherence. Dose adherence involves the number and proportion of dosages to be taken. Schedule adherence refers to the taking of dosages at the correct times daily. Lastly, dietary adherence involves taking doses with the correct foods daily. In addition to regimen adherence, the monthly attendance of clinic appointments is referred to as

adherence to care. Non-adherence may therefore involve skipping doses, not taking the treatment at the correct times daily, taking the wrong doses, or prematurely terminating the treatment (Miller, 1997).

High levels of adherence are required for effective viral suppression, to prevent resistance to drugs, to limit disease progression, and to prevent death (Paterson et al., 2000). According to Van Dulem et al. (2007) adherence amongst patients with chronic conditions such as HIV, diabetes, and hypertension is reportedly far lower than adherence amongst patients with acute illness such as flu or appendicitis. The success of the treatment hinges almost entirely on the patients pill-taking behaviour. More than 95% adherence to ART is required for optimal treatment success (Paterson et al., 2000; Bangsberg, 2006). However, studies have shown that patients receiving more potent doses of treatment drugs experience virological suppression at lower rates (70%) of adherence (Bangsberg, 2006). To achieve virological suppression it is required that patients not miss more than three doses a month (Golin et al., 2002). These seem like manageable requirements. However the regimen is complicated (Golin et al., 2002), and often results in dietary complications (Schonnesson et al., 2006) and possible side effects (Weiser et al., 2003; Hardon et al., 2007).

As mentioned previously adherence to care is one of the greatest obstacles facing persons on ART. Authors such as Machtinger and Bangsberg (2007), in their review on adherence to ART, have highlighted the concerns about providing treatment to PLWH in resource-limited settings. Amongst these concerns was that, providing treatment for PLWH in resource-limited settings would lead to widespread resistance. The next section provides evidence of adherence rates in resource-limited settings being comparable to those in resource-rich settings.

### 2.3.1 Adherence in resource-limited settings

Since 2001, the Western Cape Department of Health and Médecins Sans Frontières (MSF) have worked together to provide ART for persons living with HIV in Khayelitsha, a township near Cape Town (Coetzee et al., 2004). The rationale behind this initiative rested largely on providing evidence that persons living with HIV in resource-limited settings were able to achieve similar adherence rates to persons living with HIV in developed countries. The success of this project was mainly as a result of the strict criteria patients had to meet before enrolling (Coetzee et al., 2004). Only patients who resided in the township, had disclosed to another person and who attended clinic appointments regularly were considered for treatment. Furthermore, only patients who met the WHO stage three and stage four classification criteria and who had a CD4 cell count of less than 200 cells/$mm^3$ were eligible on clinical grounds. Patients received social support in the form of counselling sessions with trained counsellors, and peer support groups aimed at identifying any obstacles to care that patients may have been experiencing. Patients also received material support in the form of pill-boxes, drug-identification charts, diaries and educational materials to explain the risks and benefits of ART. The results of the study were comparable to those of developed countries. Patients showed excellent adherence evident with the suppression of viral replication and an almost perfect rate of patient retention to care (Coetzee et al., 2004).

Other studies conducted in resource-limited settings, such as Uganda (Weidle et al., 2006), Rwanda (Demeester et al., 2005), and Haiti (Koenig, Leandre, & Farmer, 2004), showed that high rates of adherence were achievable. Moreover, a study conducted by Orrell, Bangsberg, Badri, and Wood (2003), showed that there was no association between socioeconomic status and adherence to ART.

Much of the data collected in the above mentioned studies were confined to experimental settings where patients had to meet strict criteria. The intensity of the support received under these circumstances will most likely not reach the non-experimental setting, which is the large numbers of patients seeking HIV treatment and care. However, although these studies point to a high level of commitment to medication adherence, there persists an array of barriers (discussed later on) that impede on treatment success (Tuller et al., 2009).

## 2.4 Measuring Adherence to ART

Various studies have tried to measure (non-) adherence (Gill, Hamer, Simon, Thea, & Sabin, 2005; Turner, 2002; Gagne &Godin, 2005; White et al., 2006; Llabre et al., 2006; Johnson et al., 2007). Simoni et al., (2006) suggest that adherence to ART can be measured by either direct or indirect methods.

### 2.4.1 Direct Methods.

***2.4.1.1 Biological markers.*** An assessment of biological markers involves the analysis of active drug metabolites or other indicators in blood, urine or other bodily fluids. These methods confirm whether active drug ingestion and digestion have occurred (Simoni et al., 2006).Biological markers (e.g. blood or urine) are not always indicative of medication non-adherence as the influence of medication on these markers are often not significant over short periods of time and may be influenced by other forms of medication as well (Miller & Hays, 2000).

### 2.4.2 Indirect methods.

***2.4.2.2 Patient self-report.*** Patient self-report is one the most frequently used measures of adherence in the literature (Nieuwkerk & Oort, 2005; Ferradini et al., 2006; Ross-Degnan et al., 2010; Chalker et al., 2010). Self-report questionnaires are virtually trouble-free to administer and

remain a cost effective method of data collection (Ross-Degnan et al., 2010). However, patient self-report tends to overestimate adherence more than any of the other methods used (Golin et al., 2002; Arnsten et al., 2001). According to Gagne and Godin, (2005) self-report inaccuracy occurs as a result of two factors. Firstly, there exists an inadequate operationalization of adherent or non-adherent behaviour. The second factor that contributes to inaccuracy in self-report is not applying rigorous enough measurement techniques so as to reduce factors such as memory errors, social desirability and recall bias (Gagne & Godin, 2005; Turner, 2002). In a study conducted by Chalker et al., (2010), when compared to clinical records patients had overestimated their adherence by more than 14%.

***2.4.2.3 Pill counts.*** Pill counts may be defined as the percentage of days that patients receiving ARV's took their medication as prescribed based on pill counts conducted at each clinic visit (Chalker et al., 2010). Like self-reports pill counts also tend to overestimate adherence, as it has been reported that patients often dispose of their medication (Gagne & Godin, 2005), or forget to bring their pill bottles to clinic visits (Turner, 2002). Patients also often combine various medications into a single dosage container, and will subsequently forget to bring the correct tablets to the clinic appointments (Gagne & Godin, 2005).

***2.4.2.4 Electronic drug monitoring.*** Electronic devices that monitor pill counts like, Medication Events Monitoring System (MEMS) is a more objective measure of adherence than patient self-report (Turner, 2002). The system works by means of an electronic chip that is inserted into the cap of pill bottles and records the number of doses taken every time the bottle is opened (Turner, 2002). However, even such high-tech measures inaccurately measure patient adherence as the chip may malfunction (Turner, 2002), and patients may remove more pills from the bottle than they are supposed to which is termed, "pill-dumping" (Gagne & Godin, 2005).In a

study conducted by Honghu et al., (2001) multiple measures of adherence were assessed and MEMS was reported to underestimate adherence. However, when compared to self-report measures and pill counts electronic drug monitoring is a much more reliable measure of adherence (Chalker et al., 2010). The latest innovation in electronic drug monitoring is the Wisepill device (www.Wisepill.com). This device is no larger than a wallet and transmits signals to the clinician via cellular networks each time a patient opens the device to take a pill. The signals are transmitted in real-time meaning that the clinician is able to see exactly when a patient is opening the device to take their medication. Each time the device is opened the action is recorded and tracked in an online chart (www.massgeneralmag.org). The device has been pilot tested amongst 10 Ugandan individuals for a period of six months in a study by Haberer et al., (2010). Due to battery failure and signal interruptions some of the results of the study were compromised. However, on average the results obtained from the Wisepill device were comparable to those achieved through the MEMS system (Haberer et al., 2010).

***2.4.2.5 Pharmacy refill records.*** Pharmacy refill records have been cited as another measure of adherence (Osterberg &Blaschke, 2005; Bisson et al., 2008; Ross-Degnan et al., 2010; Chalker et al., 2010). This method of measuring adherence is useful with electronic pharmacy records as manual dispensing records are often incomplete (Ross-Degnan et al., 2010). In a study conducted by Bisson et al. (2008) pharmacy refill records were as accurate as CD4 counts for detecting virological failure in patients and were thus deemed capable of predicting future virological failure.

In the absence of a gold-standard various methods of assessment are used to measure adherence throughout studies most of which have been found to overestimate adherence (Gagne

& Godin, 2005). It may therefore be essential that future research focus on adequately defining adherence.

***2.4.2.6 Clinic attendance.*** Although not a measure of pill-taking adherence the consistency of attending clinic appointments has also been used as a measure of adherence (Ross-Degnan et al., 2010; Chalker et al., 2010). In a study conducted by Ross-Degnan et al. (2010), over 19% of the patients they followed during the course of the study had missed multiple clinic visits, despite self-report clinic adherence rates of over 70%. Clinic attendance was significantly associated with a patients weight gain, however not significantly associated with an increased CD4 count. In the study conducted by Chalker et al., (2010) a number of health facilities formed part of their study to assess different measures of adherence. Although adherence to clinic attendance ranged between 70% - 90% at most of the facilities, some facilities had clinic adherence rates as low as 14%. Ross-Degnan and colleagues (2010) argue that missed clinic appointments are fairly easy to ascertain from clinic records and that this method of measuring adherence may pick up on inconsistencies in clinic attendance fairly quickly and identify those patients that may need adherence counselling.

## 2.5 Barriers to adherence to ART

Barriers to ART can be grouped as either individual barriers (Mills et al., 2006) to adherence, or as structural barriers to adherence (Kagee et al., 2010; Coetzee et al., 2011; Kagee & Delport, 2010). The differences between these two groups are explained below.

**2.5.1 Individual barriers.** More commonly reported in the literature than structural barriers to adherence, are individual barriers to adherence to ART. These barriers are predominantly psychological and behavioural in nature, and have for the most part been identified through patient self-report (e.g. Mills et al., 2006). The WHO (2003) groups these

barriers into three factors namely, regimen characteristics, patient characteristics, and the relationship between the provider and patient. The following barriers have been identified as individual determinants of adherence; Perceived social support (Holstad, Pace, De, & Ura, 2006); substance abuse (Palepu et al., 2004; Sanjobo, Frich & Fretheim, 2008; Dahab et al., 2008; Kip, Ehlers & Van der Wal, 2009; Tucker et al., 2004); disturbance in mental health, largely depression (Kilbourne et al., 2005); forgetfulness (Chesney et al., 2003), sleeping through dosages, adverse side effects (Davies et al., 2006), the relationship with the healthcare provider (Kalichman et al., 1999); beliefs about medication (Remien, Hirky, Johnson, Weinhardt, Whittier & Minh Le, 2003) and stigma (Brown et al., 2003).

Mills et al. (2006) conducted a meta-analysis of barriers and facilitators to adherence, as reported by patients, and categorized them into (1) patient related factors, (2) beliefs about medication, (3) Interpersonal and (4) Daily schedules. The analysis draws on 37 qualitative and 47 quantitative studies regarding barriers and facilitators to adherence. The barriers were grouped into those identified in developing countries and those identified in developed countries and are summarized in the Table 1 below.

Table 1

*Individual barriers to adherence identified in developed and developing countries*

| Category | Identified in developed countries | Identified in developing countries |
|---|---|---|
| Patient-related factors | Fear of disclosure and taking medication in public | Substance addiction |
| | Depressed, hopeless, or overwhelmed feelings | Forgetfulness |
| | A concurrent addiction | Financial constraints |
| | Forgetting to take pills on time | Fear of disclosure |
| | Suspicious of treatment or medical establishment | Treatment instructions are complicated |
| | A natural approach is preferred | Concurrent disease or illness, including malnutrition |

| | | |
|---|---|---|
| | Treatment is a reminder of HIV status<br>Wanting to take control again<br>Treatment instructions are complicated<br>Doubts about HIV status<br>Lack of self-worth<br>Financial constraints<br>Homeless<br>Having a concurrent illnesses | Treatment compliance |
| Beliefs about medication | Side effects<br>Complicated regimens<br>Concerns about taste, size, dosing frequency, and/or pill count<br>Doubting the efficacy of HAART<br>A decreased quality of life<br>Uncertain about long-term effects<br>Unwanted changes in body image | Side effects<br>Regimen too complicated<br>Doubts about efficacy of treatment<br>Uncertain about long term effects<br>Concerns about taste, size, and frequency of dosing<br>Feeling fine or healthy<br>Decreased quality of life<br>Uncertain about long-term effects of HIV treatment |
| Schedule adherence | Disruptions in routine or having a chaotic schedule<br>Finding treatment difficult to incorporate with responsibilities<br>difficult to balance dietary requirements needed for treatment<br>Oversleeping and missing dose<br>Away from home and not taking medication with<br>Too distracted or busy<br>No time to refill prescriptions, or other pharmacy-related problems<br>Particular difficulty with middle-of-the-day or morning dose | Interference with work and family responsibility<br>Not receiving enough tablets<br>Away from home too long at a time<br>Too busy to comply with treatment requirements<br>Trouble incorporating work and family responsibilities with HAART<br>Traveling long distances to receive treatment<br>Running out of medications or having an irregular supply<br>Too busy or distracted to properly comply |
| Interpersonal | Lack of trust for healthcare-provider<br>Social isolation<br>Negative publicity regarding treatment or the medical establishment | |

Poor or discouraging social network

**2.5.2 Structural barriers.** Individual barriers to adherence to ART have been well researched and documented within the literature. However, the extent to which social, economic, institutional, political, and cultural aspects of larger social structures (Shriver, Everett & Morin, 2000; Sumartojo, 2000) influence adherence have not been emphasized enough. Among the first South African studies focusing on structural barriers to adherence to ART included a review by authors, Kagee, Remien, Hoffman, Campos, and Swartz (2010); and empirical investigations by authors, Coetzee, Kagee and Vermeulen (2011); Kagee and Delport (2010) and Nothling (2009). Kagee, Remien et al., (2010) categorise structural barriers into: Institution-related barriers, poverty-related and finally, cultural and politically related barriers.

***2.5.2.1 Institution-related barriers.***

*2.5.2.1.1 The healthcare environment.* One of the chief barriers to clinic attendance are health care facilities that are overburdened and characterized by inadequate infrastructure and necessary resources (Smit, 2004), insufficient staff (Benatar, 2004; WHO, 2006), and large patient numbers attending clinics for treatment (MSF, 2007). The role of providing care to PLWH has been reported an overwhelming task and forced many professional nurses to seek work in other countries (Smit, 2004). In Coetzee et al., (2011) and indicated in other studies (e.g. Gueritault-chalvin et al., 2000; Swartz & Dick, 2002; Smit, 2004; Murray et al., 2009) overburdened public health care clinics led to burn-out and work frustration among health care workers. These unsatisfactory conditions put significant strain on the patient-provider relationship (Cole & Abel, 2000; Swartz & Dick, 2002). In Coetzee et al. (2011) nurses reported observing some of their work colleagues behaving unsympathetically or even impatiently

towards patients. Patients reported feeling alienated and were therefore reluctant to attend the clinic.

*2.5.2.1.2 Lack of privacy at clinics.* Despite concerted efforts to combat the restrictions on public health care post-apartheid (Coovadia, Jewkes, Barron, Sanders & McIntyre, 2009), the healthcare system is still failing to provide adequate facilities to offer basic services to persons seeking care. In the context of large scale stigmatization against persons living with HIV, the need for privacy and confidentiality at clinics and hospitals has become of even greater importance. In Coetzee et al. (2011) a nurse reported that the lack of privacy at the clinic meant that patients were unable to communicate the deeper level issues to adherence that they were facing which disrupted the patient-provider relationship (Coetzee et al., 2011; Kagee et al., 2010).

*2.5.2.1.3 Long waiting times at the clinics.* Several studies have reported long waiting times at the clinic to be a disincentive to clinic attendance for most patients (Hardon et al., 2007; Dahab et al., 2008; Roura et al., 2009; Coetzee et al., 2011; Kagee & Delport, 2010). In a study conducted by Hardon and colleagues (2007), the average time spent at the clinic for most patients was six hours. The most important consequence of these long hours was the risk of job dismissal as many of the patients had not yet made their HIV status known to their employers.

***2.5.2.2 Poverty-related structural barriers.***

*2.5.2.2.1 Transport difficulties.* Transport-related barriers to adherence was a salient theme throughout the literature (Weiser et al., 2003; Jaffar et al., 2005; Mills et al., 2006; Mshana et al., 2006; Mukherjee et al., 2006; Miles, Clutterbuck, Seito, Sebego & Riley, 2007; Maskew, MacPhail, Menezes & Rubel, 2007; Hardon et al., 2007; Posse, Meheus, Van Asten, Van der Ven & Baltussen, 2008; Tuller et al., 2009; Coetzee et al., 2011; Kagee & Delport,

2010). Most patients attending public health clinics do not have private transport and rely completely on public transport which is for the most part expensive, unsafe and unavailable in some areas (Kagee, Le Roux & Dick, 2007). In the study by Kagee and Delport (2010), patient advocates indicated that indirect routes to the clinic resulted in patients having to travel several kilometres further to the clinic despite weather conditions or feeling physically ill. Several studies afforded the cost of transport to greatly impede patients' willingness to get to the clinic (Hardon et al., 2007; Weiser et al., 2003; Tuller et al., 2009; Ware, 2009). Taxi riots and unrest presented further obstacles to clinic adherence (Coetzee et al., 2011). According to Kagee et al., (2007) poor access to safe and adequate transport poses a barrier to adherence for many persons receiving ART.

*2.5.2.2.2 Food insecurity.* Weiser and colleagues (2010) were among the first authors to investigate the ways in which food insecurity obstructs adherence. The authors found that food insecurity and hunger presented a direct obstacle to daily adherence. In particular, the fear of hunger and food insecurity caused patients to delay treatment initiation or to discontinue treatment. The study concluded five ways in which food insecurity impedes on adherence. These were, increased hunger associated with the taking of ARVs, the side effects associated with taking food on an empty stomach, the lack of counselling required to emphasize the need to take ARVs with food, the constant negotiation between satisfying healthcare costs or food costs, and either forgetting or being too busy searching for food or work to be able to take ARVs. The above mentioned consequences of food insecurity are in accordance with several other studies (Weiser et al., 2003; Nachega et al., 2006; Hardon et al., 2007; Sanjobo, Frich & Fretheim, 2008; Tomlinson, Rohleder, Swartz, Drimie & Kagee, 2010; Gillepsie & Drimie, 2008; Ivers, Chang, Jerome & Freedberg, 2010).

*2.5.2.2.3 Substance abuse.* Many studies have reported substance abuse as an individual barrier to adherence (e.g. Holstad et al., 2006; Mills et al., 2006 & Tucker et al., 2004). However, in the context of there being limited mental health and substance abuse programs for people living in resource constrained settings, Coetzee et al. (2011) and Kagee et al. (2010) identified the lack of substance abuse programmes in resource-constrained settings as a structural barrier to adherence.

*2.5.2.2.4 Disability grants as disincentives to adherence.* An HIV diagnosis in South Africa is tied with eligibility for a government-funded monthly disability grant (Nattrass, 2006a, b). Disability grants are given to those patients with a CD4 count of less than 200 cell/$mm^3$ and deemed incapable of working (Nattrass, 2006a). However, when disability grants are linked to biological indicators like, low CD4 counts and high viral loads, many patients would terminate their treatment in order to re-qualify for the grant (Nattrass, 2006a). According to De Paoli, Grønningsæter, and Mills (2010), 10% of the participants in their study agreed that it was common place for HIV infected people to stop taking their ARVs to get sick so as to get their disability grants back. Furthermore, 51% of the sample attributed their loss of a disability grants to doctors deciding that they were no longer eligible. In Coetzee et al., (2011) doctors reported that they were sometimes threatened by patients who did not re-qualify for a grant by saying that they would stop taking their medication entirely. Venkataramani, Maughan-Brown, Nattrass, and Ruger (2009) found no statistical association between receipt of a grant and adherence.

***2.5.2.3 Cultural and political barriers.***

*2.5.2.3.1 Health Literacy.* Kalichman and Simbayi (2004) reported that as a result of poor education in resource-constrained settings many patients have a limited knowledge of health literacy. Health care providers in Botswana found that gaps in patients' knowledge about ART

directly impacted upon treatment, as patients were often not sure how to follow the regimen (Weiser et al., 2003). According to Murray et al. (2009), health literacy information is often provided in terms and in contexts that patients do not understand, and this leads to misunderstanding of the way the regimen should be followed. In accordance with Murray et al. (2009), Coetzee et al., (2011) reported that a low level of health literacy meant that several patients failed to fully understand written instructions from clinicians on how to follow the treatment regimen. Other studies have also found inadequate health literacy as a barrier to adherence (Kalichman et al., 1999; Catz et al., 2000).

*2.5.2.3.2 Stigma and disclosure.* A major barrier to retention in care and pill-taking adherence are the difficulties patients experience in disclosing their status to others; especially to those within their immediate social networks (Derlega, Winstead, Greene, Serovich & Elwood, 2002; Coetzee et al., 2011). A lack of disclosure forces patients to hide their medication which results in a change in their dosing schedules, and having to conceal obvious side effects (Brown et al., 2003). Rintamaki, Davis, Skripkauskas, Bennet and Wolf (2006), describe a conceptual model for understanding concerns that PLWH have around stigma. According to these authors, "the anxiety and fear of being stigmatized defines a person's concern for HIV stigma." In their model, they describe various pathways through which stigma concerns (such as perceptions of others' attitudes towards HIV) might impact negatively on health. A person with a high level of stigma concerns would be less likely to disclose their status, out of fear or shame. An added complication then arises when patients are forced to take medication at inopportune times and more often than not, in less-than-private environments. Coetzee et al. (2011) reported that patients often had to seek ART at clinics outside of their communities to prevent being identified as HIV positive. The travel costs associated with seeking treatment further away from home

added to the many barriers patients face in terms of adhering to clinic visits (Weiser et al., 2003; Hardon et al., 2007; Coetzee et al., 2011; Kagee et al., 2010). According to Coetzee et al. (2011) stigma made it difficult for patients to take their medication at home especially as a lack of privacy due to overcrowded living conditions was the norm. In both Coetzee et al. (2011) and Kagee and Delport (2010) participants reported that as a result of stigma, patients reported being very reluctant to inform their employers of their HIV status which made it difficult to attend monthly clinic appointments. High unemployment rates in low income countries meant that several patients were reluctant to forgo a day's wage, even if it meant missing a scheduled clinic visit. According to Shisana et al., (2005) stigma and discrimination are two of the primary barriers to HIV prevention, treatment, and care. Furthermore, and especially within resource-limited communities, an HIV –positive diagnosis may also serve as an instigator of violence. Violence, especially amongst women following an HIV-positive diagnosis, is reportedly a major contributing factor to the lack of disclosure to intimate partners. In their study on violence associated with an HIV positive diagnosis, Gielen et al., (2000) found that 13% of the women recruited in their sample experienced violence after disclosure to an intimate partner, and 32% experienced violence before and after disclosure. In their study, Gilbert and Walker (2010) interviewed 44 PLWH at an HIV/AIDS clinic in Johannesburg. The purpose of the interviews was to explore the extent to which patients on ART perceived and experienced stigma. Respondents indicated that stigma played a significant role throughout their illness as it was experienced from the early stages of getting tested, to disclosure and throughout commitment to ART. The fear of being identified as HIV positive prevents much needed disclosure of the illness (Health Resources and Services Administration [HRSA], 2003) and limits access to treatment (Mahajan et al., 2008).

*2.5.2.3.3 Migration.* In Coetzee et al. (2011) several nurses indicated that Xhosa-speaking patients often had to migrate to the Eastern Cape for family related matters. Furthermore, nurses reported that patients would remain in the Eastern Cape for extended periods of time, and disrupt the continuity of care by not having acquired the necessary transfer letters to seek treatment at hospitals within that region (Coetzee et al., 2011; Kagee & Delport, 2010). Swartz (1998) indicates that migration amongst patients who are seasonal workers often results in loss to follow-ups.

*2.5.2.3.4 Social discouragers.* In Coetzee et al. (2011) a nurse reported that some local charismatic churches were a great disincentive to medication adherence. A nurse reported that patients were encouraged to forgo biomedical treatment and that failure to do so would signal a lack of faith in prayer. Studies (Coetzee et al., 2011; Kagee & Delport, 2010; Walker, Reid, & Cornell, 2004) have also indicated that some patients showed preference for religious or traditional healing beliefs over treatment.

## 2.6 Theoretical Conceptualization of Structural Barriers to Adherence

In theoretical terms, Bronfenbrenner's Ecological Systems Theory (Bronfenbrenner, 1975) may be used to conceptualize how the social context exerts an influence on individual behaviour, in this case adherence to ART. According to Bronfenbrenner (1975), the ecological environment is a "nested arrangement" where each structure is contained within another structure. These so-called structures are named the micro-, meso-, exo- and macrosystems, where the micro-, meso, and exo- systems are contained within the macro-level as can be seen in the figure below.

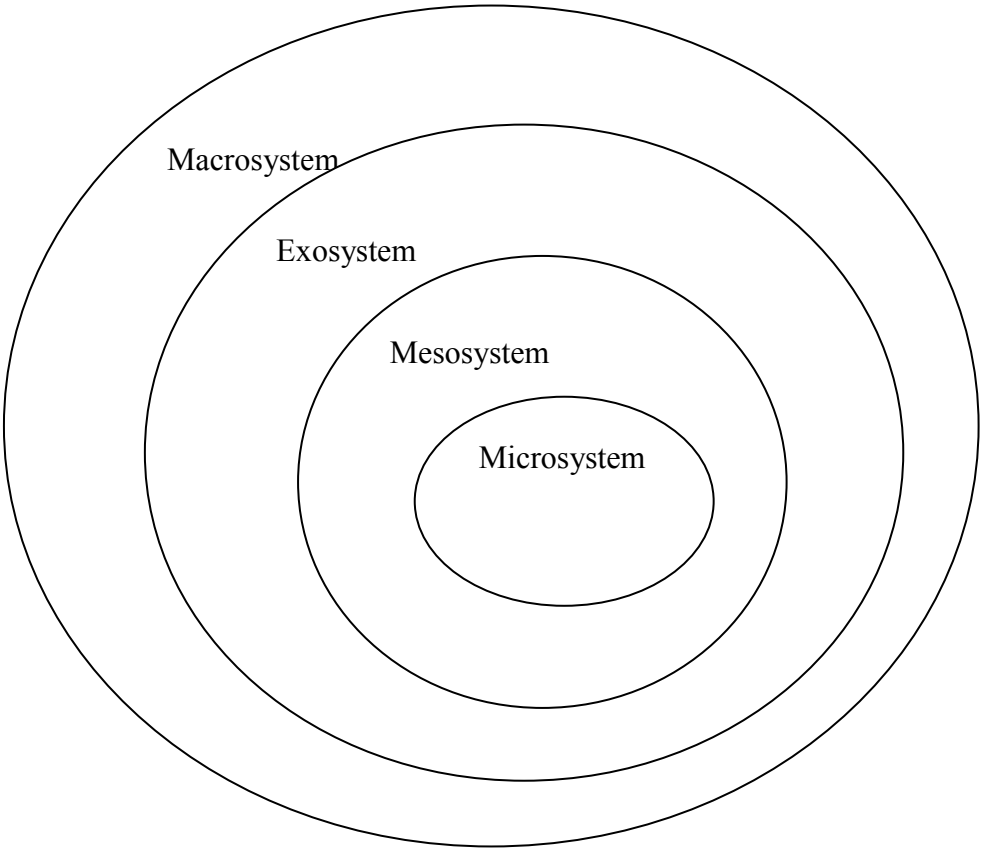


*Figure 1:* The four systems of Bronfenbrenner Ecological Systems Theory

The microsystem involves an individual's interaction with family, friends, neighbours, community members and the church (Bronfenbrenner, 1975). According to Coetzee et al., (2011) at this level, an individual is able to build social networks with others and thereby gain a valuable source of support which promotes a health enabling context. The term social capital has been used by various authors to describe the role that community cohesion may play in promoting health behaviour (Campbell 2001; 2003). The core elements of social capital include a sense of trust, reciprocity and cooperation amongst the members of a particular social network (Putnam et al., 1993). Together these factors are intended to positively influence the health behaviour of a community provided each member share the common goal of improving public health. Stigma-

related barriers and the importance of disclosure in gaining social support fall on this level as well (Coetzee et al., 2011).

The mesosystem involves interactions between the components of the microsystem (e.g. the relationship between the individual's home and workplace) (Bronfenbrenner, 1975). According to Coetzee et al., (2011), the mesosystem may be most closely associated with poverty-related barriers. The exosystem is the third component of the Ecological Model. This system involves the links between two or more settings where one link does not contain the individual concerned, but the events/settings that directly influence the immediate environment of this person (e.g. For a parent it involves the link between the school and neighbourhood). According to Coetzee et al., (2011) the structural barriers patient's face in terms of those posed by the public healthcare system for example, exists on this level.

The macrosystem contains all the other systems to embody an individual's beliefs systems, customs, and bodies of knowledge, lifestyles and opportunity structures that are embedded in each of the previously mentioned systems (Bronfenbrenner, 1994).

Roura and colleagues (2009) applied a social ecological approach to understanding both barriers and facilitators to patients' ART treatment adherence. Their approach holds that individuals adapt their behaviour based on the social environment in which they find themselves and base their decisions on the information, influence, and interactions afforded to them through social networks, institutions and relationships. The social-ecological approach considers both the individual and structural factors that influence an individual's decision making.

### 2.7 Conclusion to Chapter

A review of the literature has indicated that despite widespread access of ART, adherence to treatment remains sub-optimal. A failure to sustain the level of adherence needed for

successful treatment outcomes means patients risk virological failure and drug resistance. Treatment failure would require most patients to initiate second-line therapy which is far more expensive than first-line therapy. Despite a steadily emerging body of knowledge, structural barriers to adherence still require a greater level of understanding and research. The present study therefore aims to add to the literature by understanding and identifying the underlying factor structure of four scales assessing adherence to ART at two levels namely, adherence to clinic attendance and adherence to pill-taking. The next chapter will provide the methodology that was followed to conduct this study.

# CHAPTER 3

# METHOD

## 3.1 Research Design

The study was a research survey with a cross-sectional design. The primary purpose of the study was to construct a set of scales identifying the most salient structural barriers to adherence to ART that PLWH experience. A secondary aim of the study was to identify the underlying factor structure of the four scales and thereby justify the calculation of a total score for each scale.

## 3.2 Research Method

### 3.2.1 Participants.

A convenience sample of 291 PLWH currently receiving ART was recruited for the study. Patient advocates from a non-government organisation (NGO) in Somerset West assisted in recruiting patients from one hospital and one primary health care clinic in the Boland region. The self-report measures were administered in both English and Afrikaans.

### 3.2.2 Scale development.

The items included in the scale were constructed from the results of three previous studies (Coetzee et al., 2011; Kagee & Delport, 2010; Nothling, 2009) aimed at identifying structural barriers to adherence to ART through qualitative analysis. Coetzee et al. (2011) conducted in-depth qualitative interviews with doctors and nurses from a primary health care clinic in the Boland region. The purpose of these interviews was to gain an understanding of health care workers' (HCW's) perspectives of the structural barriers to ART adherence that patients attending their clinic may face. Kagee and Delport (2010) conducted two in-depth focus groups as well as follow up interviews with patient advocates from an NGO in Somerset West.

The focus groups were aimed at understanding what PA's considered as the key barriers patients faced in attending clinic appointments and taking their medication. Nothling, (2009), conducted semi-structured qualitative interviews with 10 patients receiving ART from a primary healthcare hospital in the Western Cape. The interviews were aimed at identifying the barriers that patients enrolled on the national ART programme in South Africa experience.

In all three studies, the interviews and focus group discussions were recorded and transcribed. The transcripts were then analysed with the assistance of Atlas.ti 4.2. Atlas.ti is a computer programme that assists in the analysis of qualitative data by allowing the user to code the data for relevant themes. The themes that emerged from that data formed the basis for the items that were constructed for inclusion in the scales.

#### 3.2.2.1 Item development.

After the qualitative data were collected, conventional guidelines for scale development were used to construct the items. Careful attention was given to include items that were clear, of an adequate length, and were not ambiguous (De Vellis, 1991).

Structural barriers to adherence were conceptualized at two levels namely, barriers to clinic attendance as well as barriers to pill taking. The items were constructed with two sets of stems. The first stem used the patient him or herself as the anchoring agent, e.g. "I do not attend my clinic appointments because…", and "I do not take my ART pills because…" The second stem asked that patients consider the barriers that other patients might face, e.g. "Patients do not attend their clinic appointments because…", and "Patients do not take their ART pills because…" This scale construction procedure produced four separate scales for measuring structural barriers to adherence to ART, namely: Barriers to MY clinic attendance: SBS-1;

Barriers to MY medication taking: SBS-2; Barriers to PATIENTS' clinic attendance: SBS-3 and Barriers to PATIENTS' medication taking: SBS-4.

On each scale patients were asked to endorse the extent to which each structural barrier applied to them on a Likert scale ranging from 1 to 5 (1=Never, 2= Rarely, 3=Some of the time, 4= Most of the time and 5= Always). Reporting on other patients' barriers to adherence ranged from 1 to 4 (1= Not true for any patients, 2= True for some patients, 3= True for most patients and 4 = True for all patients).

#### 3.2.2.2 Item refinement.

Once an initial body of items had been developed to sufficiently cover the scope of the underlying latent variable and the issues of redundancy, clarity and ambiguity had been accounted for, the items were subjected to external scrutiny. An expert in item development (Professor Deon de Bruin) reviewed the relevance and quality of each item. After taking the recommendations into account, the necessary adjustments and or removal of items were made. After making these changes, I conducted a pilot study with 20 participants to assess whether scale items were comprehensible and at an appropriate reading level. Thus, of the original 61 items on the four scales, 49 were retained in the final version of the scales. Three of the scales contain 12 items and one scale contains 13 items, yielding a total of 49 items.

## 3.3 Measuring Instruments

### 3.3.1 Demographic information (Addendum A).

A self-administered questionnaire assessed demographic information such as „gender', „ethnicity', „age', 'marital status', 'current living situation', education level', 'work situation', „annual family income', and „first language'.

### 3.3.2 Structural Barriers Scales

***3.3.2.1 Barriers to MY clinic attendance: SBS-1(Addendum B).*** The SBS-1 allows patients to identify the extent to which each structural barrier to clinic attendance applies to their own circumstances. The scale contains a total of 12 items.

***3.3.2.2. Barriers to MY medication taking: SBS-2(Addendum C).*** The SBS-2 allows patients to identify the extent to which each structural barrier to pill taking applies to their own circumstances, and contains 12 items. Items 041 and 042 were excluded from analyses as it did not make any theoretical sense to include them as they did not explain barriers to pill taking.

***3.3.2.3 Barriers to PATIENTS' clinic attendance: SBS-3(Addendum D).*** The SBS-3 contains 12 items. The scale allows patients to identify the extent to which each structural barrier to clinic attendance applies to other patients living with HIV and receiving ART.

***3.3.2.4 Barriers to PATIENTS' medication taking: SBS-4(Addendum E).*** The SBS-4 contains 13 items. This scale allows patients to identify the extent to which each structural barrier to medication taking applies to other patients living with HIV and receiving ART. Items 071 and 072 were omitted from all analyses for the same reasons as in the SBS-2.

## 3.4 Procedure

Patients living with HIV and receiving ART were recruited by patient advocates from an NGO in the Western Cape. Fifteen patient advocates were approached and recruited to assist in data collection. The patient advocates provide psychosocial support and care to patients receiving ART from both a hospital and primary health care clinic in the Boland area.

As each of the PA's do between 40 and 60 home-based visits to patients attending the hospital and clinic as mentioned above each month, it seemed a plausible way in which to recruit

patients and subsequently avoid the possibility of disrupting clinic visits. The researcher met with the patients advocates on two occasions.

The first meeting was aimed at getting to know each of them, as well as explaining the nature of the study and requesting their assistance in data collection. The second meeting involved an in depth look at the questionnaire package to be administered to patients, as well as the importance of receiving written consent following an explanation of the ethical details concerning the study.

Patient advocates received a set of flyers (Addendum F) from the researcher which were handed to patients inviting them to partake in the study. PA's informed patients of the following during home visits: (1) the nature as well as intentions of the present study, (2) the potential risks and benefits involved, (3) the confidentiality and anonymity associated with their participation, (4) that participation is voluntary and, (5) that they were allowed to stop at any point during the course of the investigation.

All patients who agreed to partake in the study signed an informed consent form (see Addendum G), acknowledging that the aforementioned was indeed explained and understood. Each of the fifteen patient advocates received 20 copies of the questionnaire package to administer to their patients during a routine home-based or clinic visit.

Upon completion of the self-report questionnaire package patients received a R 20.00 grocery voucher as a token of gratitude for participation in the study. Furthermore, as a token of appreciation for their assistance in recruiting patients for the study, PA's received a R 50.00 shopping voucher. Ethical clearance for the following study was received from the Health Research Ethics Committee of the University of Stellenbosch (Addendum H), The Western Cape Department of Health (Addendum I) and The City of Cape Town (Addendum J).

## 3.5 Data Analysis

All the statistical analyses conducted on the data gathered from this research were performed using the Statistical Package for the Social Sciences (SPSS) version 18.0. All analyses were two-tailed and alpha (α) was set at 0.05.

### 3.5.1 Data Screening.

After initial data-capturing, an integrity check was conducted to see if all the data had been entered correctly. Case summaries were calculated to determine if any data had been entered incorrectly (out of range values), to check for missing values and deciding how to deal with these values, to check for outliers and to test for normality.

Due to the random nature of the missing data, the missing variables were left as is and no subsequent analysis was done to replace this data with mean or regression substitution. Listwise deletion of missing cases was selected for the factor analyses. Listwise deletion involves the removal of an entire case, should there be any missing data for a particular participant. A complete descriptive analysis was performed on participants' demographic information. Exploratory factor analysis (EFA) was then performed on each of the SBS scales.

### 3.5.2 Statistical procedure.

***3.5.2.1 Sample size.*** An adequate sample size is essential to conduct a sufficient factor analysis. It has been suggested that as a rule of thumb there should be between 10 to 15 participants for every variable that is included in the instrument (Field, 2005). Therefore a sample of 291 participants was considered sufficient to support the EFA.

***3.5.2.2 Exploratory factor analysis (EFA).*** Factor analysis attempts to provide an explanation for the correlations seen between an observed set of variables with a smaller set of factors. EFA was chosen as it allows for the identification of underlying factor structures without

any constraints as imposed by a confirmatory factor analysis (CFA). EFA is most appropriate in the early stages of scale development, whereas CFA is most appropriate when the factor structure has been established (Fabrigar, Wegener, MacCallum & Strahan, 1999).

*3.5.2.2.1 Descriptives.* To determine whether the data was suitable for factor analysis the Kaiser-Meyer-Olkin (KMO) statistic was computed. The KMO is a ratio of squared correlations to squared partial correlations between variables. The value ranges between 0 and 1. A value close to 1 indicates "compact" patterns of correlations and therefore the analysis should yield reliable factors. As an additional screen for EFA, Bartlett's test of sphericity was computed. Bartlett's test of sphericity was used to ensure that the inter-item correlation matrix was not an identity matrix (Field, 2005 p. 640).

*3.5.2.2.2 Extraction.* The method chosen for extraction was principal components. Only factors that had eigenvalues larger than 1 were extracted and retained (Kaiser 1960, 1974). Additionally a scree plot was requested to provide a visual representation of the number of factors retained based on the Kaiser specification. Only item loadings of 0.40 or greater were retained to reveal the primary factor each item loaded onto (Field, 2005 p. 633).

*3.5.2.2.3 Rotation.* Direct oblimin was chosen as the method of rotation as it is assumed that the factors extracted from the analysis, based on theoretical reasoning, would be correlated with one another (Field, 2005). A factor correlation matrix showed significant correlations between the factors.

***3.5.2.3 Second order factor analysis.*** It was expected from the EFA that a single underlying variable or general factor would be identified that explained the largest proportion of common variance shared amongst the items. Thus the correlations that were obtained between the first order factor s (factors obtained from the principal-components exploratory factor

analysis) were used to determine the higher order or general factor by means of a Schmid-Leiman hierarchical transformation (Schmid-Leiman, 1957). The identification of a general underlying factor justified the calculation of a total score (De Bruin, 2006) for each scale.

***3.5.2.4 Reliability analysis.*** Cronbach's alpha internal reliability coefficient was computed for each SBS scale. Although the value for an acceptable Cronbach's alpha coefficient varies amongst different authors, for this study a value > 0.8 was regarded as acceptable (Field, 2005). The next chapter will present the results obtained from the study.

# CHAPTER 4

# RESULTS

## 4.1 Demographics of the Sample (Table 1)

As can be seen in Table 1, the sample consisted of 291 participants of which 63.9% was female and 35.4% male. The mean age of the sample was 35 (SD= 9.05). A large proportion of the sample was single (69.4%) and 38.5% of the sample reported living with other adults and children. Most of the participants indicated that they were unemployed (59.8%), and as much as 46% of the sample stated they were unsure how much they earned annually before tax. Only 9.3% of the sample had no formal education. However, 44.3% of the sample had attended high school but did not complete Grade 12. The majority of participants (59.1%) reported Xhosa as their first language. Approximately 22% of the sample reported Afrikaans as their first language, and 3.4% of the sample reported English as their first language. Table 1 also shows the number of participants (out of 291) who completed the information for each variable, as indicated by *n**.

Table 2

*Demographics of the sample*

| | | *n** | Frequency | (%) | M | SD |
|---|---|---|---|---|---|---|
| Age | | 279 | | | 35.49 | 9.05 |
| Gender | | 289 | | | 1.64 | |
| | Male | | 103 | 35.4 | | |
| | Female | | 186 | 63.9 | | |
| Marital status | | 274 | | | 1.82 | |
| | single | | 202 | 69.4 | | |
| | widowed | | 15 | 5.2 | | |
| | separated | | 8 | 2.7 | | |
| | divorced | | 3 | 1 | | |
| | married or living with a significant other in a marriage -like relationship | | 46 | 15.8 | | |
| Living situation | | 280 | | | 3.52 | |
| | Live alone | | 62 | 21.3 | | |
| | Live in an institution or retirement home | | 9 | 3.1 | | |
| | Live with other adults (s), no children | | 42 | 14.4 | | |
| | Live with children only | | 55 | 18.9 | | |
| | Live with other adults and children | | 112 | 38.5 | | |
| Highest level of education | | 283 | | | 2.4 | |
| | No formal education | | 27 | 9.3 | | |
| | Completed primary school | | 122 | 41.9 | | |
| | Attended high school but did not complete matric | | 129 | 44.3 | | |
| | Attended university, college or technikon but did not graduate | | 4 | 1.4 | | |
| | Graduated from university, college or technikon. | | 1 | 0.3 | | |

(table continues)

| | | | | | |
|---|---|---|---|---|---|
| Employment | | 269 | | | 2.63 |
| | Employed full time | | 25 | 8.6 | |
| | Employed part time | | 63 | 21.6 | |
| | Unemployed | | 174 | 59.8 | |
| | Homemaker | | 3 | 1 | |
| | Disabled | | 2 | 0.7 | |
| | Student | | 2 | 0.7 | |
| Annual income before tax | | 250 | | | 5.55 |
| | No income | | 1 | 0.3 | |
| | less than R 12, 000 | | 73 | 25.1 | |
| | R 10, 0001-R 40, 000 | | 3 | 1 | |
| | R 80, 001-R 110, 000 | | 12 | 4.1 | |
| | R 240, 001 and above | | 27 | 9.3 | |
| | Do not know | | 134 | 46 | |
| First language | | 261 | | | 2.74 |
| | English | | 10 | 3.4 | |
| | Afrikaans | | 65 | 22.3 | |
| | Xhosa | | 172 | 59.1 | |
| | Other | | 12 | 4.1 | |
| | English and Afrikaans | | 2 | 0.7 | |

* Number of participants that completed this question

### 4.2 Exploratory Factor Analysis (EFA)

Principal components exploratory factor analysis was conducted on all four scales in order to identify the underlying factor structure of each scale. The method of rotation used in the EFA was direct oblimin as the assumption was that the factors were correlated with one another. The determinant, of the inter-correlation matrix, was used as a test for multicollinearity. Thus only items with inter-correlations < 0.80 were included in the EFA. After the EFA had been conducted on all the scales, a second order factor analysis was performed on the factor correlations obtained from the first order analysis. The factor solution was transformed to a hierarchical solution.

### 4.2.1 Barriers to MY clinic attendance: SBS-1.

***4.2.1.1 Multicollinearity (Determinant), Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's Test of Sphericity***. On the first iteration of the EFA, inspection of the correlation matrix (R-matrix) yielded high correlations (r>0.8) between two pairs of items. The high correlations (multicollinearity) between these items suggest that one of them may be redundant and therefore need to be removed. Firstly, a high correlation (r=0.85) existed between items; "I do not attend my clinic appointments because I do not want others to see me receive HIV treatment" and "I do not attend my clinic appointments because I do not want to be identified as HIV positive". Secondly, a high correlation (r=0.80) existed between items; "I do not attend my clinic appointments because there is no place where I can speak to a nurse or counsellor without being heard by other people" and "I do not attend my clinic appointments because the nurses do not speak my language". Consequently the items "I do not attend my clinic appointments because I do not want others to see me receive HIV treatment" and "I do not attend my clinic appointments because the nurses do not speak my language" were removed. The EFA was then performed again. No items in the R-matrix correlated at a level above 0.80 with each other. The determinant was 0.001 which was greater than 0.00001, thus indicating that multicollinearity was no longer a problem (Field, 2005 p. 648).

The Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) value was 0.83. This value was close to 1.00 indicating that factor analysis (FA) was a suitable method of analysis. Hutcheson and Sofroniou (1999) state that KMO values between 0.50 and 0.70 are mediocre, between 0.70 and 0.80 are good, and values between 0.80 and 0.90 are great to indicate suitability for FA. Bartlett's Test of Sphericity was significant ($p$ <0.01) which suggested that the correlation matrix was significantly different from an identity matrix indicating that the items

correlated with one another which made the possibility of finding factors more likely (Field, 2005, p. 642).

***4.2.1.2 Primary factor structure.*** After the principal-components EFA had been conducted a total of three primary factors were extracted accounting for 69.17% of the total variance among the items. The Scree plot (*Figure 2*) and the eigenvalues>1 criterion (Kaiser 1960, 1974) showed that three factors should be retained. The correlations between these factors then formed the input data of the second-order factor analysis.

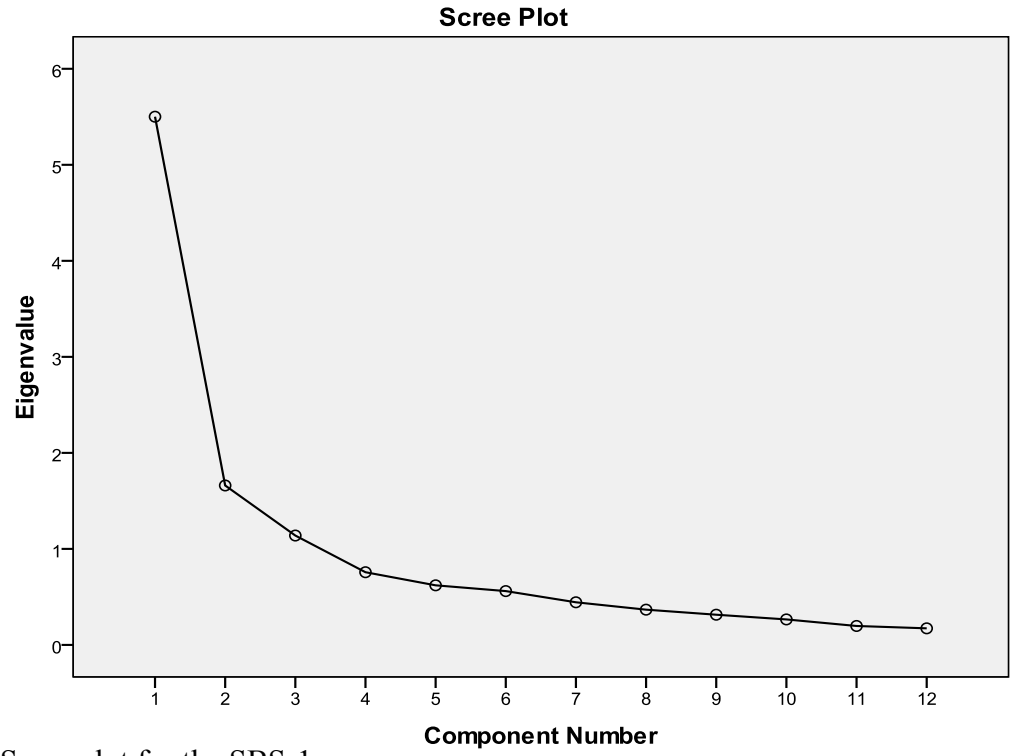


*Figure 2*. Scree plot for the SBS-1.

***4.2.1.3 Hierarchical factor structure.*** A second order factor analysis was performed on all the items included in the scale. Thus, a Schmid-Leiman hierarchical transformation (Schmid-Leiman, 1957) was performed to identify whether the items loaded strongly onto a secondary order factor. As can be seen from Table 3 below the items did indeed load saliently onto a secondary order (general) factor. This factor was named Barriers to Clinic Attendance. Thus,

although three primary factors were identified, the results in Table 3 show that 63.2% of the variance was explained by the secondary order factor. This is proportionally much more than the variance explained by the primary factors. On the basis of these results it can be concluded that the SBS-1 can be treated as a unidimensional scale. Unidimensionality validates the calculation of a total score. A maximum score of 60 and a minimum score of 12 can be obtained on the SBS-1. Thus, an overall score that exceeds 30 on this scale suggests that multiple barriers to clinic attendance were experienced. The mean score for this scale was 30.84, suggesting that most patients who completed the scale experienced structural barriers to clinic attendance as salient.

Table 3

*Factor loadings of Schmid-Leiman Solution for the SBS-1*

| Item | General | Primary1 | Primary2 | Primary3 |
|---|---|---|---|---|
| 12 | **0.67** | -0.04 | **-0.63** | 0.07 |
| 13 | **0.66** | -0.03 | **-0.62** | 0.06 |
| 14 | **0.68** | 0.18 | **-0.51** | -0.16 |
| 16 | **0.60** | **0.44** | 0.01 | -0.08 |
| 17 | **0.74** | 0.38 | 0.03 | 0.20 |
| 18 | **0.73** | 0.22 | -0.03 | 0.38 |
| 19 | **0.63** | -0.01 | -0.02 | **0.67** |
| 20 | **0.62** | 0.27 | -0.03 | 0.17 |
| 21 | **0.72** | **0.40** | -0.03 | 0.06 |
| 22 | **0.71** | 0.34 | -0.18 | -0.02 |
| 23 | **0.65** | **0.46** | 0.03 | -0.04 |
| 25 | **0.65** | 0.03 | -0.03 | **0.62** |
| % Variance explained by extracted factors | 63.2 | 11.5 | 12.7 | 12.7 |

***4.2.1.4 Reliability of the SBS-1.*** The SBS-1 showed highly satisfactory reliability (α = 0.89). Table 4 below shows the item-by-item descriptive analyses for the scale and provides further evidence for the homogeneity of the scale.

Table 4

*Item-by-item Descriptive Analyses for the SBS-1*

| Item | Description | Corrected Item-Total Correlation (*r*)** | α-iid* | M | SD |
|---|---|---|---|---|---|
| 12 | I do not attend my clinic appointments because the clinic is too far from the bus stop/ taxi rank. | 0.55 | 0.88 | 2.6 | 1.52 |
| 13 | I do not attend my clinic appointments because transport to the clinic is too expensive. | 0.56 | 0.88 | 2.34 | 1.48 |
| 14 | I do not attend my clinic appointments because it takes too much time to travel to and from the clinic. | 0.61 | 0.88 | 2.8 | 1.55 |
| 16 | I do not attend my clinic appointments because I do not want to be identified as HIV positive. | 0.58 | 0.88 | 2.99 | 1.48 |
| 17 | I do not attend my clinic appointments because the staff at the clinic is rude to me. | 0.69 | 0.88 | 2.27 | 1.3 |
| 18 | I do not attend my clinic appointments because the staff at the clinic is impatient towards me. | 0.65 | 0.88 | 2.34 | 1.31 |
| 19 | I do not attend my clinic appointments because there is no privacy at the clinic when I meet with the nurse. | 0.49 | 0.89 | 2.59 | 1.49 |
| 20 | I do not attend my clinic appointments because I cannot get time off work to do so. | 0.56 | 0.88 | 2.19 | 1.33 |
| 21 | I do not attend my clinic appointments because I have to wait too long to see the doctor, nurse, or pharmacist. | 0.68 | 0.88 | 2.75 | 1.42 |
| 22 | I do not attend my clinic appointments because I feel unsafe walking to and from the clinic. | 0.66 | 0.88 | 2.59 | 1.48 |

| | | | | | |
|---|---|---|---|---|---|
| 23 | I do not attend my clinic appointments because the clinic is too crowded. | 0.63 | 0.88 | 2.98 | 1.56 |
| 25 | I do not attend clinic appointments because there is no place where I can speak to a nurse or counsellor without being heard by other people. | 0.53 | 0.89 | 2.41 | 1.46 |

*Cronbach's alpha if item deleted, **p < 0.01

### 4.2.2 Barriers to MY medication taking: SBS-2.

***4.2.2.1 Multicollinearity (Determinant), Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's Test of Sphericity.*** On the first iteration of the analysis an inspection of the correlation matrix revealed a high correlation (r>0.80) between items "I do not take my ART pills because my traditional healer has told me not to" and "I do not take my ART pills because the church pastor has told me not to" (r = 0.82). As a result one of the items was removed, namely, "I do not take my ART pills because my traditional healer has told me not to". The EFA was then conducted again. Inspection of the correlation matrix now showed no high correlations and the determinant was satisfactory (0.002) (Field, 2005). However the pattern matrix revealed that one item did not load onto either of the two factors extracted from the EFA. This item ("I have difficulty obtaining my ART pills because the clinic is often out of stock of pills") was subsequently removed. The EFA was then performed again. The KMO statistic was 0.86, which indicated that FA was a suitable analysis for the data. Bartlett's Test of Sphericity revealed that the correlation matrix was significantly different from an identity matrix (p <0.01).

***4.2.2.2 Primary factor structure.*** Three primary factors were extracted based on Kaiser (1960, 1974) criterion of eigenvalues >1. These factors, as can be seen in the Scree plot (*Figure 3*), accounted for 64.03% of the total variance explained. The correlations between these factors

then formed part of the second-order factor analysis that was performed to identify a secondary order factor.

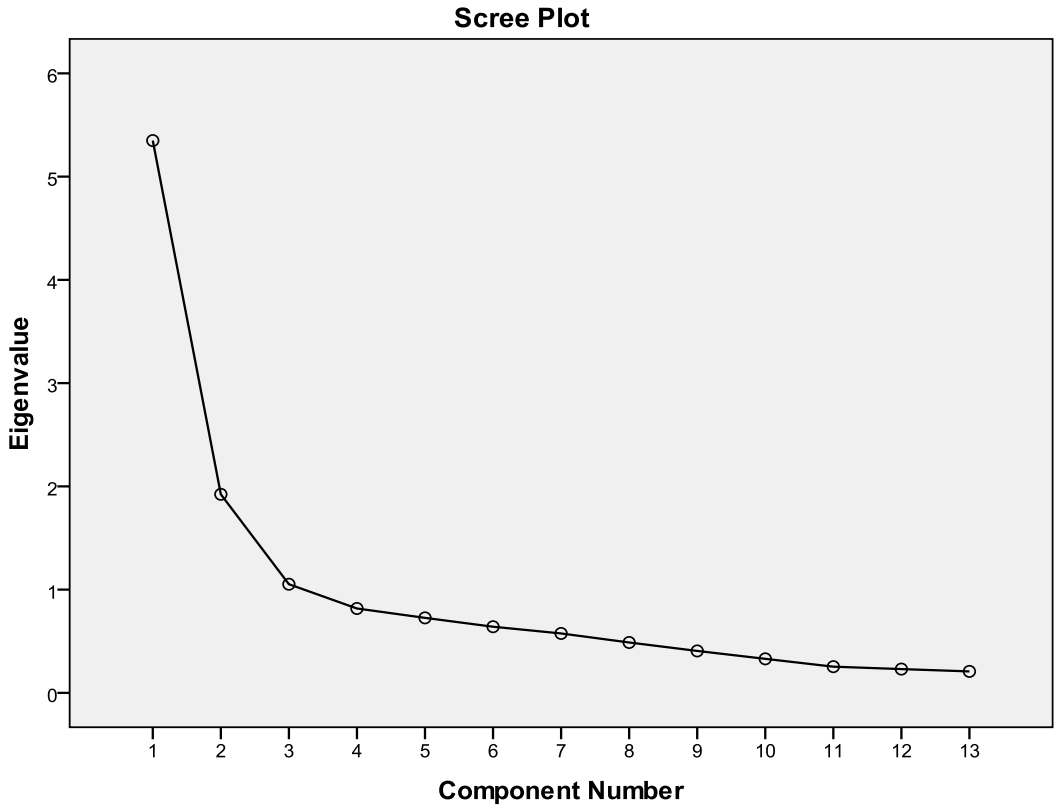


*Figure 3*. Scree plot of factors extracted for the SBS-2.

***4.2.2.3 Hierarchical factor structure.*** A second order factor analysis was performed on all the items included in the SBS 2. Thus, a Schmid-Leiman hierarchical transformation was performed to identify whether the items loaded strongly onto secondary order factor. As can be seen from Table 5 below, the items did indeed load saliently onto a secondary order factor. This factor was named Barriers to Pill Taking. Thus, although three primary factors were identified, the results in Table 6 show that 57.7% of the variance was explained by the secondary order factor. This result is proportionally much greater than the variance explained by the primary

factors. On the basis of these results, it may therefore be concluded that the SBS-2 can be treated as a unidimensional scale. Unidimensionality thus validates the calculation of a total score. A maximum score of 65 and a minimum score of 12 can be obtained on the SBS-2. The mean score for this scale was 32.39, suggesting that most patients who completed the scale experienced structural barriers to pill-taking as salient.

Table 5

*Factor loadings of Schmid-Leiman Solution for the SBS-2*

| Item | General | Primary1 | Primary2 | Primary3 |
|---|---|---|---|---|
| 26 | **0.54** | **0.62** | -0.11 | -0.01 |
| 27 | **0.61** | **0.58** | -0.03 | 0.01 |
| 28 | **0.69** | 0.34 | 0.08 | 0.23 |
| 29 | **0.76** | 0.37 | 0.31 | 0.04 |
| 30 | **0.64** | 0.08 | **0.40** | 0.14 |
| 31 | **0.70** | 0.32 | 0.36 | -0.01 |
| 33 | **0.46** | -0.12 | **0.62** | -0.06 |
| 34 | **0.76** | 0.19 | **0.41** | 0.12 |
| 35 | **0.68** | 0.21 | **0.41** | 0.02 |
| 36 | **0.52** | -0.11 | **0.63** | -0.01 |
| 37 | **0.62** | **0.54** | 0.06 | -0.03 |
| 38 | **0.48** | -0.15 | 0.06 | **0.56** |
| 40 | **0.56** | 0.12 | -0.08 | **0.50** |
| % Variance explained by extracted factors | 57.7 | 17.3 | 17.5 | 7.5 |

***4.2.2.4 Reliability of the SBS-2.*** The SBS-2 showed highly satisfactory reliability (α = 0.87). Table 6 below shows the item-by-item descriptive analyses for the scale and provides further evidence for the homogeneity of the scale.

Table 6

*Item-by-item Descriptive Analyses for the SBS-2*

| Item | Description | Corrected Item-Total Correlation (*r*) ** | α-iid* | M | SD |
|---|---|---|---|---|---|
| 26 | I have difficulty taking my ART pills because I do not always have food with which to take them. | 0.51 | 0.86 | 3.18 | 1.30 |
| 27 | Taking my ART pills when I do not have food to eat makes me feel ill. | 0.57 | 0.86 | 3.40 | 1.37 |
| 28 | I do not take my pills if I have to take it in front of others. | 0.58 | 0.86 | 3.03 | 1.36 |
| 29 | I do not take my ART pills because I do not have a way to remind me to take them. | 0.73 | 0.85 | 2.51 | 1.27 |
| 30 | I do not take my ART pills because I do not want my employer to know I use them. | 0.56 | 0.86 | 2.56 | 1.43 |
| 31 | I forget to take my ART pills. | 0.68 | 0.85 | 2.33 | 1.25 |
| 33 | I do not take my ART pills because the church pastor has told me not to. | 0.43 | 0.87 | 1.73 | 1.21 |
| 34 | When I drink alcohol I forget to take my ART pills. | 0.70 | 0.85 | 2.55 | 1.49 |
| 35 | I do not take my ART pills because I do not have someone to remind me to do so. | 0.64 | 0.85 | 2.26 | 1.19 |
| 36 | I do not take my ART pills because traditional healing works better for me. | 0.49 | 0.86 | 1.71 | 1.19 |
| 37 | I do not take my ART pills because I cannot afford the food I need to eat when I take them. | 0.59 | 0.86 | 3.09 | 1.38 |
| 38 | I do not take my ART pills in case my CD4 count increases and I may no longer qualify for a disability grant. | 0.26 | 0.88 | 1.62 | 1.57 |
| 40 | I do not take my pills because I do not like taking them in front of my family. | 0.35 | 0.87 | 2.42 | 1.30 |

*Cronbach's alpha if item deleted, **$p < 0.01$

### 4.2.3 Barriers to PATIENTS' clinic attendance: SBS-3.

**4.2.3.1** ***Multicollinearity (Determinant), Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's Test of Sphericity.*** Initial inspection of the correlation matrix revealed two variables that correlated highly with one another (r= 0.85). These were "Patients do not attend clinic appointments because they do not want others to see that they receive HIV treatment" and " Patients do not attend clinic appointments because they do not want to be identified as HIV positive". Consequently the item, "Patients do not attend clinic appointments because they do not want to be identified as HIV positive" was removed and the EFA was conducted again. The KMO was satisfactory at 0.88, and Bartlett's Test of Sphericity ($p < 0.01$) showed that the correlation matrix was significantly different from an identity matrix.

***4.2.3.2 Primary factor structure.*** A total of three primary factors (see *figure 4*) were extracted and retained after principal components EFA was conducted, accounting for 72.10% of the total variance. The correlations between these factors then formed part of the second-order factor analysis that was performed to identify a secondary order factor.

***4.2.3.3 Hierarchical factor structure.*** A second order factor analysis was performed on all the items included in the SBS-3. A Schmid-Leiman hierarchical transformation identified a secondary order factor. As can be seen from, Table 7 below the items loaded saliently onto the secondary order factor. This factor was named Barriers to Patients' Clinic Attendance. Thus, although three primary factors were identified, the results in Table 7 show that 64.1% of the variance was explained by the secondary order factor. This result was far greater than the variance explained by the primary factors. Based on the results obtained it can be concluded that the SBS-3 shows unidimensionality. Unidimensionality validates the calculation of a total score. A maximum score of 48 and a minimum score of 13 can be obtained on the SBS-3. The mean

score for this scale was 28.31, suggesting that participants considered barriers to clinic attendance as being salient for most other patients receiving ART.

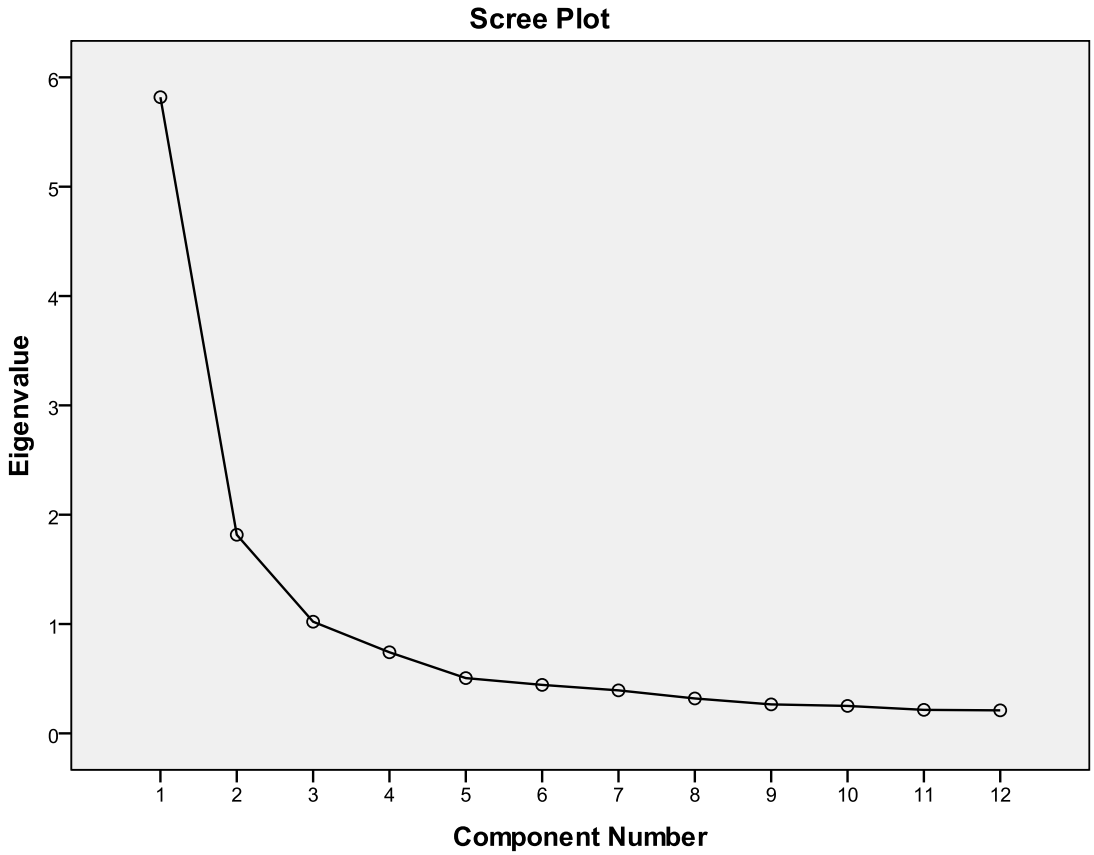


*Figure 4*. Scree plot of factors extracted for the SBS-3.

Table 7

*Factor loadings of Schmid-Leiman Solution for the SBS-3*

| Item | General | Primary1 | Primary2 | Primary3 |
|---|---|---|---|---|
| 43 | **0.59** | 0.02 | **0.73** | -0.03 |
| 44 | **0.54** | 0.09 | **0.73** | 0.05 |
| 45 | **0.68** | -0.09 | **0.51** | -0.26 |
| 47 | **0.72** | 0.26 | 0.15 | -0.17 |
| 48 | **0.70** | **0.56** | 0.10 | 0.06 |
| 49 | **0.76** | **0.52** | 0.10 | -0.01 |

| | | | | |
|---|---|---|---|---|
| 50 | **0.67** | **0.50** | -0.11 | -0.06 |
| 51 | **0.72** | 0.23 | 0.04 | -0.24 |
| 52 | **0.74** | 0.03 | -0.02 | **-0.43** |
| 53 | **0.79** | 0.00 | 0.18 | **-0.40** |
| 54 | **0.76** | 0.03 | -0.06 | **-0.46** |
| 55 | **0.62** | 0.27 | -0.15 | -0.22 |
| % Variance explained by extracted factors | 64.1 | 11.5 | 15.8 | 8.5 |

***4.2.3.4 Reliability of the SBS-3.*** The SBS-3 showed highly satisfactory reliability (α = 0.90). Table 8 below shows the item-by-item descriptive analyses for scale and provides further evidence for the homogeneity of the scale.

Table 8

*Item-by-item Descriptive Analyses for the SBS-3*

| Item | Description | Corrected Item-Total Correlation (*r*) ** | α-iid* | M | SD |
|---|---|---|---|---|---|
| 43 | Patients do not attend clinic appointments because the clinic is too far from the bus stop/ taxi rank. | .50 | .89 | 2.16 | .89 |
| 44 | Patients do not attend clinic appointments because transport to the clinic is too expensive. | .44 | .90 | 2.10 | .93 |
| 45 | Patients do not attend clinic appointments because it takes too much time to travel to and from the clinic. | .61 | .89 | 2.47 | .98 |
| 47 | Patients do not attend clinic appointments because they do not want to be identified as HIV positive. | .65 | .89 | 2.56 | .88 |
| 48 | Patients do not attend clinic appointments because some staff members at the clinic are rude to them. | .62 | .89 | 2.02 | .78 |
| 49 | Patients do not attend clinic appointments because some staff members at the clinic are impatient towards them. | .68 | .89 | 1.99 | .81 |
| 50 | Patients do not attend clinic appointments because there is no privacy at the clinic when they meet with the nurse or counsellor. | .60 | .89 | 1.83 | .85 |

| | | | | | |
|---|---|---|---|---|---|
| 51 | Patients do not attend clinic appointments because they cannot get time off work to do so. | .66 | .89 | 2.09 | .84 |
| 52 | Patients do not attend clinic appointments because they have to wait too long to see the doctor, nurse, or pharmacist. | .70 | .89 | 2.19 | .93 |
| 53 | Patients do not attend clinic appointments because they feel unsafe walking to the clinic. | .74 | .89 | 2.12 | .99 |
| 54 | Patients do not attend clinic appointments because the clinic is too crowded. | .71 | .89 | 2.35 | 1.10 |
| 55 | Patients do not attend clinic appointments because the nurses do not speak their language. | .55 | .90 | 1.88 | .90 |

*Cronbach's alpha if item deleted, **$p < 0.01$

### 4.2.4 Barriers to PATIENTS' medication taking: SBS-4.

***4.2.4.1 Multicollinearity (Determinant), Kaiser-Meyer-Olkin Measure of Sampling Adequacy (KMO) and Bartlett's Test of Sphericity*** .On the first iteration of the EFA, the correlation matrix showed a high correlation (r=0.85) between two items namely, "Patients do not take their ART pills because their traditional healers have told them not to" and "Patients do not take their ART pills because their church pastors have told them not to". Subsequently the item "Patients do not take their ART pills because their traditional healers have told them not to" was removed. The EFA was performed again. The pattern matrix revealed that the item, "Patients have difficulty obtaining their ART pills because the clinic is often out of stock of pills" did not load onto either of the two factors extracted. This item was removed and the EFA was conducted again. The determinant was satisfactory. The KMO statistic of 0.89 showed that FA was a suitable analysis for the data. Bartlett's Test of Sphericity ($p < 0.01$) showed that the correlation matrix was significantly different from an identity matrix.

***4.2.4.2 Primary factor structure.*** On the basis of the Scree plot (*Figure 5*) two factors were extracted from the principal components EFA. These factors accounted for 63.23% of the total variance explained by the model. The correlations between these factors formed part of the

second-order factor analysis aimed at identifying a general underlying factor (secondary factor) for the scale.

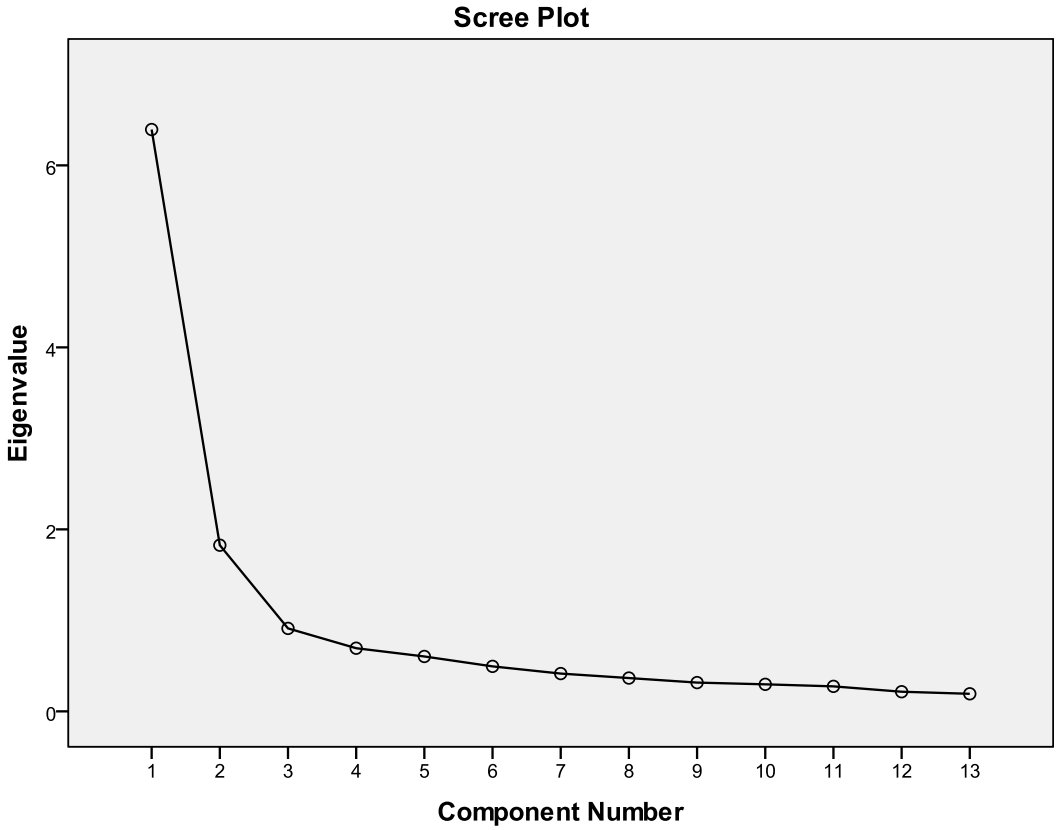


*Figure 5*. Scree plot of factors extracted for the SBS-4.

***4.2.4.3 Hierarchical factor structure.*** A second order factor analysis was performed on all the items included in the SBS-4. A Schmid-Leiman hierarchical transformation identified a higher order or general factor. As can be seen from, Table 9 below the items loaded saliently onto the secondary order factor. This factor was named Barriers to Patients' Pill Taking. Thus, although two primary factors were identified, the results in Table 9 show that 67.2% of the variance was explained by the general factor. This result was greater than the variance explained

by the primary factors extracted from the EFA. Based on the results it can be concluded that the SBS-3 is a unidimensional scale. Unidimensionality thus validates the calculation of a total score. A maximum score of 52 and a minimum score of 13 can be obtained on the SBS-3. The mean score for this scale was 30.74, suggesting that participants considered barriers to pill taking as salient for most other patients receiving ART.

Table 9

*Factor loadings of Schmid-Leiman Solution for the SBS-4*

| Item | General | Primary1 | Primary2 |
|---|---|---|---|
| 56 | **0.65** | **0.46** | 0.01 |
| 57 | **0.62** | **0.46** | -0.02 |
| 58 | **0.59** | **0.50** | -0.07 |
| 59 | **0.68** | **0.41** | 0.09 |
| 60 | **0.66** | **0.51** | -0.03 |
| 61 | **0.69** | 0.39 | 0.11 |
| 63 | **0.67** | -0.04 | **0.53** |
| 64 | **0.58** | **0.47** | -0.05 |
| 65 | **0.70** | 0.31 | 0.20 |
| 66 | **0.70** | -0.03 | **0.54** |
| 67 | **0.78** | 0.37 | 0.20 |
| 68 | **0.71** | 0.22 | 0.29 |
| 70 | **0.51** | **0.48** | -0.11 |
| % Variance explained by extracted factors | 67.2 | 23.6 | 9.2 |

***4.2.4.4 Reliability of the SBS-4.*** The SBS-4 showed highly satisfactory reliability (α = 0.91). Table 10 below shows the item-by-item descriptive analyses for scale and provides further evidence for the homogeneity of the scale.

Table 10

*Item-by-item Descriptive Analyses for the SBS-4*

| Item | Description | Corrected Item-Total Correlation (*r*) | α-iid* | M | SD |
|---|---|---|---|---|---|
| 56 | Patients do not take their ART pills because they do not always have food with which to take them. | .71 | .90 | 2.53 | .90 |
| 57 | If patients take their ART pills when they do not have food to eat then they often feel ill. | .68 | .90 | 2.61 | .94 |
| 58 | Patients do not take their ART pills if they have to take it in front of others. | .69 | .90 | 2.50 | .77 |
| 59 | Patients do not take their ART pills because they do not have a way to remind themselves to take them. | .68 | .90 | 2.19 | .73 |
| 60 | Patients do not take their ART pills because they do not want their employers to know that they are HIV positive. | .74 | .90 | 2.47 | .78 |
| 61 | Patients do not take their ART pills because they forget to do so. | .68 | .90 | 2.18 | .72 |
| 63 | Patients do not take their ART pills because the church pastors have told them not to. | .37 | .91 | 1.94 | .81 |
| 64 | Patients forget to take their ART pills when they drink alcohol. | .66 | .90 | 2.62 | .93 |
| 65 | Patients do not take their ART pills because they do not have someone to remind them to take it. | .63 | .90 | 2.19 | .67 |
| 66 | Patients do not take their ART pills because they believe traditional healing works better for them. | .40 | .91 | 2.01 | .79 |
| 67 | Patients do not take their ART pills because they cannot afford the food they need in order to take it. | .75 | .90 | 2.54 | .93 |
| 68 | Patients do not take their ART pills in case their CD4 count increases and they no longer qualify for a disability grant. | .58 | .90 | 2.55 | .99 |
| 70 | Patients do not take their ART pills because they do not like taking it in front of their families. | .61 | .90 | 2.41 | .79 |

*Cronbach's alpha if item deleted, **$p < 0.01$

Table 11

*Correlations between the total scores of each scale*

| | | Correlations | | | |
|---|---|---|---|---|---|
| | | SBS 1 | SBS 2 | SBS 3 | SBS 4 |
| SBS 1 | Pearson Correlation | 1 | **.327**** | **.305**** | 0.004 |
| | Sig. (2-tailed) | | 0 | 0 | 0.951 |
| | N | 291 | 291 | 291 | 291 |
| SBS 2 | Pearson Correlation | **.327**** | 1 | **.204**** | **.132*** |
| | Sig. (2-tailed) | 0 | | 0 | 0.024 |
| | N | 291 | 291 | 291 | 291 |
| SBS 3 | Pearson Correlation | **.305**** | **.204**** | 1 | 0.056 |
| | Sig. (2-tailed) | 0 | 0 | | 0.34 |
| | N | 291 | 291 | 291 | 291 |
| SBS 4 | Pearson Correlation | 0.004 | **.132*** | 0.056 | 1 |
| | Sig. (2-tailed) | 0.951 | 0.024 | 0.34 | |
| | N | 291 | 291 | 291 | 291 |

**. Correlation is significant at the 0.01 level (2-tailed).
*. Correlation is significant at the 0.05 level (2-tailed).

Table 11 shows the correlations between the total scores of each scale. According to Field (2005) a correlation (r) of (+-) 0.1 shows a small effect, (+-) 0.3 shows a medium effect and (+-) 0.5 a large effect. Thus, most of the correlations seen between the scales have a small effect but are significant on either the 0.01 or 0.05 levels. The correlation between the SBS 1 and SBS 2 ($r= 0.327$, $p <0.01$) is stronger (more positive) than the other scales suggesting that barriers to pill-taking are somewhat related to barriers to clinic attendance. Overall, the SBS 2 correlates significantly with all the scales.

### 4.3 Summary of Findings

Four scales assessing structural barriers to adherence to ART were developed. Each of the four scales (SBS-1, SBS-2, SBS-3 and SBS-4) demonstrated highly satisfactory reliability and item-by-item descriptive statistics provided further evidence for the homogeneity of each scale. Each scale was subjected to first-order factor analysis (principal-components exploratory factor analysis) to identify the factor correlations necessary to perform a second order factor analysis. The second order factor analysis was aimed at identifying a single general factor that accounted for the majority of the common variance. The second order factor was identified by means of a Schmid-Leiman hierarchical transformation (Schmid-Leiman, 1957). The identification of a general factor for each scale indicated that the scale was unidimensional and thus warranted the calculation of a total score across all the items for each of the scales. The total scores of each scale were correlated with one another and the significance of the correlations suggested that the barriers measured in each of the scales were either slightly or somewhat related to one another.

# CHAPTER 5

# DISCUSSION AND CONCLUSION

## 5.1 Introduction

To my knowledge this is the first study to focus on determining the underlying factor structure of structural barriers to adherence to ART in terms of clinic attendance and pill-taking. Furthermore the incorporation of qualitative data gathered from in-depth interviews (phase 1) with key stakeholders (patients, healthcare workers and patient advocates) presented a unique platform on which to build on the limited literature in this area.

A review of the literature revealed that no valid and reliable measure of structural barriers to adherence exists. Therefore, the main objective of this thesis was to construct a scale to determine the extent to which ART users experience such barriers as salient and to determine the factor structure for each measure. Consequently, four scales measuring structural barriers to adherence were constructed. The scales were designed to document the salience of the various structural barriers that patients experience when attending clinic appointments and taking their ART pills. The study also sought to identify the barriers that respondents believed other patients to be facing in the same regard.

The results indicated that all four scales, SBS 1 to 4, have good reliability with alpha coefficients ranging from 0.87 to 0.91. Thus the items included in each of the scales demonstrated excellent internal consistency. After principal-components exploratory factor analysis was performed on each scale it appeared that a factor solution of three for the SBS-1, three for the SBS-2, three for the SBS-3, and two for the SBS-4 provided the best overall fit for the items included in the scales. However, after a second order factor analysis was also performed on each of the scales by means of a Schmid-Leiman hierarchical transformation

(Schmid-Leiman, 1957), it was clear that the responses to the items included in each of the scales were dominated by secondary order or general factors. For each of the four scales the extraction of a secondary order factor provided a better overall fit for the items that were included. Thus, each of the structural barriers scales (SBS-1 to 4) demonstrated unidimensionality. Unidimensionality of a scale suggests the presence of a single higher-order factor driving the performance of the items on the scale, which in turn justifies the calculation of a total score for each of the scales (De Bruin, 2006).

### 5.2 Factor structure of the SBS-1: Barriers to MY clinic attendance

**5.2.1 Barriers to Clinic Attendance.** A total of 12 items loaded strongly onto the factor, Barriers to clinic attendance. Three of these items relate strongly to the transport difficulties experienced by patients when attending their clinic appointments. The remainder of the items relate to the patients' experiences at the clinic itself. These clinic experiences were in relation to the patient-provider relationship, waiting times and overcrowding at the clinics, as well as a fear of being identified as HIV positive by others. The barriers to clinic attendance measured by the scale are those that patients typically have little control over, such as waiting times at the clinic, overcrowding, transport difficulties and stigma. Therefore, patients who succeed in attending clinic appointments are highly motivated to negotiate and overcome these barriers despite the expected struggle.

Considering social-ecological theory (Roura et al., 2009) and the emergence of a general factor (Barriers to clinic attendance) from the results of the study, patients' decision-making process may be summarised as being based on negotiating and seeking to overcome the constraints of their social environment.

Mean descriptive statistics of each of the items (as can be seen from Table 4) that constitute the general factor indicate that items 14; "I do not attend my clinic appointments because it takes too much time to travel to and from the clinic", 16; "I do not attend my clinic appointments because I do not want to be identified as HIV positive" and 23; "I do not attend my clinic appointments because the clinic is too crowded" were highly endorsed by most patients. The high scores on these items suggest that these barriers to clinic attendance were especially difficult for most patients to overcome. Item 14 stated, "I do not attend my clinic appointments because it takes too much time to travel to and from the clinic". Various studies have cited travelling long distances as a barrier to clinic attendance (Weiser et al., 2003; Jaffar et al., 2005; Miles et al., 2007; Maskew et al., 2007; Posse et al., 2008; Coetzee et al., 2011.). In the context of poverty, most of the participants involved in this study were continually faced with resource constrained environments that consist of inadequate roads, a lack of sufficient public transport and under resourced public facilities such as public hospitals. Together the influences of these factors potentially shape the behaviour of many patients by ultimately inhibiting health promoting behaviour, such as adherence to clinic attendance and pill-taking. In the case of the participants involved in this study, many live in informal settlements and lack necessary commodities such as transport and access to health care. Many of the participants in this study may be viewed as members of communities with relatively low social capital (Campbell, 2001; 2003) and thus lack the community cohesion needed to influence behaviour change amongst those who are unable to adhere to clinic appointments as a direct result of structural factors. Campbell (2003) argues that without sufficient social capital amongst members in a community, any interventions introduced to promote health-behaviours will ultimately fail.

Item 16 stated, "I do not attend my clinic appointments because I do not want to be identified as HIV positive." It is evident that patients perceive that clinic attendance might put them at risk of being identified as HIV positive. Rintamaki et al's., (2006) model of stigma concerns, argues that perceptions of others' attitudes towards HIV may produce anxiety that one might reveal their status to others. Such situations then create dilemma's in which the importance of adherence to clinic attendance is weighed against others potentially learning about their status.

Rintamaki et al's., (2006) model fits in well with current literature. Coetzee et al., (2011) reported that several patients in their sample stated that they sought health services for HIV outside of their home environments out of fear of being identified as living with the virus. In their study on perceived HIV-related stigma and disclosure following an HIV positive diagnosis, Derlega et al. (2002) found that persons with an HIV diagnosis feared being identified as such as they believed that it would lead to rejection by community members, self-blame and would risk the security of family members or partners.

Item 23 stated, "I do not attend my clinic appointments because the clinic is too crowded." The numbers of patients seeking ART at public health care clinics has increased dramatically since the national rollout in 2004. With the large numbers of patients presenting for ART at public healthcare facilities (Dorrington et al., 2006; UNGASS, 2010), patients are not only forced to spend whole days at the clinics in uncomfortable settings, but have to settle for minimal time with clinicians. They may therefore not find it easy to communicate deeper levels issues that may serve as barriers to adherence (Coetzee et al., 2011, Kagee et al., 2010).

Extraction of the three primary factors could provide insight as to how the SBS-1 may be improved. Further research might be useful to ascertain conceptual clarity of each of the items so

that there may be no overlap in content. Overall the SBS-1 items appear to be a useful indicator of patients' subjective experience of barriers to clinic attendance.

### 5.3 Factor structure of the SBS-2: Barriers to MY pill taking

**5.3.1 Barriers to Pill Taking.** Thirteen items loaded strongly onto the factor Barriers to Pill Taking. The items covered a wide range of barriers to pill taking that patients experience such as, requiring the necessary foods with which to take the pills, having no access to remainder tools, having trouble taking the pills in front of others, being discouraged by church pastors, and having a preference for alternative healing.

As with the previous scale, decisions to either adhere to or forgo pill-taking may be based on a multitude of factors such as personal experience, information available to a patient, the experience of others and beliefs they may have about the effectiveness and effects of the medication itself (Remien et al., 2003). According to Remien et al. (2003) pill taking behaviour is affected by emotional, behavioural, and cognitive factors. Importantly, the authors note that pill-taking behaviour is not a one-dimensional or static behaviour. Therefore, depending on the circumstances in which an individual finds him/herself, adherence at one point in a patient's life may differ from adherence at another point in his or her life. Participants in this study were not given a time frame on which to base their behaviour, for example, asking them to base their scores on how structural barriers may have influenced their pill taking behaviour in the last month. By adding this dimension to the each of the scales future researchers may derive a clearer picture of whether the barriers are general or specific to circumstance.

As with the SBS-1, some items from the SBS-2 were endorsed more strongly by most patients. Means of descriptive statistics of the items (as can be seen from Table 6) showed that items, 26; "I have difficulty taking my ART pills because I do not always have food with which

to take them, 27; “Taking my ART pills when I do not have food to eat makes me feel ill”, 28; “I do not take my pills if I have to take it in front of others” and 37; “I do not take my ART pills because I cannot afford the food I need to eat when I take them” were more strongly endorsed by patients in relation to the other items.

Items 26 and 27 relate to food insecurity. Food insecurity is a major consequence of poverty, and thus a defining feature of resource-constrained environments (Tomlinson et al., 2010; Weiser et al., 2010). For persons living in resource-constrained environments there are various challenges to food security that acts as barriers to health. Persons living in poorer regions may have very little access to food, and when coupled with socio-economic inequality, increase vulnerability to HIV risk. According to Gillepsie and Drimie (2008), socio-economic inequality rather than absolute poverty is more closely associated with increased HIV risk. Lack of proper food and nutrition for persons receiving ART can render them more susceptible to AIDS-related illnesses and opportunistic infections (WHO, 2010). In a study conducted by Ivers et al. (2010), when assessed at six and twelve month intervals, patients enrolled on an HIV-program at a clinic in Haiti who had access to food showed improved adherence to clinic appointments and an increase in their body mass index (BMI). ARV’s are known to reduce nutrient absorption and therefore require intake of foods rich in nutritional value. However, patients living in resource-limited settings may not often have the finances to acquire even basic foods. Foods necessary for the treatment regimen may be even less likely to obtain.

As shown in the study conducted by Weiser et al. (2010), persons living with HIV in their study considered skipping doses or not commencing on treatment at all if they were not able to afford the food necessary for desired treatment outcomes. Side effects that are experienced from

ARV consumption may be better managed by the consumption of the necessary foods (USAID, 2005). Item 28 stated, "I do not take my pills if I have to take it in front of others."

It is evident that patients experienced an immense fear of being identified as HIV positive. Also worthy to note are those items not endorsed highly by participants. The item, "I do not take my ART pills in case my CD4 count increases and I may no longer qualify for a disability grant" had the lowest mean (M=1.62) of all the items. On closer examination, I reasoned that the item was double-barrelled in nature which meant that patients may not have understood how to answer this item. Future research might be focused on conceptual clarity of the items included in each scale.

### 5.4 Factor structure of the SBS-3: Barriers to PATIENTS' Clinic Attendance

**5.4.1 Barriers to Patients' Clinic Attendance.** Twelve items loaded saliently onto the factor Barriers to Patients' Clinic Attendance. The items assess the same barriers to clinic attendance as the SBS-1. However instead of reporting on themselves, patients were asked to indicate the extent to which other patients experienced barriers to clinic attendance. Mean descriptive statistics as can be seen in Table 8, shows that item 47 "Patients do not attend clinic appointments because they do not want to be identified as HIV positive", had the highest mean score (M=2.56) of all the items. As previously discussed, the effect of stigma on the lives of persons living with HIV is still vastly prominent in South Africa and has received much attention. Item 45, "Patients do not attend clinic appointments because it takes too much time to travel to and from the clinic" had a mean of 2.47 and was the second highest endorsed item on the scale. Both items 47 and 45 correspond to items 14 and 16 on the SBS-1. These items were similarly endorsed on both scales and thus the previous discussion accounts for this scale as well. Overall the SBS-3 proved a reliable measure for allowing patients to assess the barriers to clinic

attendance that other patients may face. On average however, participants scored patients' barriers to clinic attendance lower than they scored their own.

### 5.5 Factor structure of the SBS-4: Barriers to PATIENTS' pill taking

**5.5.1 Barriers to Patients' Pill Taking.** Thirteen items loaded saliently onto the factor Barriers to Patients Pill Taking. The items assess the same barriers to pill taking as the SBS-2. However instead of reporting on themselves, patients were asked to indicate the extent to which other patients experienced barriers to pill taking. Mean descriptive statistics as can be seen by Table 10 show that items 64 and 68 were highly endorsed by most patients. Item 68 states, "Patients do not take their ART pills in case their CD4 count increases and they no longer qualify for a disability grant" and had a M=2.55.

In South Africa, patients who are too young, too old or too sick (CD count < 200 cells/$mm^3$) to work are eligible for a disability grant (Nattrass, 2006a) worth R 1010 per month (SASSA, 2010). Once deemed capable of working, patients no longer qualify for this grant. Given the high unemployment rates, the possibility of trading off one's health to re-qualify for the grant may become an option for some (Nattrass, 2006b). However, in follow-up studies on trading off health for a disability grant, Venkataramani, Maughan-Brown, Nattrass, and Ruger (2009) found no statistical association between receipt of a grant and adherence.

Venkataramani et al., (2009) conducted a study in Khayelitsha (a township in Cape Town) where they examined the importance of the disability grant and the impact of losing it on patients receiving ART. Loss of the disability grant meant that many patients suffered a huge loss in income. However, there was no evidence of patients choosing to forgo their treatment over the loss of the grant. In Coetzee et al., (2011) doctors reported that their patients would threaten to forgo treatment if the disability grant was not renewed despite being capable of work.

Evidently there is still much debate surrounding disability grants as a disincentive to adherence, and future research should be focused on clearing this discrepancy. Item 64 stated, "Patients forget to take their ART pills when they drink alcohol." The influence of substance abuse on ART has been cited throughout the literature as an individual barrier to adherence (Palepu et al., 2004; Sanjobo et al., 2008; Dahab et al., 2008; Kip et al., 2009) rather than a structural barrier to adherence. However, Coetzee et al., (2011) refer to the lack of substance abuse treatment programs for PLWH in resource-constrained settings as a structural barrier to adherence.

Overall the SBS-4 proved to be a reliable measure of barriers to pill taking. However, on average patients scored other patients' barriers to pill taking lower than they scored their own.

**5.6 Conclusion**

In this study four reliable scales assessing structural barriers to adherence to ART were constructed. The underlying factor structure of each of the scales was derived at by means of exploratory factor analysis. A general factor for each scale emerged after second order factor analysis had been performed. A general factor emerged for each scale because patients may have considered the extent of the influence of each structural barrier on either clinic attendance or pill taking as equally salient. However, there were certain items that individually posed a greater threat to adherence. Despite fairly satisfying results from the study there is still room for improvement on each of the scales which requires further research and application. These are discussion below.

**5.7 Limitations of the study**

The study should be considered in light of its many limitations.

Firstly, due to financial constraints the measure was not translated into a Xhosa version. Considering that the majority of the participants indicated Xhosa as their first language, the study

may have been limited by not having the translated version available to them. Secondly, patient advocates were asked to assist in recruitment of patients. This method of sampling may have resulted in not gaining access to those patients who are more serious defaulters, and perhaps identify more closely with the structural barriers indicated on the scales. Future research might expand further on the population from which the sample was recruited.

Thirdly, the number of items in each of the questionnaire packages may have led to responder fatigue, and may thus have contributed to incomplete questionnaires. The number of variables may also have led to the response bias (circling one's throughout) evident in some of the questionnaire packages. Lastly, as patient advocates assisted patients in completion of the instruments the results may have been confounded by social desirability and demand characteristics.

**5.8 Implications for future research**

Future research might be aimed at refining the items of each scale and focus on the conceptual clarity of each. Item refinement may be focused on ensuring that no item is double-barrelled. The scales might also function more accurately if a time frame be put into place, i.e. asking respondents to answer items based on how salient they might have been in the past week, or past month. Furthermore, as there is yet to be a gold standard for measuring adherence by self-report, researchers may consider focusing attention on understanding every dimension of non-adherence as well as possible. The results of this study have indicated that intervention research may help illuminate ways of helping patient's problem-solve and thereby negotiate the most salient barriers. The development, refinement and implementation of such an intervention may potentially rest on the data yielded by the present study.

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## Addendum A: Demographic information

**RESEARCH STUDY ON BARRIERS TO ADHERENCE TO ANTIRETROVIRAL TREATMENT**

Thank you for agreeing to participate in this study. You have been asked to participate in this study because you are receiving antiretroviral treatment for HIV.

If you are not receiving medicine for HIV, please do not proceed with this questionnaire.

You are free to refuse to participate in this study or to stop answering this questionnaire at any time.

All of the information you provide us will remain confidential. No one will have access to the data except for the Stellenbosch research staff. ***No one else*** will see your responses to the questions.

All data will be kept in a locked cabinet at the University of Stellenbosch. If the data are used in any publications, you will not be identified by name.

***Where necessary: Please mark your answer with an X***

| | | | |
|---|---|---|---|
| 001_age | Please write your age here: | | |
| 002_birth | What is your date of birth: | | |
| 003_gender | What is your gender? | Male | Female |
| 004_mstatus | What is your current marital status? | Single | Widowed |
| | | Separated | Divorced |
| | | Married or living with a significant other in a marriage-like relationship | |
| | | | |
| 005_living | What is your current living situation? | Live alone | Live in an institution or retirement home |
| | | Live with other adults(s), no children | Live with children only |
| | | | |

| | | | |
|---|---|---|---|
| | | Live with other adults and children | |
| 006_edu | Please select the highest level of education that you have completed: | No formal education | Completed primary school |
| | | Attended high school but did not complete matric. | Attended university, college or technikon but did not graduate |
| | | Graduated from university, college or technikon. | |
| 007_work | What is your current work situation? | Employed full time | Employed part time |
| | | Unemployed | Homemaker |
| | | Disabled | Student |
| | | Retired | |
| 008_income | Which of the following best describes your approximate annual family income from all sources, before taxes? | Less than R12,000 | R110,001-R170,000 |
| | | R10,001-R40,000 | R170,001-R240,000 |
| | | R40,000-R80,000 | R240,001 and above |
| | | R80,001-R110,000 | Do not know |
| 009_pob | Where were you born (Town/ City)? | | |
| 010_lang | What is your first language? | | |
| 011_other | Which other languages do you speak? | | |

## Navorsing Studie

Dankie dat u ingestem het om deel te neem aan hierdie studie. Jy is gevra om deel te neem aan hierdie studie omdat jy anti-retrovirale behandeling ontvang vir MIV.

As jy nie medisyne vir MIV ontvang nie, moenie hierdie vraelys voltooi nie.

Jy mag weier om deel te neem aan hierdie studie of om te stop met die beantwoording van hierdie vraelys om enige tyd.

Al die inligting wat u verskaf sal vertroulik bly. Niemand behalwe die studie leier van Stellenbos sal toegang he tot die inligting,. ***Niemand anders*** sal jou antwoorde op die vrae sien nie.

Alle inligting sal gehou word in 'n geslote kas by die Universiteit van Stellenbosch. As die data in enige publikasies gebruik word, sal jy nie per naam geïdentifiseer wees nie.

***Waar nodig: Merk asseblief u antwoord met 'n X***

| | | |
|---|---|---|
| Skryf asseblief jou ouderdom hier: | | |
| Wat is jou geboorte datum: | | |
| Wat is jou geslag? | Man | Vrou |
| Wat is jou huidige huwelikstatus? | Enkel | Weduwee/Wewenaar |
| | Vervreem | Geskei |
| | Getroud of leef saam met 'n belangrike ander in' n huwelik-soort verhouding | |
| | | |
| Wat is jou huidige verblyfs omstandighede? | Leef alleen | Lewe in 'n inrigting of aftree huis |
| | Woon saam met ander volwassenes (s), geen kinders | Lewe met slegs kinders |
| | | |
| | Woon saam met ander volwassenes en kinders | |
| Kies die hoogste vlak van opleiding wat u voltooi het: | Geen formele onderwys | Primêre skool voltooi |
| | Hoërskool bygewoon, maar het nog nie matriek voltooi nie. | Universiteit, kollege of technikon bygewoon, maar nie graad gevang nie. |

| | | |
|---|---|---|
| | Gegradueer aan die universiteit, kollege of technikon. | |
| Wat is jou huidige werk situasie? | Voltydse diens | Deeltyds in diens |
| | Werkloos | Tuisteskepper |
| | Gestremd | Student |
| | Afgetree | |
| Watter van die volgende beskryf die beste jou benaderde jaarlikse familie inkomste uit alle bronne, voor belasting? | Minder as R12, 000 | R110,001-R170,000 R110 ,001-R170, 000 |
| | R10,001-R40,000 R10 ,001-R40, 000 | R170,001-R240,000 R170 ,001-R240, 000 |
| | R40,000-R80,000 R40 ,000-R80, 000 | R240,001 en bo |
| | R80,001-R110,000 R80 ,001-R110, 000 | Weet nie |
| Waar is jy gebore (dorp / stad)? | | |
| Wat is jou eerste taal? | | |
| Watter ander tale kan jy praat? | | |

**Addendum B: Barriers to MY clinic attendance: SBS-1**

Below is a list of statements that reflect some reasons why you MAY NOT ATTEND CLINIC APPOINTMENTS. Please circle the number that best applies to your circumstances.

**Please circle or mark one number per line to indicate your response.**

| | | Never | Rarely | Some of the time | Most of the time | Always |
|---|---|---|---|---|---|---|
| | | | | | | |
| 012_taxi | I do not attend my clinic appointments because the clinic is too far from the bus stop/ taxi rank. | 1 | 2 | 3 | 4 | 5 |
| 013_expensive | I do not attend my clinic appointments because transport to the clinic is too expensive. | 1 | 2 | 3 | 4 | 5 |
| 014_traveltime | I do not attend my clinic appointments because it takes too much time to travel to and from the clinic. | 1 | 2 | 3 | 4 | 5 |
| 016_stigma2 | I do not attend my clinic appointments because I do not want to be identified as HIV positive. | 1 | 2 | 3 | 4 | 5 |
| 017_rudestaff | I do not attend my clinic appointments because the staff at the clinic is rude to me. | 1 | 2 | 3 | 4 | 5 |
| 018_impatient | I do not attend my clinic appointments because the staff at the clinic is impatient towards me. | 1 | 2 | 3 | 4 | 5 |
| 019_privacy | I do not attend my clinic appointments because there is no privacy at the clinic when I meet with the nurse. | 1 | 2 | 3 | 4 | 5 |
| 020_worktime | I do not attend my clinic appointments because I cannot get time off work to do so. | 1 | 2 | 3 | 4 | 5 |
| 021_HCWtime | I do not attend my clinic appointments because I have to wait too long to see the | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | doctor, nurse, or pharmacist. | | | | | |
| 022_unsafe | I do not attend my clinic appointments because I feel unsafe walking to and from the clinic. | 1 | 2 | 3 | 4 | 5 |
| 023_crowded | I do not attend my clinic appointments because the clinic is too crowded. | 1 | 2 | 3 | 4 | 5 |
| 025_privacy2 | I do not attend clinic appointments because there is no place where I can speak to a nurse or counsellor without being heard by other people. | 1 | 2 | 3 | 4 | 5 |

Hier volg 'n lys van stellings wat n paar redes stel waarom jy dalk NIE JOU KLINIEK AFSPRAKE bywoon nie. Omkring die nommer wat die beste by jou omstandighede van toepassing is.

**Plaas 'n sirkel of merk een getal per lyn om jou antwoord aan te dui.**

| | | Nooit | Selde | Sommige van die tyd | Die meeste van die tyd | Altyd |
|---|---|---|---|---|---|---|
| | | | | | | |
| 012_taxi | Ek woon nie my kliniek afsprake na nie, omdat die kliniek te ver van die bus stop / taxi-staanplek is. | 1 | 2 | 3 | 4 | 5 |
| 013_expensive | Ek woon nie my kliniek afsprake na nie, omdat die vervoer na die kliniek te duur is. | 1 | 2 | 3 | 4 | 5 |
| 014_traveltime | Ek woon nie my kliniek afsprake na nie, omdat dit te veel tyd vat om te reis na en van die kliniek af. | 1 | 2 | 3 | 4 | 5 |
| 016_stigma2 | Ek woon nie my kliniek afsprake na nie, want ek wil nie geïdentifiseer word as MIV-positief is. | 1 | 2 | 3 | 4 | 5 |
| 017_rudestaff | Ek woon nie my kliniek afsprake na nie, | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| | omdat die personeel by die kliniek onbeskof is met my. | | | | | |
| 018_impatient | Ek woon nie my kliniek afsprake na nie,<br>omdat die personeel by die kliniek ongeduldig is teenoor my. | 1 | 2 | 3 | 4 | 5 |
| 019_privacy | Ek woon nie my kliniek afsprake na nie,<br>omdat daar geen privaatheid is as ek deur die verpleegpersoneel behandel word nie | 1 | 2 | 3 | 4 | 5 |
| 020_worktime | Ek woon nie my kliniek afsprake na nie,<br>omdat ek nie tyd kan afkry by die werk nie. | 1 | 2 | 3 | 4 | 5 |
| 021_HCWtime | Ek woon nie my kliniek afsprake na nie<br>omdat die wagperiodesom die dokter, verpleegster of apteker te sien te lank is. | 1 | 2 | 3 | 4 | 5 |
| 022_unsafe | Ek woon nie my kliniek afsprake na nie<br>omdat ek onveilig voel om na en van die kliniek af te stap. | 1 | 2 | 3 | 4 | 5 |
| 023_crowded | Ek woon nie my kliniek afsprake na nie,<br>omdat die kliniek oorvol is. | 1 | 2 | 3 | 4 | 5 |
| 025_privacy2 | Ek woon nie my kliniek afsprake na nie,<br>want daar is geen plek waar ek kan praat met 'n verpleegster<br>of berader sonder om deur ander mense gehoor te word nie. | 1 | 2 | 3 | 4 | 5 |

**Addendum C: Barriers to MY medication taking: SBS-2**

Below is a list of statements that reflect some reasons why you MAY NOT TAKE YOUR MEDICATION in the way you are required to:

**Please circle or mark one number per line to indicate your response.**

| | | Never | Rarely | Some of the time | Most of the time | Always |
|---|---|---|---|---|---|---|
| | | | | | | |
| 026_food | I have difficulty taking my ART pills because I do not always have food with which to take them. | 1 | 2 | 3 | 4 | 5 |
| 027_food2 | Taking my ART pills when I do not have food to eat makes me feel ill. | 1 | 2 | 3 | 4 | 5 |
| 028_stigma3 | I do not take my pills if I have to take it in front of others. | 1 | 2 | 3 | 4 | 5 |
| 029_remind | I do not take my ART pills because I do not have a way to remind me to take them. | 1 | 2 | 3 | 4 | 5 |
| 030_employer | I do not take my ART pills because I do not want my employer to know I use them. | 1 | 2 | 3 | 4 | 5 |
| 031_forget | I forget to take my ART pills. | 1 | 2 | 3 | 4 | 5 |
| 032_t.healer | I do not take my ART pills because my traditional healer has told me not to. | 1 | 2 | 3 | 4 | 5 |
| 033_church | I do not take my ART pills because the church pastor has told me not to. | 1 | 2 | 3 | 4 | 5 |
| 034_alcohol | When I drink alcohol I forget to take my ART pills. | 1 | 2 | 3 | 4 | 5 |
| 035_remind2 | I do not take my ART pills because I do not have someone to remind me to do so. | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| 037_food3 | I do not take my ART pills because<br>I cannot afford the food I need to eat when I take them. | 1 | 2 | 3 | 4 | 5 |
| 038_diabilitygrant | I do not take my ART pills in case my CD4 count increases and I may no longer qualify for a disability grant.<br>*Please tick this block if you do not receive a disability grant.* | 1 | 2 | 3 | 4 | 5 |
| 040_stigma4 | I do not take my pills because<br>I do not like taking them in front of my family. | 1 | 2 | 3 | 4 | 5 |

Hier volg 'n lys van stellings wat n paar redes stel waarom jy NIE JOU MEDIKASIE in die manier waarop jy verplig is neem nie: **Plaas 'n sirkel of merk een getal per lyn jou antwoord aan te dui.**

| | | **Nooit** | **Selde** | **Sommige van die tyd** | **Die meeste van die tyd** | **Altyd** |
|---|---|---|---|---|---|---|
| | | | | | | |
| 026_food | Ek ondervind dit moeilik om my ART pille te neem omdat ek nie altyd kos het om saam met dit te neem nie. | 1 | 2 | 3 | 4 | 5 |
| 027_food2 | As ek my ART pille neem as ek nie kos het om tee et nie, voel ek siek. | 1 | 2 | 3 | 4 | 5 |
| 028_stigma3 | Ek neem nie my pille as ek dit voor ander moet neem nie. | 1 | 2 | 3 | 4 | 5 |
| 029_remind | Ek neem nie my ART pille nie, omdat ek nie a manier het om my daaraan te herinner nie. | 1 | 2 | 3 | 4 | 5 |
| 030_employer | Ek neem nie my ART pille nie, want ek wil nie he my werkgewer moet weet dat ek dit gebruik nie. | 1 | 2 | 3 | 4 | 5 |
| 031_forget | Ek vergeet om pille te neem ART my. | 1 | 2 | 3 | 4 | 5 |
| 033_church | Ek neem nie my ART pille nie, omdat die kerk pastoor vir my gesê het om dit nie te gebruik nie. | 1 | 2 | 3 | 4 | 5 |
| 034_alcohol | As ek alkohol drink vergeet ek om my ART pille te neem. | 1 | 2 | 3 | 4 | 5 |
| 035_re | Ek neem nie my ART pille nie, omdat ek | 1 | 2 | 3 | 4 | 5 |

| | | | | | | |
|---|---|---|---|---|---|---|
| mind2 | nie iemand het om my daaraan te herinner nie. | | | | | |
| 036_t.healer2 | Ek neem nie my ART pille nie, omdat my tradisionele genesing vir my beter werk. | 1 | 2 | 3 | 4 | 5 |
| 037_food3 | Ek neem nie my ART pille nie, omdat ek nie die voedsel kan bekostig om te eet voor ek my medikasie neem nie | 1 | 2 | 3 | 4 | 5 |
| 038_diabilitygrant | Ek neem nie my ART pille nie in die geval as my CD4 verhoog is ek nie langer kan kwalifiseer vir die ongeskiktheids-toelaag nie.<br>Dui asseblief in hierdie blokkie aan as jy nie' n ongeskiktheids-toelaag ontvang nie. | 1 | 2 | 3 | 4 | 5 |
| 040_stigma4 | Ek ondervind dit moelik om my ART medikasie te neem, omdat ek nie daarvan hou om dit voor my familie te gebruik nie. | 1 | 2 | 3 | 4 | 5 |

**Addendum D: Barriers to PATIENTS' clinic attendance: SBS-3**

Below are some reasons that OTHER patients MAY NOT ATTEND THEIR CLINIC APPOINTMENTS. Please indicate to what extent YOU THINK these statements are true for people receiving medicines for HIV. Please circle or mark one number per line to indicate your response.

| | | Not true for any patients | True for some patients | True for most patients | True for all patients |
|---|---|---|---|---|---|
| | | | | | |
| 043_busstop | Patients do not attend clinic appointments because the clinic is too far from the bus stop/ taxi rank. | 1 | 2 | 3 | 4 |
| 044_transportexp | Patients do not attend clinic appointments because transport to the clinic is too expensive. | 1 | 2 | 3 | 4 |
| 045_travelclinic | Patients do not attend clinic appointments because it takes too much time to travel to and from the clinic. | 1 | 2 | 3 | 4 |
| 046_stigma5 | Patients do not attend clinic appointments because they do not want others to see that they receive HIV treatment. | 1 | 2 | 3 | 4 |
| 048_rude | Patients do not attend clinic appointments because some staff members at the clinic are rude to them. | 1 | 2 | 3 | 4 |
| 049_impatientstaff | Patients do not attend clinic appointments because some staff members at the clinic are impatient towards them. | 1 | 2 | 3 | 4 |
| 050_clinicprivacy | Patients do not attend clinic appointments because there is no privacy at the clinic when they meet with the nurse or counsellor. | 1 | 2 | 3 | 4 |
| 051_getoffwork | Patients do not attend clinic appointments because they cannot get time off work to | 1 | 2 | 3 | 4 |

| | | | | | |
|---|---|---|---|---|---|
| | do so. | | | | |
| 052_HCWtime | Patients do not attend clinic appointments because they have to wait too long to see the doctor, nurse, or pharmacist. | 1 | 2 | 3 | 4 |
| 053_unsafetowalk | Patients do not attend clinic appointments because they feel unsafe walking to the clinic. | 1 | 2 | 3 | 4 |
| 054_crowdedclinic | Patients do not attend clinic appointments because the clinic is too crowded. | 1 | 2 | 3 | 4 |
| 055_speaklang | Patients do not attend clinic appointments because the nurses do not speak their language. | 1 | 2 | 3 | 4 |

Hier is 'n paar redes waarom ANDER pasiënte NIE TEENWOORDIG BY HUL KLINIEK AFSPRAKE IS NIE.Dui asseblief aan in watter mate dink jy dat hierdie stellings waar is vir die mense wat medisyne vir MIV ontvang.Plaas 'n sirkel of merk een getal per lyn aan om jou antwoord aan te dui.

| | | **Nie waar vir enige pasiënte nie** | **Waar vir sommige pasiënte** | **Geld vir die meeste pasiënte** | **Geld vir alle pasiënte** |
|---|---|---|---|---|---|
| 043_bus stop | Pasiënte woon nie hul kliniek afsprake na nie, omdat die kliniek te ver is van die bus stop / taxi-staanplek. | 1 | 2 | 3 | 4 |
| 044_transportexp | Pasiënte woon nie hul kliniek afsprake na nie, omdat die vervoer na die kliniek te duur is. | 1 | 2 | 3 | 4 |
| 045_travelclinic | Pasiënte woon nie hul kliniek afsprake na nie, omdat dit te veel tyd vat om te reis na en van die kliniek af. | 1 | 2 | 3 | 4 |
| 046_stigma5 | Pasiënte woon nie hul kliniek afsprake na nie, omdat hulle nie wil he ander moet sien as hulle MIV-behandeling kry nie. | 1 | 2 | 3 | 4 |

| | | | | | |
|---|---|---|---|---|---|
| 047_stigma6 | Pasiënte woon nie hul kliniek afsprake na nie, want hulle wil nie geïdentifiseer word as MIV-positief is. | 1 | 2 | 3 | 4 |
| 048_rude | Pasiënte woon nie hul kliniek afsprake na nie, omdat die personeel by die kliniek onbeskof is met hulle. | 1 | 2 | 3 | 4 |
| 049_impatientstaff | Pasiënte woon nie hul kliniek afsprake na nie, omdat die personeel by die kliniek ongeduldig is teenoor hulle. | 1 | 2 | 3 | 4 |
| 050_clinicprivacy | Pasiënte woon nie hul kliniek afsprake na nie, omdat daar geen privaatheid is as hulle deur die verpleegpersoneel behandel word nie | 1 | 2 | 3 | 4 |
| 051_getoffwork | Pasiënte woon nie hul kliniek afsprake na nie, omdat hulle nie tyd kan afkry by die werk nie. | 1 | 2 | 3 | 4 |
| 052_HCWtime | Pasiënte woon nie hul kliniek afsprake na nie omdat die wagperiodesom die dokter, verpleegster of apteker te sien te lank is.. | 1 | 2 | 3 | 4 |
| 053_unsafetowalk | Pasiënte woon nie hul kliniek afsprake na nie omdat hulle onveilig voel om na en van die kliniek af te stap. | 1 | 2 | 3 | 4 |
| 054_crowdedclinic | Pasiënte woon nie hul kliniek afsprake na nie, omdat die kliniek oorvol is. | 1 | 2 | 3 | 4 |
| 055_speaklang | Pasiënte woon nie hul kliniek afsprake na nie, omdat die verpleegsters nie hul taal praat nie. | 1 | 2 | 3 | 4 |

**Addendum E: Barriers to PATIENTS' medication taking: SBS-4**

Below are some reasons that OTHER patients MAY NOT TAKE THEIR ART MEDICATION. Please indicate to what extent YOU THINK these statements are true for people receiving medicines for HIV. Please circle or mark one number per line to indicate your response.

| | | Not true for any patients | True for some patients | True for most patients | True for all patients |
|---|---|---|---|---|---|
| 056_nofood | Patients do not take their ART pills because they do not always have food with which to take them. | 1 | 2 | 3 | 4 |
| 057_food/ill | If patients take their ART pills when they do not have food to eat then they often feel ill. | 1 | 2 | 3 | 4 |
| 058_stigma7 | Patients do not take their ART pills if they have to take it in front of others. | 1 | 2 | 3 | 4 |
| 059_reminders | Patients do not take their ART pills because they do not have a way to remind themselves to take them. | 1 | 2 | 3 | 4 |
| 060_employers | Patients do not take their ART pills because they do not want their employers to know that they are HIV positive. | 1 | 2 | 3 | 4 |
| 061_forgetting | Patients do not take their ART pills because they forget to do so. | 1 | 2 | 3 | 4 |
| 063_Churches | Patients do not take their ART pills because the church pastors have told them not to. | 1 | 2 | 3 | 4 |
| 064_drinking | Patients forget to take their ART pills when they drink alcohol. | 1 | 2 | 3 | 4 |
| 065_remindersupport | Patients do not take their ART pills because they do not have someone to | 1 | 2 | 3 | 4 |

| | | | | | |
|---|---|---|---|---|---|
| | remind them to take it. | | | | |
| 066_Thealing | Patients do not take their ART pills because they believe traditional healing works better for them. | 1 | 2 | 3 | 4 |
| 067_affordfood | Patients do not take their ART pills because they cannot afford the food they need in order to take it. | 1 | 2 | 3 | 4 |
| 068_disability | Patients do not take their ART pills in case their CD4 count increases and they no longer qualify for a disability grant. | 1 | 2 | 3 | 4 |
| 070_stigma8 | Patients do not take their ART pills because they do not like taking it in front of their families. | 1 | 2 | 3 | 4 |

Hier is 'n paar redes waarom ANDER pasiënte NIE HUL ART MEDIKASIE gebruik nie. Dui asseblief aan watter mate dink jy dat hierdie stellings waar is vir die mense wat medisyne vir MIV ontvang. Sirkel asseblief of merk een getal per lyn om jou antwoord aan te dui.

| | | **Nie waar vir enige pasiënte** | **Waar vir somige pasiënte** | **Geld vir die meeste pasiënte** | **Geld vir alle pasiënte** |
|---|---|---|---|---|---|
| 056_nofood | Pasiënte neem nie hul ART pille nie omdat hulle nie altyd voedsel het om saam dit te neem nie. | 1 | 2 | 3 | 4 |
| 057_food/ill | As pasiënte hul ART pille sonder voedsel neem dan voel hulle dikwels siek. | 1 | 2 | 3 | 4 |
| 058_stigma7 | Pasiënte neem nie hul ART pille as hulle dit voor die ander moet neem nie. | 1 | 2 | 3 | 4 |
| 059_reminders | Pasiënte neem nie hul ART pille nie, omdat hulle nie self 'n manier het om hul daaraan te herinner om hulle te neem nie. | 1 | 2 | 3 | 4 |
| 060_employers | Pasiënte neem nie hul ART pille nie, omdat hulle nie wil hê dat hul werkgewers weet dat | 1 | 2 | 3 | 4 |

| | | | | | |
|---|---|---|---|---|---|
| | hulle MIV-positief is nie. | | | | |
| 061_forgetting | Pasiënte neem nie hul ART pille nie, omdat hulle vergeet om dit te doen.. | 1 | 2 | 3 | 4 |
| 063_Churches | Pasiënte neem nie hul ART pille nie, omdat hulle kerkpastore hulle vertel het om dit nie te neem nie. | 1 | 2 | 3 | 4 |
| 064_drinking | Pasiënte vergeet om hulle ART pille te neem as hulle alkohol drink. | 1 | 2 | 3 | 4 |
| 065_remindersupport | Pasiënte neem nie hul ART pille nie, omdat hulle nie iemand het om hul daaran te herinner nie. | 1 | 2 | 3 | 4 |
| 066_Thealing | Pasiënte neem nie hul ART pille nie, omdat hulle glo tradisionele genesing beter vir hulle werk. | 1 | 2 | 3 | 4 |
| 067_affordfood | Pasiënte neem nie hul ART pille nie, omdat hulle nie die kos wat hulle nodig kan bekostig om saam met dit te neem nie. | 1 | 2 | 3 | 4 |
| 068_disability | Pasiënte neem nie hul ART pille nie in die geval dat hul CD4 verhoog is ek nie langer kan kwalifiseer vir die ongeskiktheids-toelaag nie. | 1 | 2 | 3 | 4 |
| 070_stigma8 | Pasiënte neem nie hul ART pille nie, omdat hulle nie daarvan hou om dit voor hul gesinne te neem nie. | 1 | 2 | 3 | 4 |

**Addendum F: Participant flyer**

UNIVERSITEIT•STELLENBOSCH•UNIVERSITY
jou kennisvennoot • your knowledge partner

# PLEASE JOIN THIS STUDY!

## Assessing Barriers to adherence to ART

You are invited to participate in a study conducted by Stellenbosch University! All you have to do is complete a few forms and you will receive a R20 shopping voucher!!

## INTERESTED?

Please come and find the research assistant ☺

**Addendum G: Participant informed consent form**

## PARTICIPANT INFORMATION LEAFLET AND CONSENT FORM

**TITLE OF THE RESEARCH PROJECT:**

**THE DEVELOPMENT OF A SCALE TO ASSESS STRUCTURAL BARRIERS TO ANTIRETROVIRAL THERAPY ADHERENCE**

**PRINCIPAL INVESTIGATOR:**
**BRONWYNE COETZEE**

**ADDRESS:**
**28 FIR ROAD OAK GLEN BELLVILLE 7530**

**CONTACT NUMBER:**
**0722415028**

You are being invited to take part in a research project. Please take some time to read the information presented here, which will explain the details of this project. Please ask the study staff or doctor any questions about any part of this project that you do not fully understand. It is very important that you are fully satisfied that you clearly understand what this research entails and how you could be involved. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.

This study has been approved by the **Health Research Ethics Committee (HREC) at Stellenbosch University** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

### What is this research study all about?

The following study will be conducted at Helderberg Hospital, Ikhwezi Hospital and at the Philippi Trust (NGO) in Somerset West. Approximately 200 participants will be invited to take part in this study. The following study aims to develop a scale that can identify barriers that you as a patient experience when taking you ARV medication. The scale will help doctors and nurses to identify difficulties that you face and are then able to help you in overcoming them. If you agree to participate in this study you will complete 1. Demographic information. 2. The structural Barriers scales. 3. The functional assessment of HIV. 4. The SF-12 and lastly 5. The HSCL-25.

**Why have you been invited to participate?**

You have been invited to participate in this study because:

1. You have been diagnosed with a chronic illness.
2. You have been prescribed medication to control your illness.

**What will your responsibilities be?**

As a participant in this study you will have no direct responsibilities.

**Will you benefit from taking part in this research?**

As a participant it is not intended that you will benefit directly from this research. However, if the scale proves to identify structural barriers adequately clinicians will be able to help you and future patients with difficulties you face when taking your medication or attending clinic appointments. Your participation will help the researchers further their understanding of ART adherence.

*** Are there in risks involved in your taking part in this research?**

There are no foreseeable risks and you may stop your participation at any time. Should you become distressed at any point during the completion of the questionnaires you will be given information about where to seek psychological services. Should your involvement in the study cause severe psychological distress as any point, you will be referred to a trained counsellor. The costs concerned with treatment will be taken care of by the principal investigator.

**If you do not agree to take part, what alternatives do you have?**

If you do not wish to participate in the study, you are not obliged to continue in anyway. There are no alternatives available to this study.

**Who will have access to your medical records?**

The use of your medical records is not applicable to this study and therefore no one will have access to your records.

***What will happen in the unlikely event of some form injury occurring as a direct result of your taking part in this research study?**

This study poses no physical threat to you. Should any unforeseeable events occur the necessary services will be provided. Should your involvement in the study cause severe psychological distress as any point, you will be referred to a trained counsellor. The costs concerned with treatment will be taken care of by the principal investigator.

**Will you be paid to take part in this study and are there any costs involved?**

No you will not be paid to take part in the study but you will receive a R20 shopping voucher to thank you for your participation. There will be no costs involved for you, if you do take part.

You can contact **Bronwyne Coetzee** at cell: **072 241 5028** if you have any further queries or encounter any problems.
You can contact the **Health Research Ethics Committee** at **021-938 9207** if you have any concerns or complaints that have not been adequately addressed by your study doctor.
You will receive a copy of this information and consent form for your own records.

**Declaration by participant**

By signing below, I ……..……. agree to take part in a research study entitled *(insert title of study)*.

I declare that:

- I have read or had read to me this information and consent form and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the study doctor or researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…..…….. On (*date*) ……...…….. 2009.

..... .....
**Signature of participant** **Signature of witness**

**Declaration by investigator**

I Bronwyne Coetzee……..…… declare that:

- I explained the information in this document to ……..
- I encouraged him/her to ask questions and took adequate time to answer them.
- I am satisfied that he/she adequately understands all aspects of the research, as discussed above
- I did/did not use an interpreter. (*If an interpreter is used then the interpreter must sign the declaration below.*

Signed at (*place*) .....…….....…….. On (*date*) ……...…….. 2009.

..... .....

**Signature of investigator** **Signature of witness**

**Declaration by interpreter**

I *(name)* ……..…… declare that:

- I assisted the investigator (*name*) ……. to explain the information in this document to (*name of participant*) ……..…….. using the language medium of Afrikaans/Xhosa.
- We encouraged him/her to ask questions and took adequate time to answer them.
- I conveyed a factually correct version of what was related to me.
- I am satisfied that the participant fully understands the content of this informed consent document and has had all his/her question satisfactorily answered.

Signed at (*place*) .....…….....…….. on (*date*) ……...……..

..... .....

**Signature of interpreter** **Signature of witness**

# DEELNEMERINLIGTINGSBLAD EN -TOESTEMMINGSVORM

**TITEL VAN DIE NAVORSINGSPROJEK:**

**DIE ONTWIKKELING VAN 'N SKAAL OM STRUKTURELE HINDERNISSE TOT ANTIRETROVIRALE TERAPIE TE ASSESSEER**

**HOOFNAVORSER:**

**BRONWYNE COETZEE**

**ADRES:**

**28 FIR LAAN OAKGLEN BELLVILLE 7530**

**KONTAKNOMMER:**

U word genooi om deel te neem aan 'n navorsingsprojek. Lees asseblief hierdie inligtingsblad op u tyd deur aangesien die detail van die navorsingsprojek daarin verduidelik word. Indien daar enige deel van die navorsingsprojek is wat u nie ten volle verstaan nie, is u welkom om die navorsingspersoneel of dokter daaroor uit te vra. Dit is baie belangrik dat u ten volle moet verstaan wat die navorsingsprojek behels en hoe u daarby betrokke kan wees. U deelname is ook **volkome vrywillig** en dit staan u vry om deelname te weier. U sal op geen wyse hoegenaamd negatief beïnvloed word indien u sou weier om deel te neem nie. U mag ook te eniger tyd aan die navorsingsprojek onttrek, selfs al het u ingestem om deel te neem.

**Hierdie navorsingsprojek is deur die** Komitee vir Mensnavorsing van die Universiteit Stellenbosch **goedgekeur en sal uitgevoer word volgens die etiese riglyne en beginsels van die Internasionale Verklaring van Helsinki en die Etiese Riglyne vir Navorsing van die Mediese Navorsingsraad (MNR).**

**Wat behels hierdie navorsingsprojek?**

*Die volgende studie sal gedoen word by Helderberg Hospitaal, Ikhwezi-hospitaal en* by die Philippi Trust (NRO's) in Somerset-Wes. Ongeveer 200 deelnemers sal genooi word om deel te neem aan hierdie studie. Die doel van hierdie studie is om n skaal te ontwikkel wat die strukturele hindernisse wat u as pasient ervaar wanneer u ARV-medisyne neem te identifiseer. Die skaal sal dokters en verpleegsters help om struikelblokke wat u nakom te identifiseer en dan u hulp dit oorkom . As U deel neem aan hierdie studie sal u die volgende voltooi 1. Persoonlike inligtig 2. Die strukturele Hinderniss Skaal 3. Die FAHI 4. Die SF12V2 en 5. Die HSCL-25.

**Waarom is u genooi om deel te neem?**

U is uitgenooi om deel te neem aan hierdie studie omdat:

1. U gediagnoseer is met 'n chroniese siekte.
2. U gebruik voorgeskrewe medikasie om U siekte te *beheer.*

**Wat sal u verantwoordelikhede wees?**

As „n deelnemer aan hierdie studie het u geen direkte verantwoordelikhede nie.

**Sal u voordeel trek deur deel te neem aan hierdie navorsingsprojek?**

As 'n deelnemer is dit nie bedoel dat u direk sal baat uit hierdie navorsing nie. Maar, as die skaal bewys om strukturele hindernisse voldoende te identifiseer sal klinici in staat wees om met u en toekomstige pasiënte se probleme met die neem van medikasie of bywoning van jou kliniek afsprake te help. Jou deelname sal navorsers help om ART behandeling beter te verstaan.

**Is daar enige risiko's verbonde aan u deelname aan hierdie navorsingsprojek?**

Daar is geen voorsienbare risiko's nie en jy kan om enige tyd jou deelname aan die studie stop. As u ongemaklik of benoud raak op enige tyd tydens die voltooiing van die vraelyste, sal inligting oor sielkundige dienste aan u verskaf word. Indien u betrokkenheid by die studie ernstige sielkundige nood benodig , sal u verwys word na' n opgeleide berader. Die koste betrokke by die behandeling sal verskaf word deur die hoof ondersoeker.

**Watter alternatiewe is daar indien u nie instem om deel te neem nie?**

As u nie wil deelneem aan die studie nie, is u nie verplig om voort te gaan nie. Daar is geen alternatiewe beskikbaar vir die studie nie.

**Wie sal toegang hê tot u mediese rekords?**

Die gebruik van u mediese rekords is nie van toepassing op hierdie studie nie, en dus sal niemand toegang tot u rekords he nie.

**Wat sal gebeur in die onwaarskynlike geval van ’n besering wat mag voorkom as gevolg van u deelname aan hierdie navorsingsprojek?**

Hierdie studie het geen fisiese bedreiging tot u nie. Indien enige onvoorsiene gebeure plaasvind sal die nodige dienste voorsien word. Indien u betrokkenheid by die studie ernstige sielkundige nood benodig, sal u verwys word na' n opgeleide berader. Die koste betrokke by die behandeling sal verskaf word deur die hoof ondersoeker.

**Sal u betaal word vir deelname aan die navorsingsprojek en is daar enige koste verbonde aan deelname?**

Nee u sal nie betaal word om deel te neem aan die studie, maar u sal 'n R20 geskenkbewys ontvang om u te bedank vir u deelname. Daar sal geen koste aan u verbonde wees om aan die studie deel te neem nie.

U kan **Bronwyne Coetzee** kontak by **072 241 5028** indien u enige verdere navrae of probleme.

U kan die **Komitee vir Mensnavorsing** kontak by 021-938 9207 indien u enige bekommernis of klagte het wat nie bevredigend deur u studiedokter hanteer is nie.

U sal ’n afskrif van hierdie inligtings- en toestemmingsvorm ontvang vir u eie rekords.

**Verklaring deur deelnemer**

Met die ondertekening van hierdie dokument onderneem ek,

…….....……...……..……., om deel te neem aan ’n navorsingsprojek getiteld

(*Titel van navorsingsprojek).*

**Ek verklaar dat:**

- Ek hierdie inligtings- en toestemmingsvorm gelees het of aan my laat voorlees het en dat dit in ’n taal geskryf is waarin ek vaardig en gemaklik mee is.
- Ek geleentheid gehad het om vrae te stel en dat al my vrae bevredigend beantwoord is.
- Ek verstaan dat deelname aan hierdie navorsingsprojek **vrywillig** is en dat daar geen druk op my geplaas is om deel te neem nie.
- Ek te eniger tyd aan die navorsingsprojek mag onttrek en dat ek nie op enige wyse daardeur benadeel sal word nie.
- Ek gevra mag word om van die navorsingsprojek te onttrek voordat dit afgehandel is indien die studiedokter of navorser van oordeel is dat dit in my beste belang is, of indien ek nie die ooreengekome navorsingsplan volg nie.

Geteken te *(plek*) .....……. op *(datum*) ……...…….. 2005.

..... .....

**Handtekening van deelnemer** **Handtekening van getuie**

**Verklaring deur navorser**

Ek *Bronwyne Coetzee* verklaar dat:

- Ek die inligting in hierdie dokument verduidelik het aan …….....…….

- Ek hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek tevrede is dat hy/sy al die aspekte van die navorsingsprojek soos hierbo bespreek, voldoende verstaan.
- Ek 'n tolk gebruik het/nie 'n tolk gebruik het nie. (*Indien 'n tolk gebruik is, moet die tolk die onderstaande verklaring teken.)*

Geteken te *(plek*) .....…….. op *(datum*) ……...…….. 2005.

..... .....

**Handtekening van navorder** **Handtekening van getuie**

**Verklaring deur tolk**

Ek *(naam)* ……..…… verklaar dat:

- Ek die navorser *(naam*) …….....……. bygestaan het om die inligting in hierdie dokument in Afrikaans/Xhosa aan *(naam van deelnemer)* …….....  te verduidelik.
- Ons hom/haar aangemoedig het om vrae te vra en voldoende tyd gebruik het om dit te beantwoord.
- Ek 'n feitelik korrekte weergawe oorgedra het van wat aan my vertel is.
- Ek tevrede is dat die deelnemer die inhoud van hierdie dokument ten volle verstaan en dat al sy/haar vrae bevredigend beantwoord is.

Geteken te *(plek)* .....…….. op *(datum)* ……...…….. 2005.

| | |
|---|---|
| ..... | ..... |
| **Handtekening van tolk** | **Handtekening van getuie** |

## Addendum H: Health Research Ethics Committee of the University of Stellenbosch

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

13 September 2010 **MAILED**

Ms B Coetzee
Department of Psychology
Stellenbosch University
Private Bag X1
Matieland
7602

Dear Ms Coetzee

**"The development of a scale to assess structural barriers to adherence to antiretroviral therapy."**

**ETHICS REFERENCE NO: N10/02/041**

**RE : USE OF PATIENT ADVOCATES FOR DATA COLLECTION**

Your letter dated 10 August 2010 refers.

The chairperson of Health Research Ethics Committee has approved your request to use patient advocates for data collection.

Yours faithfully

**MR FRANKLIN WEBER**
**RESEARCH DEVELOPMENT AND SUPPORT**
Tel: +27 (0)21 938-9657 / E-mail: fweb@sun.ac.za
Fax: +27 (0)21 931-3352

13 September 2010 14:28 Page 1 of 1

Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

Verbind tot Optimale Gesondheid · Committed to Optimal Health
**Afdeling Navorsingsontwikkeling en -steun · Division of Research Development and Support**
Posbus/PO Box 19063 · Tygerberg 7505 · Suid-Afrika/South Africa
Tel.: +27 21 938 9075 · Faks/Fax: +27 21 931 3352

UNIVERSITEIT·STELLENBOSCH·UNIVERSITY
jou kennisvennoot • your knowledge partner

26 March 2010 **MAILED**

Ms B Coetzee
Department of Psychology
Stellenbosch University
Private Bag X1
Matieland
7602

Dear Ms Coetzee

**"The development of a scale to assess structural barriers to adherence to antiretroviral therapy."**

**ETHICS REFERENCE NO: N10/02/041**

**RE : APPROVAL**

At a meeting of the Health Research Ethics Committee that was held on 3 March 2010, the above project was approved on condition that further information is submitted.

This information was supplied and the project was finally approved on 26 March 2010 for a period of one year from this date. This project is therefore now registered and you can proceed with the work.

Please quote the above-mentioned project number in ALL future correspondence.

Please note that a progress report (obtainable on the website of our Division: www.sun.ac.za/rds should be submitted to the Committee before the year has expired. The Committee will then consider the continuation of the project for a further year (if necessary). Annually a number of projects may be selected randomly and subjected to an external audit.
Translations of the consent document in the languages applicable to the study participants should be submitted.

Federal Wide Assurance Number: 00001372
Institutional Review Board (IRB) Number: IRB0005239
The Health Research Ethics Committee complies with the SA National Health Act No.61 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 Part 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes 2004 (Department of Health).

Please note that for research at a primary or secondary healthcare facility permission must still be obtained from the relevant authorities (Western Cape Department of Health and/or City Health) to conduct the research as stated in the protocol. Contact persons are Ms Claudette Abrahams at Western Cape Department of Health (healthres@pgwc.gov.za Tel: +27 21 483 9907) and Dr Hélène Visser at City Health (Helene.Visser@capetown.gov.za Tel: +27 21 400 3981). Research that will be conducted at any tertiary academic institution requires approval from the relevant hospital manager. Ethics approval is required BEFORE approval can be obtained from these health authorities.

Approval date: 26 March 2010 Expiry date: 26 March 2011



Fakulteit Gesondheidswetenskappe · Faculty of Health Sciences

## Addendum I: The Western Cape Department of Health

26.APR.2010 11:46 0214839335 MDHS #5243 P.001 /001

Verwysing
Reference
Isalathiso RP59 /2010

Navrae
Enquiries
Imibuzo Dr A Dearham

Telefoon
Telephone
Ifowuni 021 483 4193

Department van Gesondheid
Department of Health
iSebe lezeMpilo

Department of Psychology
Stellenbosch University
Private Bag X1
Matieland
7602
FAX: 021 8083584

Dear Ms Coetzee

RE The development of an inventory to assess structural barriers to adherence to antiretroviral therapy.

Thank you for submitting your proposal to undertake the above-mentioned study. We are pleased to inform you that the department has granted you approval for your research. Please contact the following members of staff to assist you with access to the facilities:

**Helderberg Hospital – Dr Erasmus or Dr Stuve 021 8511170**

Kindly ensure that the following are adhered to:

1. Arrangements can be made with managers, providing that normal activities at requested facilities are not interrupted.
2. Researchers, in accessing provincial health facilities, are expressing consent to provide the department with an electronic copy of the final report within six months of completion of research. This can be submitted to the provincial Research Co-ordinator (healthres@pgwc.gov.za).
3. The reference number above should be quoted in all future correspondence.

We look forward to hearing from you.

Yours sincerely

DR J CUPIDO
DEPUTY-DIRECTOR GENERAL
DISTRICT HEALTH SERVICES AND PROGRAMMES
DATE: 15/04/2010

CC: DR E ERASMUS MS: HELDERBERG HOSPITAL

Page 1 of 2

Dorpstraat 4
Posbus 2060
KAAPSTAD
8000

4 Dorp Street
PO Box 2060
CAPE TOWN
8000

## Addendum J: The City of Cape Town

CITY OF CAPE TOWN | ISIXEKO SASEKAPA | STAD KAAPSTAD
CITY HEALTH — City Health

2010-05-07

**Re: Research Request: The development of an inventory to assess structural barriers to adherence to antiretroviral therapy (ID: 10174)**

Dear Ms Coetzee,

Permission has been granted for you to do the research as per your protocol at Ikhwezi Clinic subject to space being available.

**Contact People:**

Dr P Nkurunziza: Sub District Manager: Eastern Sub District

Tel/Cell: (021) 850-4315 / 084 800 0644

Ms T Mgqweto: Head: Personal PHC & Programme

Tel/Cell: (021) 850-4312 / 084 222 1487

**Please note the following:**

1. Space at Ikhwezi Clinic is very problematic and this will have to be negotiated with the relevant Managers. Researchers often hire space from other organisations close to the clinic e.g. schools or NPO's
2. All individual patient information obtained must be kept confidential.
3. Access to the clinic and its patients must be arranged with the relevant Manager such that normal activities are not disrupted.
4. A copy of the final report must be sent to the City Health Head Office, P O Box 2815 Cape Town 8001, within 3 months of its completion and feedback must also be given to the clinic involved.

5. Your project has been given an ID Number (10174). Please quote this in any future correspondence regarding this project.

Thank you for your co-operation and contact me if you require any further information or assistance.

Yours sincerely

Dr G H Visser

Manager: Specialised Health

cc. Dr P Nkurunziza & Ms T Mgqweto

Dr K Jennings