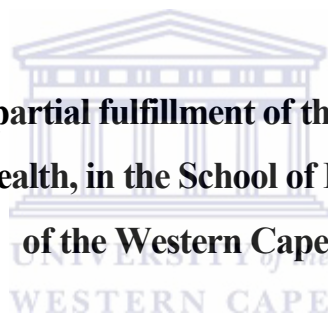


**BARRIERS TO ADHERENCE TO ANTIRETROVIRAL TREATMENT IN
A REGIONAL HOSPITAL IN VREDENBURG, WESTERN CAPE**

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**A mini-thesis submitted in partial fulfillment of the requirements for the degree
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ABBREVIATIONS AND ACRONYMS

AIDS	Acquired immunodeficiency syndrome
PLWHA	People living with HIV and AIDS
PLWH	People living with HIV
UNAIDS	Join United Nations Programme on HIV and AIDS
WHO	World Health Organization
HAART	Highly Active Antiretroviral Therapy
ART	Antiretroviral Therapy
ARV	Antiretroviral
STIs	Sexually Transmitted Infections
TB	Tuberculosis
MSF	Médecins Sans Frontières
CD4	Cluster of Differentiation 4
DOT	Directly Observed Therapy
DoH	Department of Public Health
MEMS	Medication Events Monitoring System
NGO	Non Governmental Organization
FBO	Faith Based Organization
VCT	Voluntary Testing and Counseling
HTC	HIV Testing and Counseling
PMTCT	Prevention of Mother to Child Transmission
NPS	National Strategic Plan
SADC	South African Development Community

ABSTRACT

Background

South Africa has one of the most severe HIV epidemics globally, with an estimated 737,000 AIDS related deaths annually and over a million children rendered orphans due to AIDS in 2006. However in 2007, the South African government made a giant commitment to dealing effectively with the AIDS epidemic by implementing a National Strategic Plan (NSP), which had as one of its principal objectives the provision of antiretroviral medications to 80% of all people in need of the treatment by 2011. By the end of June 2011, the rollout of antiretroviral therapy continued to be successful with 1.4 million persons started on antiretroviral therapy and treatment initiation rates reaching 30, 000 per month.

Patients have to subject to an uncompromising adherence of taking at least 95% of antiretroviral medication as prescribed, because poor adherence to ART leads to treatment failure, viral mutations and the development of drug resistance. Of major concern to ART programmes are the current obstacles that patients' face in lieu of treatment.

Aim

The aim of this study was to explore the barriers to adherence to antiretroviral treatment among patients in a public ART programme in Vredenburg, Western Cape.

Methodology

An explorative qualitative study was conducted where data was collected through interviews with 18 patients receiving treatment from the Vredenburg hospital. Data was audio-tape recorded, transcribed in full and thematic content analysis done.

Results

The study identified awareness of HIV status, disclosure, unemployment, lack of transport, insufficient feeding, disability grants, alcohol and alternative forms of therapy as well as stigma as major barriers to adherence. Whereas inadequate follow ups, recklessness in the way patients' HIV results were handled, long waiting times and the fear of picking up other types of infections from other patients in the OPD also came under major criticisms from patients. Finally, the sharing of experiences at clinic visits, good healthcare provider's patient relationships, believing in the treatment, good treatment literacy, being a parent and having children to take care of, the use of pill boxes, social and spiritual support from family members and friends were identified as factors that positively influenced adherence.

Conclusion

HIV/AIDS has been a stigmatized illness since its onset in the early 1980s and, these results highlight that such stigma has yet to dissipate in Vredenburg. Therefore, stigma and disclosure must remain at the forefront of the ART programme implementation in Vredenburg; while long term projects that can support ART users economically should be created through partnerships with non-governmental organizations and the government of South Africa to optimize adherence in the community.



DECLARATION

I declare that, “Barriers to Adherence to Antiretroviral Treatment in Vredenburg, Cape Town, Republic of South Africa,” is my own work, that it has not been submitted for any degree examination in the university and that all the sources I have used or quoted have been indicated and acknowledge by complete references.

Full Name:AZIA IVO NCHENDIA

Signed: Date:



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CHAPTER ONE

INTRODUCTION

1.1 Background

HIV/AIDS is one of the leading causes of death worldwide with an estimated 22.4 million people known to be living with HIV globally in 2008 (UNAIDS, 2009). Sub-Saharan Africa remains the most severely affected region accounting for 67% of all global HIV infections, 68% of all new infections among adults and 91 % of new infections among children (*ibid*). Of the estimated total of 22.4 million people infected with HIV infections globally in 2008, South Africa had the highest number, with over 5.7 million people living with HIV, including 300,000 children below the age of 15 years old (*ibid*). South Africa was considered to have the most severe HIV/AIDS epidemic, with an estimated 737,000 AIDS-related deaths and over a million children rendered orphans due to AIDS related deaths in 2006 (Van Wyk *et al.*, 2006; Shaik, 2007). However in 2007, the South African government made a giant commitment to dealing effectively with the AIDS epidemic by appointing a new minister of health who pledged to implement a National Strategic Plan (NSP) that included a target of providing antiretroviral drugs (ARV) to 80% of all people in need of the treatment by 2011 (NSP, 2007). By the end of November 2009, over 940,000 patients were already enrolled on the national ART programme.

Antiretroviral medications are essential components of comprehensive approaches to curbing the HIV/AIDS epidemic (Simon, Frick, Lockhart & Liebovitz, 2002). Remarkable benefits have been recorded globally especially in Sub-Saharan Africa from the use of ART in the management of HIV/AIDS, following their introduction in the early 1990s (Palella, 1998; Hogg, 1998). Even though antiretroviral medications do not cure HIV/AIDS, they have demonstrated outstanding results in reducing the viral load of people living with HIV/AIDS (PLWHA), reinforcing their immune systems and hence curbing HIV/AIDS related morbidity and mortality (Holmes *et al.*, 2007). In low income countries such as Uganda, the use of ART has been acknowledged to decrease HIV transmission by 50% (Gray *et al.*, 2003; Chi-Tai *et al.*, 2004; Spacek *et al.*, 2006). ART have reduced mortality in HIV infected populations by 95% while significantly decreasing mother-to-child transmission of HIV (Mermin *et al.*, 2008). The appropriate utilization of ART has equally improved the CD4 cell counts of HIV/AIDS patients thus changing the nature of AIDS from a disease with a death sentence to a chronic and more controllable illness (Ledergerber *et al.*, 1999).

However, in order to enjoy these massive benefits of antiretroviral medication, patients must subject to an uncompromising and long-term optimal adherence of taking at least 95% of their antiretroviral medication as prescribed (Miller & Hays, 2000). It has been established that poor adherence is well known to accelerate the progression of HIV to AIDS, the development of multidrug resistance and even death due to opportunistic infections (Weiser *et al.*, 2003).

1.2 Forms of Adherence

According to WHO (2003), adherence is defined as the ability of patients to follow their treatment plans, take their different medications at prescribed times and frequencies, and also follow restrictions regarding their life styles, food and other medications. Adherence to ART of over 95% as prescribed by the doctors including restrictions regarding life styles, food and other medications is known as optimal adherence (WHO, 2003). This form of adherence has been proven to yield the most desirable health benefits of viral suppression and the improvement of the CD4 cell counts of HIV/AIDS patients (Miller & Hays, 2000; Paterson *et al.*, 2000; Gross *et al.*, 2001; Lyon *et al.*, 2003). Adherence rates to ART of between 70% and 89% are considered as sub-optimal adherence (Bangsberg *et al.*, 2003; Hardy, 2003). Unlike other chronic diseases where sub-optimal adherence rates are acceptable, in ART sub-optimal adherence is associated with the harmful consequences of drug resistance (Bangsberg *et al.*, 2003; Hardy, 2003). It has been demonstrated that sub-optimal adherence levels of between 70% and 95% are associated with the highest probability of developing drug resistance. This is because drug exposure at this level of adherence is insufficient to achieve viral suppression but still high enough to provide a selective pressure. The selective pressure exerted by inadequate uses of ART causes rapid emergence of mutations and drug resistance. This puts the moderately well but not perfect adherers at even a higher risk of developing drug resistance compared to the poorer adherers (Bangsberg *et al.*, 2003; Hardy, 2003).

Hill *et al.* (2003) conducted a study to explore patterns and explanations of adherence to antiretroviral therapies from patients' perspectives through 78 in-depth interviews with patients attending an HIV clinic in New Orleans and Louisiana. In this study most respondents did not consider taking ART for a few days as inadequate adherence vis-à-vis not taking it for several weeks or months. The perception by ART users that sub-optimal adherence to ART is acceptable is unsafe to ART programmes as it can mislead patients and cause them to develop drug resistance. It has been equally cautioned that when aiming to improve adherence great care should be taken to avoid increasing it just enough to put the

ART users at a high risk group of sub-optimal adherence (Hill *et al.*, 2003). Further research on sub-optimal adherence and the factors influencing it, is critical in this era of rapid ART rollouts to avert the development of drug resistance.

1.3 Forms of Non-adherence

When patients fails to adhere to instructions given to them regarding their antiretroviral medications or follow restrictions regarding their life styles, food and other medications they are said to be non-adherent (WHO, 2003). Studies seeking to understand non-adherence to ART have identified three forms of non-adherence namely: *erratic* non-adherence, *unwitting* non-adherence and *intelligent* non-adherence (Donovan & Blake, 1992).

Erratic non-adherence

Erratic non-adherence is the form of non-adherence in which patients understand their prescriptions and are willing to adhere to the prescriptions, but they still skip doses because of other factors out of their control such as: forgetfulness, changing schedules or busy life styles or because they have not yet prioritized the management of their health problem. Erratic non-adherence is considered the most regular and most recognized form of non-adherence in chronic diseases such as AIDS (WHO, 2003; Donovan & Blake, 1992). Documented strategies that have yielded good results in curbing erratic non-adherence for other chronic diseases which can be deployed to decrease erratic non-adherence to ART include: once dosing, learning new habits and the use of memory aids and pills organizers (WHO, 2003).

Unwitting non-adherence

Unwitting non-adherence is another form of non-adherence in which patients may be involuntarily non-adherent to prescribed therapies because they failed to understand fully the specifics of the regimen or the necessity of adherence (WHO, 2003). Studies in both urban and rural settings have demonstrated that 13% to 14% of patients often misunderstand their prescriptions (Bangsberg *et al.*, 2001; Miller & Hays, 2000). Some reasons for the prevalence of unwitting non-adherence to regimens include the use of pill bottles, or pill boxes or packages not carrying proper labels with clear dosing instructions. This form of non-adherence will most likely occur in settings where high levels of illiteracy predominate or where instructions are given to the patients through translators or in other languages not well mastered by the patients. It is of utmost importance to health care providers to therefore ensure that patients understand their ART regimens including food, water and life style

restrictions to enable them adhere properly to ART and obtain the health benefits associated with consistent adherence (Bangsberg *et al.*, 2001; Miller & Hays, 2000).

Intelligent non-adherence

Intelligent non-adherence like other forms of non-adherence is the only form of non-adherence in which patients calculatingly alter, discontinue or even fail to take their therapy as prescribed (WHO, 2003). Patients may exhibit this form of non-adherence in chronic diseases due to: feeling better, stigma and discrimination, fear of perceived short or long-term side effects, bad taste of the therapy and or the complexity of the therapy interfering with the daily lives of the patients (WHO, 2003). Though combating intelligent non-adherence may be intricate, understanding it can greatly enhance the development of strategies that will optimize adherence and the prevention of drug resistance in ARV users exhibiting this form of non-adherence.

1.4 Challenges to Life-time Adherence

Despite the immense benefits derived from appropriate antiretroviral therapy use to PLWHA, public health, and health care providers; sustaining ART adherence is still a major challenge to many ART programmes worldwide (Weiser *et al.*, 2003). In South Africa sustaining adherence rates of greater than 95% to ART medications has been a challenge to both the healthcare providers and HIV/AIDS patients due to the many barriers that hinder them from achieving their desired treatment success rates (MSF, 2010). Presently, many ART programmes are concerned about the obstacles that patients are faced with which interrupt their commitment to ARV medications (Mombassa ART Project, 2004). Although some forms of supports have been provided by ART programmes to help patients adhere to treatment, in South Africa like in Botswana, Tanzania and Uganda, most common barriers to adherence faced by HIV/AIDS patients include: financial, social, cultural, religious and health care systems constraints (Hardon, 2006). The ART service providers themselves also face political, human resources, infrastructural and financial constraints that prevent them from achieving the desired service delivery goals (MSF, 2010). Given that adherence to ART medication is a dynamic process, current knowledge of the obstacles that interrupt HIV/AIDS clients from their daily commitments to taking ARV medications is of critical importance to ART programmes in many parts of the world.

1.5 Problem Statement

According to the project manager of the HIV/AIDS initiative group which offers voluntary counseling and testing in Vredenburg, HIV stigmatization, discrimination and denial still persist in the town; and as a result of it, only a very few people come for HIV testing (Palitza, 2010). Most HIV infected people in Vredenburg only find out about their HIV status when they have repeated incidences of opportunistic infections such as TB; and by the time they get treated of the opportunistic infections to enable them start with their ART, it becomes too late (Palitza, 2010). Although the TB/HIV Care Association, an NGO in Cape Town, has trained home-based care workers to support HIV/AIDS clients on ART in Vredenburg and in so doing counter HIV/AIDS related stigma in the community, no studies have been conducted in Vredenburg to ascertain the range and extend of the barriers these HIV/AIDS patients face while on treatment.

1.6 Outline of the Mini-thesis

The description of the study, its findings and recommendations are covered in:

Chapter 1: Introduction

Chapter 2: Literature Review

Chapter 3: Research Methodology

Chapter 4: Presentation of Results

Chapter 5: Discussion of Results

Chapter 6: Conclusions, recommendations, suggestions for further research and the strengths and limitations of the study.

Summary

This chapter highlighted the present situation of the HIV epidemic and the rollout of ART in South Africa. It also looked at three major forms of non-adherence and the challenges to life-time adherence to therapy. The chapter was then concluded with the problem statement for the study and an outline of the mini-thesis.



CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter will focus on a succinct description of HIV care and treatment in South Africa, followed by a review of factors that influence ARV users to fall short in their daily commitments to taking their ARVs as prescribed by the doctors.

2.2 HIV Care and Treatment in South Africa

HIV testing

In South Africa, there are numerous entry points into HIV care which include: VCT venues, prevention of mother to child transmission (PMTCT) programmes, clinics offering reproductive health and sexually transmitted infection (STI) services, hospitals, prisons, primary healthcare facilities and TB clinics (DOH, 2004). VCT services are usually offered free of charge in all the primary healthcare clinics and community health centers upon request by clients. Before an HIV test, pre-testing counseling is provided by a community health worker, while the actual testing is done by registered nurses and the results are made available between five to ten minutes (Ruud, Srinivas & Toverud, 2009). All clients who take the HIV test receive personal post-test counseling together with their HIV tests results. These counseling sessions are sometimes accompanied by appropriate support and advice depending on their HIV-status. A provider-initiated HIV testing and counseling (HTC) approach for all patients whose clinical presentations might result from underlying HIV infections, is now recommended by the South African development community (SADC) as a standard part of medical care for all patients attending healthcare facilities (Setswe, 2009). The approach has yielded better results than the previous VCT approach, as it is presently increasing HTC uptake and the timely identification of PLWHA who should be on HIV care by instigating HIV testing in all clients who use the healthcare facilities (*ibid*).

Patient initiation on ART

Following the South African 2010 clinical guidelines for the management of HIV and AIDS in adults and adolescences, the initiation of adults and adolescents on ART is based on both medical and psycho-social factors that are assessed by a multidisciplinary team of experts (DOH, 2010). However, the final decisions for initiation are made at the discretion of the health care provider (HCP) team, after taking into consideration the prognosis as determined

by the CD4 cell count and the viral load of the patients, the potential risks and benefits of ART as well as the readiness of the patients to start with long-term therapy (DOH, 2010). Positive patients not yet eligible for ART are usually transferred to wellness programmes for regular follow up and repeated clinical assessments for about 6 months, while those initiated on ART are still followed up at the district hospital for three to six months, to monitor adherence and any drug reactions (Ruud, *et al.*, 2009). Even though loss of follow up sometimes occur, special records of patients who are expected to return to the PHC clinics are kept, should they not honour their appointments at the clinics. Common reasons for not respecting referral dates to report to the PHC clinics by patients include adverse drug reactions or poor responses to the therapy (Ruud *et al.*, 2009). Nevertheless, patients who encounter complications are either referred to the district hospitals or can return to the PHC clinics on specific dates during which a doctor is available to consult them. In other cases, where appropriate expertise exists, ART may also be initiated at the primary and community level where the patients will receive counseling, nutritional support psychosocial support and appropriate social welfare evaluation when necessary (DOH, 2003). Central in the achievement of good patient follow-up and continuity of HIV care are important linkages for care and support, facilitated by nurses and/or counselors in the communities through: subsidiary community-based services as home based care, care provided by traditional health practitioners, hospices, and calming care provided by a range of non-governmental organizations (NGOs), faith based organizations (FBOs) and support groups run by PLWHA.

2.3 Barriers to Adherence

Globally, a variety of obstacles are known to inhibit ART users from taking their medications as prescribed which have resulted in HIV/AIDS related morbidity and mortality. These barriers to adherence to ART have been documented and categorized as: socioeconomic, healthcare team and system-related, therapy-related and patient-related factors (WHO, 2003).

2.3.1 Socioeconomic Barriers

Demographic variables such as: age, gender, ethnicity and level of education are known to be inconsistent in predicting adherence (Moralez *et al.*, 1998). The potency of demographic characteristics in influencing adherence to ART is closely examined below.

Age

In a review of published articles and abstract reports on patient's adherence to HIV medication regimens, Fogarty *et al.* (2002) found that personal attributes showed a mixed relationship in

which gender was not consistently related to adherence while younger age was associated to lower adherence. Similarly, in a study carried out in Burundi, Cameroon and the Democratic Republic of Congo, Newman *et al.* (2011) demonstrated better adherence among older people compared to younger people. A number of factors related to: family issues, unreliable care givers, and fear of being different from their peers, unpalatable liquids and forgetfulness have been identified to contribute to poor adherence among young adults and children (Heyer & Ogunbanjo, 2006).

Gender

More often than not evidence regarding the relationship between adherence and gender is generally weak (Fogarty *et al.*, 2002; Orrell, Bangsberg & Wood, 2003; Safren *et al.*, 2005). Nonetheless, in Nigeria, being a woman and less than 35 years old have also been associated with poor adherence (Ozuchukwu *et al.*, 2009). On the other hand, Godin *et al.* (2005) found that Canadian men were twice as likely to be adherent compared to the women. Similarly, lower adherence in women compared to men has been reported by Zorrilla (2000) in the United States of America. This author explained that the multiple roles of women in their families as care givers and their fear of disclosing their HIV status to others are some of the remote factors resulting to the low adherence rates in women compared to men. Another study that looked at adherence in injecting drug users (IDU) in Vancouver, Canada revealed that despite the universal access to free HIV treatment and medical care, female IDU were still less likely to access and adhere to ART (Tapp *et al.*, 2011). In African communities as well, poor adherence among women have been linked to the fear of maltreatment from their husbands should they disclose their HIV status first in their relationships. This fear of abuse in marital homes as a result of being HIV positive causes women to hide or to stop taking their ARVs in the presence of their husbands or other family members (De Paoli, 2010).

Ethnicity

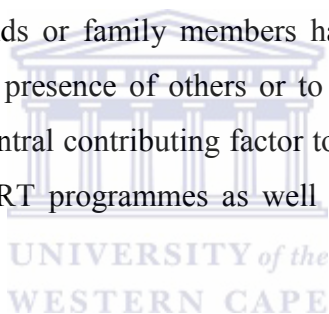
While Fogarty *et al.* (2002) reported lower adherence among minority groups in a review of published articles and abstract reports on patient's adherence to HIV medication regimens, Wagner *et al.* (2002) found no association between adherence and ethnicity in African American males on ART in Los Angeles. Even though Mannheimer (2002) found that poor adherence was associated with non-white races, most of the studies that have looked at adherence and ethnicity have been done in the developed world especially in North America and cannot be used as a prognostic evidence for Southern Africa (Heyer & Ogunbanjo, 2006).

2.3.2 Social Barriers

Adherence to ART is a multifaceted problem that involves a wide range of variables. Social variables such as stigma and discrimination, disclosure and lack of social support are important factors that influence it.

Stigma and discrimination

From a sociological background, stigma is an attribute, behaviour, or reputation which is socially discrediting in a particular way; it causes an individual to be mentally classified by others in an undesirable, rejected stereotype rather than in an accepted, normal way (Reitzer, 2006). As a result of stigma, people who suffer from certain chronic diseases as AIDS, leprosy and tuberculosis are treated differently; in most cases they are not treated decently. From the early 1980s, HIV/AIDS has been a stigmatized illness and as a result of the stigma attached to the disease, many HIV/AIDS patients have faced violence, rejection, avoidance, isolation, denial, loss of employment, social support and even divorces. The fear of being stigmatized by love ones, friends or family members has prompted many patients to stop taking their medications in the presence of others or to skip doses (Nachega *et al.*, 2006). Stigma is also known to be a central contributing factor to the low uptake of VCT, disclosure of HIV status, enrolment in ART programmes as well as adherence to therapy (Kagee & Delpont, 2010).



Disclosure

Disclosure is defined as the ability of a person to make public secret information as an individual's HIV status (Rabkin *et al.*, 2005). The confidentiality involved in most HIV testing ensures that results are made known to the individual alone. However, upon receipt of the results the individual has the discretion to keep it a secret or to tell others. Disclosure of HIV status is regarded as a fundamental step in accepting one's HIV status and the readiness to live with the disease (Levy *et al.*, 1999; Paxton, 2002). Some reasons why patients often find it difficult to disclose their HIV status are: the fear of rejection by their loved ones or family members or the fear of unfair dismissal from jobs as well as the fear of taking the blame of infidelity which may lead to divorce especially in societies where HIV stigma and discrimination persist (WHO, 2006).

On the contrary, disclosure of HIV status has enabled some patients to lobby for social, physiological, economical and spiritual support from family members, friends and love ones thus enabling them to step up their adherence (Mills et al., 2006).

Lack of social support

A successful ART provision requires both medical care and a long term social and psychological support which includes the encouragement and the monitoring of adherence (Beals, *et al.*, 2006). Persons on ARVs face the challenge of making sure that their medications are taken regularly and on time as well as respecting appointments for the replenishment of their medications over a prolonged period of time and such challenges require different forms of support (Hope & Israel, 2007). Social, financial and psychosocial supports are examples of forms of support from love ones, family members, friends and treatment supporters that enable patients' on-care to remember medication times, follow up visits and obtain food. Support is particularly important to HIV patients in the first three months of treatment when they are still very sick, reacting to drugs and battling to cope with their HIV status (Burrage & Demi, 2003). People who live in isolation and do not have psychosocial support have been associated with poor adherence (Williams & Friedland, 1997). Nonetheless, good psychological and spiritual support from peer groups of PLHWA, treatment supporters, NGOs, churches and employers have also been associated with good adherence (Hardon *et al.*, 2006; Farmer, 2001).

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2.3.3 Economic Barriers

Poverty, unemployment and food insecurity are some of the economically related factors that also play an important role in adherence to ART as discussed below.

Poverty

Financial constraints are known to disrupt adherence to ARV in both developed and less developed countries. Literature has consistently revealed that patients on higher incomes have less difficulty with adherence compared to patient with low income levels (Pratt *et al.*, 1998). In the early years of ART in South Africa, patients had to buy antiretroviral medications. As many patients were poor and could not afford the treatment due to financial constrains, and this led to treatment interruptions (DOH, 2008). Even though ART programmes have made ARVs more affordable to patients by providing them free of charge at the points of delivery, liquid cash is still needed to cover other costs such as transportation, medical tests and food supplements (Weidle *et al.*, 2002). Financial constrains are most likely to hinder patients' abilities to adhere to ART

particularly in rural areas and townships where patients are unemployed and cannot afford good nutrition as well as the transport cost to access good healthcare in the urban areas (Simoni, Frick & Liebovitz, 2002; Kagee, Le Roux & Dick, 2007).

Food insecurity

Many studies have highlighted the importance of good nutrition in the proper absorption of medications as an essential component of adherence. Thus the absence of good nutrition in patients on ART will lead to poor ART adherence outcomes in the patients (Larkin, 1998; Bukusuba, Kikafunda & Whitehead, 2007). Food insecurity has been documented as a common and an important barrier to accessing medical care and ARV adherence in Uganda (Weiser *et al.*, 2010). In a qualitative study with 47 individuals living with HIV/AIDS recruited from an AIDS treatment programme at Mbarara and Kampala in Uganda, Weiser *et al.* (2010) revealed that food insecurity contributed to ART non-adherence and treatment interruptions or to postponing ART initiation in the following ways:

- 1) ARVs increased appetite and led to intolerable hunger in the absence of food.
- 2) Side effects of ARVs were exacerbated in the absence of food.
- 3) Participants believed that they should skip doses or not start on ARVs at all if they could not afford added nutrition.
- 4) Competing demands between costs of food and medical expenses led people either to default from treatment, or to give up food and wages to get medication.
- 5) While working for food for long days in the fields, participants sometimes forgot their medications doses.

Since food insecurity is a major health problem in many sub-Saharan Africa communities thus adherence to ART in these communities will be hindered if proper majors are not taken by ART programmes to alleviate the existing food insecurity (Uthman, 2008).

2.3.4 Healthcare Team and System-related Barriers

Inadequate human resources

Whereas 36 out of the 57 countries that have a critical shortage of health workers are from sub-Saharan Africa, these countries do not only faced massive shortages of qualified health workers but also have a high prevalence of HIV/AIDS that has further deteriorated their already weakened healthcare systems (WHO, 2006). These countries now encounter a double challenge of providing basic health care services to the population as well as trying to effectively deal with the burden of rapidly scaling up ARV (WHO/UNAIDS/PEPFAR, 2008). The shortage of

qualified doctors, pharmacists, nurses, laboratory technologists, counselors and other support staff has negatively impacted on the scaling up of ART services and the efficient management of ART programmes. This shortage of skill personnel in the health facilities has contributed to congestion in ART clinics, long waiting times, loss of adherence follow up and poor adherence counseling sessions (Ickovics & Meade, 2002). For example, in a study from Tanzania, long waiting hours and the spending of over ten hours in a hospital setting to access ART services during visits was reported to reduce clinic attendance and consequently hindered adherence (WHO, 2006). Even though South Africa has 393 nurses and 74 doctors per 100,000 people, a high percentage of the health workers are found only in the private sector and acute shortages still exist in some public health facilities and the rural provinces of the Eastern Cape, Limpopo and Northern Cape (Breier, 2007). The principal reasons behind the shortage of health workers are long working hours, extra work loads involved in the provision of ART services, low salaries and little motivation from the employers. These poor working conditions have discouraged and pushed many qualified health workers to migrating from Africa to the developed countries for greener pasture (Schneider, *et al.*, 2006). In an effort to mitigate human resource (HR) shortages, a strategy to shift some tasks from qualified health professionals to lower cadres or trained laypeople has been implemented in ART services (WHO, 2006). For example, in a Zambian, the use of adherence support workers (ASWs) in adherence counseling and treatment retention have shifted the workload from health care workers to ASWs without compromising the quality of counseling and has also reduced loss to follow-up rates of new clients from 15% to 0% (Torpey *et al.*, 2008). Although the use of non-health professionals in ART delivery systems can decrease HR constraints without compromising the quality of some services, they cannot effectively substitute the professional health workers in the delivery of ART services.

Healthcare providers-patients' relationship

An essential healthcare team and systems-related factor which has been shown to influence adherence to ART medications is the healthcare providers' relationship with patients (Beyene *et al.*, 2009; Godin *et al.*, 2005). Poor healthcare providers' approaches such as condemnatory behaviours, stereotyping, homophobia and failing to address cultural issues when administering care by healthcare providers are likely to negatively influence some HIV/AIDS patients to avoid accessing these healthcare facilities (Chesney, 2003). A qualitative study with physicians by Dzinza (2007) in the South East of Botswana demonstrated that the poor adherence of HIV/AIDS clients on ART was linked to the way they physicians communicated with the patients about ARV medications. Chesney (2003) urged healthcare providers to work with patients as "partners"

in care and also to involve representatives from the entire HIV community in ART programmes. On the other hand, good quality patient-healthcare providers' relationship such as providing clear instructions to patients, with adequate knowledge about the relationship between adherence and resistance, with kindness and the willingness to include them in treatment decisions have been associated with good adherence. Good quality healthcare services that have the adequacy of referrals and the convenience of visiting the doctors with proper support from pharmacists and nurses are likely to positively influence adherence (Ammassari, 2002). In a study in Botswana, Weiser *et al.* (2003) found that 96% of patients were motivated to adhere to ART because the providers treated them with respect and dignity. Other good healthcare providers' practices that have yielded good adherence results include: the writing of clear instructions on pills boxes, providing pill boxes to patients, asking questions of how the treatment can fit into daily activities and the use of medication events monitoring feedbacks (Carpenter, *et al.*, 2000; Fogarty *et al.*, 2002).

2.3.5 Therapy-Related Barriers

Complexity of regimens

The complex nature of antiretroviral regimens with a high number of pills, number of daily doses, foods and fluids restrictions makes fitting regimens into daily living activities difficult and likely to negatively influence adherence (Ammassari *et al.*, 2002; Deschamps *et al.*, 2004). The complex nature of antiretroviral regimens can also become a barrier to religious groups where fasting and restrictions from food and fluids are strictly observed by faithful members of such religions as Islam (Aadil, Houti & Mousasamih, 2004).

The antiretroviral regimen HAART which consists of three or more ART medications that should be taken alongside with other drugs to prevent opportunistic infections makes the pill burden sum up to between 16 and 20 pills a day (Mombasa ART project, 2004). Adhering to such a large number of pills can be challenging and may lead to poor adherence outcomes (Mombassa ART Project, 2004). Patients would if at all possible, choose taking two or less pills a day, with no dietary restrictions and the pills should be made small in size with all drugs combined in a pill of once a day dosing (Maggiolo, Ripamonti & Suter, 2003). However, interventions directed towards increasing adherence such as the use of pill boxes labelled with the dosing regimens and instructions, using timers and fitting medications into daily schedules are known to improve adherence (Chesney *et al.*, 2000; Fogarty *et al.*, 2002; Simoni *et al.*, 2003). In order to resolve the pill burden of ART regimens, recent innovations have been made which consist of the production of one to three tablets which are taken twice a day (Stone, 2002). While the complex nature of ART regimen has been identified as a barrier to adherence,

some studies from Africa have found no association between adherence and medical restrictions. For example in a South African study, Orrell *et al.* (2003) found no significant association between adherence and medication restrictions combined with taking over 10 tablets per day. Also in another study in Botswana, even though 30% of the patients complained of the high number of pills, pill burden only hindered adherence in 5% of the patients (Weiser *et al.*, 2003).

2.3.6 Patient-related Factors

The most outstanding patient related factors that are constantly linked with poor adherence have been forgetfulness, being too busy, and change in daily routines, traveling without medication and difficult dosing schedules (Chesney *et al.*, 2000; Fogarty *et al.*, 2002; Simoni *et al.*, 2003). However, solutions such as the use of pill boxes labelled with clear instructions, the use of timers and fitting medications into daily schedules are currently being used to curb patient related barriers to adherence (Chesney, *et al.*, 2000; Fogarty *et al.*, 2002; Simoni *et al.*, 2003).

Beliefs about ART

Poor adherence has been associated with fear, skepticism, mistrust and myths regarding ART (Fogarty *et al.*, 2002). Adherence to ART may be negatively influenced by a patient's belief about the medication. Patients who have low confidence in the efficacy of medication and perceived minimal benefits from ART are less likely to be adherent (Mehta, Moore & Graham, 1997). Moreover lack of faith in medication combined with poor outlook for the future has been noted to leave patients with little motivation to adhere to proscribe pharmacotherapy (Peltzer *et al.*, 2008). The belief that ARV could cure HIV has been noted to hinder adherence in the sense that when patients start feeling better they believe that they have been completely healed from HIV/AIDS and withdraw from the therapy (Eholie *et al.*, 2007).

Substance abuse

The use of substances such as alcohol and illicit drugs is associated with non-adherence (Palmira *et al.*, 2005). In a qualitative study conducted in Brazil between 2001 and 2002, in which some physicians cited patients' social habits and routines as impacting negatively on adherence, the use of alcohol and illicit drugs was associated with non-adherence (Malta *et al.*, 2005). Substance abuse is known to negatively impact on adherence as it impairs the judgment of the patients, affects their concentration and memory, and their motivation to

continue taking the ART. It has been shown that, substances abusing patients tend to be more socially shattered thus making it difficult for them to receive any psychosocial and family support necessary for upholding adherence (Kagee, 2004). In communities with high rates of substance abuse, adherence may likely be negatively influenced in those patients involved in such social habits and routines.

Cultural and religious beliefs

In African societies, religious and cultural factors have major influences on people's lifestyles and choice of treatment of illnesses due to the important role culture and religion play in healthcare in these societies (Van Dyk, 2001). There are growing fears by healthcare providers and ART users that the activities of traditional healers and religious prophets are leading to the concomitant use of ARV medication and traditional medicines or causing patients to switch from one form of treatment to another thereby compromising adherence (Nyika, 2007). According to Van Dyk (2001), people in several African communities believed that HIV is transmitted by witchcraft and as a result of this belief, visit traditional healers for solutions to their health problems. The traditional healers in response give their HIV and AIDS clients' traditional medicines and instruct them to discontinue ARV medications or any other medications. Studies have also revealed high rates of traditional medicine utilization amongst PLWHA ranging from 15% to 79%, with some researchers suggesting that people infected with HIV use traditional medicines at substantially higher rates than people with other illnesses (Wiwanikit, 2003; Dhalla, Montaner *et al.*, 2006).

In South Africa, it is reported that 75% of HIV-infected people use remedies (*muti*) dispensed by traditional healers to cure HIV and AIDS (Ojikutu, Jack & Ramjee, 2007). The use of traditional medicines while on ART has been reported as a potential barrier to adherence (Dahab *et al.*, 2008). Although the South African National ART guidelines state that patients must disclose the use of any other over-the-counter drug use and traditional medicines due to potential contraindications and adverse interactions, previous studies from the USA have shown that up to 70% of patients who use such therapies, do not inform their doctors (Dwyer *et al.*, 1995). A number of patients have been known to resort to traditional medicine after experiencing side effects from ART but among such patients there is limited data available on the prevalence and patterns of traditional and alternative therapy use (Peltzer *et al.*, 2008).

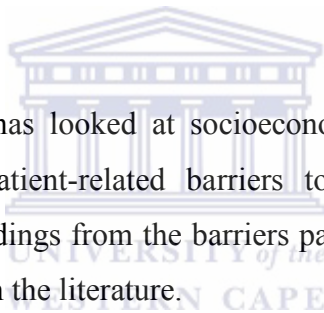
In a study by Zou *et al.* (2009), it was found that a greater fraction of Pentecostal church members than Catholic or Lutheran church members believed that prayers and holy water

only, could cure HIV/AIDS with some Christians admitting that they would refuse ART in preference to prayers and holy water from their pastors for a cure to their HIV/AIDS. The response from 6.3% of a sample of Christians in rural and urban Tanzania said they would decline ART if they became HIV-infected and a doctor recommended them to starting ART. A significant percentage of those surveyed in the study believed that people who are HIV infected have not followed the words of God and that HIV is a punishment from God which can be reversed through prayers. Beliefs like these are likely to negatively influence adherence to ART in many Christian communities.

Other evidence from a quantitative study in Uganda by Wanyama *et al.* (2007) showed that 6 out of 558 HIV patients on ART discontinued their ART treatment because they believed they had been cured of HIV/AIDS through prayers. Adherence can also be negatively affected in forms of religions where fasting, restrictions from food and fluids are strictly observed by faithful members such as in Islam during Ramadhan (Aadil, Houti & Mousasamih, 2004).

2.4 Conclusion

Though this literature review has looked at socioeconomic, healthcare team and system-related, therapy-related and patient-related barriers to adherence, it is hoped that on completion of this study the findings from the barriers patients face while taking their ARVs in Vredenburg will fill in gaps in the literature.



CHAPTER THREE

METHODOLOGY

In this chapter, the aim, objectives, research design and method as well as the demographic characteristics of the patients are presented.

3.1 AIM

This study aimed to explore barriers to adherence to antiretroviral among patients in a regional hospital in Vredenburg, Western Cape.

3.2 SPECIFIC OBJECTIVES

- To describe the experiences of HIV/AIDS clients in Vredenburg about accessing ART.
- To explore social and cultural factors that influence adherence to antiretroviral medication in Vredenburg.
- To identify factors related to treatment regimen that influence adherence in Vredenburg.
- To identify healthcare factors that influence adherence in Vredenburg.
- To identify economic factors that influence adherence to antiretroviral in Vredenburg.

3.3 Study Design

A qualitative paradigm was employed for this study. According to Stommel and Wills (2004), a qualitative research focuses on interpretive, non-numerical, narrative interpretations and does not put emphasis on quantitative measures. As a result of the sensitive nature of the topic, the researchers employed an exploratory qualitative study approach that allowed the participants to tell their story in their own words so that the researcher could explore the factors that influence adherence to ART in Vredenburg. The choice of a qualitative approach in this study was motivated by the fact that, the researchers were interested in a rich data from the participants to enable an accurate description of the experiences of patients on ART as well as those factors that influence adherence in Vredenburg, by letting them tell their story in their own very words. The qualitative method permitted the researchers to explore and bring out those values, beliefs and life experiences related to ART adherence that would not have been easily achieved by a quantitative approach (Meyer, 2000). Through this approach the

researcher was able to uncover the obstacles that patients on ART faced that interrupt their commitment as well those factors that influenced them to visit religious prophets, traditional healers and or seek for alternative therapy to provide solutions or cure to HIV/AIDS in Vredenburg because the approach is best suited for studies that are aimed at exploring health behaviours (Pope & Mays, 1995).

3.4 Study Setting

Vredenburg is a small town of the West Coast in the Western Cape Province of South Africa, located about some 138 Kilometers to the north of Cape Town. It is the capital of the Saldanha Bay Local Municipality in the West Coast District and also a conglomeration of fish factories, local services such as banks, hospitals, shopping malls and a local tourist attraction of the Fossil Park. According to the population census of 2001, Vredenburg had a total population of 31,000 people. Most of the people in Vredenburg speak Afrikaans followed by isiXhosa and a few of the population speak English (Korpela *et al.*, 2008).

Among other (STIs), HIV has a high prevalence in the town. Between 2001 and 2004 the HIV prevalence in the community increased from 8.9% to 13.0% in 2004 (Shaikh *et al.*, 2006). Despite the numerous HIV awareness campaigns that have been launched by the South African Government and civil organizations throughout the past decade, the Vredenburg health officials revealed that stigmatization, discrimination and denial of HIV still persist in Vredenburg (Palitza, 2010).

3.5 Study Population

The study population comprised of all adult male and female HIV and AIDS patients who were enrolled in the Vredenburg provincial hospital ART programme for greater than six months and the health care providers of the health facility who were actively involved in the ART programme at the time of the study such as: clinicians, nurses, counselors, health surveillance assistants (HSAs) and pharmacy technicians. A study population is an entire set of people, objects, or events of concern to a research study from which a sample is selected Williams, Tutty and Grinnel (1995).

3.6 Sampling Procedure

Purposeful sampling was employed to ensure that a rich variety of cases of poor adherers in the Vredenburg provincial hospital ART programme were all well represented. Purposeful sampling is a strategy often designed to enhance understanding of selected individuals or groups' experiences or for developing theories and concepts. Researchers seek to accomplish

this goal by selecting “information rich” cases that are individuals, groups, organizations or behaviours that provide the greatest insight into the research question Kelly *et al.* (2000). Patients who had been enrolled on the ART programme for greater than six months and were physically and mentally able to undergo an in-depth interview were identified and contacted by a nurse or the doctor working on the programme. Other patients who fulfilled the eligibility criteria were sorted by designated clinicians and nurses using the medical records at the health facility. Eligible participants were contacted and provided with an explanation of the purpose of the study. Patients who did not fulfill the eligibility criteria included those patients who were not physical and mentally fit for in-depth interviews or patients who could not be reached by any means or were patients who were not yet eligible for ART and were transferred to wellness programmes for regular follow up and repeated clinical assessments for 6 months. Finally a sample of 18 information rich patients was purposefully drawn from those patients who met the eligibility criteria and who were willing to participate in the study.



Table 1: The Demographic Characteristics of the Patients

No	Name	Age	Sex	Race	Place of birth	Marital status	Parental status	Education	Employment	Date tested for HIV	Date started with ARVs
1	Julian	38	M	Coloured	Mauritzburg	Single	None	Standard 8	No	2005	2005
2	Thumeka	33	F	Colored	Malmesbury	Widow	2 girls	Standard 8	No	2009	2009
3	Kuthala	38	F	Black	Eastern Cape	Widow	2 girls	Standard 9	No	2002	2007
4	Rachael	25	F	Coloured	Vredenburg	Single	1 girl	Standard 9.	No	2004	2005
5	Christine	38	F	Black	Northern Cape	Single	1 girl	Grade 12	Yes	2005	2005
6	Abraham	28	M	Coloured	Langebaan	Single	None	Grade 10	No	2002	2002
7	Susanna	63	F	Coloured	Lamberts Bay	Single	None	None	No	2009	2009
8	Richard	29	M	Black	Durban	Single	None	Grade 9	Yes	2006	2006
9	Reginah	45	F	Black	Queenstown	Single	None	Grade 11	No	2007	2008
10	Velda	32	F	Coloured	Siyabonga	Married	2 boys 1 girl	Grade 9	Yes	2004	2004
11	Amanda	45	F	Coloured	Vredenburg	Divorced	3 sons	Grade 7	Yes	2006	2007
12	Ben	51	M	Black	Not Info	Single	None	Not known	No	2009	2009
13	Nontsikelelo	18	F	Black	Eastern Cape	Married	None	Grade 11	No	2007	2007
14	Alida	32	F	Coloured	Vredenburg,	Boy friend	2 Children	Grade 8	Yes	2001	2001
15	Michael Britton	51	M	Coloured	Saldanha	Single	None	Grade 7	No	2003	2003
16	Anna	60	F	Coloured	No info	Single	3 children	None	No	2004	2005
17	Elsie	53	F	Coloured	Williston	Single	2 daughters 1 boy	Not known	No	2008	2008
18	Joslin	31	F	Coloured	Saldanha	Single	1 boy	Grade 8	No	2007	2007

3.7 Data Collection

The main source of data for the study was semi-structured in-depth interviews with non-adhering patients that were audio-taped and transcribed verbatim. The use of audio tape recorders allowed for much fuller records to be taken than the written note questionnaires methods. Kumar (1995) recommends audio tape recorded interviews for a qualitative study like this one, since such interviews are suitable for both adults and children who are literate or not literate and it also allowed the respondents to express their feelings, beliefs, knowledge and points of view easily; while equally permitting an immediate verification of answers, expression of ideals and clarification of points made during the process of interviewing. Non-adhering patients were interviewed based on the obstacles they face that interrupt their commitment to their ART medications as well as those factors that motivated them to take their ART. The semi-structured interviews employed, encouraged the patients to talk freely and therefore presented their information easily on the factors that influenced their adherence (Robson, 1993). The interviews were conducted in the language of the participants' choice and at a place of their choosing thus encouraging them to talk freely about their feelings, illnesses and other experiences. The participants' voices were of optimum importance and the interviewers were guided by the participants' responses in deciding when to probe the emerging themes. An interview guide was also compiled and used throughout the study to ensure standardization and consistency across the interviews with the participants (Appendix B). Field notes were taken and the raw data as well as the field notes were later expanded and re-written into well-organized field notes, which also formed part of the data set.

3.8 Data Analysis

At the beginning of the data analysis, the transcripts were carefully read several times while taking note of similar topics, which were then grouped and arranged manually into major topics. Thematic analysis was done on the first set of twelve transcripts following the five stages of thematic analysis illustrated in Pope *et al.* (2000) which are: the familiarization stage, the theme identification stage, the indexing stage, the charting stage and the mapping and interpretation stages. In the process of familiarization, the transcripts and field notes were read through repeatedly while taking note of important themes, words and phrases that emerged from the transcripts and field notes. The next step of the data analysis was the identification stage; in which major themes, important words and phrases were written down and decontextualized in order to identify the main codes, themes and subthemes. Finally, the variables that influenced adherence to ART in the regional hospital of Vredenburg were identified and placed under the following groups: awareness of HIV status, economic factors, social factors, and health team

and system factors, therapy related factors, patient related factors, cultural factors, and institutionally related factors. The indexing stage was the third stage of the data analysis in which concepts were put side by side while sub-themes were regrouped into major themes and this was submitted several times to the supervisor for approval. Once the first two steps of the data analysis were approved, the researcher then repeated the same procedure on the remaining six transcripts and compared the two sets of data analyzed. After comparing the two sets of data, the factors that influenced adherence that were not found in the first set of data analyzed were then added as well as important quotes. Indexing was the third stage of data analysis, at this stage transcripts were orderly arranged with numerical codes from the index. Charting was done in the fourth stage of the analysis in which similar topics were then grouped together according to the appropriate framework to which they related forming the charts. Mapping and interpretation was done in the last step of the data analysis; at this stage the identified themes were grouped and interpreted in a meaningful way guided by the research objectives, the emerged themes and also supplemented with extra information from the literature search as guided in Mays and Pope (2000).

3.9 Rigour

When carrying out a qualitative research like this one, rigour is of paramount importance to ensure that results and interpretations obtained from the study are trustworthy and credible. The basic approach used to ensuring rigour in qualitative research includes: a systematic and self-conscious research design, data collection, interpretation and communication (Mays and Pope, 1995).

Trustworthiness

The trustworthiness of the study was addressed through ensuring credibility, transferability, dependability and conformability according to Lincoln and Cuba (1985).

Credibility

In order to ensure credibility in the study, the following steps were taken: the participants were allowed to share their experiences without being judged, the researcher endeavored to establish a good relationship with the participants to respond freely about their experiences during the interviews. Also, during the interviews, facial and body expressions were documented in a notebook by the interviewer and intergraded later into the field notes. The in-depth interviews were transcribed verbatim and field notes were further reviewed to ensure that non-verbal information was not lost but integrated into the data. The field notes were also

numbered accordingly to eliminate the possibility of missing out any data as guided by Denzin and Lincoln (1994). An interview guide was compiled and used throughout the study to ensure standardization and consistency across interviews with participants. The researcher worked together with the supervisor of this mini-thesis throughout the process of the research design, data collection, and data analysis. In addition to this, many meeting sessions were held with the supervisor and during such meetings the researcher presented the any difficulties that were encountered during the research to the supervisor and solutions were immediately sorted out. Lastly, during data analysis the results of the study were triangulated with raw data and field notes that were expanded and re-written into well-organized notes and then together with other sources reported in the literature the data were examined to validate conclusions about meanings.

Transferability

To meet the criteria for transferability, the researcher provided in the report, the aim, objectives, research design and methods including the demographic characteristics of the participants as well as the research findings. The researcher made sure that the raw data and field notes that were expanded and then re-written into well-organized field notes that formed part of the data set, were kept in secured place for future cross checking or verifications. The detailed information provided in the report ensured the medium through which the study findings could be applied or transferred to other situations.

Dependability

To make sure that the aspect of dependability was taken care of, the researcher shared the transcripts with experienced researchers at the University of the Western Cape who independently did an analysis and compared notes. The data analysis was then checked for differences and similarity, and where discrepancies occurred they were resolved through ‘member checking’ with the different researchers.

Conformability

To meet the criteria for conformability, the researcher held several meetings with the supervisor during which the approach to data collection and decisions about what data was to be collected as well as the interpretation of data that was to be collected were taken and during these meetings minutes were taken. This step was important in ensuring that other knowledgeable researchers could also arrive at the same conclusions about the data as we did.

3.10 Ethical Considerations

The ethical approval for this study to proceed was sought from the School of Public Health, in the University of the Western Cape and the City of Cape Town Health Department's Ethical Committees. The researcher visited the Vredenburg hospital health officers to plead for permission to make use of the hospital's resources for the study. The report of the finding of the study adhered to the principles of clarity, honesty, comprehensiveness and accountability. Participation in the study was voluntary and the participants were free to withdraw from the study at any stage without sustaining any penalty for withdrawing. The researcher ensured that no risks was involved in participating in this study, by making sure that all information collected from the participants was treated with all confidentiality. No other persons had access to this information except the researchers. An inform consent with a brief explanation of the purpose and nature of the study was provided to the participant to sign as an agreement to participant in the study (Appendixes A). In a situation where a conflict came up between the researchers and the participants, the interest of the participants took precedence. All interviews were conducted in the language of preference of the participant and at a time and place convenient to the participants.



CHAPTER FOUR

RESULTS

In this chapter the results of this study will be discussed along the themes and categories that were derived from the data; where applicable direct quotes were used to substantiate relevant results. The data collected from the interviews with 18 participants was organized around the following themes: a) Awareness of HIV status; b) Economic barriers; c) Social barriers; d) Health team and system barriers; e) Therapy related barriers related barriers; f) Patient related barriers; and g) Cultural barriers. The table below shows an outline of the themes, sub-codes and codes from the data analysis.

Table 2: Themes, Sub-Themes and Codes from the Data Analysis

THEMES	SUB THEMES	CODES
1. Awareness of HIV status of patients	1.1 Circumstances leading to HIV testing	<ul style="list-style-type: none">- Protracted illnesses- Pregnancy- Providers initiated HIV tests- VCT
	1.2 Acceptance of HIV diagnosis	<ul style="list-style-type: none">- Denial of HIV results- Shocked by HIV results- Not surprised by HIV results
	1.3 Disclosure	<ul style="list-style-type: none">- Partial disclosure- Full disclosure
2. Economic barriers	2.1 Poverty	<ul style="list-style-type: none">- Lack of finance for needs- Lack of money for transport- Food shortage- Disability grant
	2.2 Unemployment	<ul style="list-style-type: none">- Lack of a source of income- Loss of employment

THEMES	SUB THEMES	CODES
3. Social barriers	3.1 Unintended disclosure of HIV status	<ul style="list-style-type: none"> - Fear of unintended disclosure by talking to community HIV care providers - Fear of unintended disclosure leading to the clandestine buying of ART
	3.2 Stigma and discrimination	<ul style="list-style-type: none"> - Peer influence - Humiliation - Rejection
	3.3 Social support	<ul style="list-style-type: none"> - Lack of family support - Emotional distress - Lack of moral support - Lack of spiritual support
4. Health team and system barriers	4.1 Treatment literacy	<ul style="list-style-type: none"> - Misunderstanding of prescriptions retractions - Misunderstanding of prescriptions - Poor HIV counseling
	4.2 Quality of care	<ul style="list-style-type: none"> - Long waiting times - Inconsistent doctors - Lack of confidentiality - Dissatisfaction with the location of the ART clinic - Fear of picking up different infections from other patients in the OPD - Lack of follow up



THEMES	SUB THEMES	CODES
5. Therapy related barriers	5.1 Side effects	<ul style="list-style-type: none"> - Discomfort - Dizziness - Rashes - Loss of appetite - Drug interactions - Sleepless nights - Stress - Depression - Drowsiness - Fatigue and low performance at work
	5.2 Feeling well	<ul style="list-style-type: none"> - Carrying on with normal life styles - Stop treatment
6. Patient related barriers	6.1 Substance abuse	<ul style="list-style-type: none"> - Alcohol consumption - Tobacco use
	6.2 Emotional distress	<ul style="list-style-type: none"> - Forgetfulness - Confusion of doses
	6.3 Fatigue	<ul style="list-style-type: none"> - Hard work - Tiredness
7. Cultural barriers	7.1 Use of traditional medicine and the activities of traditional healers	<ul style="list-style-type: none"> - Use traditional concoctions to cure HIV - Simultaneous use of traditional concoctions while on ART
	7.2 Religious beliefs	<ul style="list-style-type: none"> - Believes that traditional concoctions can cleanse patients internally of HIV - Believes in holy water and prayers for the cure HIV

4.1 Awareness, Acceptance and Disclosure of HIV Status

4.1.1 Awareness of HIV Status

The circumstances that made the respondents in this study to know their HIV status were placed under four groups namely: conditions of protracted illnesses, conditions of pregnancies, providers initiated HIV testing and voluntary HIV testing.

Awareness of HIV status through conditions of protracted illnesses

In general, most male respondents tested for HIV only when they were suffering from protracted illnesses that required HIV tests to assist the medical diagnosis to their health problems.

“I got tested for HIV because I was very sick and was taken to the hospital where they tested me for both HIV and Tb” (Male, 28 yrs).

Awareness of HIV status through conditions of pregnancies

Comparatively, a majority of the female respondents who had unprotected sex sometimes in the past and accessed prenatal care during pregnancy became aware of their HIV statuses only through the compulsory HIV tests that were administered to them during pregnancy to prevent mother to child transmission of HIV.

“I was five months pregnant...then I was tested” (Female, 25 yrs).

Awareness of HIV status through provider initiated HIV testing

Only a single female respondent in the study knew about her HIV status through a provider initiated HIV test that she took during a visit to the hospital for a different health problem. The 60 years old female respondent mentioned that when she went to the Groote Schuur hospital for her eyes and it was suggested that she test for HIV. When she did the test and the results came she found out that she was HIV positive and did not want to believe it at first.

Awareness of HIV status through VCT

Once more, just one female respondent knew her HIV status through a voluntary HIV test. The 38 years old female respondent mentioned that, she was reckless with her life in the past but when she was counseled during a peer counseling course that she attended, she decided to do the HIV test and found that she tested HIV positive.

“After my course, my Peer counseling course I, I, I started, I got tested for HIV, 2003, the same year” ... “Yeah, Yeah, I had an idea because I was, I was a supervisor in first aid and we were careless with our, ourselves” (Female, 38 yrs).

4.1.2 Acceptance of HIV Diagnosis

Three categories of acceptance of HIV diagnosis were recorded in the study. In the first category are placed those respondents who at first denied their HIV diagnosis, this was followed by the second category of respondents who were shocked by their HIV diagnosis. In the last category, are found those respondents who were not very surprised by their HIV results because they were not taking HIV prevention seriously and thus prepared their minds to receive their HIV test results.

Respondents who denied their HIV diagnosis

A 28 years old male respondent denied his HIV results at first and had to be taken to a psychologist for counseling to come to terms with his HIV status. Similarly, a 53 year old female respondent denied her results at first and only came to terms with it after receiving confirmatory results from three different doctors.

“Ja-ja-ja-ja-ja, ek was, ek weet nie hoe, ek meen.... I didn't know how to accept it; but as time when on I met some other people with the same disease and we talk about it when we meet at the clinic and it made me feel a little bit better (Male, 38 yrs).

This 38 years old male respondent denied his HIV diagnosis at first because he thought he could never become infected with HIV like other patients in the community. After constant counseling combined with exchange of experiences and discussions with other patients at the ART clinic the patient was able to come to terms with his HIV status.

Respondent who were shocked by their HIV diagnosis

Many respondents were shocked by their HIV diagnosis. What made some respondents more worried about their HIV diagnosis was how to cope with HIV for the rest of their lives while others were more concerned about the future of their children if they died prematurely from HIV/AIDS.

“It is for the rest of my life...And I want to ask if... what I think in my life. When I think about my children, mean my children are still small. What they're going to do if I'm dead and not there?”(Female, 33yrs)

Respondents who were not very surprise by their HIV diagnosis

Those respondents who did not take HIV prevention seriously were not very surprise by the HIV results.

“I had an idea because I was, I was a supervisor in first aid and we do lot of carelessness we did a lot of carelessness things with ourselves.” (Female, 38 yrs).

The 38 years old female respondent above admitted that, she had an idea of her HIV test results before it was disclosed to her because she knew she did not take HIV prevention seriously in her past social life. Another female respondent also admitted that she did not take HIV prevention seriously and blamed her present HIV status on her reckless past life in which she had unprotected sex with different men for financial gains.

“No you see the truth is that, during the stressful days that there was no money, you fuck the next person, fuck the world out there and no one can tell me it’s my life I will do as I wish but at the end of the day who are you going to blame every day, you blame yourself” (Female, 38 yrs).

4.1.3 Disclosure of HIV Status

Two forms of disclosures were recorded namely: partial and full disclosures. Most respondents at first disclosed partially to friends, aunts, uncles, family members’ healthcare officials or other HIV positive patients and later on disclosed fully in order to gain some forms of financial, psychological, moral, material and spiritual support.

Partial disclosure

According to some respondents they decided to disclose partially because of they were afraid of stigmatization, rejection and social exclusion or because they had an inner feeling of shame. As such they carefully selected those people they trusted would not stigmatize and or discriminate against them and who will also be supportive to them financially, morally or materially and spiritually.

“I haven’t told anybody but my aunt... My mother knows and my sister’s knows and one of my aunt’s, my uncle and my boyfriend also know but not any other people.” (Female, 33 yrs).

This respondent carefully selected those people she trusted will keep her HIV status confidential and will not stigmatize against her and then disclosed her HIV status to them.

“The news will go also to other people and maybe they will see me and they say ‘ooh, I don’t want to go to, walk with that one or eat with that one’ you know, some of your good friends if they see you are on ARV or have, HIV then they don’t want to be friends with them” (Female, 33 yrs).

Other respondents carefully selected only their immediate family members and confided in them their HIV status.

“Same with... and my brothers, they know, my mother know, my father know, they all of them living....They support me” (Male, 38 yrs)

Many patients preferred disclosing their HIV status to other HIV positive patients on the background that, other HIV patients were not going to be of any harm to them because they all shared one thing in common which was their HIV positive status.

“I would be able like, hmm, becoming close friends, very close because for me it’s like we have the ‘same sickness’...” (Female, 25 yrs).

Full disclosure

In this group, the respondents started by disclosing their HIV partially to a selected group of people but as time when on, they saw the need to disclose fully either because they wanted to take off the burden of carrying the secret of being HIV positive from them or because they wanted to gain some form of support or create HIV awareness in the community.

“For me to disclose is in the hands of God, I had to start to set myself free from the world outside and pray to God and he was going to help me. Everyone in the street knows about my HIV but they laugh at me they say, “hey you talking nonsense... I go to them..I’m HIV positive, they don’t believe me, you go and seek boyfriends outside the door but your parents they look after you maybe you must listen to them”(Female, 38 yrs).

The 38 years old female respondent publicly disclosed her HIV status in order to raise awareness in the community about HIV.

4.2 Barriers to Adherence

4.2.1 Economic Barriers

The economically related factors that obstructed the respondents from taking their ART as prescribed were: poverty and unemployment, lack money for transport, lack of food and disability grants.

Poverty and unemployment

Many respondents reported that they skipped taking their ART because they were poor and unemployed and therefore could not raise enough money to meet their other personal needs as well as to buy food to enable them feed properly so as to take their ART as prescribed.

“I don’t work, I’m not eating properly, I don’t have food, I don’t have money and those thing and the baby is...you see for me why would I drink the pills it doesn’t help me at the end of the day”(Female, 38 yrs).

Lack money for transport

A 63 years old female respondent said that, she missed her appointments with the ART clinic because she did not have money for transport; she further complained that the Vredenburg clinic was too far for her to pick up her medications.

“There are sometimes that I will need to go to the clinic and have no money so I will ask for assistance from my children and sometimes when I have no money for transport I hike to the ART clinic” (Female, 60 yrs)

It was reported that a taxi fare to go the ART clinic and return at the time of this study was R36.

Lack of food

A 53 year old female respondent complained that she did not take her ART for some days because she did not have any food to eat.

“I’m not eating properly, I don’t have food, I don’t have money and those thing and the baby is...you see for me why would I drink the pills it doesn’t help me at the end of the day”(Female, 38 yrs).

Disability grants

It was reported that some patients deliberately discontinued taking their ART in order to became very sick and have their CD4 count drop to a very low level. Such patients also

dishonestly told the doctors that they had no form of financial support so that the doctors could qualify them for a disability grant on the bases of their illness, low CD4 count and also due to the fact that they had no source of income or financial support.

“Maybe you will qualify for a Grant which the doctor will see you don’t have an income and you can’t work, you are weak. So most of them, they just uh...Stop with the medication because they want to receive a Grant, (Female, 33 yrs).

4.2.2 Social Barriers

Some socially related factors that hampered adherence to ART were: fear of unintended disclosure by using the ART clinic, fear of unintended disclosure when seen talking to community HIV care providers, fear of unintended disclosure leading to the clandestine buying of ART, stigma and discrimination, peer influence and the fear of being humiliated by others if known to be HIV positive in the community.

Fear of unintended disclosure of HIV status from using the ART clinic

A small number of HIV positive patients were reported to have terminated the use of the ART clinic because they were afraid that their HIV status could be unintentionally disclosed to others if they were seen queuing up at the ART clinic regularly.

“They don’t want to talk about it. They don’t want that other people to know they have HIV. Or maybe they don’t want it known or want to be seen”. (Female, 33 yrs)

Fear of unintended disclosure of HIV status from talking to community HIV care providers

It was noted that the community members used workers providing HIV care as markers of PLWHA in the community and as a result of this; if someone was seen having a lengthy discussion with any HIV care providers, that person’s HIV positive status was automatically assumed and this caused some patients to miss important appointments with HIV care providers.

“...So if they see someone from the community speaking with these ART workers for a long time, they assume that person speaking with them is HIV positive” (Female, 60 years)

Fear of unintended disclosure of HIV status leading to the clandestine buying and selling of ART

It was reported that some patients in the community stopped going to the ART clinic because they did not want others to know about their HIV status. This group of patients was reported to have been going behind the healthcare providers and instigating other patients using the ART services to clandestinely steal some of their pills and sell the stolen pills to them.

“I heard that other people saying maybe if, I’m working now and I have a friend who is HIV now that friend don’t want to come to the doctor then maybe I steal the tablets here and then I take it to her. I heard other people saying like that”. (Female, 33 yrs).

Stigma and discrimination

Some patients discontinued taking their ART and started drinking heavily in order to cope with the emotional depression that they developed from being stigmatized and discriminated against by their friends and some family members at home.

“Okay? So some of my friends, they don’t worry about me, they ignore me or if I came to her she will say, “oh! I want to go there or there or something like that. So the experience was - some of the people don’t want you - because of the sick that you have, they don’t want to drink in your cups or eat out of your bowl. My mother was doing that, because I was having my own glass, my own cup and my own plate, it made me feel like I never wanted to live anymore. So! That is why I started drinking.” (Female, 25 yrs).

Peer influence

A respondent reported that she took advantage of her improved health and deliberately terminated her ART because she wanted to carry on with her social life as she did prior to developing AIDS.

“ I was not taking them, and the weekend I was not taking them. , because I was for a year and two months without, without my pills....It was on my birthday when I start drinking, July month” (Female, 25 yrs).

The use of the HIV status of PLWHA as a device to humiliate them

A 32 years old female also reported that she discontinued taking her ART for 7 days because her boy friend used her HIV status to disgrace her openly.

“I stopped taking my ART for about two weeks because my boyfriend humiliated me that, I was an HIV patient” (Female, 32 yrs).

4.2.3 Health System Barriers

Some of the health system related factors that negatively influenced adherence were: the lack of follow up of patients, dissatisfaction about the quality of ART services provided, lack of confidentiality in the way patients HIV results were handled, long waiting times in queues at ART clinics, the fear of picking up infections from other patients in the OPD and the fear of unintentional disclosure of HIV status as a result of the exposed location of the ART clinic in the hospital.

Lack of follow up

A respondent missed taking his ART due to the inadequate follow up on his ART treatment by the nurse in charge of him at the rehabilitation unit. As a result of this negligence of duty, his ART got finished without the nurse taking note of this thus he missed his pills for four days after which they were then replenished.

“When I was leaving all the pills were finished. So I left, I was for 4 days, without it”...
(Male, 38 yrs)

4.2.4 Therapy Related Barriers

Two therapy related factors that hindered adherence to ART were side effects and feeling better after commencing with treatment.

Side effects and discomfort

Some respondents reported that they stopped taking their ART when they experienced side effects.

“I said Doctor, I just stopped my pills for three weeks I got fed up of with these pills, you know what I’m saying and now I experienced the itching and all those things and I’m stressed out all those things”. (Female, 38 yrs).

The 38 years old female was the only respondent who stopped taking ART for three weeks because she got fed up with the itches she experienced when she started taking the treatment.

Feeling better

Some respondents terminated their ART when they started feeling better and wanted to carry on with their lives just in the same way as they did before they were placed on ART.

“So at the time, when, the first time I got sick, I got really, really sick and I was taken to Siyabonga, I got strong and I was on my own, started drinking and smoking again and that is why I dropped my pills; and then I came again back to Siyabonga because I was sick,” (Female, 25 yrs)

4.2.5 Patient Related Barriers

The following patient related factors that negatively affected adherence were: alcohol abuse and smoking, emotional distress, forgetfulness, confusion, fatigue and hard labour.

Alcohol abuse and smoking

Alcohol is known to impair peoples reasoning and can therefore negatively affect adherence. Most respondents who started drinking heavily and smoking while on ART reported that, heavy drinking and smoking hindered them from taking their ART as prescribed. While those who drank heavily and smoked only occasionally during weekends and birth-day parties also reported that they missed taking their ART after drinking heavily.

“I was on my own, started drinking and smoking again and that is why I dropped my pills and now I am back on treatment.” (Female, 25 yrs)

Emotional distress

Emotional distress can disrupt peoples' modes to concentrate on taking their ART. According to some respondents they did not concentrate on taking their ART as prescribed because they were emotionally distressed by either broken relationships or by stigmatization and rejection at home.

“Something that happened between us so; we were not married... So I decided to leave her alone. I couldn't use that medication and I came to the doctor and I'm told him but-but this woman, what she has done to me I can't take it any longer so I, I started drinking”...
(Male, 38 yrs).

Forgetfulness

Many respondents said that they missed taking their ART most of the times due to forgetfulness. A 38 years old male respondent explained that he missed taking his ART because he often forgot about them especially when he was overtaken by sleep and did not hear the alarm of his clock or phone.

“You see that happened to me, not so, so far away from 7 o’clock, it happened once with me, say that; the morning 7 o’clock né? I drink my pills but at that time its 7 again...I forgot, but it was ‘to 8” (Male, 38 yrs).

Confusion

Some respondent mentioned that they did not take their ART accurately at the prescribed time because they were often confused and unable to recall exactly the time and the right number of pills to be taken. One respondent said that due to confusion on the accurate time and the number of pills to be taken, he sometimes took some pills later on or took more pills that the doctors prescribed in order to chat-up with the pills that he had missed the previous day.

“Then I asked her ‘Sister hmm, why do you give me this one in the morning and this one in the afternoon, say when I am going to sleep?’ She said ‘I learnt that from the doctor that you must drink the 2 in the morning and when you go to sleep, say from between 12.”(Male, 36 yrs)

Fatigue and hard labour

A male respondent reported that he skipped taking his ART at night before sleeping because he got too tired from working very hard during the day and was overtaken by sleep.

“Wednesday, Thursday I’m working so hard, sometimes I come home and sit down, and I fall asleep” (Male, 38 yrs).

4.2.6 Cultural Barriers

A culturally related factor that had a negative effect on adherence was the simultaneous use of concoctions from traditional healers and ART.

The simultaneous use of concoctions from traditional healers and ART

The use of concoctions from traditional healers and ART simultaneously obstructed adherence as it was reported that some respondents were still using concoctions prepared by traditional healers for cleansing their bodies internally even though they were also taking ART.

“No, no! I’m using the mixture, it’s the mixture that must make me like this, and it’s cleaning me.” That’s my concern. (Female 38 yrs).

A 38 year old female respondent confirmed that she was of the opinion that one could take mixtures from traditional healers while on ART as long as one informed both the traditional healers and their doctors about the different medications they were using.

“You have to take both of them, and you have to tell your traditional healer you are on ARV’s.....” (Female 38 yrs).

4.3 Motivators and Facilitators of Adherence

4.3.1 Social Motivators and Facilitators

More socially related factors influenced adherence compared to others factors. The following are the socially related factors that were recorded to positively influence adherence: emotional and family support, disclosure, having children to look after, having spiritual support from the church, TV programmes, phone, radios and alarm clocks, belonging to an HIV support group and receiving words of encouragement from an intimate person.

Emotional and family support

Many respondents reported that they were motivated to continue taking their ART as prescribed from the emotional support that they received from their family and loved ones.

“My brothers, they know, my mother knows, my father knows, they are all of them living.... They support me” (Male, 38 yrs).

A number of respondents mentioned that even though they were not receiving any disability grants, they were able to use their partial disclosure to gain different forms of support from their family members and friends as well.

A female respondent narrated how she was able to receive moral support from her family members when she partially disclosed her HIV status to them.

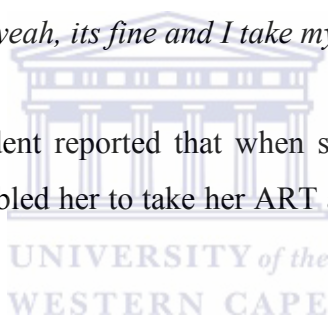
“ I said, no I did work and I did buy food but sometimes they come and check themselves and from there on you want to disclose to your family and friends so that you can be helped in getting stronger every day”...(Female, 38 yrs).

Disclosure

Disclosure of HIV status is a difficult process and is a fundamental step in accepting one's HIV status and the readiness to live with the disease and therefore a good predictor of adherence to treatment.

“...I just put all my pills in my bag and I don't worry about which tablets, whoever sees me taking out there, “what are you doing, I'm taking my pills I'm HIV positive, hey uyageza wena!” Ngithi, yeah, its fine and I take my pills and drink.”... (Female, 38 yrs).

A 38 years old female respondent reported that when she fully disclosed her HIV status to people in the community, it enabled her to take her ART anywhere and at any time without the fear of stigma.



Having children to take care of

Many mothers reported that they were inspired to adhere to their ART despite the challenges they were going through while taking the treatment because they had children to take care of.

“I am really glad that I am here at Siyabonga so that I can get my life back on track and for my child's sake - so I am gonna take my treatment, so that I can live longer. Wasn't it for my child then I wasn't gonna worry on, gonna take my pills again or something like that. So it is only for my child that I do it” ... (Female, 25 yrs).

Spiritual support from the church

A good number of respondents reported that they drew their inspiration to continue taking their ART from constantly reading their bibles and fellowshiping with other Christians and also from the prayer sessions that were organized at different homes by their pastors.

“I use my Christianity with my doctor and I take what I get in the hospital and go and tell my Reverend or some, or somebody at my church I-I know I have to communicate with. Then the side effect of the treatment, everything, I have to communicate with; I have to take my Christianity and my, my medication and my doctor and put them together”... (Female, 38 yrs).

TV programmes, phones, radios and clock alarms

A patient reported that he used articles such as radios, alarm clocks and TV programmes like 7de Laan as reminders to enable him remember when to take his ART.

“Yes I have my phone, I have that small radio clockand I know but at that time for 7de Laan then I’m taking my pills. It is only that 3 then I’m holding it in my hands and when 7de Laan is finished, I just run into the kitchen and/or ask the guy ‘can you just get me a glass of water... (Male, 38 yrs).

Belonging to an HIV support group

A fifty-one year old male respondent mentioned that, the Mfesane support group that he was told by his home based care giver to join was supporting him with food, vegetables and other things to do which were helping him to adhere to the treatment.

“The support group is fine they give me food, vegetables and things to do”,
(Male, 51 yrs).

4.3.2 Health System Related Motivators and Facilitators

Four health system related factors that influenced adherence positively are: sharing experiences and difficulties with other patients, good service delivery by the healthcare providers, believing in the treatment and good treatment literacy; and the use of pill boxes.

Sharing experiences and difficulties with other AIDS patients

Most respondents reported that at first they did not know how to accept their HIV status but after constantly sharing some experiences and difficulties with other patients at the ART clinic, they were encouraged to stay focused on taking their ART as prescribed.

“As I, I, I come here to the ARV clinic I don’t see why people should stop their medication because we, as we sit there we name that ‘our place of school’ because there we share and we talk, we talk our problems and we share our problems and

sometimes - and also the workers at our/the ARV clinic - we don't feel nervous or what or what"... (Female, 38 yrs).

Good service delivery from the healthcare providers

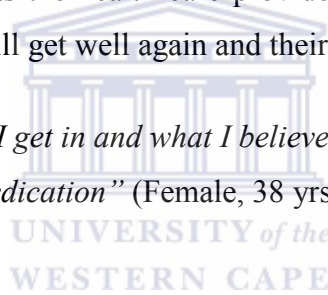
Many respondents reported that the good services that they were receiving from their doctors, nurses, pharmacists and counselors gave them new strength to continue with their ART.

"I see it as a good system because last time I visited Eastern Cape, I was at one of the Eastern Cape hospital, I can't remember/name the hospital now... uh. As I sat there and saw how they treat their patients. I said, I can, I can clap hands for the Western Cape".
(Female, 38 yrs).

Believing in the treatment and good treatment literacy

Many respondents said that they were encouraged to take their ART because they believed that if they continued taking them as the health care providers told them to do, their CD4 counts were going improve and they will get well again and their lives will be prolonged as well.

"What I believe is what I get in and what I believe in and what I think is that you have to continue with your medication" (Female, 38 yrs).



Pill Boxes

One female respondent reported that the pills boxes that she was using made it easier for her to take her ART at night and in the morning without any difficulty.

"Yeah it's easy now in this pill box cause I'm already taking the pills during the night you see, and then this morning I just take out in the bag, get myself ready put it straight and then go and I'm back out there"... (Female, 38 yrs).

4.3.3 Patient and Therapy Related Motivators and Facilitators

The patient and therapy related factors that motivated and positively influenced adherence were: the hope to live longer, the fear of the deadly consequences of poor adherence from patients using traditional mixtures, learning from the past experiences of poor adheres and feeling better after commencing with treatment.

The hope to live longer

Many respondents reported that even though they knew that the ART was not going to heal their HIV positive status completely, they were still encouraged to continue taking them because they nursed the hope that the treatment will prolong their lives.

“I am really glad that I am here at Siyabonga because that I can get my life back on track and for my child’s sake - so I am gonna take my treatment, that I can live longer” ... (Female, 25 yrs).

The fear of the deadly consequences of poor adherence from patients using traditional mixtures

Most respondents said that they were inspired to continue taking their ART because they knew some friends in the community who died shortly after abandoning their ART for mixtures from traditional healers.

“I saw people going to the healers outside there but end of the day they are underground you see, they are dying outside there because they are believing in the healers outside there and they are not taking the pills” ... (Female, 38 yrs).

Learning from the past experiences of poor adherence

Many respondents reported that they were inspired to adhere to their ART because when they stopped taking them for a short time they got very sick again and started developing the AIDS-like symptoms which they did not want to experience again.

I got sick, I got really, really sick and I was taken to Siyabonga, I got strong and I was on my own, started drinking and smoking again and that is why I dropped my pills; and then I came again back to Siyabonga because I was sick again” (Female, 25 yrs).

Feeling better

A majority of the respondents reported that they were motivated to adhere to their ART because they regained their health when they started taking them and the AIDS-like symptoms that they had developed when they were very sick disappeared.

“The ARVs works well when one takes it regular, you need to take it regular ‘cause there was a time when I wasn’t doing it regularly then I get some rash on my skin, skin rash and so on; my tongue was sore and all those things” ... (Female, 38 yrs)

4.3.4 Economic Motivators and Facilitators

The following economic factors that were found to have motivated and facilitated adherence were: disability grants and being employed.

Disability grants

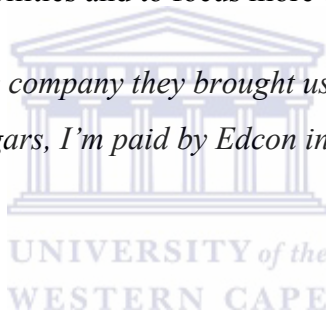
Some respondents confirmed that the disability grant that they were receiving helped them to buy basic needs and settle bills and thus relieved them of some financial constraints and also facilitated them to focus on taking their ART properly.

*“It’s a small Grant because it’s not a normal Grant. It’s uh, it’s something minimal...
No I’m not working now; I’m looking for a job now”... (Female, 38 yrs)*

Employment

A female respondent reported that the money she earned from her counseling job enabled her to take care of her family responsibilities and to focus more on taking their ART as prescribed.

*“No, Edcon is just a private company they brought us on the umbrella of Jet stores and
CNA and working with Edgars, I’m paid by Edcon in Edgars in the mall” ...
(Female, 38 yrs).*



Summary

In this chapter data was analyzed and factors that negatively influenced adherence identified as: awareness of HIV status, disclosure, unemployment, lack of transport, insufficient feeding, disability grants, alcohol and illicit trade in ART, alternative forms of therapy and stigma. It was also noted that, inadequate follow up, recklessness in the way patients’ HIV results were handled, long waiting times and the fear of picking up other types of infections from other patients in the OPD also came under major criticisms from patients. Finally, the sharing of experiences at the clinic visits, good healthcare provider-patient relationships, believing in the treatment, good treatment literacy, being a parent and having children to look after, the use of pill boxes, social and spiritual support from family members, friends and loved ones were also identified as factors that positively influenced adherence.

CHAPTER FIVE

DISCUSSION

Introduction

This final chapter will focus on discussion, conclusion and recommendations as well as the strengths and limitations of the study. The first part of the chapter examines the findings obtained on awareness, acceptance and disclosure of the HIV status of the participants and is closely followed by the next section that explores other factors that influenced adherence. The results of the study are discussed along the themes and categories that were derived from the data and where necessary, citations are used to substantiate relevant results. The chapter is concluded with recommendations and the strengths and limitations of the study.

Awareness and acceptance of HIV diagnosis

Awareness of HIV status was found to be an important predictor of poor adherence. Our results revealed that, those respondents, who became aware of their HIV status through conditions of protracted illnesses or providers initiated HIV testing, adhered poorly to therapy while those who became aware of their HIV status through VCT, had a better adherence. Acceptance of one's HIV status was found to be the rate determining step towards one's dedication to taking the ART as prescribed. Those participants who easily accepted their HIV status were found to be more committed to taking their ART and thus showed a better adherence to therapy compared to those who took a longer time to accept their HIV status. These findings are similar to those obtained from studies in Cote d' Ivoire, the Republic of South Africa and the United States of America that acceptance of HIV diagnosis and the commitment to taking one's ART were vital steps towards good adherence (Eholie *et al.*, 2007; Gilbert *et al.*, 2009; Godin *et al.*, 2005).

Poverty

Financial constraints as unemployment, lack of transport and food insecurity were found to obstruct adherence. This is consistent with literature that patients on higher incomes have less difficulty with adherence compared to patients with low income levels (Pratt *et al.*, 1998). In our study, many respondents missed hospital appointments and or their doses either because they were unable to raise enough money for transport or because they were unable to buy food and feed properly to enable them take the medications as prescribed. These findings are also in line with many adherence studies in Africa and other parts of the world which have already reported unemployment, lack of

transport and insufficient feeding as factors negatively impacting on adherence (WHO, 2006; WHO, 2010). Even though ART programmes are presently making them more affordable to ART users by providing them free of charge at the points of delivery, unemployment, transportation cost, child care, school fees, and lack of food as well as loss of earnings are still major concerns to adherence in many resource limited countries (Weidle *et al.*, 2002).

Disability grants

Disability grants were of a particular importance in this study, for the reason that, it had a positive and a negative influenced on adherence. For instance, some ART users in the study were reported to have discontinued taking their therapy in order to get very sick, keep their T-cells count below the 200 limit so as to meet some of the requirements needed for the grants or to regain the grants. It has been previously reported that, in South Africa the loss of the disability grant as a result of improved health, has a significant impact on the physical and emotional health of PLWHA, as this leads to high levels of stress on PLWHA because healthy diets may no longer be accessible and this could in turn undermine their adherence (De Paoli & Mills, 2010). However, contrary to this, our study found that, the disability grant also assisted some participants to settle bills, buy food and address other personal and family problems enabling them to focus more on taking their ARVs correctly.

Disclosure of HIV status

Disclosure of HIV status was found to be very fundamental in HIV care. Disclosure of one's HIV status was a difficult process and a primary step in accepting one's HIV status and the readiness to live with the disease. A number of patients in our study skipped their doses or missed hospital appointments because they were afraid that, their HIV status could unintentionally be disclosed if they were seen in queues at the ART clinics regularly. These findings are common to those obtained in an Ethiopian study where patients who did not disclosed their HIV-positive status traveled long distances to obtain anonymous treatment, hid or skipped pills to ensure that families' members and employers did not know about their status (Mekonnen *et al.*, 2010). Nonetheless, disclosure was also found to play a positive role in adherence given that those patients who intentionally disclosed to family members, friends or religious groups, gained some form of social, physiological, economical and spiritual support which motivated them to step up their adherence.

It has been noted that various forms of social support from family and friends to PLWHA can influence their behavior and decisions regarding treatment (Roura *et al.*, 2009). Individuals can develop a willingness to sustain adherence in a challenging context but are more likely to do so

within supportive family and community environments (Roura *et al.*, 2009). A South African study also found that social support was instrumental in helping ART patients to achieving compliance beyond the first three months of treatment (Nachega *et al.*, 2006; Roura *et al.*, 2009).

Stigma and emotional distress

Stigma was found to be pivotal in steering up discrimination against people living with AIDS in the community and thus negatively influenced adherence in our study. Stigma and discrimination have been reported as two important variables greatly contributing to the low uptake of VCT, disclosure, and poor adherence to ART (Kagee & Delpont, 2010). In this study, stigma was found to have provoked discrimination, rejection and the isolation of PLWHA. This poor treatment created the emotional distress that pushed some patients to skip doses and to take up heavy drinking as a way of comfort. These findings are comparable to those obtained by Moore and Graham (1997) and Nachega *et al.* (2006) where stigma and discrimination was found to have negatively influenced adherence by subjecting ART users to heavy alcohol consumption which made them to forget taking their doses as prescribed.

Inadequate follow up and dissatisfaction in ART services

In a study from Tanzania, long waiting hours and the spending of over ten hours in a hospital setting to access ART care was reported to reduce clinic attendance and consequently hindered adherence (WHO, 2006). Inadequate follow ups on some patients, the lack of confidentiality in the way HIV results were handled, long waiting times in queues at ART clinic as well as the fear of picking up other infections from other patients in the OPD, were reported as major concerns in this study. These concerns require special attention as they may in the long run negatively influence adherence. On the other hand we found that, the sharing of experiences at the clinic visits, good healthcare provider's patient relationships, believing in the treatment, good treatment literacy and the use of pill boxes positively influenced adherence.

Side effects and discomfort

While therapy related variables such as the complex nature of antiretroviral regimens, high number of pills, foods and fluids restrictions as well as the difficulty of fitting regimens into daily living activities were reported by Ammassariet *et al.* (2002) to negatively influence adherence, the same variables did not seem to have an effect on adherence as reported by Deschamps *et al.* (2004). However, in our study only one of respondent reported that she stopped taking her medications for two weeks because of the unbearable itches that she

experienced. Our findings are comparable to the results obtained from a majority of other studies from Africa, which did not find any association between pill burden and the side effects of taking ARVs as a major barrier to adherence (Gilbert and Wilker, 2009). Even though the adverse side effects of taking antiretroviral medications have been reported to hinder adherence in studies from South Africa, Nigeria and the USA, Malangu (2008) and Uzochukwa *et al.* (2009), the hazardous practical experiences of living with untreated HIV/AIDS experienced in Sub-Saharan Africa, have been suggested to be the driving force behind the better adherence results reported in these African adherence studies (Nachega *et al.*, 2005; Weiser *et al.*, 2003).

Feeling better and the hope to live longer

Feeling better in this study was like a double edged sword which positively and negatively influenced adherence in some patients. While some ART users believed in the treatment because they were sure to regain their health, others took advantage of their improved health and deliberately terminated their ART in order to carry on with their past risky social life styles. Outstandingly, the hope to live longer and the disastrous experience of some poorly adhering patients was found to have motivated good adherence in some patients. Nonetheless, having children to look after was found to be a great motivator of good adherence to the female patients than to the male patients. The hoped that ART was going to enable some patients to regain their health and continue to work in order to support their families financially was also a good motivator of adherence in both male and female respondents. This results matches those obtained by Watt *et al.* (2009) that men were motivated to adhere to treatment because it provided them with an opportunity to return to their work, support their families, and care for their children. Even though in this study, more women than men expressed children as a motivator of good adherence, the fact that good adherence could give them a chance to continue to work and support their families, motivated both male and female patients equally to adhere to the treatment. The same study revealed that women have set schedules, often bound to responsibilities of the home, which make it easier to incorporate pill-taking in their daily schedules (Watt *et al.*, 2009).

Substance abuse, forgetfulness and fatigue

Heavy alcohol consumption which is well known to impair judgment, affect concentration, memory and motivation was found to negatively influence adherence in this study. These findings corroborates to published reports in a study of 1889 HIV clients on ART medications which showed that non-adherence was linked to heavy alcohol drinking (Tucker *et al.*, 2004). In this study, we also found that most of our respondents who started drinking heavily and

smoking while on ART reported that, heavy drinking and smoking hindered them from taking their ART as prescribed. Substance abuse in patients taking ART have been noted to have far reaching consequences on their ability to adhere to therapy, as it makes it difficult for them to receive any form of social and family support which can motivate them to adhere properly to therapy (Kagee, 2004). Although alcohol and smoking were found to negatively influence adherence, other factors associated with substance abuse such as forgetfulness, fatigue and confusion were also recorded to have negatively influenced it.

The use of alternative therapy

The use of traditional medicines while on ART has been previously reported as a potential barrier to adherence (Dahab *et al.*, 2008). In this study, many respondents on ART were reported to have been using concoctions prepared by traditional healers for cleansing their bodies and others were of a strong opinion that, one could take mixtures from traditional healers while on ART, if one informed both parties. This suggests that, the concomitant use of traditional mixtures while on ART could be a barrier to adherence in the community. Fears of compromising adherence by the activities of traditional healers and religious prophets leading to the concomitant use of ARV medication and traditional medicines, or causing patients to switch from one form of treatment to another have long been reported (Nyika, 2007). In Van Dyk (2001), it was reported that people in several African communities believed that HIV was transmitted by witchcraft and as a result of this belief, visit traditional healers for solutions to their health problems. On the contrary, this believe did not influence our respondents' choice of therapy and none of them associated their HIV status to witch craft. It is worth mentioning that some respondents were still visiting traditional healers and religious prophets for prayers and other solutions to their HIV problems. The findings from this study are parallel to those in Zouet *al.* (2009), that a greater fraction of Pentecostal church members than Catholic or Lutheran church members believed that prayers and holy water only, could cure HIV/ AIDS with some Christians admitting that they would refuse ART in preference to prayers and holy water from their pastors for a cure to their HIV/AIDS. More investigations are required to give us a more accurate data on the scale of the use of alternative therapy in Vredenburg for the cure of HIV.

CHAPTER SIX

CONCLUSIONS AND RECOMMENDATIONS

This study sought to explore barriers to adherence to antiretroviral among patients in a regional hospital in Vredenburg, Western Cape. The explorative study conducted on patients accessing ART from the Vredenburg hospital thus reveals the intricacy of adherence vis-à-vis the barriers patients in Vredenburg face in their attempts to access and adhere to ART. This study identified financial constraints as a major factor that obstructs adherence in Vredenburg. Although ART are provided free of charge at the points of delivery, transportation cost, child care, school fees, lack of food, loss of earnings as well as unemployment are still reported as obstacles to adherence. It worth mentioning that many patients missed hospital appointments and or their doses either because they were unable to raise enough money for transport or because they were unable to buy food and feed properly to enable them take the medications as prescribed by the doctors. Other studies have already reported financial constraints linked to unemployment, lack of transport and insufficient feeding as factors negatively impacting on adherence in other parts of Africa (WHO, 2006).

Inadequate follow ups on patients, confidentiality in the way patient's HIV results were handled, long waiting times in queues at the ART clinic as well as the fear of picking up infections from other patients in the OPD came under major criticisms from patients. On the other hand, the sharing of experiences at the clinic visits, good healthcare provider patient relationships, being a parent and having children to look after, believing in the treatment, good treatment literacy and the use of pill boxes also significantly influenced adherence positively.

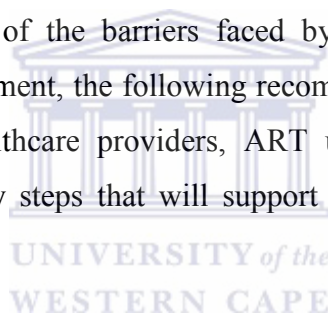
This study further identified that, patients in Vredenburg were still facing significant barriers surrounding stigma; as stigma and discrimination greatly contributed to the low uptake of VCT and disclosure. Disclosure of one's HIV status was a difficult process and a fundamental step in accepting one's HIV status and the readiness to live with the disease. As such a number of patients skipped their doses or missed hospital appointments because they were afraid that their HIV status could unintentionally be disclosed if they were seen in queues at the ART clinics regularly. Stigma was also found to have provoked discrimination in some people, causing them to reject and isolate people living with AIDS in the community. The rejection and isolation experienced by people living with AIDS as a result of their status, emotionally distressed them and made some patients to develop depressions which caused them to skip

doses or to the take up heavy drinking as a way out of the HIV burden. Many patients in the study also feared that they would lose support from their loved ones, marriages, and their jobs based on peoples perspectives surrounding HIV/AIDS in the community.

Finally, even though barriers such as financial constraints, substance abuse, alternative therapy disclosure and recklessness in healthcare services obstructed adherence in this study, HIV/AIDS has been a stigmatized illness since its onset in the early 1980s and, these results highlight that such stigma has yet to dissipate in Vredenburg. Therefore, stigma and disclosure must remain at the forefront of the ART programme implementation in Vredenburg, while long term projects that can support ART users economically should be created through partnerships with non-governmental organizations and the government of South Africa to optimize adherence in the Vredenburg.

Recommendations

After an in-depth exploration of the barriers faced by people PLWHA in their everyday attempts to adhere to HIV treatment, the following recommendations have been made to assist the community members, healthcare providers, ART users, policymakers and programme managers to take the necessary steps that will support and maintain good adherence in the community.



Community members

- To show love and respect to people living with HIV/AIDS in the community.
- To provide more supportive home based environments to HIV/AIDS clients at all times.
- To build up better collaborations between traditional healers, religious prophets and healthcare providers in sensitizing the community on HIV/AIDS and to plan strategies to improve adherence.
- To organize and intensify community sensitizations on HIV/AIDS addressing stigma and discrimination.
- To create long term projects that will support ART users economically for as long as possible through partnerships with non-governmental organizations and the government of the Republic of South Africa.
- To carry out further studies that will give a more accurate data on the scale of the use of alternative therapy in Vredenburg for the cure of HIV/AIDS.

Healthcare providers

- To serve and treat their clients with love and respect.
- To decentralize ART health services and provide them at a community based level.
- To extend their opening hours and also to provide ART services on public holidays.
- To provide ART services in a convenient environment that would not lead to the unintentional disclosure of the HIV status of their clients to other patients in the health facility.
- To intensify follow ups on ART users who have defaulted due to one reason or another.
- To develop checklists, reminder cards and the sending of short messages via mobile phones to help ART users not to forget taking their pills as prescribed.
- To conduct further studies to determine the magnitude and factors influencing the illicit trade in ART in the community.
- To intensify research on a possible vaccine or cure of HIV/AIDS.

ART users

- To fully disclosed their HIV status in order to disperse the stigma attached to HIV/AIDS in Vredenburg.
- To put into action the lessons they are taught in their support groups meetings and to share their difficulties as well as experiences with other patients and the healthcare providers.
- To build enough confidence to speak to the community members about HIV/AIDS, treatment adherence, and gender issues, such as men's ability to support their female partners in treatment.
- To trust their healthcare providers and belief in the therapy which they are using.

Policy makers

- To promote and improve legislation surrounding poverty and the employment of people living with HIV/AIDS.
- To promote and implement legislation that would lead to the reduction of stigma and discrimination against PLWHA in the Vredenburg.
- To educate PLWHA on their rights in Vredenburg.

ART programme planners

- To build the capacity of PLWHA to initiate awareness-raising and educational activities related to issues of stigma and discrimination in the community.
- To intensify sensitizations on HIV testing reluctance, disclosure of positive status and the acceptance of HIV status.
- To develop and implement policies that will decentralize ART health services and make them more community based.

Strengths and Limitations of the Study

The principal aim of this qualitative study was not to generalize the findings to a larger population as is the case with quantitative studies, but to elicit insights to develop action that is sensitive to local circumstances. However, barriers to adherence to antiretroviral medications among patients in a regional hospital in Vredenburg were what this study was interested in. Given that these barriers are not easily revealed by traditional epidemiological methods, we used in-depth interviews to gather the desired data for the study.

Strengths of the study

This study like other qualitative studies has strengths worthy of mentioning. The following are some of the strengths of the study: a purposeful sampling technique was used which ensured that a rich variety of cases of poor adherers in the ART programme of the Vredenburg provincial hospital were all well represented. Good eligibility criteria were used to exclude those patients who were not physical and mentally fit for in-depth interviews or patients who could not be reached by any means as well as those patients who were still on the wellness programmes. A sample of 18 information rich patients was purposefully drawn from those patients who meet the eligibility criteria including both male and female cases to avoid gender bias in the results. The interviews were audio-taped, conducted in the language of the participants' choice and at a place of their convenience which encouraged them to talk freely about their feelings, illnesses and other experiences.

Limitations of the Study

The limitations of the study included the following: data was not collected from some key informants as clinicians, nurses, health surveillance assistants (HSAs) and pharmacy technicians, traditional healers and religious prophets which could have also had an influence on the quality of the data.

There was also not enough time and financial resources to allow the researcher to personally monitor how all the interviews were conducted and this could also have had an influence on the quality of the data as well as the results that we have obtained from this study.



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APPENDIX A
Consent Form



UNIVERSITY of the WESTERN CAPE
School of Public Health



Barriers to Adherence to Antiretroviral Treatment in Vredenburg, Cape Town

INTRODUCTION

I am Azia Ivo Nchendia, a Master's Degree Student of the Department of Community Health Science at the University of the Western Cape. As part of my Mini-thesis I am carrying out a study to explore the barriers to adherence to antiretroviral treatment in Vredenburg. I will like to take some of your time to interview you in connection to the above study using an audio tape recorder. There are no risks of participating in this study and all information that you will give me will be treated strictly as confidential and no one will have access to this information except the researchers. All information collected from you will be preserved and stored in a way that confidentiality will be strictly maintained. Your participation in the study is voluntary and you may withdraw from the study at any time without sustaining any penalty for your withdrawer.

The results from this study will be beneficial in developing strategies to effectively promote optima adherence to ARV medications by HIV/AIDS patients in this community.

If you would like to participate in this study, please sign at the bottom of this letter.

You can contact Mr. Azia Ivo Nchendia on telephone number at work 0215105055 or at home on 0782015547. Or e-mail. aziaan@yahoo.com or aziaanster@gamil.com

Signature _____

Date _____

APPENDIX B

Questionnaire to non-adhering HIV/AIDS patients on the ART Programme in the Vredenburg Hospital



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School of Public Health



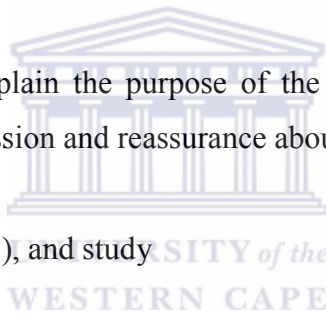
Barriers to Adherence to Antiretroviral Treatment in Vredenburg, Cape Town

Name of the health facility: _____

Name of interviewer : _____

Date of interview : _____

Short introductory remarks, explain the purpose of the study, and define what is meant by adherence, purpose of the discussion and reassurance about confidentiality.



Introduction of the interviewer(s), and study

1) Sociodemographic information of the non-adhering HIV/AIDS patients on the ART programme in the Vredenburg Hospital

a) Sex	
b) Age	
c) Educational level	None, primary, secondary, tertiary etc.
d) Who they live with	Spouse, children, house girl, friend etc.
e) Distance from the facility	In Km etc

i) How do you get to the facility?

ii) Are you employed? If not what is your source of income? (probe, prostitution, stealing etc)

2). Medical history of the patient

- a) When and where you were first diagnosed of HIV?
- b) What made you decide to go for testing?
- c) Did you start ART immediately after being diagnosed HIV (+Ve)? Can you kindly explain to me a little further what happened after you were diagnosed HIV (+Ve)?
- d) When did you start taking your ART?
- e) How do you feel about your health since you started the treatment?
- f) How many times are you supposed to take the medications?
- g) What helps you to take the medication as instructed by the health officers?
- h) What makes it difficult for you to take your ART medications as instructed by the doctor?
- i) Does your family know that you are on ART?
- j) How is your family treating you now that they know you are on ART treatment?
- k) What factors or things in the community help you to live positively with your HIV status?
- l) What factors or things in the community make it difficult for you to live positively with your HIV status?
- m) What do you perceive as the biggest problem regarding taking your ART treatment?
- n) Do you take your ART medications as prescribe? Why and why not? Can you please explain to me a bit further?
- o) Are there times when you have failed to take medications as prescribed by the doctor?
- p) What are the reasons why you have not visited the hospital to take your medication etc?
- q) Do you have friends who are on ART who do not take medications as prescribed by the doctor? What reasons do they give for not take medications as prescribed by the doctor
Probe the possible obstacles for adherence such as drugs availability, attitudes of health workers, financial etc.
- r) Who do you think could be done to improve adherence?
- s) Is there anything else you will like to tell me about HIV and ART medications?

