KNOWLEDGE, ATTITUDES, BELIEFS AND ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG PEOPLE LIVING WITH HIV/AIDS RECEIVING TREATMENT AT SHONGWE HOSPITAL IN NKOMAZI REGION, MPUMALANGA PROVINCE

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A mini-thesis submitted in partial fulfillment of the requirements for the degree of Masters in Public Health at the School of Public Health, University of the Western Cape

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November 2009

KEYWORDS

Knowledge

Attitudes

Beliefs

Adherence

Antiretroviral

Therapy

Poor adherence

Non-adherence

Social support

Social capital

ABSTRACT

Background: HIV and AIDS is one of the major public health problems facing South Africa today. In 2005, it was estimated that 5.54 million people were living with HIV in South Africa, which means that 18.8% of the population between the ages of 15 – 49 years are infected with HIV. This makes South Africa the developing country worst affected by the HIV pandemic. The severity of the HIV epidemic is closely linked to poverty and other socio-economic factors. The National Department of Health of South Africa launched the National Operational Plan for Comprehensive HIV and AIDS management, treatment, care, and support in 2007 to ensure that ART is freely available in the public health sector. It is estimated that by mid-2008 approximately 568, 000 HIV infected patients were receiving ART at South African hospitals.

Suboptimal adherence to ART is pervasive despite specific protocols to prepare patients for long-term adherence prior to treatment initiation. Known barriers to ART adherence have been categorized as patient, socio-economic, service, therapy/regimen and community-related factors. Effective delivery of ART services requires an understanding of patients' knowledge, attitudes, and beliefs about ART and how these influence their adherence.

Aim: The aim of the study was to assess adherence to antiretroviral therapy and knowledge, attitudes and beliefs about ART among people on ART at Shongwe hospital in Nkomazi region in Mpumalanga province, South Africa.

Methodology: A descriptive, cross-sectional survey was conducted among 184 patients receiving ART at Shongwe hospital in Mpumalanga. Data was collected through self-

administration and face-to-face interviews. Quantitative data was analysed using the SPSS version 16.0 and for stratification Epi-Info version 3.4.1 was used.

Results: All participants were on first line regimens: lamivudine/stavudine/stocrine or efivarenz (65.6%); and lamivudine/stavudine/nevirapine (34%). Self-reported adherence was high - 92.4% and 84.2% of participants reported optimal adherence over the previous two days and seven days, respectively. Disclosure of HIV status and being on ART was high among the respondents (97% and 97.3%) respectively. The most common barriers to missing doses were problems travelling to the clinic (22.3%), forgetting (19.6%), and sleeping away from home (18.5%). There was significant association between participants knowing that *"missing doses of ART leads to disease progression"*, and ART adherence on two day recall (p=0.00) and seven day recall (p=0.02). There was a significant association between disclosure of HIV status and ART adherence on two day recall (p=0.01). Significantly more participants who disclosed being on ART (98.2%) reported optimal adherence over the previous two days (p = 0.00) and seven days (p = 0.00) compared to those who did not disclose being on ART. Participants who reported forgetfulness were 76% less likely (95% CI: 0.09-0.65) and 92% less likely (95% CI: 0.04 – 0.17) to have optimal adherence over two and seven days, respectively, than participants who did not report forgetfulness to be a barrier.

Conclusion: Adherence levels in Nkomazi region are to be comparable with those in other regions in South Africa, despite the fact that participants were facing financial constraints and high unemployment rates. These study findings emphasize the need for strengthening communication between patients and health care providers, and the need for overcoming access barriers related to the services, forgetfulness and sleeping away from home.

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DECLARATION

I declare that **Knowledge, attitudes, beliefs and adherence behaviour to antiretroviral therapy among patients on ARVT at Shongwe hospital in Ehlanzeni Nkomazi region, Mpumalanga Province** is my own work piece of work, that it has not been submitted before for any degree or examination in any University or College, and that all the sources I have quoted or used have been indicated and acknowledged as complete references.

Thuli G. Mthembu   **November 2009**

Signed…………………………….

ACRONYMS

AIDS: Acquired Immunodeficiency Syndrome

ART: Antiretroviral Therapy

ASSA: Actuarial Society of South Africa

HAART: Highly Active Antiretroviral Therapy

HIV: Human Immunodeficiency Virus

CD4: Cluster of Differentiation

NSP: National Strategic Plan

PLWHA: People Living with HIV and AIDS

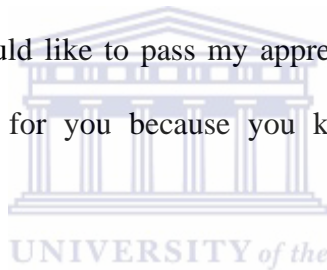STI: Sexual Transmitted Infections

WHO: World Health Organization

ACKNOWLEDGEMENTS

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CHAPTER ONE

INTRODUCTION

1.1 Background

HIV and AIDS is one of the major public health problems facing South Africa today (Hosegood *et al.,* 2007; Department of Health, 2007; Woods, Cope and Eley, 2008). The Joint United Nations Programme on HIV/AIDS and World Health Organisation (WHO) estimated the number of people living with HIV and AIDS (PLWHA) at the end of 2006 to be 39.5 million worldwide (UNAIDS, 2004; WHO, 2005). Approximately 10% of the world's population live in sub-Saharan Africa, 64% of all people living with HIV live in this region. According to UNAIDS (2005), about 3.28 million pregnant women who were HIV infected gave birth and 75% of this group of women reside in sub-Saharan Africa. This situation leads to 700 000 new HIV infections in children in this region.

1.1.1 Human Immunodeficiency Virus (HIV)

This is a virus that directly attacks human immune system and cripples the physiological defences designed to fight and protect people from diseases (Metzler, 2007). HIV slowly diminishes the total number of CD4 cell count in the human body and makes the body ineffective to diseases (Van Dyk, 2001). HIV infection is linked with a clinically stable asymptomatic stage that can last for several years.

1.1.2 Acquired Immune Deficiency Syndrome (AIDS)

This means that a person gets infected with HI virus, and then the virus weakens the body's immune system that fights diseases. When a person is HIV infected possibilities of experiencing health problems are very high. According to Van Dyk (2001), AIDS is the combination of many different diseases that manifest in the body after HIV has weakened the body's immune system to such an extent that it can no longer fight diseases. AIDS is caused by HIV, which can be spread through sperm, blood, breast milk and vaginal secretions. The most common route of transmission is unprotected sex. However, among particular risk groups, other methods of transmission may be dominant. For instance, among intravenous drug users the use of contaminated needles is a major cause of transmission. HIV spreads rapidly in situations where conflict, disasters, or socioeconomic pressures contribute to the displacement of people and disruption of family life. In these situations, women and children are especially vulnerable (WHO, 2006).
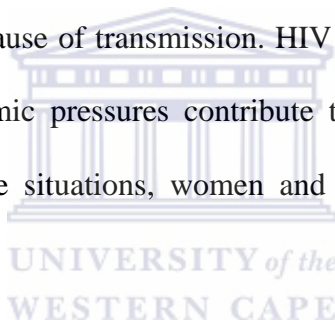
1.2 **HIV and AIDS in South Africa**

According to World Health Organisation (2005), South Africa's prevalence rate of HIV is estimated at 16.2%. According to the Department of Health (2007), about 5.54 million people were estimated to be living with HIV in South Africa in 2005; that means that 18.8% of the populations between the ages of 15 – 49 years are infected with HIV. This makes South Africa one of the developing countries worst affected by the HIV epidemic. The severity of the HIV pandemic is closely linked to poverty and other socio-economic factors (Booysen, 2004; Mills *et al.,* 2006; Department of Health, 2007). In addition, a study conducted in South Africa indicated that 49% of people are dependent on social grants for survival (Louwagie, Bachmann, Meyer,

Booysen, Fairall and Heunis, 2007). Department of Health (2007) and Bradshaw and Nannan (2006) point out that HIV/AIDS is the leading cause of death among South Africans: 1.8 million AIDS related deaths had occurred in South Africa since the beginning of the HIV epidemic. The Department of Health (2007) reports that around 740 000 deaths in South Africa occurred in 2006, of which 350 000 deaths were due to AIDS related diseases. In addition, the Department of Health (2007) reports that 71% of all the deaths were within the 15 – 49 age groups in the country and were due to AIDS related diseases. This shows that HIV and AIDS negatively affected adolescents, early and middle adulthood. South Africa is experiencing the devastating effects of the AIDS epidemic on families and communities, children, grandparents, economy and health and more than a million children were orphaned because of the disease in 2006 (Van Wyk *et al.,* 2006; Shaikh, 2007; Hosegood *et al.,* 2007). The number of orphans and vulnerable children is increasing because their parents died of AIDS related diseases. In 2004, it was projected that there were 2.2 million orphaned children; meaning 13% of all children under 18 had lost either mother or father due to AIDS-related diseases (UNICEF/UNAIDS, 2004). In South Africa 300 000 children under the age of 18 years experienced the death of their parents (Department of Health, 2007). The Department of Health and Actuarial Society of South Africa (2006) also reports that 1.5 million children under the age of 18 were maternal or double orphans (that is had lost a mother or both parents), and 66% of these children had been orphaned as a result of HIV and AIDS. UNAIDS (2006) reports that people in productive age are hardest hit by HIV; leading to the destabilizing of the local economy and many children being orphaned.

1.3 **Highly Active Antiretroviral Therapy**

Highly Active Antiretroviral Therapy (HAART) is a triple therapy used to prevent HIV from developing resistance to ART drugs, also uses three or more antiretroviral medication from at least two of the classes and is the recommended form of treatment (WHO, 2006; Metzler, 2007; National Department of Health, 2007; Duse *et al.,* 2008). The purpose of these three drugs is to stop the progression of the HI virus, to reduce the HIV viral load in the blood, and improve the CD4 cell count of the patient to remain at a baseline count between 500 and 2010 cells/mm³. ART drugs are divided into different classes according to where they act in the life cycle of HIV. These drugs are not a cure, if taken correctly, as instructed they make patients healthy and extend their lives. At the moment there are three classes of drugs available in South Africa. The first class is the Nucleosidal Reverse Transcriptase Inhibitors (NRTIs) which is used to block the enzyme reverse transcriptase indirectly. The second class is made up of Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) which is used to block the enzyme reverse indirectly. Thirdly, Protease Inhibitors are used to blocks the action of protease.

1.3.1 Advantages of HAART

Highly Active Antiretroviral Therapy (HAART) is a treatment that reduces morbidity and mortality in PLWHA (Gebo, Keruly and Moore, 2003; Hofer, Schechter and Harrison, 2004; Mills *et al.,* 2006; Dieckhaus and Odesina, 2007). HAART is effective in controlling the level of the HI-virus to a point where it is no longer possible to detect any HIV in the blood of HIV infected individuals. Furthermore, HAART prevents the HIV from multiplying rapidly and it boosts the body's immune system to cope with the HI-virus. As a result ART increases the

length and improves the quality of life of patients (Hofer *et al.*, 2004; Carrieri *et al.,* 2006; Dieckhaus and Odesina, 2007). In addition, ART treatment enables patients to live full and productive lives. The ART treatment brings back hope to the patients once they adhere to antiretroviral treatment regimen (Carrieri *et al.,* 2006). According to Jaffar *et al.* (2005), many African countries decided to introduce HAART in their public health services in order to decrease the disease progression and increase their survival.

1.3.2 Challenges to HAART

According to Roberts (2000), HAART's regimens are extremely complicated and have strict rules regarding as to when the patients must take the drugs. In addition, these antiretroviral drugs are demanding with patients being needed to swallow number of pills each day. The ART medication is also known in producing side effects. Negative impact about the triple therapy is that if HIV infected individual do not use their ART medication as they are expected. Resistance to HAART can come about if patients on ART miss doses or take the drugs improperly.

1.3.3 ARV medication initiation

Department of Health (2003) and National Department of Health (2007) assert that eligibility criteria for initiating ARV medication are based on both clinical assessment and CD4 cell count. These are the factors that determine whether HIV medication should be started, or be delayed. According to WHO (2002) and Southern African HIV Clinicians Society clinical guidelines of (2002),   an HIV infected individual must have a CD4 cell count below 200 and/or stage IV illness in order to qualify for ART. HIV infected individual who qualifies for ART can access

the ARV medication in government clinic and hospitals when considered to be ready to initiate medication. Department of Health (2003) strongly emphasized that the decision to initiate therapy must therefore be taken not only on meeting the criteria and being ready. However, the HIV infected person needs to be committed to adhere to the medication over a long term. WHO (2002) recommends that for ARV medication programmes in resource-limited settings, HIV infected adolescents and adults should be initiated on ART when they have met one of the following criteria:

WHO stage IV of HIV disease (clinical AIDS) regardless of the CD4+ cells count;

WHO stage I, II, III of HIV diseases with a CD4+ cell count below 200 cells/mm³; or

WHO stages II or III of HIV with total lymphocyte count below 1200 cells/mm³.

The Southern African HIV Clinicians Society (SAHCS) (2002) clinical guidelines recommend that patients in the CD4 stratum 200 – 350 cells/mm³ should be started on ARV medication. The SAHCS also point out that starting patients on HIV medication based on WHO stage 3 is attractive for resource-poor countries, particularly for those without access to flow cytometry for CD4+ lymphocyte count monitoring. From evidence based it is indicated that starting HAART at CD4 200 – 350 cells/mm³ leads to a better outcome than at <200 cells/mm³ (Maartens, 2005).

1.4 **Antiretroviral therapy in South Africa**

In November 2003, the National Department of Health in South Africa launched the National Operational Plan for Comprehensive HIV and AIDS management, treatment, care, and support

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(Department of Health, 2003; Department of Health, 2007). This launch was done in response to the HIV and AIDS epidemic and the need to ensure that ART is freely available in the public health sector (Department of Health, 2003; WHO, 2006; Department of Health, 2007). It is estimated that in 2006 approximately 230, 000 HIV infected patients were receiving ARV at South Africa's hospitals (Actuarial Society of South Africa [ASSA], 2006). Furthermore, ASSA projected that 540 000 HIV infected people who were eligible for ART, but they were already sick with AIDS not receiving ART (Department of Health, 2007). As a result, the Department of Health reviewed the operational plan formulated in 2003 and introduced HIV and AIDS and STIs National Strategic Plan (NSP) for South Africa, 2007 - 2011 to reduce HIV and AIDS morbidity and mortality as well as its socioeconomic impacts (Department of Health, 2007). This review was also done to provide appropriate packages of treatment, care and support to 80% of HIV positive people and their families by 2011. The other primary aim of the NSP is to reduce the number of new HIV infections by 50%. A drastic transition has been observed after the review of the NSP. Evidently, a recent study conducted in South Africa estimated that in the middle of 2008, there were 568 000 adults and children receiving antiretroviral treatment (Muhammad and Leigh, 2009). Furthermore, the number of adults and children on antiretroviral treatment has increased from 4.9% in 2004 to 40.2% in 2008.

1.5 **Study Setting**

The proposed study was conducted at Shongwe Hospital, a district hospital situated in Ehlanzeni district in Mpumalanga Province. Health services are planned and delivered according to the needs of the community based on the principles of the comprehensive primary health care

(CPHC) approach (Mpumalanga Department of Health, 2007). Shongwe hospital is one of the first sites in Mpumalanga to be accredited (June 2004) to rollout antiretroviral therapy. The clinic inside the hospital operates from Monday to Friday from 08H30 hours. In the morning everyday starts with a morning prayer and health education planned by the health care providers for patients (new and follow-up) in the clinic. Currently, there are more than 3,000 patients on ART at the hospital. ART is freely available in the public sector, but the majority of PLWHA who qualify for ART start at a later stage when they are already symptomatic. The reason for people living with HIV and AIDS to initiate ART late is that they delay to test and discover their HIV status.

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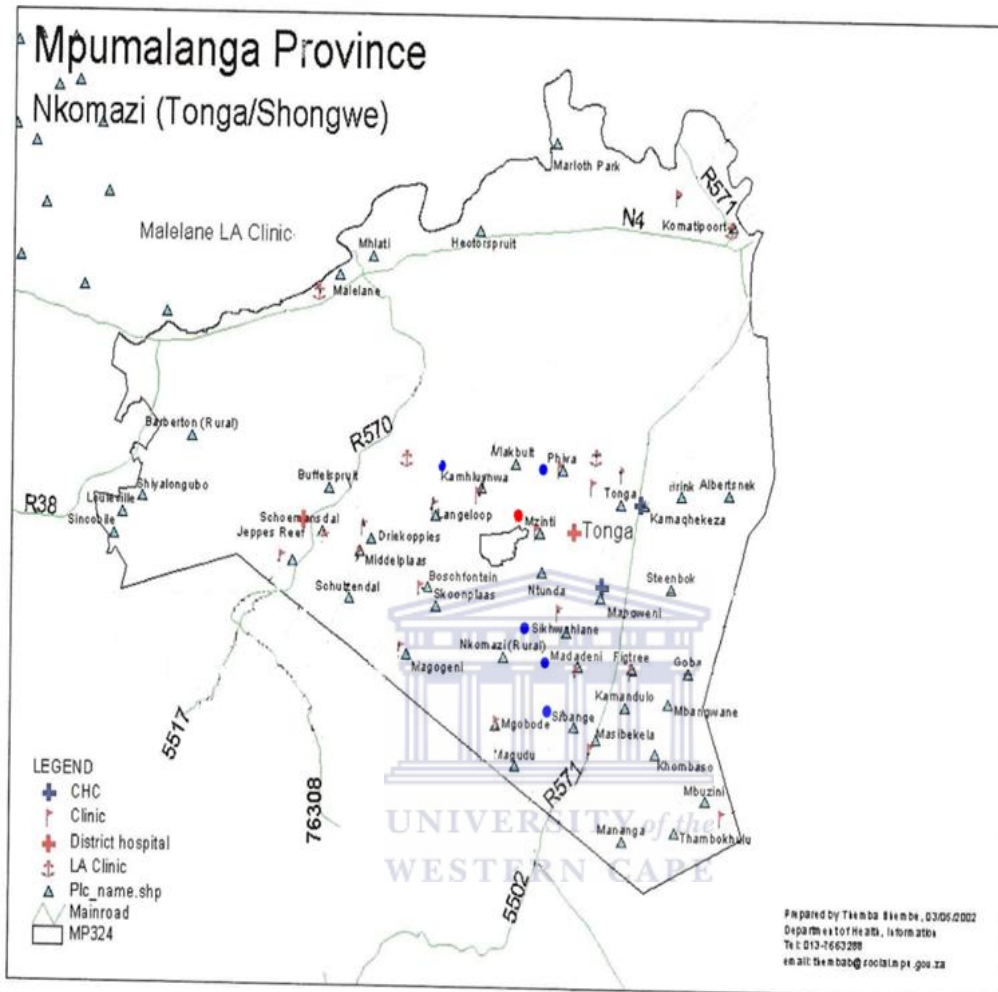
Figure 1: Map of Nkomazi area

1.6 **Problem statement**

Antiretroviral therapy has been available through public health centres in South Africa since 2003. Lack of adherence is still a major challenge to AIDS care in sub-Saharan Africa (Hofer, 2004; WHO, 2006). This "has challenged the abilities of ART services to monitor and retain large numbers of patients within the programmes effectively" (Wood *et al.,* 2008: 44). Antiretroviral medication has been available to improve lives of HIV infected people however many HIV infected people do not adhere to HAART treatment regime as a result it poses a huge challenge to health care system as this brings about highly resistant viruses to HIV treatment. The effective delivery of ART requires an understanding of patients' knowledge, attitudes, and beliefs about antiretroviral therapy and their adherence behaviour.
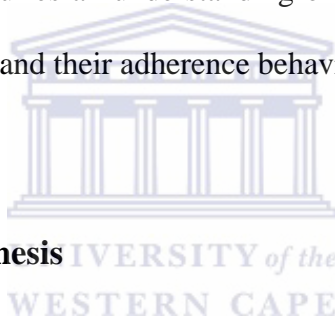
1.7 **Organization of the Mini-thesis**

Chapter 2

The second chapter reports on the literature reviewed for the study. This includes a definition of the concept, adherence, non-adherence and poor adherence, measurement of adherence, and the factors affecting adherence to antiretroviral therapy.

Chapter 3

In this chapter, the aim and objectives of the study are presented. The third chapter articulates the research methodology that was used in the study. This chapter further discusses about the study design used in the research. Furthermore, study population, sampling and sample size are discussed. In addition, data collection and processing, and data analysis explained.

The chapter also includes explanation of validity and reliability. This chapter ends with a report on the ethical considerations taken in this study.

Chapter 4

The fourth chapter reports on the research findings.

Chapter 5

In the fifth chapter, the discussion of the research findings is covered. The discussion interpreted the current study findings and compared them to the results of similar studies.

Chapter 6

The sixth chapter contains the conclusions and recommendations based on the research findings.

CHAPTER TWO

LITERATURE REVIEW

This chapter will deal with six themes. Firstly, an explanation of the major terms used in this study will be provided. Secondly, a detailed discussion of adherence to antiretroviral therapy and ART regimen as well as benefits of adherence to ART medication will be provided. Thirdly, description of strategies for measuring of adherence to antiretroviral therapy will be covered. Fourthly, factors associated with adherence to antiretroviral therapy are discussed in detail. Lastly, this chapter presents conceptual framework of factors associated with adherence to ART.

2.1 Definition of terms

Knowledge

Knowledge is defined as the information, understanding and skills that are gained through education or experience (WHO, 2006). For the purpose of this study, knowledge refers to how ART work and how they should be used. ART is not a cure and that they have to be taken for life.

Attitudes

According to Coulson, Goldstein and Ntuli (1998), attitudes are described as being a fairly stable set of feelings towards a particular issue. Attitude is also defined as a complex mental state involving beliefs and feelings and values and dispositions to act in certain ways (Worchel,

Cooper, Goethals and Olson, 2000). For the purpose of this study attitudes toward treatment adherence are a person's evaluative opinions, both positive and negative.

Beliefs

Beliefs are defined as a cognitive content held as true (Montgomery, Joseph, Ostrow, Kessler and Kirscht, 1989). For the purpose of this study belief refer to confidence that patients on ART have in their ability to adhere to their treatment. It further indicates that patients on ART with poor belief system give up easily when faced with obstacles and discontinue taking treatment as expected, whereas patients on ART with strong belief system would persist when encountering obstacles.

Highly Active Antiretroviral Therapy

Highly Active Antiretroviral Therapy or HAART is defined as a HIV treatment involving the use of a triple combination of antiretroviral drugs (WHO, 2006).

Antiretroviral therapy

Antiretroviral Therapy or ART is medication that stops HIV from making new copies of itself in an HIV infected patient (National Department of Health, 2004).

Adherence

Adherence is described as the 'extent to which a person's behaviour- taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health provider' (WHO, 2003: 3). The concept, *adherence*, emphasizes the patient's ability and willingness to take a therapeutic regimen, based on an informed and autonomous choice, as determined by a process of shared decision-making between the patient and health

care provider (WHO, 2003; Bader *et al.*, 2006). Adherence is also defined as a way of taking tablets in all the prescribed doses at the correct time, in the correct doses and in the correct way (Roux, 2004; Aspeling, 2006).

Non-adherence

According to WHO (2003), non-adherence to medication refers to failure to take medication as prescribed, by discontinuing medication before completion of the course, taking more or less medication than prescribed, and also by taking dosages at the wrong time.

Poor adherence

According to WHO (2001, 2003), poor adherence means that patients are not following the prescribed antiretroviral regimens in accordance to time and dietary requirement.

Therefore, for the purpose of this study non-adherence and poor adherence will be used interchangeable.

Social support

Social support is defined as the attachment among individuals or between individuals and groups which improves adaptive competence in dealing with short-term crises and life transitions as well as long-term challenges, provisions and stresses (Caplan and Killilea, cited in Moratioa, 2007).

Social capital

Social capital has been defined as those features of social organization- such as the extent of interpersonal trust between citizens, norms of reciprocity, and density of civic associations that facilitate cooperation for mutual benefit (Kawachi, Kennedy and Glass, 1999). However, Putman (2000) refers to social capital as connections among individuals including social networks and norms of reciprocity and trustworthiness that arise from them.

2.2 Adherence to antiretroviral treatment

According to World Health Organization (2006), adherence to ART involves an ongoing engagement and active participation of an informed patient in a plan of care to adhere to ART. Consentual partnership between patient and health care provider, wherein the patients are able and willing to make decisions about their medication results in high adherence to ART. The good relationship plays an important role in patients' motivation to adhere to ART and to keep their appointments for follow-up because they were part of the treatment plan. Studies by Mehta, Moore and Graham (1997) and Bader *et al.* (2006) refer to the above mentioned partnership as a constructive relationship where both parties have a role to play to ensure that support and education about the treatment are frankly discussed to sustain adherence.

For optimal adherence to ART patients are expected to take more than 95% of their prescribed medication over the previous year which is equivalent to missing not more than one dose in a ten year period. Adherence to ART includes taking multiple drugs 2 to 4 times a day according to strict schedule (Department of Health, 2003). The ART regimen is a strictly regulated treatment programme (Machtinger and Bangsberg, 2005; Marais, 2006; Simoni *et al.*, 2006).

Thus, adherence to medications is crucial for effective therapy. Although, it is complex, its dynamic process affects the outcome of antiretroviral therapy and patient's health status (Horton, 2000; WHO, 2001, 2006). In addition, Akpomiemie (2005) and Moratioa (2007) suggest that adherence can be achieved through commitments of all stakeholders including patient, health care providers, family and community to the therapeutic process. Furthermore, Akpomiemie in his study conducted in Helen Joseph hospital found that 92.4% of the participants were adherent to their ART.
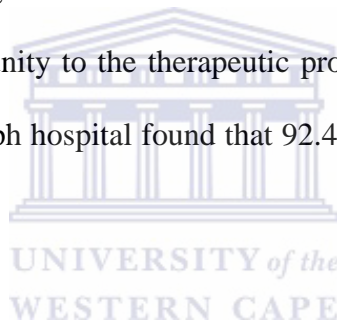
2.2.1. Antiretroviral regimens

Two regimen are recommended for patients who are ready to commence antiretroviral therapy known as first-line regimen 1a and 1b, and second-line regimen 2 (Department of Health, 2003). These two ART regimens are mostly utilized in the public health sector.

Antiretroviral regimen 1a

According to the National Department of Health (2003), first-line therapy regimen 1a is the regimen used for patients who are initiating ART medication. This regimen has been cited as a regimen prescribed for all men and women who are able to stick to injectable contraception and condoms. Therefore, these man and women start with regimen 1a which consists of stavudine,

lamuvudine and efavirenz or stocrine. In this regimen patients are expected to take 5 tablets a day (2 tablets in the morning and 3 in the evening). Dennill (2008) said that regimen 1b consists of stavudine (d4T), Lamivudine (3TC), and nevirapine for women in childbearing age who find it difficult to guarantee reliable contraception while on therapy take 6 tablets a day (3 in the morning and 3 in the evening). This first-line regimen is very potent and has fewer side effects than all other regimens. Furthermore, first-line regimen drugs are easier to take than the second-line regimen. Lastly, this regimen does not need to be kept in a fridge.

Antiretroviral regimen 2

The second-line therapy regimen 2, is the regimen used for patients who experience incomplete viral load suppression or virologic rebound after complete suppression and if viral load above is 5 000 copies/mm³, despite demonstrated adherence of a patient on ART may be switched to schedule 2 (National Department of Health, 2007). The reasons for changing ART to this regimen include treatment failure resulted from failure to suppress viral replication with the development of viral resistance. Regimen 2 consists of Zidovudine (AZT), Didanosine (ddl), lopinavir or ritonavir. The National Department of Health in South Africa recommends that patients who have experienced high viral load while on regimen 2 should receive increased adherence support. Patients on this regimen are expected to take 6 tablets. The second-line regimen has more side effects than first-line regimen. Furthermore, this regimen is more complicated than the first-line regimen. Some of the drugs in this regimen need to be kept in a temperature below 20ºC so is a challenge for patients on ART who do not have the fridge.

2.2.2 Benefits of adherence to antiretroviral therapy

Adherence to medication is crucial for effective therapy. Therefore, strict adherence is considered to be one of the key elements to the benefits of patients' well being. Studies by Chesney (2000), WHO (2002), Gebo (2003), Coetzee *et al.* (2004), Hofer (2004), Moore *et al.* (2005), Ware *et al.* (2005), WHO (2006) and Dickhaus and Odesina (2007) have shown that patients on ART are more likely to receive the following benefits when they adhere to their antiretroviral medication:

- Decrease viral load

- Increase CD4 lymphocyte count

- Decrease hospitalizations

- Decrease morbidity and mortality

- Delayed onset of opportunistic infections

- Stronger immune system due to delayed progression of disease

- Longer life-span to fulfil dreams and goals

- More time to see children grow up and go through life stages

- Opportunity to convey one's life experience

- An opportunity to use the experience of HIV-diagnosis to make life more fulfilling

- The opportunity to continue earning a living (i.e. more productive life years)

- More time to await (and possibly benefit from) the outcomes of scientific research

- Better quality of life

- More time to do the things you enjoy.

2.2.3 Strategies for measuring adherence to ART

Studies by Fogarty *et al.* (2002), Wagner (2002), da Salviera *et al.* (2003), Roux (2004), Levine *et al.* (2006), Liu *et al.* (2006), Marias (2006), Simoni *et al.* (2006) and Dzinza (2007), declare that measuring adherence to ART is a difficult activity in both clinical and research setting. These authors point that there is a controversy regarding the reliability of current methods used to measure adherence to antiretroviral therapy. Nevertheless, a range of strategies for measuring adherence have been formulated. Each of these strategies has its own advantages and disadvantage. Various strategies used for measuring adherence to antiretroviral therapy include patient self reporting, pill counts, electronic event monitoring systems (MEMS), and biological and therapeutic drug monitoring (viral load and CD4 counts) (Fogarty *et al.*, 2002; Wagner, 2002; da Salviera *et al.*, 2003; Roux, 2004; Levine *et al.*, 2006; Liu *et al.*, 2006; Marias, 2006; Simoni *et al.*, 2006 and Dzinza, 2007; Thobias, 2008).
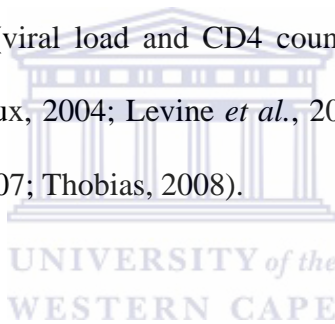
Self-reports

This is the method that relies more on the information provided by the patients about their adherence to ART but this has limitations in that patients may not be truthful. According to Chesney (2000), patients are requested to reveal information about their adherence to treatment in self-report. Furthermore, the data are easily collected and can assist to determine the reasons why patients are poor adherents. Patients disclose information about the number of pills that they take a day or number of pills they miss in two days and in a week. The dimensions used for self-reports consists of face to face interviews, questionnaires, calendars and diaries as well as visual analogue (WHO, 2006). Self reports have the advantages of low-cost and flexibility of design

and data collected can help to determine the reasons for sub-optimal adherence because there is no procedure and equipment needed (Chesney, 2000; Liu *et al.*, 2006). Furthermore, self-reports are reasonably correct in producing the gist of sub-optimal adherence. Self-reporting has however limitations such as overestimation of adherence, due to patients being unable to accurately recall missed doses of their treatments. In self reports patients are more likely to deny poor adherence to ART (Chesney, 2000, Liu *et al.*, 2006).

Pill counts

Pill count involves counting the remaining doses of medication when ART patients visit the health facility for his/her scheduled follow up appointment (Chesney, 2000). According to Chesney (2000), a pill count provides the health care providers with tangible evidence of poor adherence to ART because patients return all pills that were left in the container. Dzinza (2007) observed in her study that all physicians used pill counting as a method to assess adherence to ART with the patient. Counting of pills is used in the first three months of initiating ART. This method has limitations as physicians reported in the study that patients dump pills so that they can be seen as to be complying with treatment. Liu *et al.* (2006) point out that pill counting is time consuming, sometimes is difficult to ascertain because patients are more likely to dump pills. Pill counts are also inaccurate to provide indication of poor adherence because patients tend to forget the packages or discard them.

Medication Electronic Monitoring Systems (MEMS)

Roux (2004) explains that MEMS caps are a form of measuring adherence whereby a special medicine bottle is used with computer chip in the cap. Every time the bottle is opened, it is recorded and results can then be downloaded, printed and analysed. Studies have found that, MEMS is an objective and accurate measure of adherence to antiretroviral medication (Chesney, 2000; Liu *et al.*, 2006; WHO, 2006). MEMS also allow detailed view of non-adherence and are best correlated with virologic outcomes. Nevertheless, Liu *et al.* (2006) argue that MEMS has limitations such as that it is expensive and a complicated tool to implement.

Biological and therapeutic drug monitoring

CD4+ lymphocyte count is extremely important in the assessment of the effectiveness of antiretroviral therapy. Dzinza (2007) reports that physicians measure adherence by monitoring the CD4 cell counts and viral load. The CD4+ lymphocyte also assists in the assessment of immunological failure on therapy. According to World Health Organisation (2002), measuring CD4 counts is too expensive to perform and not available in resource constrained areas.

According to Coetzee *et al.* (2004), viral load measurements can be utilized as a marker of adherence in the first year on ART. There are, however, limitations in some instances. For example, a high viral load does not necessarily indicate poor adherence but that there may also be other factors contributing to high viral load. Despite the limitations of these measurement techniques, adherence measures provide valuable insight into the association between drug taking and viral load, as well as approaches that may be useful for improving adherence (Thobias, 2008).

In conclusion, even though there is no single measure gold standard is appropriate for measuring adherence to ART. Various studies are in favour that self-report is mostly utilized measure of adherence to antiretroviral medication because of low-cost and flexibility of design. The use of more than one measure of adherence allows the advantages of each tool to compensate for the disadvantage of the other and to more accurately capture the data required to determine adherence levels (Chesney, 2000; WHO, 2006).

2.3 Factors that affect ART adherence

Constraints to adherence to antiretroviral therapy among historically disadvantaged rural patient populations in developing countries are poorly understood (Kagee, Le Roux and Dick, 2007). Sustained adherence depends on a multitude of factors, many of which fall outside the patient's immediate control (WHO, 2003). This section will describe several factors that affect adherence to ART. These factors will be classified as patient-, socio-economic-, health services-, therapy-, illness- as well as community factors.

2.3.1 *Patient-level factors*

Patient-level factors that are associated with adherence to antiretroviral therapy include age, patient knowledge, level of education, social support, coping skills, attitudes and beliefs, patient forgetfulness (WHO, 2006; Mills *et al.,* 2006a; Mills *et al.,* 2008). These factors seem to be impacting negatively on patient's ability and motivation to adhere to medication.

Age

Studies by Mehta, Moore and Graham (1997), Gordillo, del Amo, Soriano and González,-Lahoz (1999) and Chesney (2000) that younger individuals struggle to comply with treatment because of dependence to their caregivers to administer their medication. According to Naar-king *et al.* (2006), children and adolescents with HIV may experience difficulties to take their medication because their families' desire for secrecy about their illness. Families with children who are HIV-infected prefer to keep the child's HIV status as secret because they are afraid of being severely stigmatized, discriminated and rejected as a result children struggle to adhere to medication (Hammami, Nostlinger, Hoerée, Lefèvre, Jonckheer and Kolsteren, 2004).

Patient knowledge

Non-adherence among patients on ART has been found to be significantly associated with the patient not knowing the correct dose of medication (Mehta, Moore and Graham, 1997). The authors also report that patients' lack of knowledge of their diagnosis and expected course of their illness or medications has also been associated with decreased adherence. Nevertheless, patients who learned the names of their medications were cited to be adherent than those who did not know the medication names.

Level of Education

Low level of education was found to be associated with poor adherence and may impact negatively on some patient's ability to adhere, while a higher level of education has a positive impact to medical treatment (Gordillo *et al.*, 1999; Kalichman, Ramachandran and Catz, 1999;

Heath, Singer, O'Shaughnessy, Montaner and Hogg, 2002; Pinherio *et al.*, 2002; Reynolds *et al.*, 2004; Hofer, Schechter and Harrison, 2004; Kagee, Le Roux and Dick, 2007; Falagas, Zarkadoulia, Pliatsika and Panos, 2008). Patients experience difficulties to follow physician, nurse and other health workers instruction on taking treatment. Patients on ART with low level of education/knowledge struggle to follow instructions because of difficulties in recognizing correctly their current medications (Pinheiro *et al.*, 2002). This has an impact on PLWHA to take their treatment as they are informed by the health care providers in the health facility. These authors also report that self-efficacy about antiretroviral therapy was found to be extremely high in ART patients with more years of schooling in Brazil. The greater prevalence of adherence among patients with more years in school was reported because increased level of education provided the patients with skills such as planning, organizing and integration
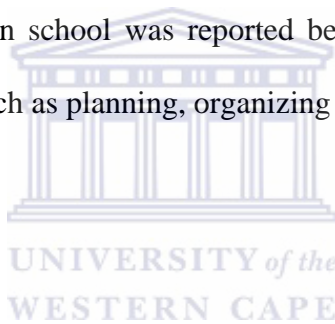
Social Support

Research has shown that consistent support from family members and significant others is a strong indicator of medical adherence (Chesney *et al.*, 2000; Bearman and La Greca, 2002; Simoni, Frick, Lochkart and Liebovitz, 2002; Attawell and Mundy, 2003; Hofer, Schechter and Harrison, 2004; Skhosana, 2006; Kagee, Le Roux and Dick, 2007). Family members who openly provide social support to patients on ART increases probability that the patients will disclose their HIV status and adhere to antiretroviral treatment. Social support provides motivation and encourages adherence to therapy as well as promoting other healthy behaviours. Whereas, Van Dyk (2001) and Timmons and Lynch (2004) pointed out that some people living with HIV/AIDS receive positive support from their loved ones, others are discriminated against, rejected and isolated from their families. That is why the authors referred to these kinds of experiences as a

"double-edged sword" because they break or build up a person's motivation. It is reported that problems in relationships such as rejection by sexual partners, family members, friends, and community members are often experienced by PLWHA after disclosure, which can deter them from taking treatment openly (Qwana, Mkaya, Dladla and Lurie, 2000; Nachega *et al.*, 2005; Toivo, 2005; Mills *et al.,* 2006a). This has devastating impact on patients on ART when they are expected to comply with treatment. According to Attawell and Mundy (2003), buddy support and support groups play a crucial role in HIV medication compliance.

Coping skills

ART patients have a tendency to mix different forms of treatment including faith based healing, alternative and conventional medicine and traditional medicine (Van Dyk, 2001; Aidsguide, 2006 cited in Marais, 2006). Bader *et al.* (2006) found that the majority of the women use prayers as a coping skill because of the belief that they might be healed from the illness. Dzinza (2007) reports that physicians in her study were concerned about the information spiritual leaders gave to their patients such as advising the patients to stop taking ART as they would pray for them and cure the disease. Dzinza (2007) also report that physicians were concerned about the negative effect of herbal treatment to adherence of ART. The implication of herbal medicine in patients who are taking ART is that it affects the interaction of treatments at the end results to sub-optimal adherence. This seems to be impacting negatively on patients' adherence as some patients seek help from traditional healers whilst they are already on ART.

Attitudes and beliefs

Reynolds *et al.* (2004) describe beliefs as the level of confidence that patients have in their ability to adhere/comply with treatment. In this regard, a strong belief in one's ability to adhere to antiretroviral therapy could potentially enhance the patient's capacity to comply with therapeutic regimen. According to World Health Organisation (2001), (2006) and Mills *et al.* (2006a) patient's beliefs about their illness and effectiveness of medication are predictive of adherence. A good level of understanding about HIV by the patient, a belief that antiretroviral therapy is effective, and prolongs life, recognition that poor adherence may result in viral resistance and treatment failure. All these beliefs impact negatively upon a patient's ability to adhere to ART (Montgomery *et al.*, 1989; Mehta, Moore and Graham, 1997; WHO, 2001; 2006). These authors also argue that the patients' acceptance of the disease and perceptions about the benefits of the treatment influences their adherence behaviour. According to Becker (1974), and Pinheiro *et al.* (2002), beliefs in personal abilities govern the health behaviour which is adherence to antiretroviral therapy.

Patient forgetfulness

Patient forgetfulness cited as a barrier to adherence to ART (Roberts, 2000; Reynolds *et al.*, 2004; Marais, 2006; Mills *et al.,* 2006a, WHO, 2006; Dieckhaus and Odesina, 2007, Wang and Wu, 2007; Amberir *et al.,* 2008; Thobias, 2008; Malangu, 2008). These authors mentioned that patients on ART simply forget to take treatments due to being away from attending social events such as night vigil, funerals, weddings and parties.

2.3.2 *Socio-economic factors*

Socioeconomic factors such as social habits and lifestyle, financial constraints, and poverty are found to be barriers to adherence to ART (Louw, Van Ede and Louw, 1998, da Salviera *et al.*, 2003; WHO, 2006, Falagas *et al.*, 2008).

Social habits and lifestyle

Active alcohol consumption and drug abuse have been cited to be associated with poor adherence to ART (Golin *et al.*, 2002, Golin *et al.,* 2004; Mills *et al.,* 2006b; WHO, 2006). These authors report that alcohol, and drug abuse is impacting negatively to adherence as they lead patients to forget not to take their HIV medication. Furthermore, these factors increase the possibility of patients to engage in unhealthy risk behaviours.
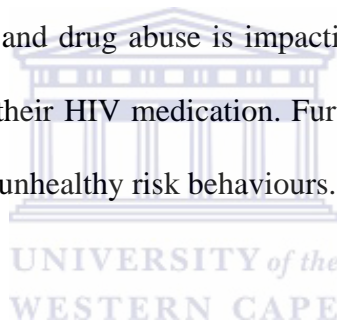
Financial and distance constraints

Studies by Pinheiro, de Carvallo-Leite, Drachler and Silveira (2002), Attawell and Mundy (2003), Marais (2006), Moratioa (2007), Mills *et al.* (2006a) and Uzochukwu, Onwujekwe, Onoka, Okoli, Uguru and Chukwuogo (2009) show that financial resources to travel to health facilities for patients in order to collect their ART are challenges resulting in patients missing their follow-up appointments. Specifically, it is not easy for patients in rural areas to have access to the health facilities because of the poor roads, long distances and the cost of the transport (Jaffar *et al.*, 2005; Popa-Lissenanu *et al.*, 2005). Various studies in developing countries revealed that living in economically disadvantaged and resource-limited contexts contribute to

poor adherence amongst patients who are on ART. According to Weiser *et al.* (2003) and WHO (2006), patients on ART travel long distances to health facility cited as a significant barrier to adherence to antiretroviral medication. Some patients in Botswana mentioned that they lived 800 to 1000km away from the clinic and had to travel that distance on monthly basis (Weiser *et al.*, 2003). The long distances negatively impacting on patients to comply with ART.

According to World Health Organisation (2006) and Falagas, Zarkadoulia, Pliatsika and Panos (2008), economic support has been cited as directly related to the level of adherence to ART. For example, in a cross-sectional study in Brazil Gordillo *et al.* (1999), observed that there was better adherence to ART medication among patients on ART who were having sustainable occupation and chances of them to follow ART instructions were high.

Poverty

Poverty does not operate on its own as a risk factor for adherence to antiretroviral therapy. However, there are poverty-related stressors arising from aspects of poverty in disadvantaged areas such as inadequate food and unemployment have been shown to be associated with poor adherence. Lack of food has been cited as a problem in Uganda, Botswana and Tanzania for most patients on antiretroviral therapy. Unemployed patients who are on ART seriously lack food as a result suffers from hunger and they are unable to satisfy their increased appetites stimulated by their medication (da Salviera *et al.*, 2003; Kalichman, Simbayi, Kagee, Toefy and Jooste, 2006; Marais, 2006; WHO, 2006; Moratioa, 2007; Spies, 2007; Thobias, 2008). This means that patients on ART stop taking medication due to shortage of food in the household. In addition, lack of food disrupts the daily schedule for taking medication and negatively influence

adherence (Thobias, 2008). Hunger seems to be a profound problem to patients on ART because it disrupts the process of medication absorption in the body (Larkin, 1998; Bukusuba, Kikafunda and Whitehead, 2007).

2.3.3 *Health-services factors*

Health service factors that affect adherence to antiretroviral therapy include doctor-patient relationship, quality care, lengthy waiting times and distances to health facilities and follow-up schedules (WHO, 2006). These factors are explained.

Health provider-patient relationship

According to Chesney (2000), World Health Organisation (2006) and Marais (2006), doctor-patient relationship predicts the success and failure of antiretroviral medication among the patients taking the medication. In this relationship patient's involvement as an active member is crucial in the process of decision-making during discussion of treatment options and information exchange so that patients on ART will adhere to their treatment (Cassidy 1999; Bader *et al.*, 2006). Involvement of patients in decision making makes the patient to have trust in the health provider and clinic staff and builds satisfaction (Barker *et al.*, 2004). If the relationship is build on the foundation of respect and effective relationship such as warmth, openness and cooperation chances of adherence are high. In other cases health providers ill-treat patients on ART inhumanely calling them by names, like "cattle or a number" and "guinea pigs" (Remien *et al.*, 2003).

Quality care

Health care workers with a poor understanding of dynamics of adherence and patients reduce the quality of care patients on ART. This has a negative impact on the quality care delivered to patients on ART as the health care workers might not be able to identify clients with poor adherence. Shortage of staff is a major constraint to quality care and results in overworking of the available staff. This is also a serious problem because it leads to inability or unwillingness to engage the patients who are on ART in the planning and management of quality care.

Waiting times in health facilities

The problem of long waiting times was mentioned as a major challenge to adherence among patients who are on ART in Botswana, Tanzania and Uganda (WHO, 2006). Patients spent an average time of five hour while waiting for consultation and medication. Prolonged waiting times have negative effect on both follow-up appointments and adherence (Dehab *et al.,* 2008). The World Health Organisation recommended that health facilities should avoid keeping patients waiting for long period of time waiting for consultation and medication in order to maintain high adherence levels over a long period.

Attitudes of health care providers

Thobias (2008) notes that patients have often mixed attitudes about the health care providers. Thobias further reports that there were patients who were generally satisfied with the behaviour of the health care providers; others however, were completely dissatisfied with their attitudes.

Follow-up schedules

Appointment dates have been cited as a key challenge for patients on ART to adhere to their medication (Spies, 2007; Thobias, 2008). This is a challenge to patients because of their inability and unwillingness to contribute in decision making about their medication.

2.3.4 *Therapy-related factors*

Therapy-related factors include a number of pills and side effects. These factors were reported to be associated with devastating impact to adherence to ART (da Silveira, de Lourdes Drachler, de Cartalho Leite and Pinheiro, 2003; Wang and Wu, 2007; Roberts, 2008).
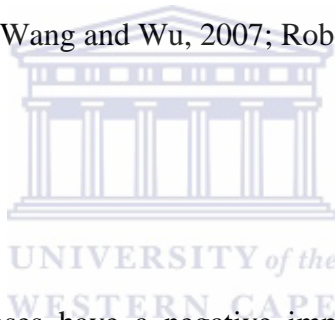
Number of pills

High pill burden and frequent doses have a negative impact to adherence to ART because patients on ART struggle to comply with the complicated regimen (Roberts, 2000; Pinheiro *et al.*, 2002; Popa-Lissenanu *et al.*, 2005; Mills *et al.,* 2006a; Uzochukwu, Onwujekwe, Onoka, Okoli, Uguru and Chukwuogo, 2009). In a qualitative study among a diverse sample of HIV positive men and women in four U.S. cities most of the respondents expressed that their medication were irritating and challenging (Remien *et al.*, 2003). Hammami, Nostlinger, Hoerée, Lefèvre, Jonckheer and Kolsteren (2004) and Nachega, Stein, Lehman, *et al.* (2004) report that medication related factors such as volume, taste, diet prescriptions, intake pills, strict timing of doses, and side effects are difficult to overcome. The participants in a qualitative study in Belgium were concerned about the number of pills, the frequency of the doses, size and the taste

of the pills. Literature on HIV antiretroviral and treatment adherence indicates that patients with prescriptions of three to four daily doses were 53 % less likely to comply with treatment than patients who had been prescribed a two-dose regimen (da Salviera *et al.*, 2003).

Side effects

Marais (2006) comments that all forms of adverse effects influence patients on ART from adhering to their treatment. The side effects include nausea, diarrhoea, headache, rash, vomiting, and sleep disturbance. These adverse effects have profound impact to adherence to antiretroviral medication, activities of daily as well as obligations and quality of life (Gordillo *et al.*, 1999; Roberts, 2000; Heath *et al.*, 2002; Remien *et al.*, 2003).
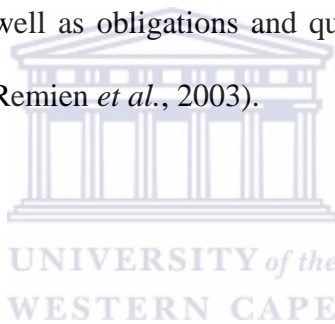
2.3.5 *Illness-related factors*

Illness-related factors that influence adherence to antiretroviral therapy such as depression, stress, and anxiety were reported to be associated with adherence.

Depression, stress and anxiety

Emotional and psychological distresses are commonly associated with decreased adherence in HIV infected patients (Mehta, Moore and Graham, 1997; Thobias, 2008). Research shows that there is a strong relationship between adherence and depression (Ciechanowski, Katon and Russo, 2000; Mills *et al.,* 2006a). Major depression is commonly cited psychiatric problem among HIV infected individuals with prevalence rates ranging from 17 to 30% (Mehta, Moore

and Graham, 1997). Studies have shown that depressive syndromes are the most prevalent mental disorders related to HIV infection (Pinheiro *et al.*, 2002; Starace *et al.*, 2002). Depression has been cited as having negative effect on the quality of life of PLWHA and is associated with poor adherence to HIV treatment (Reynolds *et al.*, 2004; WHO, 2006). Depressive symptoms that patients on ART experience are social withdrawal, occupational dysfunction, sexual rejection as well as restriction in the activities that give meaning to life, loss of physical and financially independence and uncertainty about the effectiveness of ART.

2.3.6 Community factors

Community factors consist of problems such as stigma and discrimination. These problems have been cited as impacting negatively to adherence to ART medication (WHO, 2006; Department of Health, 2007).
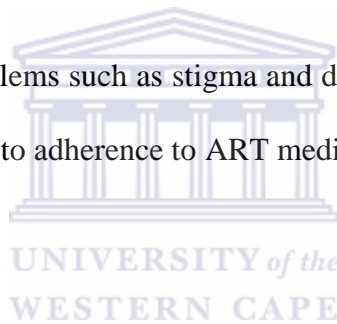
Stigma and discrimination

Most of HIV positive patients decide to not disclose their HIV status, reasons being that they fear stigmatization, discrimination and isolation (Mills *et al.,* 2006a; Department of Health, 2007; Thobias, 2008; Uzochukwu, Onwujekwe, Onoka, Okoli, Uguru and Chukwuogo, 2009). This has an impact on patients who are supposed to take their treatment in public places; therefore coping with the secrecy is difficult because they are depriving their rights to ART medication. When patients on antiretroviral therapy experience difficulties end up hiding everything related to their medication (WHO, 2006). The problem of stigma and discrimination forces HIV infected patients to engage in high-risk behaviour that affects adherence (Qwana *et al.*, 2000). According

to Thobias (2008), negative attitudes and discriminating behaviours towards patients on ART in Namibia includes gossiping, avoidance, isolation, labelling and rudeness.

2.4 **Summary**

The factors that influence adherence to antiretroviral therapy (patient, socioeconomic, health service, therapy, illness, and the community), identified in the preceding literature review can be summarised by conceptual framework (Figure 2) below. These six groups of factors interact resulting in poor adherence to antiretroviral therapy among patients, and form the conceptual basis for the current study.

Figure 2: Factors leading to poor adherence to ART
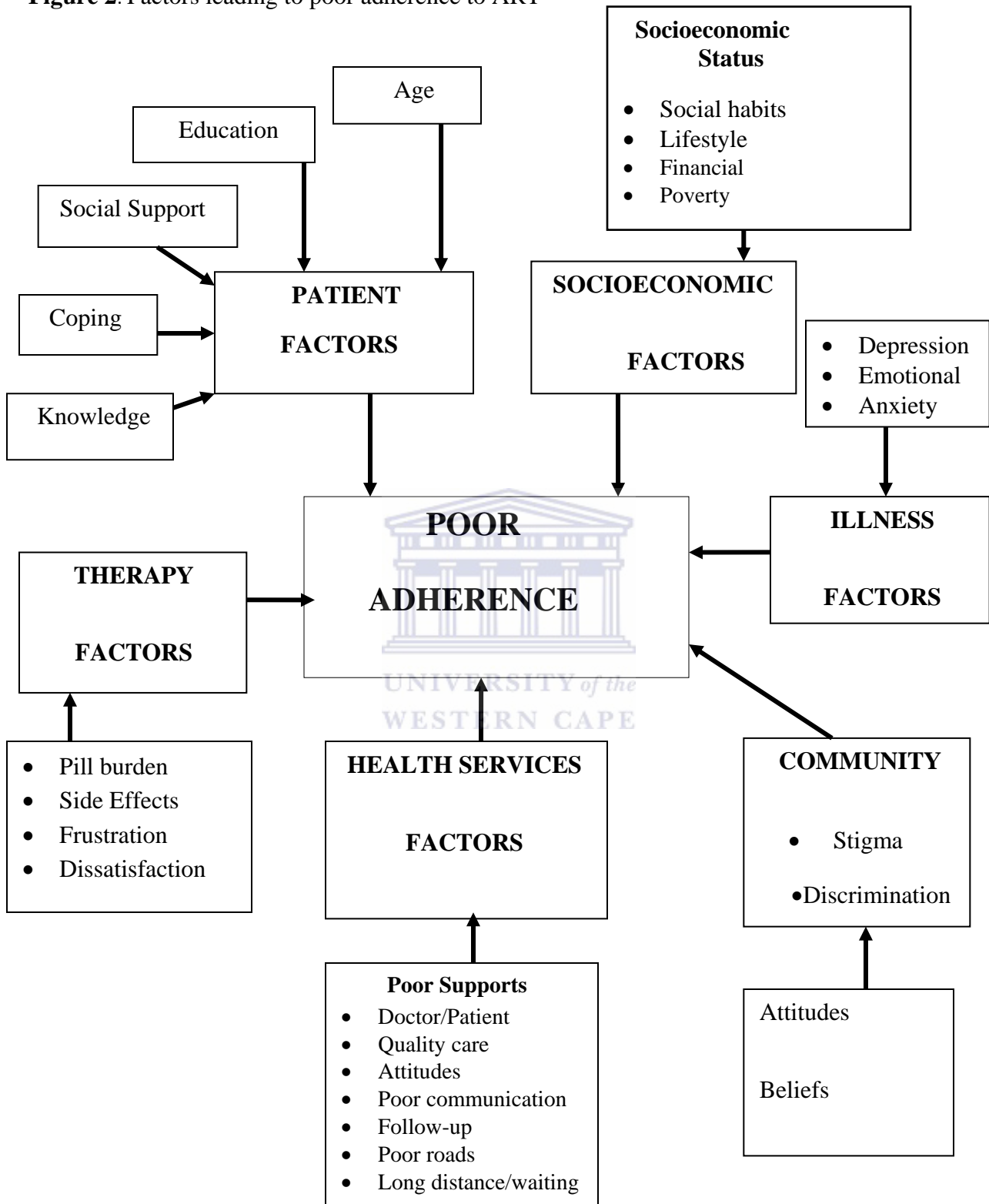
CHAPTER THREE

METHODOLOGY

In this chapter, a description of the aim and objectives of the study is covered. This section covers the study design, study population, sample size, sampling procedure, data collection and processing, data analysis, validity, pilot study and reliability, as well as ethical considerations.

3.1 Aim and objectives of the study

The aim of the study was to assess the factors associated with poor adherence to antiretroviral therapy including knowledge, attitudes and beliefs to ART among people on ART at Shongwe hospital.
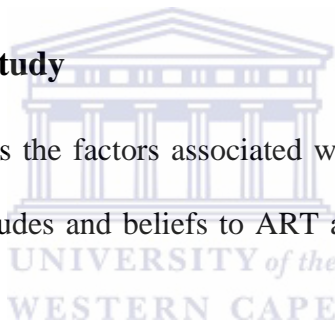
The objectives of the study were to: -

- describe knowledge, attitudes and beliefs about of patients on ART;

- describe the levels of adherence amongst patients on ART using 2-day and 7-day recall;

- describe social support and coping skills of patients on ART;

- describe health services factors that may influence adherence to ART; and

- analyse associations between self-reported adherence and various patient, social capital and health services factors.

3.2 **Study Design**

A descriptive, cross-sectional survey aimed at describing the knowledge, attitudes, beliefs and adherence behaviour of PLWHA to antiretroviral treatment (ART) at Shongwe Hospital in Nkomazi region in Mpumalanga province, South Africa was conducted. A descriptive study was chosen in order to describe the phenomenon of interest and observed associations in order to estimate certain parameters (Bowling, 1997). According to Couglan, Cronin and Ryan (2007), Vaughan and Morrow (1989) and Beaglehole, Bonita and Kjellström (1993), descriptive cross-sectional surveys are useful to measure the relationship between two or more variables, and analyse significance of statistical associations.

3.3 **Study population**

The study population consisted of patients (males and females) who were on ART for at least six months, between the ages 15 and 65 years, and registered in the HAART programme at the Shongwe hospital. There were 3,000 people on the register for ART by mid 2008.

3.4 **Sampling Procedure**

Burns and Grove (2005) describe eligibility criteria or inclusion criterion as a list of characteristics essential for eligibility in the study population. All patients on ART meeting the eligibility criteria of the study were randomly selected to ensure that every patient on ART has an equal chance of being selected for the study (Wegner, 2007). Participants were identified for the study from the ART register of the hospital using simple random sampling. This was done to

avoid bias. A number was assigned to each name on the list e.g. 1 to 3000. Numbers were written on a piece of paper; all the papers were folded and put in a box. 184 papers were taken out of the box (by a neutral person) and the numbers were recorded as a sample for the study.

3.5 **Sample Size**

The sample size for the study in order to obtain an estimated proportion of 95% confidence level was estimated using the StatCalc design in Epi-Info version 3.4.1. The estimated total number of patients on ART in Shongwe hospital at the time of study was 3000. This was based on the assumption that 20% of the patients achieve optimal adherence to ART. Using the StatCalc in Epi-Info version 3.4.1 (with expected rates of 20% and worst acceptable estimate 15%) the sample size was estimated to be **184**.
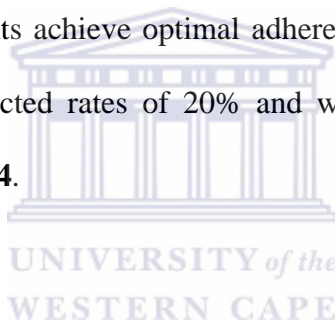
3.6 **Data Collection**

A permission to conduct the study was obtained from the Mpumalanga Department of Health Provincial Research and Ethics Committee (Appendix 2). The acting Chief Executive Officer and Medical Manager of Shongwe hospital were also furnished with the letter of approval from the Provincial Research and Ethics Committee. The purpose of the study was explained to the participants of the study and the consent was signed before completion of the questionnaires. Participants were also informed about their right to withdraw from the study and issues of confidentiality were explained. The researcher assisted participants who were struggling with writing when completing the questionnaires. Participants were allowed to ask for clarification from the researcher at any point in the completion of the questionnaire. The questionnaire was

administered from the 2nd of March to the 17th of March 2009. The questionnaire was translated to the local language (siSwati) of the participants.

The questionnaire was a method of gathering self-reported information from respondents through self-administration and face-to-face interview. Furthermore, this method of data collection involves respondents in conversation (Bless and Higson-Smith, 2000; Leedy and Ormord, 2005). A previously validated questionnaire about antiretroviral treatments and people living with HIV was adapted to suit patients on ART for the study (Godin, Gagné and Naccache, 2003; WHO, 2006b; WHO, 2008). Validated questions from the 1998 South African Demographic and Health Survey were also included (Department of Health, Medical Research Council and Macro International Incorporated, 1998). The questionnaire consisted of four sections, namely demographic characteristics, social support, knowledge, attitudes and beliefs about ART as well as health services (Appendix 5).

The coded questionnaire was piloted among patients on ART, and then adjustments were made before final implementation of the study. Patients on ART were approached about participation in the study while waiting for their appointments in the waiting rooms of the clinic. Questionnaires were checked and completed on site before the interviewer departed. Questionnaires were checked for errors before a patient on ART was released after questioning and any errors made were immediately corrected.

3.7 **Data Analysis**

Quantitative data was analysed using the SPSS version 16.0 and for stratification Epi-Info version 3.4.1 software was used. In addition, data was numerically captured twice in separate files using Microsoft excel program. It was then imported to the SPSS 16.0 version 2007 for further analysis with the help of the statistician. **Completeness**: all data collected with the questionnaires was checked before it was entered into the SPSS 16.0 and Epi-Info 3.4.1 software. **Proper Place**: the data was often checked to see if it had been correctly entered in the correct item blocks or lines as the data could easily entered in the incorrect place. The questions in the questionnaire to map the data based on numerical and categorical. Statistical analysis that was followed in the study includes three essential steps in data analysis. Firstly, each variable was analysed separately, one after the other, for the distribution of counts in each category. For the numerical data such as age, hours spent in the hospital, minutes spent while waiting to be attended, and total number of pills missed as well as the total times pills missed were analysed. These numerical data were analysed to obtain means, range, and standard deviation. All categorical data were analysed to produce the frequency distributions. The one-way tabulation was performed to inform the researcher about the responses from the participants.

Secondly, analyses were done on pairs of variables that were relevant and stratified according to such variables as age, gender, education and economic status. This cross-tabulation was produced to show any associations from the findings.

Thirdly, calculations were done to obtain adherence rates and dichotomized into two categories, namely ≥ 95% (optimal) adherence and ≤ 95% (sub-optimal) adherence. These categories were also analysed to understand the associations. Adherence measured through self-report only

reflected the adherence over the period of recall (e.g. 2 days and 7 days). The formula used to calculate adherence level:

$$\% \text{ Adherence} = \frac{\text{\# of doses patient should have taken} - \text{\# of doses missed}}{\text{\# of doses patient should have taken}} \times 100$$

Further analysis were done by looking for associations between gender related to knowledge about ART, gender related to employment status, level of education related to knowledge about ART, health services related to gender variables and to check whether any apparent differences were significant or not. The statistical significance was assessed at $p<0.05$ level. This helped to rule out one important threat to validity and the result could be due to chance rather than to real difference (Couglan, Cronin and Ryan, 2007). Data is presented using tables, pie charts, bar charts and box plots.

Independent t-tests between <95% adherence and ≥95% adherence and time spent during last visit to health service, and waiting time.

3.8 **Validity**

Face validity is the appearance of the questionnaire (De Vos *et al.*, 2005) and content validity is the validity is content particular construct an appropriate strategy concerned with a test's ability to include or represent the entire construct (Burns and Groove, 1993; Rungtusanatham, 1998). Furthermore, content validity is based on the extent to which a measurement reflects the specific intended domain of the content. This approach assumes that a good detailed description of the content domain. Health care providers at Wellness clinic were provided with a sample

questionnaire so that they could assess its validity. The inputs from the consultation with the health workers assisted in rephrasing of the questions. The questionnaire was compiled in English then translated into siSwati as the first language of the most study population. The questionnaire was found to be relevant by the health care providers to the context of Shongwe hospital.

3.9 **Pilot study**

A pilot study was conducted prior to the collection of the main of the data of the study to test the construct of the questionnaire. This was done to test whether participants understood the questionnaire and completed it comprehensively. In addition, pilot study was conducted to determine the content validity of the questionnaire and identify changes needed before they were administered.
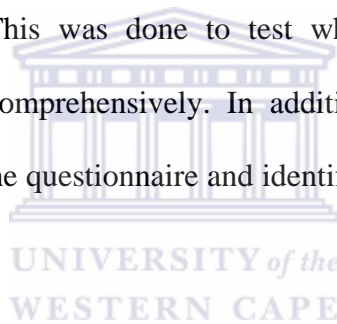
3.10 **Reliability**

Instrument bias was reduced by using structured questionnaires adapted from Casey (2004) and Godin, Gagné and Naccache (2003). Furthermore, assistants were trained in the administration of the questionnaire before the beginning of the study to ensure standardization and to avoid misclassification. Reliability was enhanced by ensuring that questions were asked according to the set order on the questionnaire. Similarly, the researcher and assistants did not expand and probe more than it was anticipated in the questionnaire. A pilot study was conducted to test the instrument for further adjustment to avoid ambiguity. The findings of the study were generalized to the study population. It was ensured that the method used for data collection was reliable so

that there would be repeatability in order to produce the same results. This would help with consistency of the same information of patients on ART in Shongwe hospital. Nonetheless, it was anticipated that the findings would have relevance more broadly to the needs of patients on ART.

3.11 **Ethical Considerations**

Burns and Grove (1993) point out that conducting the research ethically goes from the identification of the research topic to the publication of the study results. An application for ethics approval was submitted for approval, and then was accepted by the University of the Western Cape Ethics Committee and Higher Degrees Committee (Appendix 1). Permission was obtained from the Mpumalanga Provincial Research Ethics Committee Department of Health and Shongwe Hospital for ethical approval (Appendix 2). Participation in the study was voluntary for all patients on ART. The participants were provided with a letter explaining the purpose of the research study requesting their participation and assuring them confidentiality (Appendix 3). Participants gave informed consent to participate in the study. Furthermore, the participants had the right and opportunity to withdraw from the study at anytime. A consent form used to for participants (Appendix 4) was given and attached to the questionnaires and signed by the participants after the study had been fully explained to them. The participants' right to anonymity was observed by using numbers instead of respondents' names, as confidentiality would be assured during dissemination of results. Respondents were informed that no harm or benefits could be expected from the study, as it was being conducted for academic purposes. Furthermore, the respondents were protected no physical, emotional or social harm was caused to participants. Respondents were informed in advance that participation in the study is voluntary and they may withdraw at any stage.

CHAPTER FOUR

RESULTS

In this chapter, the results of the study are presented. The first section contains a description of the study sample. Thereafter, the results from the findings will be presented according to the objectives of the study. Subsequently, statistical analysis will be covered in order to explore the associations between different factors and adherence levels to ART.

4.1 Description of study participants

A total of 184 questionnaires were completed by patients on ART receiving their medication at Shongwe hospital, Mpumalanga Province (Table 1). The mean age of participants was 38.9 years with a standard deviation of 10.27 years. The median age was 37.5 years, with a minimum age of 16 years and maximum age of 65 years. The majority of the participants (71.2%) were females. Slightly more than half of the participants (54.9%) were single, while 23.9% reported being married or living with a partner. More than half of the participants (54.3%) had secondary education and 2.2% had tertiary qualifications. Less than one in five participants (16.3%) reported that they were employed. Of those participants who were employed, half (16/30) earned more than R1000 per month.

Table 1: Demographic characteristics of participants (N=184)

Variable	N (%)	Mean (Standard Deviation)
Age (in years)	___	38.9 (10.27)
15 – 40	113 (61.4)	
40 – 65	71 (38.6)	
Gender		
Male	53 (28.8)	
Female	131 (71.2)	
Marital Status		
Single	101 (54.9)	
Married/Cohabitation	44 (23.9)	
Widowed	30 (16.3)	
Divorced/Separation	9 (4.9)	
Education		
No schooling	20 (10.9)	
Primary School	60 (32.6)	
Secondary School	100 (54.3)	
Tertiary	4 (2.2%)	
Employment status		
Employed	30 (16.3)	
Unemployed	154 (83.7)	

4.2 **Knowledge about antiretroviral therapy**

4.2.1 Knowledge about Regimen

When participants were asked to indicate the name of the ART regimen they were on, all
participants could name their regimen and describe the correct methods of taking their

medication. Most participants (65.6%) were on Regimen 1a, which consisted of lamivudine/stavudine/stocrine or efivarenz; a third (34%) of participants were on Regimen 1b, taking the lamivudine/stavudine/nevirapine combination; and no participants were on Regimen 2 (lamivudine/stavudine/kaletra) (Table 2). These ART regimens had dosing schedules of two doses a day and 5 – 6 pills per dose. Most participants (71.7%) reported that they suffered from side effects upon initiation of ART.

Table 2: Regimens of antiretroviral therapy by gender

	Female	Male	Total
Regimen 1a	67	53	120
Regimen 1b	63	0	63
Regimen 2	1	0	1

4.3 **Knowledge and beliefs about Antiretroviral Therapy**

Knowledge about ART in this study was classified into two categories: knowledgeable (correctly answered the entire questions = 100%) and poor knowledge (incorrectly answered some of the questions less than 100%). Knowledge about ART was rated using 12 questions worth one point each. About 55.7% (102/184) participants obtained a score of 100% suggesting that they were knowledgeable about antiretroviral therapy (ART), while less than half 44.3% had poor knowledge. All participants reported that they believe that ART is effective, and that it could improve their quality of life. Knowledge of the importance of adherence was shared among all participants as they correctly indicated that missing doses of ART leads to disease progression. A small proportion (23.9%) of participants, though, erroneously believed that HIV can be cured

with ART. A further 20.3% of the participants did not believe that ART can prevent transmission of HIV from mother to child. More than half of the participants (53.3%) believed that ART is harmful to their body. Most (92%) participants correctly identified that ART has side effects.

Almost all participants (98.4%) believed that taking ART prevents disease progression. However, small minorities of the participants did not believe that missing doses of ART increases the risk of transmitting (3.3%). All the participants reported that they did not believe that traditional medicine is more effective than HIV medication (Table 3).

Table 3: Knowledge and beliefs about antiretroviral therapy

	Total	**Female**	**Male**
ART prevent to mother to child transmission	146 (79.3%)	114 (87%)	32 (60.4%)
HIV can be controlled by ART	180 (97.8%)	128 (97.7%)	52 (98.1%)
ART is effective and prolongs life	184 (100%)	131 (100%)	53 (100%)
HIV can be cured by ART	140 (76.1%)	100 (76.3%)	40 (75.5%)
Taking ART prevents disease progression	181 (98.4%)	130 (99.2%)	51 (96.2%)
Not starting ART when indicated can make you sick	184 (100%)	131 (100%)	53 (100%)
ART improves quality of life	184 (100%)	131 (100%)	53 (100%)
Antiretroviral medicine can cause side effects	171 (92.9%)	123 (93.9%)	48 (90.6%)
Missing doses of ART leads to disease Progression	183 (99.5%)	130(99.2%)	53(100%)
Missing doses of ART increases the risk of transmitting HIV	178 (96.7%)	127 (96.9%)	51 (96.2%)
Believe ART is harmful to your body	98 (53.3%)	67(51.1%)	31(58.5%)
Believe traditional medicine is more effective than prescribed medication	184 (100%)	131(100%)	53(100%)
Total	102/184 (55.7%)		

4.4 **Self reported Adherence**

4.4.1 Two-day recall

Most (92.4%) participants reported optimal adherence taking more than 95% of their pills as prescribed to ART over the last two days (Figure 3). A small proportion (4.3%) of participants reported missing two pills over the past two days (3.3%) participants mentioned that they missed 3 pills. This translates to sub-optimal adherence taking less than 95% of the ARV medication.

4.4.2 Seven-day recall

Most (84.2%) participants reported optimal (≥ 95%) adherence to ART over the past seven days (Figure 3). However, there was a small proportion of 15.8% (29/184) participants reported sub-optimal (<95%) adherence to ART (Figure 3).
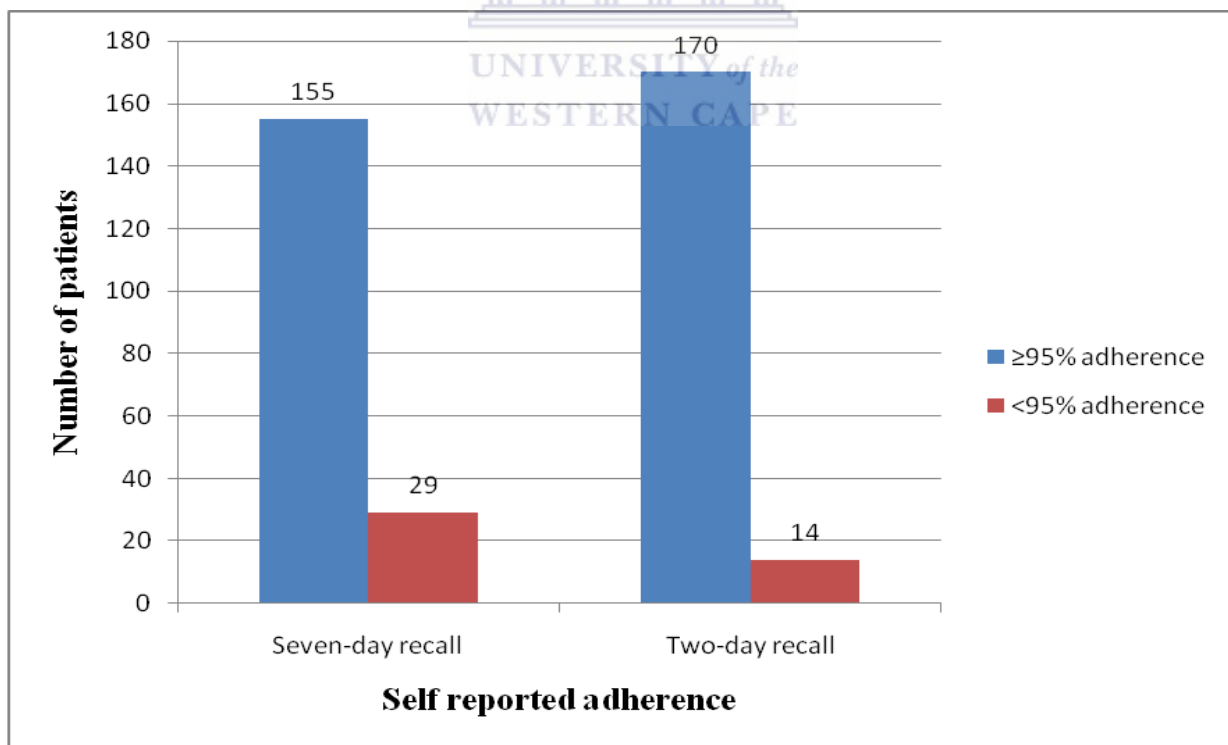
Figure 3: Self-reported adherence to antiretroviral therapy

4.4.3 Barriers to adherence to antiretroviral therapy

Small proportion (15.8%) of participants reported experiencing barriers to follow the ART regimen. The most frequently cited barriers were problem with travelling to the clinic 41(22.3%), forgetting to take ART medication 36(19.6%), sleeping away from home 34(18.5%), visiting bars 14(7.6%) and the daily routine/work (1.6%) (Figure 4).
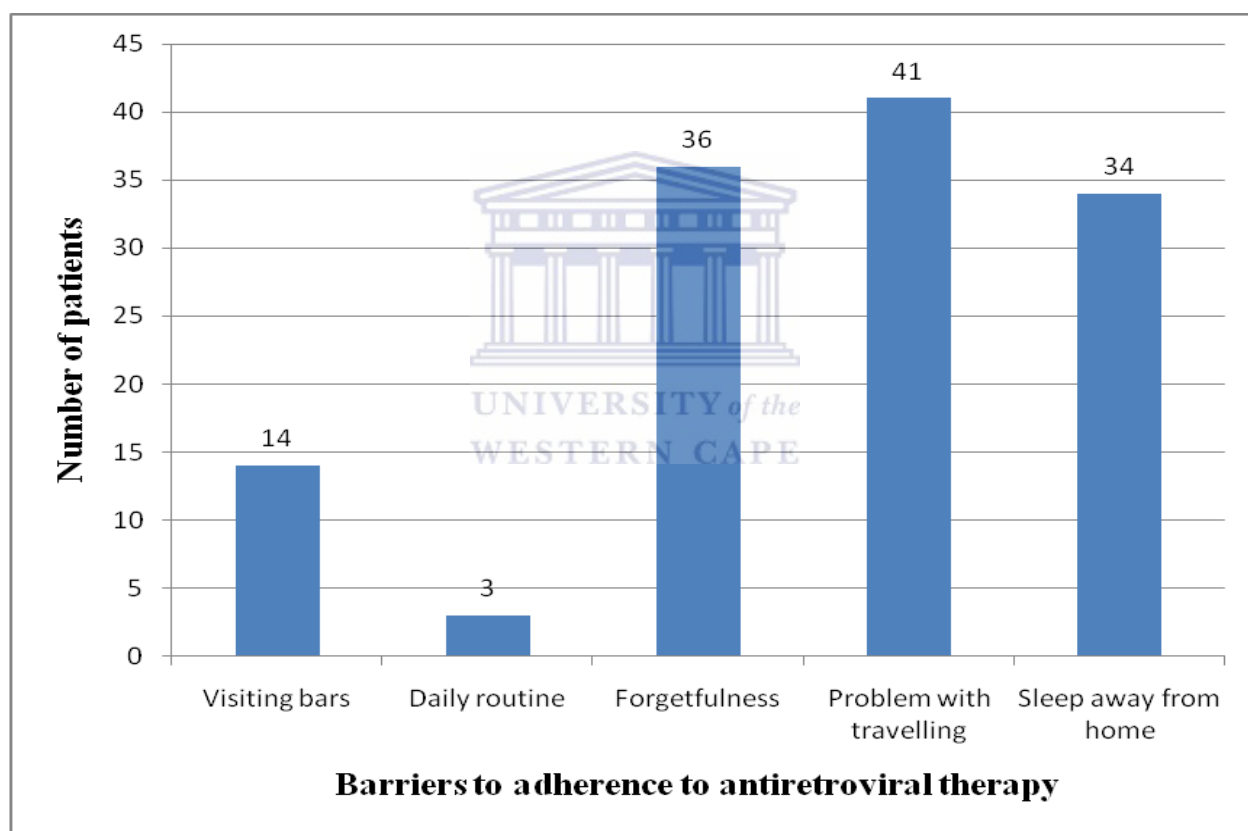
Figure 4: Barriers to adherence

4.5 **Social capital**

4.5.1 Disclosure of HIV status and being on antiretroviral therapy

Disclosure of HIV status was high among the respondents, with 97% having disclosed their HIV status. Participants reported that they disclosed their HIV status to family members which include siblings 49.5% (91/178), parents 45.1% (83/178), grandparents 5.45% (10/178) and aunt/uncle 9.8% (18/178). Surprisingly, less than half 42.4% (78/178) of the respondents reported that they disclosed their HIV status to their partner (Figure 5).
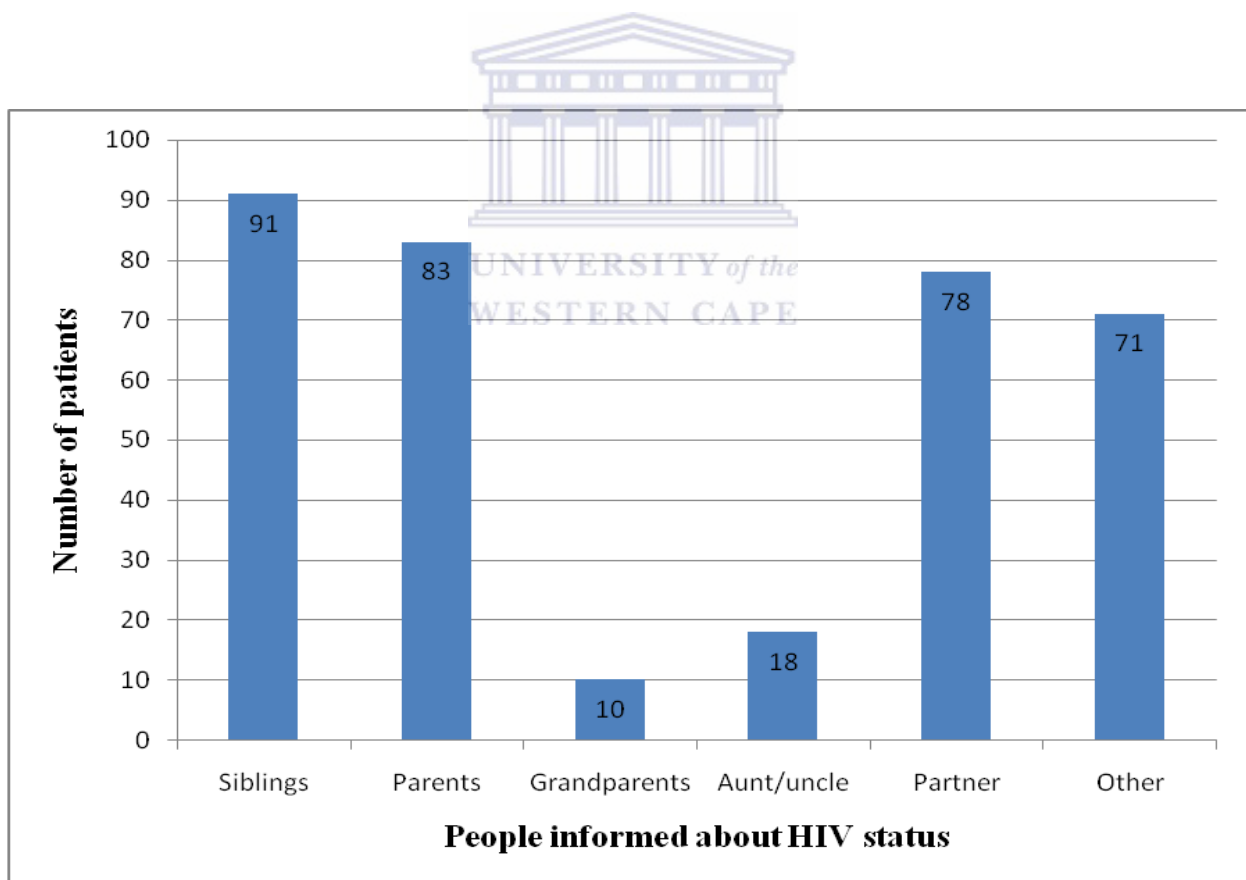
Figure 5: Disclosed HIV status

Almost all (97.3%) participants reported that they disclosed being on ART to someone. The majority (97.7%) of female participants reported that they disclosed being on antiretroviral medication (Figure 6). Interestingly, most (96.2%) of male participants indicated that they have disclosed being on ART.
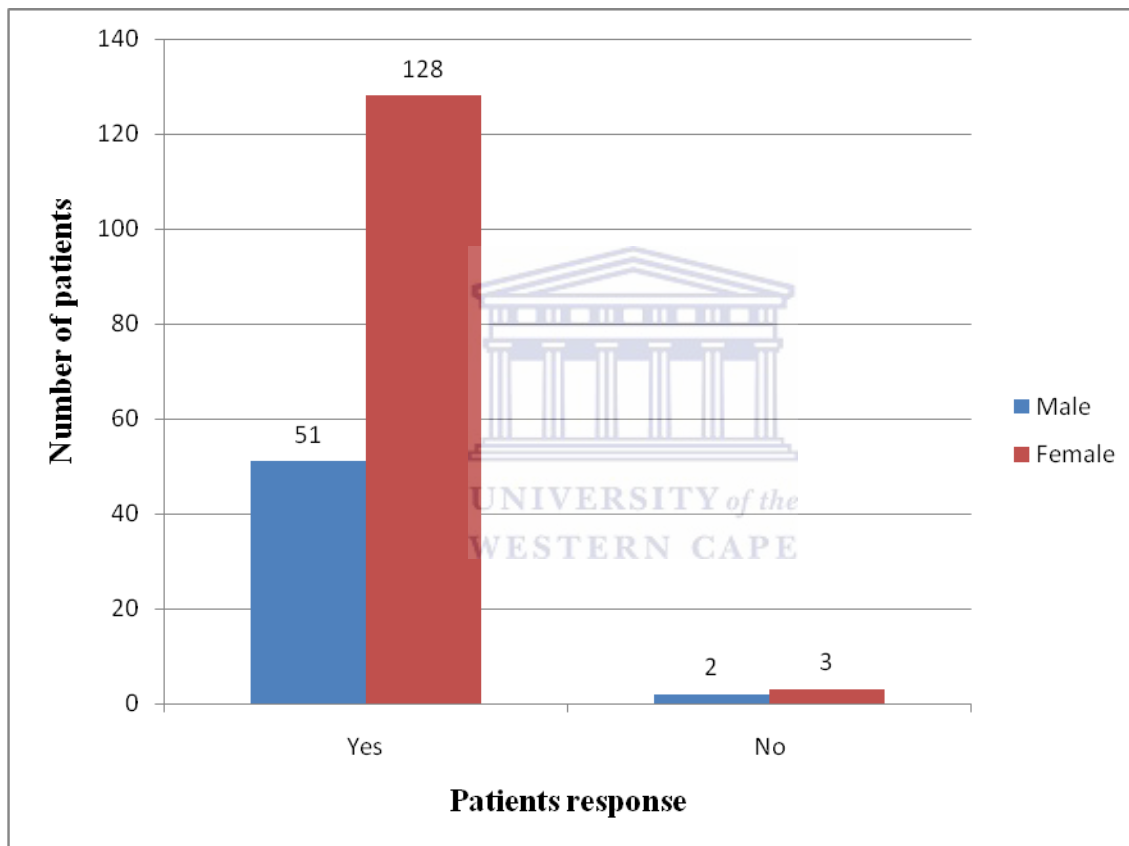
Figure 6: Disclosure of being on antiretroviral treatment

4.5.2 Fear of discrimination

Forty-three participants (23.4%) indicated that they fear discrimination from friends, partners (6.6%) and family (13.6%), if they discover that they are on ART (Table 4).

4.5.3 Financial support

It was observed that 83.7% (154/184) of the participants who were unemployed and did receive financial support of any kind; 19.6% reported that they received financial support from their family, 69% received social grants, 30.4% child grants and only 0.5% unemployment grants (Table 4). Twenty-one percent female participants reported that they were receiving financial support from their family, whereas 8(15.1%) male participants also mentioned that their family support them financially. The majority (83.7%) of unemployed participants stated that they relied on the government for financial support.

Psychosocial support

Only a small proportion 26.1% (48/184) of the participants participated in support groups in their community.

4.5.4 Social activities

Only a small proportion (11.4%) of the participants reported that they participated in leisure activities (watching soccer at the local sport grounds) during the previous seven days, and 7.6% reported having visited a bar in this period (Table 4). Only 66 participants (35.9%) stated that

they visited friends or family, whereas less than half (40.8%) received visits from friends or family. A small proportion (10.9%) of participants reported eating out at a restaurant, and 8.7% attended a party. The most frequent activity reported (54.3% of participants) over the last seven days was attending (church) meetings.

Table 4: Social capital indicators

	TOTAL	Female	Male
Fear of discrimination by:			
Friends	43 (23.4%)	37(28.2%)	6(11.3%)
Partners	12 (6.6%)	12(9.2%)	-
Family	25 (13.6%)	22(16.8%)	3(5.7%)
Financial support			
Family support	36 (19.6%)	28(21.4%)	8(15.1%)
Unemployment grant	154 (83.7%)	1(0.8%)	0(0%)
Social grants	127 (69%)	95(72.5%)	32(60.4%)
Child grants	56 (30.4%)	54(41.2%)	2(3.8%)
Social support			
Attend a support group	48 (26.1%)	34(26%)	14(26.4%)
Social activities over the past 7 days			
Took part in leisure activities	21 (11.4%)	7(5.3%)	14(26.4%)
Visited bars	14 (7.6%)	3(2.3%)	11(20.8%)
Attend meetings	100 (54.3%)	75(57.3%)	25(47.2%)
Visited friends/family members	66 (35.9%)	47(35.9%)	19(35.8%)
Received visitors	75 (40.8%)	55(42%)	20(37.7%)

4.6 **Health services factors**

4.6.1 Perceptions of Quality of Health Care

Almost all participants (98.9%) indicated that health care providers treated them with respect

(Table 5). The majority (87.5%) of the participants reported that they were given the chance to

state their problems and ask questions (Table 5). Almost all the participants (99.5%) reported that they trusted their health care providers and had excellent relations with them. About 96.2% (177/184) of the participants reported that in the ART facility they were treated in privacy and with confidentiality while 3.8% (7/184) indicated that were not treated in privacy during consultation and counselling (Table 5).

Table 5: Health services factors

	TOTAL	Female	Male
Experienced problems travelling to hospital	41 (22.3%)	26(19.8%)	15(28.3%)
Able to attend hospital during service hours	180 (97.8%)	128(97.7%)	52(98.1%)
Chance to state problem and ask questions	161 (87.5%)	111(84.7%)	50(94.3%)
Difficult to get extra ART if they finished	18 (9.8%)	16(2.2%)	2(3.8%)
Privacy during consultation and counselling	7 (3.8%)	5(3.8%)	2(3.8%)
Takes lot of effort and time to get ART	62 (33.7%)	45(34.4%)	17(32.1%)
Treated with respect by health care providers	2 (1.1%)	2(1.5%)	
Trust health workers with their duties	1 (0.5%)	1 (0.8%)	

4.6.2 Accessibility of services

Access to the health facility was reported to be a problem for a small proportion (22.3%) of participants. A third of respondents (32.3%) indicated that it takes a lot of time and effort to

receive their ART on the collection day. Almost 97.8% (180/184) participants reported that they were able to attend the hospital during the service hours, although more than half (52.2%) travelled more than 10 kilometres to get to the hospital. Thirty-five (19%) participants cited travelling more than 30 kilometres to the hospital (Figure 7).
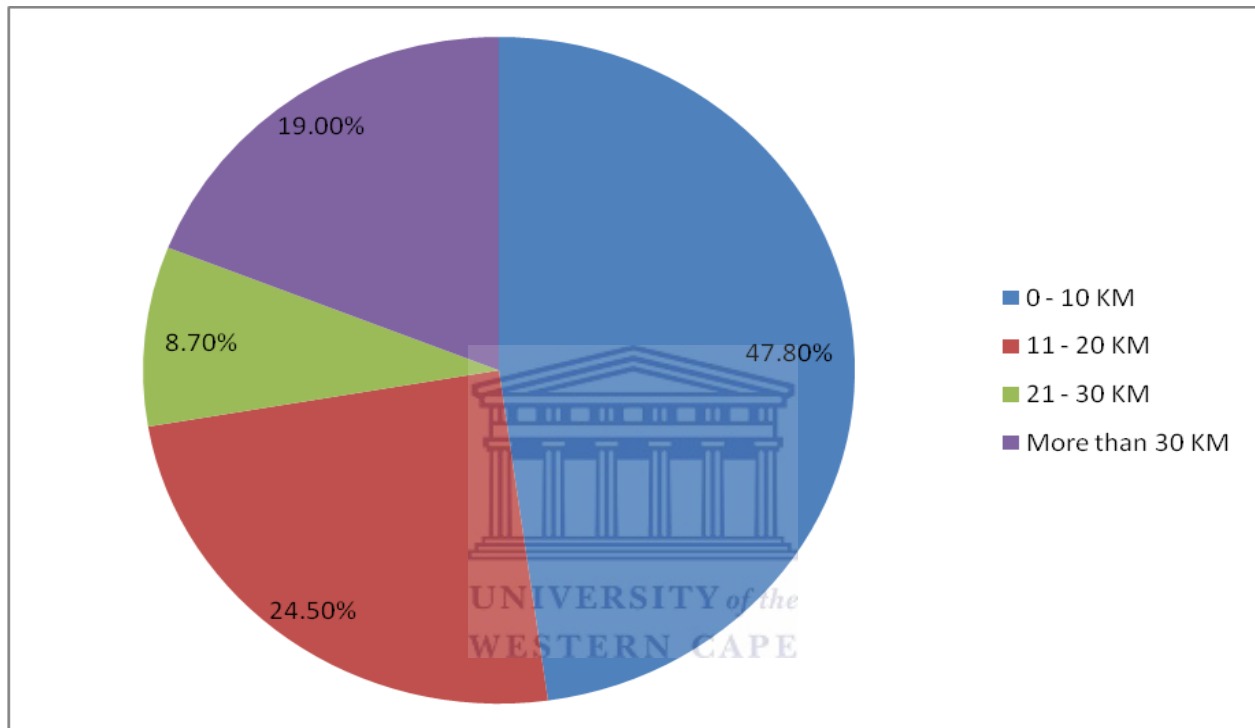
Figure 7: Distance to hospital (N=184)

4.6.3 Waiting times in the ART site

A major concern that was raised by the participants was the lengthy waiting times to receive their hospital file in the outpatient department. The median waiting time in the Wellness clinic at the hospital participants spent was 32.5 minutes and IQR was 10 to 60 minutes (Figure 8). The median time they spent at the hospital was 3 hours (IQR: 2 - 4 hours) (Figure 9).
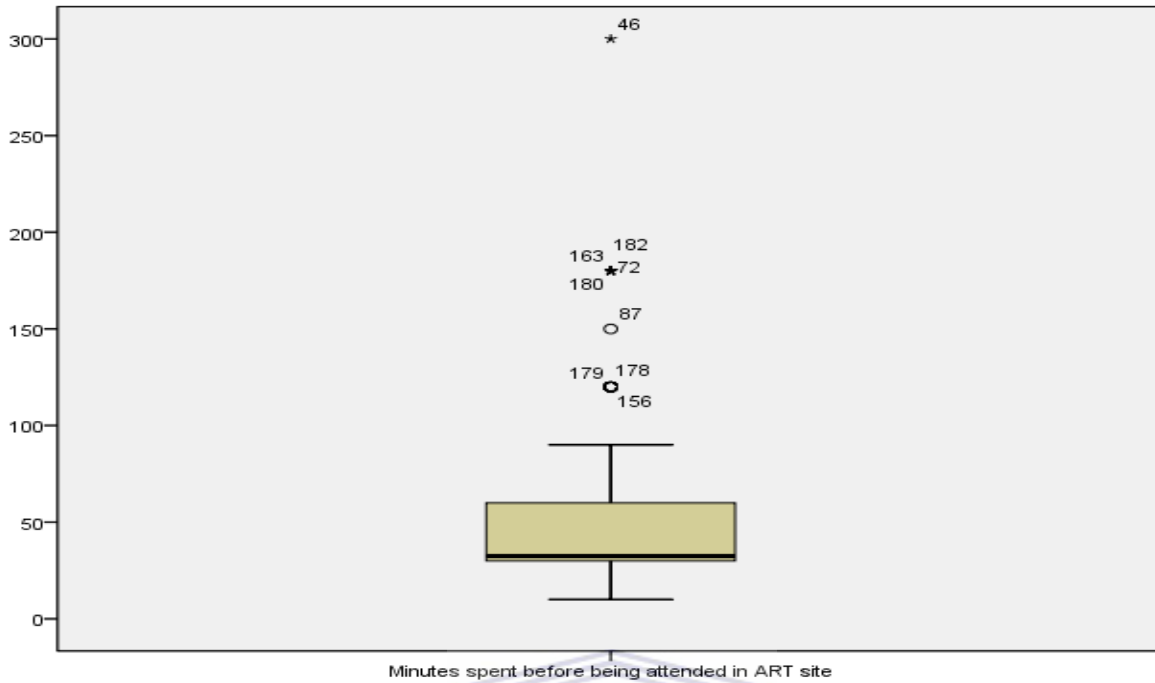
Figure 8: Waiting time for services
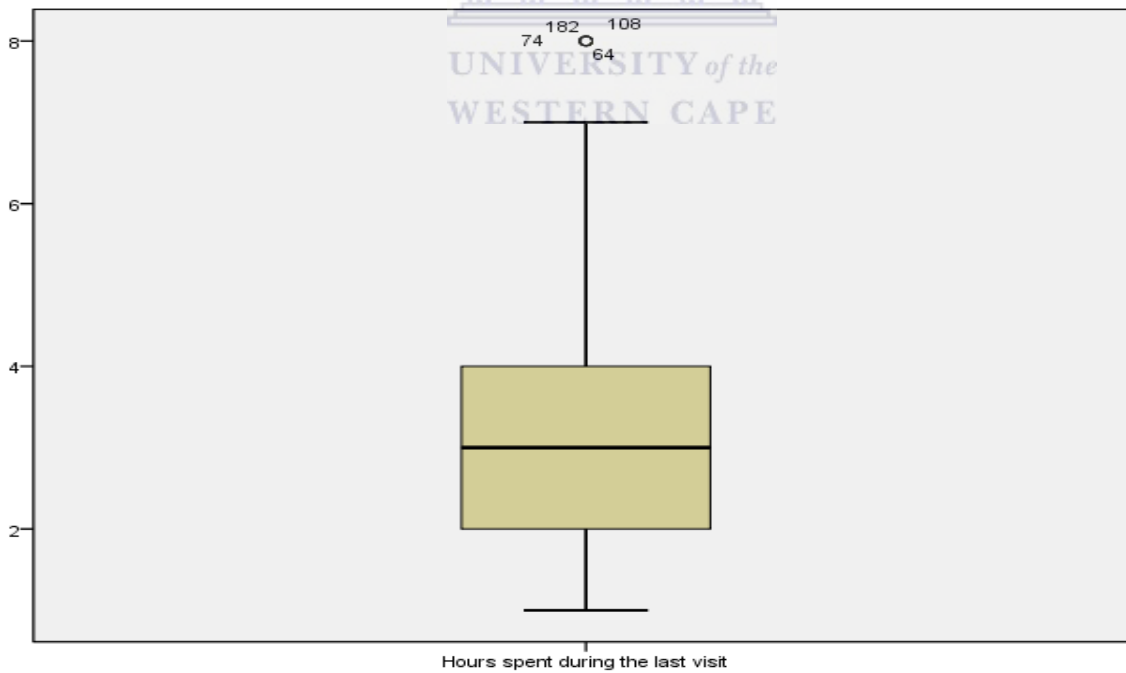
Figure 9: Time spent during the last visit for reassessment and ART collection

4.7 **Factors associated with adherence behaviour**

The ensuing section is organised to present two by two tables for socio-demographics and adherence, association between adherence and knowledge about antiretroviral therapy, association between knowledge and beliefs about antiretroviral therapy, association between adherence and social capital and association between adherence and health services factors. Furthermore, this section presents the two by two tables in self-reported adherence two day recall and seven day recall respectively.

4.7.1 Socio-demographic characteristics and Adherence

Self-reported adherence based on two day and seven day recall were not significantly associated with age, gender, employment status, marital status and education level (Table 6).

Table 6: Socio-demographic characteristics and Adherence

	Adherence			
	Two day recall		**Seven day recall**	
	χ^2	**p-value**	χ^2	**p-value**
Age	0.833	0.36	0.006	0.93
Gender	0.402	0.52	0.083	0.77
Employment status	0.292	0.58	3.211	0.07
Marital status	2,209	0.53	1.655	0.64
Education level	2.297	0.51	1.552	0.67

4.7.2 Side –effects and Adherence

There was no association between participants reporting having experienced side effects and adherence based on two day (χ^2 = 0.349; p=0.55) or seven day recall (χ^2 = 1.588; p=0.20) (Table 7). However, there was an association observed between females who experienced side effects and ART adherence based on seven-day recall (χ^2 = 4.6197; p=0.03) (Table 7). Female patients who experienced side-effects after initiating antiretroviral therapy, were almost 3 times less likely (95% CI: 1.0682 – 7.4849) to have optimal adherence than those who did not report side effects.

Table 7: Self-reported adherence and side effects

	Adherence			
	Two day recall		Seven day recall	
	χ^2	p-value	χ^2	p-value
Experienced side effects	0.349	0.55	1.588	0.20
Female	0.036	0.84	4.6197	0.03*
Male	1.034	0.30	1.0542	0.30

4.7.3 Knowledge about ART and Adherence

There were no statistically significant associations found between knowledge about ART and adherence on the two day and seven day recall (χ^2 = 0.44; p=0.50 and χ^2 = 0.77; p=0.37) (Table 8). The individual responses to the *knowledge and beliefs about ART* questions were not

meaningful in distinguishing reported adherence behaviour, with one exception. There was a statistically significant association found between participants knowing that *"missing doses of ART leads to disease progression"*, and ART adherence on two day recall (χ^2 = 12.2092; p=0.00) and seven day recall (χ^2 = 5.3740; p=0.02). Participants who knew that missing doses of ART leads to disease progression were 14 times less likely (95% CI: 8.33-23.77) and 7 times less likely (95% CI: 4.65-9.19) to have optimal adherence over the past two days and 7 days, respectively, than participants who did not know this.

Table 8: Knowledge and beliefs about ART and adherence
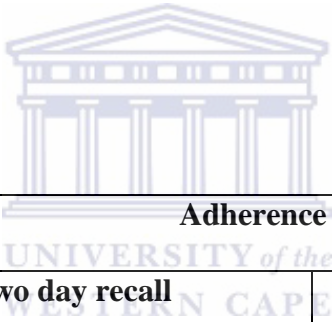
	Adherence			
	Two day recall		**Seven day recall**	
	χ^2	**p-value**	χ^2	**p-value**
Knowledgeable about ART	0.4490	0.50	0.7777	0.37
ART prevent to mother to child transmission	0.01	0.91	0.44	0.50
ART control HIV	0.33	0.56	0.26	0.60
HIV can be cured by ART	0.05	0.82	0.19	0.65
Taking ART prevent disease progression	0.25	0.61	0.57	0.45
Antiretroviral medicine can cause side effects	1.15	0.28	0.00	0.96
Missing doses of ART leads to disease progression	12.209	0.00*	5.374	0.02*
Missing doses of ART increases the risk of HIV transmission	0.72	0.39	1.44	0.23
Believe that ART is harmful to your body	0.74	0.39	2.07	0.14

4.7.4 Disclosure and Adherence

There was a significant association between disclosure of HIV status and ART adherence (two day recall: $\chi^2 = 5.83$; p=0.01). The point of estimation was undefined (Table 9). However, this difference was not observed when considering adherence based on the seven day recall ($\chi^2 = 0.00$; p=0.95).

Significantly more participants who disclosed being on ART (167/179 = 98.2%) reported optimal adherence over the previous two days ($\chi^2 = 7.67$; p = 0.00) and seven days ($\chi^2 = 7.576$; p = 0.00) compared to those who did not disclose being on ART.

Table 9: Disclosure and adherence

Disclosure	Adherence			
	Two day recall		Seven day recall	
	χ^2	p-value	χ^2	p-value
HIV status	5.83	0.01*	0.00	0.95
Being on ART	7.67	0.00*	7.57	0.00*

4.7.5 Social capital and Adherence

An association was observed in participants who attended support group and ART adherence than participants who did not attend support group (two days recall: $\chi^2 = 5.34$; p = 0.02). The point of estimation was undefined in output of the results. Attending a support group was not a discriminator of adherence levels (seven days recall: $\chi^2 = 0.43$; p = 0.50) (Table 10).

There was no association observed between adherence based on 2-day and 7-day recall and fear of discrimination by friends (χ^2= 0.03; p=0.85; χ^2= 0.13; p=0.71), family (χ^2 = 0.79; p = 0.37; χ^2= 0.30; p=0.57) or partner (χ^2 = 0.00; p = 0.92; χ^2= 2.41; p=0.11), respectively, if ART status is disclosed (Table 10).

Table 10: Social capital and adherence to antiretroviral therapy

	Adherence			
	Two day recall		**Seven day recall**	
	χ^2	**p-value**	χ^2	**p-value**
Support groups	5.34	0.02*	0.43	0.50
Fear of discrimination by family	0.79	0.37	0.30	0.57
Worried about friends	0.03	0.85	0.13	0.71
Worried about partner	0.00	0.92	2.48	0.12

4.7.6 Barriers to adherence

Leisure activities

There was no association detected between adherence based on 2-day and 7-day recall took part in leisure activities and adherence (χ^2= 1.50; p=0.22) and (χ^2 = 2.93; p= 0.08) respectively. However, female participants who took part in leisure activities were 75% less likely (95% CI: 0.0672-0.9601) and 69% less likely (95% CI: 0.1222 – 0.8377) to have optimal adherence over two and seven days, respectively, than participants who did not take part in leisure activities.

There was a statistically significant association found between female participants who took part in leisure activities and ART adherence on two day recall (χ^2 = 3.91; p=0.04) and seven day recall (χ^2 = 4.35; p=0.03) (Table 11).

Attending Party

There was no association found between attending a party and ART adherence (two day recall: χ^2= 1.44; p= 0.22; seven day recall: χ^2= 1.1267; p=0.28).

Attending meetings

Participants who attended meetings were 61% less likely (95% CI: 0.1654–0.9481) to have optimal adherence over the past seven days than participants who did not attend meeting (χ^2= 4.5286; p= 0.03) (Table 14). However, this association was not observed with reported adherence based on two day recall (χ^2= 0.8064; p = 0.36). Female respondents, who attended meetings were 4 times less likely (95% CI: 1.01 – 15.84) to have optimal adherence over the previous two days than females who did not attend meetings. Therefore, a significant association was observed between female participants who attended meetings and ART adherence (χ^2= 4.4098; p = 0.03).

Eating at a restaurant

There was no correlation observed between eating at a restaurant and ART adherence based on two day recall (χ^2= 0.21; p=0.64) and on seven day recall (χ^2= 1.44; p=0.22) respectively.

Received visitors

There was an association between received visitors and ART adherence based on 2-day and 7-day recall (χ^2= 7.09; p=0.00) and (χ^2 = 5.74; p= 0.01) respectively. Participants who received visit from friends or family were 10 times less likely (95% CI: 1.20 - 66.93) and 2 times less likely (95% CI: 1.13 – 6.17) over two and seven days, respectively, to have optimal adherence than those did not receive visit.

Visited friends

There was no association detected between adherence based on 2-day and 7-day recall and visited friends (χ^2= 0.35; p=0.55) and (χ^2 = 0.45; p= 0.50) respectively.
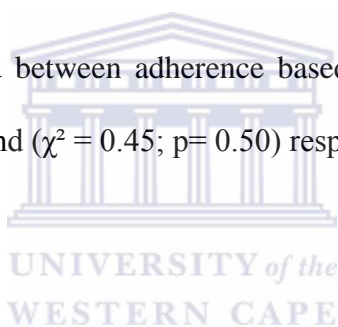
Visited a bar

Participants who visited a bar were 61% less likely (95% CI: 0.18 – 0.88) to have optimal adherence than those did not visit a bar. This was found to be associated with adherence behaviour (χ^2= 4.5440; p=0.03) on the seven day self report. However, there was no association observed between visited a bar and ART adherence on the two day self report.

Forgetful

A significant association was observed between forgetfulness and ART adherence over the previous two days (χ^2 = 8.91; p= 0.00) and seven days (χ^2 = 69.33; p = 0.00). Participants who

reported forgetfulness were 76% less likely (95% CI: 0.09-0.65) and 92% less likely (95% CI: 0.04 – 0.17) to have optimal adherence over two and seven days, respectively, than participants who did not report forgetfulness to be a barrier. There was no association observed between female participants who forgot to take their doses of ART and adherence based on the two day recall (χ^2= 2.61; p= 0.10). However, a significant association was observed between female participants who forget to take their doses of ART and adherence (χ^2= 42.12; p= 0.00). Based on seven-day recall participants who forgot to take their doses of ART and adherence were 96% less likely (95% CI: 0.01 – 0.13) to have optimal adherence than those who did not forget to take their doses of ART (Table 11).

Sleep away from home

Participants who slept away from home were 76% less likely (95% CI: 0.13 – 0.45) to have optimal adherence than participants who did not sleep away from home. This was found to be statistically significant (χ^2= 20.29; p = 0.00) over seven day recall. However, there was no association was observed on the two day recall (χ^2= 1.0247; p=0.31) between sleep away from home and ART adherence.

Daily routine

It was observed that there was a significant correlation between daily routine and ART adherence (χ^2= 16.30; p=0.00) on seven day recall. Participants who cited that their daily routine was a barrier affected them in taking medication at specific times were 86% less likely (95% CI:

0.1006 – 0.2050) to have optimal adherence than participants who cited that daily routine was not barriers for taking medication. However, no association was observed between daily routine and ART adherence over two day recall (χ^2= 2.87; p=0.90) (Table 11).

Table 11: Barriers to adherence

	Two day recall		Seven day recall	
	χ^2	p-value	χ^2	p-value
Attend meetings	0.80	0.36	4.529	0.03*
Female (n= 75)	4.40	0.03*	1.567	0.21
Took part in leisure	1.50	0.22	2.93	0.08
Female	3.91	0.04*	4.35	0.03*
Attend a party	1.44	0.22	1.12	0.28
Eating at a restaurant	0.21	0.64	1.44	0.22
Received visitors	7.09	0.00*	5.74	0.01*
Visit friends	0.35	0.55	0.45	0.50
Visited a bar	0.00	0.94	4.54	0.03*
Forgetful	8.91	0.00*	69.33	0.00*
Female	2.61	0.10	42.12	0.00*
Sleeping away from home	1.02	0.31	20.29	0.00*
Daily routine	2.87	0.90	16.30	0.00*

4.7.7 Health services factors

There were no statistically significant associations found between lost or ran out of ART and adherence based on the two day and seven day recall (χ^2= 0.348; p=0.55 and χ^2= 2.1701; p=0.14)

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(Table 12). Furthermore, there was no association was observed between privacy during consultation and counselling and ART adherence (two day recall: $\chi^2= 0.461$; p=0.49) and (seven day recall: $\chi^2= 0.012$; p=0.91). There was a significant association observed between privacy during consultation and counselling and adherence (two day recall: $\chi^2= 8.975$; p=0.00). However, privacy during consultation and counselling was not a barrier to ART adherence levels based on seven day recall ($\chi^2= 2.7068$; p=0.09).

Based on two day and seven day recall, there was no significant association detected in: takes lot of time and effort to receive ART ($\chi^2= 1.021$; p=0.31; $\chi^2= 0.1009$; p=0.74), given the chance to state problems and ask questions ($\chi^2= 0.044$; p=0.83; $\chi^2= 0.988$; p=0.32) , attend hospital services during set time ($\chi^2= 0.337$; p=0.56; $\chi^2= 0.263$; p=0.67), treated with respect by the health care providers ($\chi^2= 0.167$; p=0.68; $\chi^2= 0.378$; p=0.53) respectively.

Participants who trusted health care provider were 14 times less likely (95% CI: 8.3361 – 23.7713) to have adherence than those who did not trust health care providers in two day recall. Therefore, there was an association between trust health care providers and ART adherence ($\chi^2 = 12.209$; p = 0.000). Nevertheless, there was no association was observed between trust health care providers and ART adherence based on seven day recall ($\chi^2= 0.1881$; p=0.66).

Participants who had problems with travelling to hospital in two day recall were 75% less likely (95% CI: 0.082 – 0.761) to have optimal adherence than those indicated that they do not have problem with travelling to hospital. In other words, there was an association between problems travelling to hospital and ART adherence ($\chi^2= 0.722$; p=0.01). However, there was no significant association between experiencing problems travelling to hospital and adherence based on seven day recall ($\chi^2= 2.959$, p=0.08).

Table 12: Health services factors and adherence

	Adherence			
	Two day recall		**Seven day recall**	
Barrier	χ^2	**p-value**	χ^2	**p-value**
Lost/ran out of ART	0.348	0.55	2.1701	0.14
Privacy during consultation and counselling	0.461	0.49	0.012	0.91
Privacy during consultation and counselling (Male unemployed)	8.975	0.00*	2.7068	0.09
Lot of time and effort	1.021	0.31	0.109	0.74
Attend hospital services during set time	0.337	0.56	0.263	0.60
Trust health care providers	12.209	0.00*	0.1881	0.66
Chance to state problem and ask questions	0.044	0.83	0.988	0.32
Treated with respect	0.167	0.68	0.378	0.53
Travelling problem to hospital	6.722	0.01*	2.959	0.08

Hours spent during previous review were observed to be associated with adherence based on seven day recall ($p < 0.05$). However, there was no relationship between waiting time at health service and adherence was observed on both two day and seven day recall (Table 13).

Table 13: Waiting and service times and Adherence

	Adherence			
	Two Days Recall		**Seven Days Recall**	
	t-test	**P-value**	**t-test**	**P-value**
Time spent during past visit to health service	0,240	0,810	1,968	0,050
Waiting time at health service	1,797	0,074	1,436	0,152

4.8 **Summary**

The results of this study show that more females than males participated in the study. More than half of the participants were single. All participants managed to name the regimen and describe the correct methods of taking ART. Most of the participants in this study were knowledgeable about ART and indicated that ART is effective and improves quality of life. Interestingly, self-reported adherence based on two day recall was more than seven day recall. The three leading barriers to adherence were problems with travelling to hospital, forgetfulness, and sleeping away from home. Majority of the participants in this study disclosed HIV status and being on ART. However, there were participants who feared discrimination but this was not associated with adherence.

CHAPTER FIVE

DISCUSSION

In this section, the discussion attempts to explain and interpret the current study findings and compare them to the results found in similar studies. Therefore, discussion of the results will follow the following sub-groups: description of study participants, participants' information about antiretroviral therapy, perceptions and beliefs about ART, adherence assessment, social support, coping skills and health services factors as well as factors associated with adherence. Lastly, this section will also acknowledge the limitations of the study.
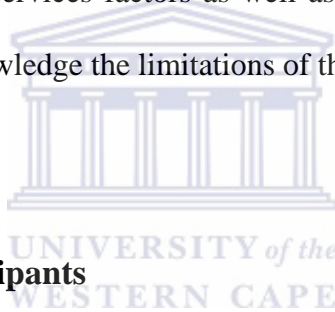
5.1 Description of study participants

A total of 184 participants participated in the study and were selected using a sample random sampling method. The participants were on ART for at least 6 months and were between the ages of 15 – 65 years. The data were collected from the participants using a structured questionnaire.

5.1.1 Age

The mean age of participants on ART is fairly low 38.9 years. This confirms the high prevalence of HIV among adolescents and middle adulthood from the age group of 15 – 65 years. This could be due to that within this age group; human beings have a marked tendency to engage in sexual activities and in high risk behaviours which results in contracting HIV infection. These age groups were selected because Department of Health in South Africa (2007) and WHO

(2006) illustrated that in this age group more people are more likely to be HIV infected. This study also indicated that more than half of the participants 54% had achieved at a secondary level of education, showing a high level of literacy. Nevertheless, age was found to be not associated with adherence to antiretroviral therapy. Although studies by Mehta, Moore and Graham (1997), Gordillo, del Amo, Soriano and González,-Lahoz (1999), Chesney (2000) have identified that younger individuals struggle to comply with treatment because of dependence to their caregivers to administer their medication.

5.1.2 Gender

The study comprised of 72% female participants and 28% male participants. The finding is also consistent with another study which found that women are more likely to be vulnerable to HIV infection than men (WHO, 2006) and interestingly, they also tend to use health services facilities as shown by this study. This suggest that there is a need of a study to find out about the perception of men about visiting wellness clinic for voluntary counselling and testing. However, gender was not associated with adherence to antiretroviral therapy between the two day and seven day self-report.

5.1.3 Employment status

A unique finding from this study is that 83.7% of the participants were unemployed. This could be explained by the fact that Nkomazi region is rural and employment opportunities are scarce. Sixty-nine percent of the participants in the present study indicated that they were receiving disability grant, and some of the female participants (30.4%) also receive child grants. This is in

line with a studies done by Booysen (2004) and Louwagie, Bachmann, Meyer, Booysen, Fairall and Heunis (2007) that found that most of the households in South Africa depended on the social and child grants that are provided by the government. In addition, this issue of financial constrains is supported by Mills *et al.* (2006a) and the National Department of Health (2007) which cited that severity of the HIV epidemic is closely linked to poverty and other socio-economic factors. This finding was expected because most of PLWHA are likely to struggle with finances. In addition, this is supported by UNAIDS (2006) who found that people in productive age are badly affected by HIV and they also unable to meet their basic needs such as food, health care, and shelter. These difficulties are also experience by their children who end up being orphans as their parents passed away due illness related to HIV/AIDS. Hence, it can be suggested that a future research which can investigates the impact of poor economic status in patients receiving ART in rural areas. However, employment status was not significantly associated with adherence to antiretroviral therapy.
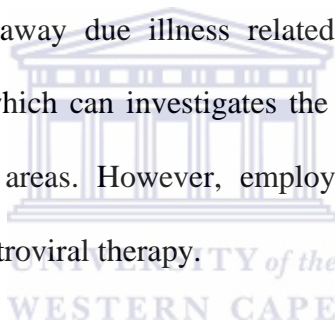
5.2 **Knowledge about antiretroviral therapy**

5.2.1 ART regimen

Patients' knowledge has previously been cited to be closely associated with adherence to ART (Mehta, Moore and Graham, 1997). The result of this study indicated that majority of the participants were able to report about the doses of their ART. Ten percent of those participants who reported that they did not attend school were able to identify their medication in different containers. Although, these results differ from some published studies which indicated that low level of education was associated with poor adherence and may impact negatively on some

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patient's ability to adhere (Gordillo *et al.*, 1999; Kalichman, Ramachandran and Catz, 1999; Heath, Singer, O'Shaughnessy, Montaner and Hogg, 2002; Pinherio *et al.*, 2002; Reynolds *et al.*, 2004; Hofer, Schechter and Harrison, 2004; Kagee, Le Roux and Dick, 2007; Falagas, Zarkadoulia, Pliatsika and Panos, 2008).

A small proportion of patients reported missing pills over the past two days and seven days (Table 4). The most frequently cited barriers were problem with travelling, forgetting to take ART, sleeping away from home, and the daily routine/work (Table 6). This finding confirms what is well established from the literature that forgetfulness and being away from home affect adherence to antiretroviral therapy negatively (Roberts, 2000; Reynolds *et al.*, 2004; Marais, 2006; WHO, 2006; Dieckhaus and Odesina, 2007; Wang and Wu, 2007; Thobias, 2008; Malangu, 2008).
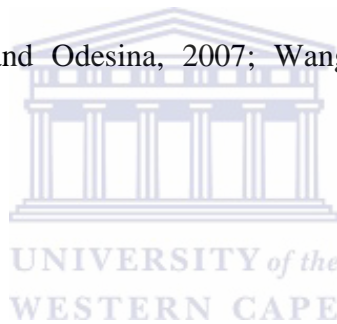
5.2.2 Side-effects

In this study, one hundred and thirty-two participants cited that they did experience side-effects in their lives after initiating ART. It is possible, therefore, that the statistical significance found in seven-day recall between side-effects and adherence to ART, might be explained by the fact that the experience of side effects did not influence the participants from taking their medication. However, the findings of the present study do not support the past research. Side-effects have been identified in various studies as significant barriers to optimal adherence (Gordillo *et al.*, 1999; Roberts, 2000; Heath *et al.*, 2002; Remien *et al.*, 2003; Marias, 2006). The authors found that side-effects have a negative impact on adherence to ART, activities of daily living and quality of life.

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5.3 **Knowledge and beliefs about antiretroviral therapy**

The findings of this study show that patients on ART were excessively positive and confident on the questions of attitudes and beliefs about ART. Of the participants (98%) accepted that taking ART prevents disease progression; (100%) ART is effective and prolongs life, (100%) not starting ART when indicated can make them sick, (100%) ART improves quality of life and (99%) missing doses of ART leads to disease progression also (96%) increase the risk of transmitting HIV. A possible explanation for this might be that these participants were fully involved in their adherence education and consistently attend adherence counselling. Another explanation for this might be that participants already experienced the benefit of ART. This study produced results which corroborated with the findings of a great deal of the previous work in this field. Studies by Chesney (2000), WHO (2002, 2006), Gebo (2003), Coetzee *et al.* (2004), Hofer (2004), Moore *et al.* (2005), Dickhaus and Odesina (2007) have shown that participants are more likely to receive benefits when they adhere to their antiretroviral medication.

The most interesting finding was that 100% of the participants cited that they do not believe that traditional medicine is more effective than prescribed medication. Furthermore, this result could be explain by that patients tried to use traditional medicine prior to initiating ART but realized that traditional medicines were not working then they alternatively switched on to ART.
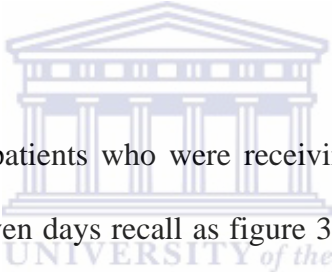
The study found that other participants' level of knowledge and beliefs about antiretroviral treatment was incorrect. Less than half of the participants (23%) mentioned that HIV can be cured by ART. The reason for this perception might be that participants of this study noticed that their quality of life has improved after they initiated ART. In addition, the current study found

that 53% of the participants believe that ART is harmful to their bodies while 47% did not believe that ART is harmful to their bodies.

On the question of patients' perceptions and attitudes believe that missing doses of ART leads to disease progression, this study found that this was associated with adherence to ART. The possible explanation is that participants had time to contemplate and take action to adhere to ART.

5.4 **Adherence assessment**

5.4.1 Self-report

In this study, high proportion of patients who were receiving ART had optimal adherence to ART, by self-report in two and seven days recall as figure 3 indicates. The results of this study show that 92.4% of the patients on ART were having more than 95% adherence to ART in two-day recall, whereas in seven-day recall 84.2% of the patients on ART were found to be having more than 95% adherence to ART. This is also in line with the study of Akpomiemie (2005) who also found that 92.4% of the population receiving ART having more than 95% adherence to their HIV medication. The higher percentages of adherence to ART support the work of Reynolds *et al.* (2004) that strong internal commitment to health related behaviour influences the ability of an individual to adhere to their medication. This also confirms the findings from past research on health belief model that show that when patients perceive benefits of ART are more likely to adhere to their medication (Reynolds *et al.*, 2004). However, these data must be interpreted with caution because the tool used to measure adherence to ART has strengths and weaknesses. There are several possible explanations for this result. In two-day recall has the advantage that

participants were able to recall in a short time span, which suggests that memory of medicine intake is likely to be good. However, it can overestimate medicine intake because participants may feel ashamed to disclose to forgetting to take their medications so recently. It is difficult to explain the result of reduced adherence to ART in seven day recall, but it might be related to recalling information of long-term memory of the past seven days. These explanations are consistent with those of Fogarty *et al.* (2002), Wagner (2002), da Salviera *et al.* (2003), Roux (2004), Levine *et al.* (2006), Liu *et al.* (2006), Marias (2006), Simoni *et al.* (2006) and Dzinza (2007), declare that measuring adherence to ART is a difficult activity in both clinical and research setting. These authors point that there is a controversy regarding the reliability of current methods used to measure adherence to antiretroviral therapy.
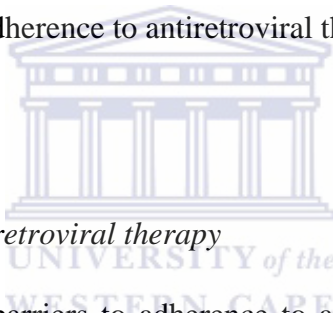
5.4.2 Barriers to adherence to antiretroviral therapy

The study found that there were barriers to adherence to antiretroviral medication among the participants. Small proportion (15.8%) of participants reported experiencing barriers to follow the ART regimen. With regard to barriers for missing doses, the findings of this study indicated that travelling, forgetting to take ART medication, sleeping away from home, and the daily routine/work were most common. These findings concurred with other research. Patient forgetfulness cited as a barrier to ART adherence (Roberts, 2000; Reynolds *et al.*, 2004; Marais, 2006; WHO, 2006; Dieckhaus and Odesina, 2007; Wang and Wu, 2007; Thobias, 2008; Malangu, 2008). These authors mentioned that patients on ART simply forget to take treatments due to being away from home attending social events such as night vigil, funerals, weddings and parties.

5.5 **Social capital**

5.5.1 Disclosing HIV status and antiretroviral therapy

It is interesting to note that the vast majority of the participants cited that they have disclosed their HIV status to various people such as siblings, grandparents, aunt/uncle, partner and other as presented in figure 5. Less half than half (42.5%) participants disclosed their HIV status to their partners. This might be a challenge for the participants who did not disclose HIV status to their partners because they experience difficulties to use their medication. It is difficult to explain this result, but it might be that persons with HIV infection are realizing that secrecy would not help them. The present findings seem to be consistent with other research which found that disclosing HIV status result in support from family members and significant others and is a strong indicator of medical adherence (Chesney *et al.*, 2000; Bearman and La Greca, 2002; Simoni, Frick, Lochkart and Liebovitz, 2002; Attawell and Mundy, 2003; Hofer, Schechter and Harrison, 2004; Mills *et al.,* 2006b; Kagee, Le Roux and Dick, 2007). This is also in line with the work of Dunn, McClain, Brown and Youngstrom (1998) which emphasized that human performance is the interaction between a person and environment which affects human behaviour and task performance. Moreover, the majority of participants who disclosed their HIV status indicated that they were not worried that loved ones and significant people would find out about their HIV status. This may be explained by the fact that these participants are excessively positive and motivated about their medication. It can thus be suggested that openness about the HIV status and taking ART provide the participants with the support and adhere to their medication without fear.

In this study, however, it was found that there were participants who cited that they did not disclose their HIV status to anyone. In addition, six percent of the participants who participated in the study were concerned about the reactions of their sexual partners and family members if find out that they were HIV infected. This finding may be explained by the fact that people with HIV infection are likely to experience rejection and discrimination in their families and communities as well as fear of their partners' reactions as some literature has demonstrated that disclosing HIV status is a "double edge sword" as it builds or breaks up a person motivation (Van Dyk, 2001; Timmons and Lynch, 2004). The present findings seem to be consistent with other research which found that people living with HIV and AIDS receive positive support from their loved ones, other are discriminated against, rejected and isolated from their families.

The findings of this study show that 97% of the participants disclosed being on ART as illustrated (Figure 6). A possible explanation for this might be that participants are fully aware and educated that it is important to inform someone about taking ART medication for support. In the findings of the study, 2% of participants did not tell anyone about using ART.   This confirms the findings of Qwana *et al.* (2000) and Nachega *et al.* (2005) who cited that patients who did not divulge information about taking ART medication were concerned about rejection by sexual partners, family members, friend and community members. The authors also reported that rejection has a devastating impact on participants when they are expected to comply with their ART medication. These findings suggest that unsafe sexual activities and HIV transmission would continue to be a problem if the participants are still not accepted by their partners.

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5.5.2 Support groups

The findings of the study indicated that there were participants who participate in support groups in the community where they live. The findings are confirmed by those of Attawell and Mundy (2003) who found that buddy support and support groups play an important role for participants in order to adhere to their medication. However, there is a need for further research to be conducted, in order to develop a better understanding of the role of support groups in the life of the participants on ART.

5.5.3 Traditional medicine and prayers

The findings of this study revealed that all the participants (100%) they did not believed that traditional medicine is more effective than ART. However, the findings of the current study do not support the previous research by Van Dyk (2001) and Aidsguide (2006) cited in (Marais, 2006) cited that participants have a tendency to mix different forms of treatment including faith based healing, alternatives and conventional and traditional medicine.

In this study, participants reported that they do attend church, therefore, it was found to be associated with adherence. This is supported by other prior studies who reported that some of the women used prayers as a coping skill because of the belief that they might be healed from the disease (Bader *et al.*, 2006; Thobias, 2008). A similar trend was also reported by Dzinza (2007) who found that physicians in Botswana were concerned about the information spiritual leaders gave their participants such as advising to stop taking ART as they would pray for them and cure the disease.

5.5.4 Social events

The results of this study have shown that 11% of the participants were mixing with other people in the community when they go out for leisure activities such as watching soccer in the local sport ground. A possible explanation for this might be that these participants benefited from watching the soccer to relieve their personal stresses.

5.6 **Health services**

5.6.1 Perceptions of Quality of Health Care

The improvement in the quality of care of patients' life and motivation for adhering to ART medication is influenced by the behaviour of both participants and health care provider. Therefore, in this study it was found that the relationship between patient and health care provider is associated with adherence to ART. A possible explanation for this might be that the participants had trust on their health care providers and had excellent relationship with them. Another possible explanation for this is that participants in the study site were treated with respect by the health care providers. There are, however, other possible explanations such as participants were treated with privacy and confidentiality during consultation and counselling by the health care providers. The findings also support Chesney (2000), Marias (2006) and WHO (2006) that the relationship between patient and health care provider predicts the success and failure of ART in the improvement of quality life. Furthermore, these findings are consistent with other studies and suggest that participants are supposed to be active members in decision-making during discussion of ART medication options and information exchange (Barker *et al.*,

2004; Bader *et al.*, 2006). This is also supported by Prochaska (2008) who also cited that decision making is an integral part of behaviour change.

This study has not been able to demonstrate that participants were ill-treated by the health care providers as Remien *et al.* (2003) found that participants were inhumanely treated such as being called names, like "cattle or number" and "guinea pigs".

5.6.2 Accessibility of services

The findings showed that 77% of the participants were able to come to the hospital during services hours and set dates. This result may be explained by the fact that 87.5% of the participants cited that they were given opportunity to state their problems and ask questions during consultation on the day of follow-up with the health care providers. It is hypothesized that when participants are involved in decision making for follow-up appointments probability of respecting their appointments are high. This hypothesis is confirmed by the findings of the study, it became apparent that ability and willingness of health care providers to involve the participants resulted in positive impact on participants. Therefore, the findings of the current study support previous research by Thobias (2008) who found that appointment dates were often a challenge to adhere to for participants in Namibia as they were not involved in decision-making of follow-up dates. This is also supported by Pinheiro *et al.* (2002), Attawell and Mundy (2003), Marias (2006) who found that financial resources to travel to the health facilities were problematic resulting in participants missing their follow-up appointments. It can also therefore be assumed that the lack of financial resources would make participants to miss their appointment dates.

From the findings of this study figure 7 indicated that some participants who travelled a distance of more than 30KM to the hospital in order to receive their ART medication. The present findings seem to be consistent with the study conducted by Wieser *et al.* (2003) and WHO (2006) who found that participants travelled a distance of 800 to 1000KM.

From the findings of this study, there was a significant association between problems with travelling to hospital and adherence to ART. Given that some of the prior literature has consistently demonstrated that cost for transport to travel to health facility is often a challenge for participants (Jaffar *et al.*, 2005; Popa-Lissenanu *et al.*, 2005).

5.6.3 Waiting times

From the findings, figure 8 and 9 indicated that some of the participants spend long hours as well as minutes in the hospital on the follow-up day. The participants had at least one complaint against the outpatient department (OPD) that they waste lot of time waiting to receive their hospital files. These findings are consistent with those of WHO (2006) who found that long time waiting is a major challenge to adherence among ART participants in Botswana, Tanzania and Uganda. In addition, WHO indicated that prolonged waiting times have negative effect to follow-up appointments and adherence. On that note WHO recommended that health facilities should avoid long waiting of participants to consultation and medication in order to maintain high adherence levels over long period.

5.7 **Factors associated with adherence to ART**

Various factors associated with adherence to ART in the present study were identified during self-report in two days recall and seven days recall.

5.7.1 Disclosing HIV status and antiretroviral therapy

Ninety-seven percent of the participants disclosed their HIV status to their loved ones. This factor was identified as having a potential association with adherence to ART. This could be explained by the fact that there were participants who believed that antiretroviral medicine improves the quality of life. This also could be linked with the fact that some of the participants were not concerned about the reactions of their families, friends and partners.
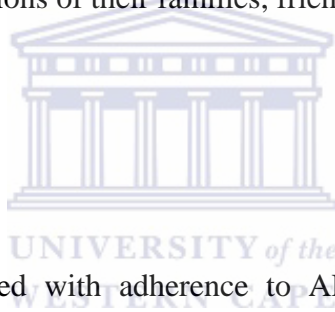
5.7.2 Daily routine/work

Daily routine work was associated with adherence to ART. Although the reason for this association is unknown, possibilities include that carrying medication to work made it for one to remember to take medication when others are also doing the same. Forgetting taking medication however, could have a negative impact to their health.

5.7.3 Missing doses of ART leads to disease progression

Participants' believed that missing doses of ART leads to disease progression and was associated with adherence to ART. The reasons for this are not clear but it may have something to do with informational support about ART and could be that participants were aware that ART decrease morbidity and mortality.

5.7.4 Problems with travelling to hospital

Having problems coming to hospital had statistical significance with adherence to ART. It seems this is due to economic problems. This finding is in line with Mills *et al.* (2006a) who found that daily schedules were barriers to ART adherence during the systemic review.

5.7.5 Trust health care providers

Participants' trust on health care providers was strongly associated with adherence to ART. This could be explained by several possible reasons that will be discussed in health services specifically in quality of care.

5.7.6 Visiting bar

Visiting bar was found to be connected with adherence to ART. This finding is in line with other studies that found that active alcohol consumption and drug abuse result in forgetfulness to take ART medication and increase probabilities of engaging in health risk behaviours (Golin *et al.*, 2002; WHO, 2006; Mills *et al.,* 2006b).

5.7.7 Sleep away from home and patient forgetfulness

With regard to reasons cited for missing doses, the findings from this study concur with reports from literature that sleeping away from home and patient forgetfulness both were found to be strongly associated with adherence to ART. This is consistent with the studies of Mehta, Moore and Graham (1997), Roberts (2000), Reynolds *et al.* (2004), Marais (2006), Mills *et al.* (2006a),

WHO (2006), Dieckhaus and Odesina (2007), Wang and Wu (2007), Malangu (2008) and Thobias (2008) who found that forgetting to take medication due to social events such as funeral, night vigil, parties and weddings was a barrier to adherence to ART.

5.7.8 Attending meetings and receive visit from friends or family members

Attending meetings/church and receive visit from friends or family members both factors were associated with adherence to ART. This could be explained by the fact that participants had opportunity to share their knowledge with other people in the community.

Total ART missed, hours spend past visit and total times missed in taking ART were found to be associated with adherence to ART.

5.8 **Limitations of the study**

There are several limitations to the present study that may affect the validity and generalizability of the results. Therefore, the findings of this study must be interpreted in the light of its limitations. The following limitations are relevant:

- The study was conducted at a single site at Ehlanzeni district, Nkomazi region which roll-out ART and did not cover other health facilities rolling-out ART. Therefore, the findings of this study may not be generalized to other health facilities delivering ART services because of small sample size.

- The study used self-report for measuring adherence to ART in two days and seven days. However, this method of measuring adherence is known to overestimate and recall bias.

- The study planned to measure adherence to ART with viral load and CD4 cell counts however, due to time constraints and cost, the biological assays could have provided more information on the adherence level to ART

- This study used cross-sectional survey due to the nature of this design which is known to only provide prevalence ratio not causes. Therefore, it will be inappropriate to imply that factors found to be associated with adherence to ART are main causes.

- This study did not include the health care providers who are receiving ART in the site. Their participation would be of help to describe their perception about the adherence behaviour.

5.9 **Summary**

The discussion dealt with the major findings of the study. Similarities with other studies were found with regard to knowledge, attitude, belief and adherence behaviour of patients on ART. The limitations of the study have also been described. The summary of the study, conclusion and recommendations based on the findings will be presented in the next chapter.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

In conclusion, participants' adherence levels in Nkomazi region appear to be comparable with those in other regions in South Africa, despite the fact that participants in Nkomazi region faced financial constraints and high unemployment rates. The findings of this research can contribute to developing expertise around adherence to ART among patients before initiation of treatment and during treatment. This expertise can be used in the development of effective support groups. Furthermore, the research can be used for lobbying policies aimed at issuing two month's supply of ART in order to promote adherence to ART. Lastly, it is hoped that the results and learning as well as recommendations from this study can be used by future researchers in the field to conduct research and improve on the current study. The study also revealed that there were patients who did not inform their sexual partners about their HIV status and taking of ART. These findings also suggest that people living with HIV and AIDS are still experiencing stigma in their families and communities.

It was evident that the health services environment was conducive for patients receiving ART as it was indicated that they were treated with respect and all issues discussed were always kept confidential. Some of the patients on ART in this study indicated that there were several occasions on which they did not take their HIV medication either because they forgot or because

they were busy with their daily routine work. This was also common to patients receiving ART in different settings as discussed in the literature review.

6.2 **Recommendations**

Recommendations are grouped in 4 themes, relating to health care providers, comprehensive policy guideline to address adherence to ART, Community and Future Research.

Health Care Providers

o It emerged from this study that health care providers treat patients with care and empathy during consultation and counselling, therefore it is important that health care providers should assess and monitor challenges to ART adherence among the patients receiving ART.

o The findings revealed that some of the patients had problems with travelling to hospital for ART. This may be the opportunity for health care providers to advocate for patients to be down referred to local clinics.

o The findings shown that there was a significant association between forgetfulness and ART adherence over the previous two days and seven days. Therefore, health care providers should encourage patients to use reminders such as cell phones, family members and treatment buddies.

A comprehensive policy guideline to address adherence to ART

o From the results, it was noted that majority of the patients were unemployed. Therefore, there is a need for strengthening intersectoral collaboration among different departments to enhance Integrated Development Plan (Department of Health, Department of Social Development, Department of Agriculture and Department of Labour). Furthermore, the intersectoral collaboration could assist in establishing income generating projects for people living with HIV and AIDS so that they can meet their financial needs that affect their well being.

Community

o The study noted that less than half of the patients participated in support groups in the community. Therefore, it is important to encourage patients to establish support groups in their communities in order to share knowledge, experiences and coping skills as they are using ART

o From the study, it was observed that there were few male patients attending ART services. In response to this, it may be important to involve men in the issues of HIV and AIDS in order to reduce denial, rejection and stigma.

Future Research

o As the study was a cross sectional, therefore is a need to conduct a qualitative study to explore and describe patients' perceptions about utilization of antiretroviral therapy.

o Further research aimed at assessing men's knowledge, attitudes, beliefs about HIV/AIDS and antiretroviral therapy in Nkomazi region.

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Appendices

Appendix 1: Approval from University of the Western Cape Higher Degrees Committee

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Tel: +27 (0) 21 959 2163
Fax: +27 (0) 21 959 2755
E-mail: csjohnson@uwc.ac.za

HIGHER DEGREES COMMITTEE

9 December 2008

TO WHOM IT MAY CONCERN

Dear Sir/Madam

Research Project of Mr Thuli Sibambo (Student Number: 2118489)

This letter confirms that Mr T. Sibambo is a registered student in the Faculty of Community and Health Sciences at the University of the Western Cape.

His research proposal entitled *"Factors associated with poor adherence to antiretroviral therapy including knowledge, attitudes and beliefs on antiretroviral treatment"* submitted in fulfilment of the requirements for Masters in Public Health has been examined by the Higher Degrees Committee and found to be of high scientific value, methodologically sound and ethical.

We fully support the research and kindly request that you allow her/him access to your organization.

Sincerely

DR GAVIN REAGON
Chairperson: Higher Degrees Committee

UNIVERSITY *of the*
WESTERN CAPE

A place of quality, a place to grow, from hope to action through knowledge

110

Appendix 2: Mpumalanga Province Department of Health Research Ethics Approval

health
Department:
Health
MPUMALANGA PROVINCE

No. 7 Government Boulevard
Riverside Park
Extention 2
NELSPRUIT
1200

Private Bag X 11285
NELSPRUIT
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Tel.: +27 13 766 3429
Fax: +27 13 766 3458

Litiko LeteMphilo   UmNyango WezaMaphilo   Departement van Gesondheid

Enquiries: Molefe Machaba (013) 766 3009/3235

02 February 2009

Mr Thuli Sibambo

PO Box 1593

Shongwe Mission

1331

Dear Mr Thuli Sibambo

APPLICATION FOR RESEARCH & ETHICS APPROVAL: KNOWLEDGE, ATTITUDES, BELIEFS AND ADHERENCE TO ANTIRETROVIRAL THERAPY AMONG PEOPLE LIVING WITH HIV/AIDS RECEIVING TREATMENT AT SHONGWE HOSPITAL IN NKOMAZI REGION, MPUMALANGA PROVINCE.

The Provincial Research and Ethics Committee has approved your research proposal in the latest format that you sent. No issues of ethical consideration were identified.

Kindly ensure that you provide us with the report once your research has been completed.

Kind regards,

Molefe Machaba
Research and Epidemiology

17 - 02 - 2009
Date

Mpumalanga PHREC
Chairperson: Mosa Moshabela

17 - 02 - 2009
Date

MPUMALANGA PROVINCE
DEPARTMENT OF HEALTH
PLANNING & INFORMATION

2009 -02- 17

PRIVATE BAG X 11285
NELSPRUIT 1200

We care   Do you?

Siyanakekela

MPUMALANGA

Appendix 3: Participant Information Sheet

UNIVERSITY OF THE WESTERN CAPE

School of Public Health

Private Bag X17 ● **BELLVILLE** ● 7535 ● South Africa

Tel: 021- 959 2809, Fax: 021- 959 2872

PARTICIPANT INFORMATION SHEET

Introduction: You are invited to take part in a research study entitled "Knowledge, attitudes, beliefs and adherence to antiretroviral therapy among People living with HIV/AIDS receiving treatment at Shongwe Hospital in Nkomazi region, Mpumalanga Province".

This consent form provides information about the research study. I will be available to answer your questions and provide further explanations. If you agree to take part in the research study, you will be asked to sign this consent form. This process is known as Informed consent. You are free to withdraw from participating in the study. The researcher is Thuli Mthembu.

Purpose: As a student of University of the Western Cape (Cape Town, Republic of South Africa). I am conducting a research study to assess the factors associated with adherence including knowledge, attitudes and beliefs. Furthermore, this study will assists in promoting adherence among ART patients.

Eligibility: Patients on antiretroviral therapy.

Procedures:

Possible risks: The data collected will not be utilized to cause you any form of harm.

Possible benefits: You will not obtain any personal benefit from participating in this study. You will only be able to express your views and feelings, for the benefit of the patients on antiretroviral therapy.

Costs: There are no costs to you for participating in this study. Only your time shall be requested.

Privacy of research records: The interview will be private. Supervisor representing University of the Western Cape may review the data collected. If that happens, I will give them copies of the information that are only related to the study. These copies will not have any information that can link you to the study. The data derived from the questionnaires will be used for research purposes only and at the end of the study; all records will be destroyed and shred.

Questions: If you have any questions about the study, please speak to Mr. T.G. Mthembu in person. Contact: 0723101503

Signatures: By signing this consent form, you agree that you have read this (If) you understand what is involved; you agree to participate in this study.

Signature…………………………………..Date…………………………..

Witness…………………………………………..Date…………………………..

Appendix 4: CONSENT FORM

Title of Research Project: Knowledge, attitudes, beliefs and adherence to antiretroviral therapy among People living with HIV/AIDS receiving treatment at Shongwe Hospital in Nkomazi region, Mpumalanga Province.

The study has been described to me in language that I understand and I freely and voluntarily agree to participate. My questions about the study have been answered to my satisfaction. I understand that my identity will not be disclosed and that I may withdraw from the study without giving a reason at any time and this will not negatively affect me or the treatment that I receive at this facility in any way.
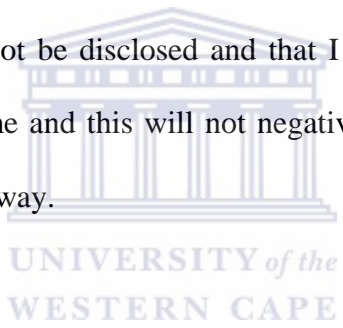
Participant's name………………………..

Participant's signature…………………………….

Date………………………

Appendix 5: QUESTIONNAIRE

I wish to learn about your Knowledge, attitudes, beliefs and adherence regarding ART. I hope to understand your needs and the best way to bring information to you, as well as barriers to seeking medical care. The information you provide will be used to improve ART. Your answers will not be released to anyone and will remain anonymous. Your name will not be written on the questionnaire or be kept in any other records. Participation is voluntary and you may choose to stop the interviews at anytime.

Thank you for your assistance.

SECTION A (DEMOGRAPHIC)

1. How old are you?

2. **Gender of respondents**	
Male	1
Female	2

3. **What is your current marital status?**	
Single	1
Married	2
Widowed	3
Divorced	4

4. **What is your highest level of education obtained?**	
No schooling	1
Primary Schooling	2
Secondary	3
Post Secondary	4
Tertiary	5

5. **What is your employment status?**	
Employed	1
Unemployed	2

6. **What is your approximate monthly salary/income?**	
R200 or less	1
R300 – R500	2
R600 – R700	3
R800 – R1000	4
>R1000	5

7. **How far do you have to travel today to come to the hospital?**	
0 – 10 Kilometers	1
11 – 20 Kilometers	2
21 - 30 Kilometers	3
More than 30 Kilometers	4

SECTION B SOCIAL SUPPORT

1. **Have you disclosed your HIV status?**	
Yes	1
No	2

2. **If Yes to whom?**	
Sibling	1
Parent	2
Grandparent	3
Aunt or Uncle	4
Partner	5
Other	6

3. **Did you tell anyone about being on ART?**	
Yes	1
No	2

4. **Are you worried about friends finding out you are on ART?**	
Yes	1
No	2

5. **Are you worried about your family finding out you are on ART?**	
Yes	1
No	2

6. **Are you worried about your partner finding out you are on ART?**	
Yes	1
No	2

7. **Does anyone in the family support you financially?**	
Yes	1
No	2

8. **Which of the following financial support do you receive?**	
Social grant	1
Child grant	2
Unemployment grant	3

9. **Do you participate in support groups of people living with HIV/AIDS in the community?**	
Yes	1
No	2

10. **Have you ever suffered from any side effects?**	
Yes	1
No	2

SECTION C (KNOWLEDGE, ATTITUDES AND BELIEFS ABOUT ART)

1. Indicate the name of the antiretroviral medications you take. Next, enter the number of pills that you have to take each day for each of these medications. (please refer to the chart provided)

Name of antiretroviral medication*	Number of antiretroviral pills		
	Wake-up, breakfast, Morning	**Lunch, Afternoon**	**Supper, evening, bed-time**
Example: lamiduvine (3TC, Epivir)* 1	1		1
1.			
2.			
3.			

*Indicate one of the names of the medication

2. How many antiretroviral pills have you missed **during the last 2 days?**

(If you haven't missed any, write down the number "0")

	Number of antiretroviral pills that you have missed …		
	Wake-up, breakfast, Morning	**Lunch, Afternoon**	**Supper, evening, bed-time**
Example	0		0
Yesterday			
Day before yesterday			

3. During the last 7 days, did you …

	YES	NO		YES	NO
• Go out for a leisure activity? (movie, show, physical activity, etc.)?	☐	☐	• Go to a restaurant?	☐	☐
• Go to a bar?	☐	☐	• Go to a party?	☐	☐
• Sleep away from home?	☐	☐	• Attend a meeting?	☐	☐
• Visit friend(s) or family member(s)?	☐	☐	• Receive a visit from friend(s) or family members(s)?	☐	☐

4. **During the last 7 days,** did one of the situations listed in question Q3 prevent you from taking all your antiretroviral pills?	
Yes	1
No	2

5a. During the last 7 days, how many times, in total, did you miss taking one or more

of your antiretroviral pills? (If you haven't missed any, write down the number "0")

_____ TIMES
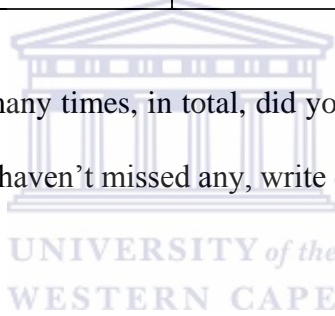
5b. In total, this represents how many antiretroviral pills? **_____PILLS**

6. Please identify and tick barriers to your treatment

Identify barriers to adherence	YES	NO
Forgetfulness		
Sleeping away from home		
Daily routine		
Alcohol and drug use		

Attitudes and beliefs about medication

1. ART prevent mother to child HIV transmission	
Yes	1
No	2

2. HIV can be controlled by ART	
Yes	1
No	2

3. ART is effective and prolongs life	
Yes	1
No	2

4. HIV can be cured by ART	
Yes	1
No	2

5. Taking ART prevents disease progression	
Yes	1
No	2

6. Not starting ART when indicated can make you sick	
Yes	1
No	2

7. ART improve quality of life	
Yes	1
No	2

8. ART medicine can cause side effects	
Yes	1
No	2

9. Missing doses of ART leads to disease progression	
Yes	1
No	2

10. Missing doses of ART increases the risk of transmitting HIV	
Yes	1
No	2

11. Do you believe ART is harmful to your body? Circle answer.	
Yes	1
No	2

12. Do you believe traditional medicine is more effective than prescribed medication?	
Yes	1
No	2

Is there anything in your daily routine or work that would make it difficult to take medication at specific times?	
Yes	1
No	2
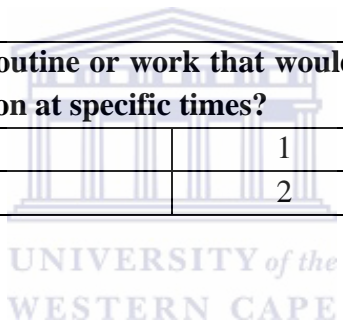
SECTION D HEALTH SERVICES

1. It takes a lot of time and time and effort to get your HIV medication	
Yes	1
No	2

2. If you lost or ran out of your HIV medications it would be hard to get more	
Yes	1
No	2

3. Are you given the chance to state your problem and ask questions?	
Yes	1
No	2

4. Are you able to attend the clinic/hospital during the service hours?	
Yes	1
No	2

5. Do you have any problem with travelling to the clinic/hospital?	
Yes	1
No	2

6. Are you treated with respect?	
Yes	1
No	2

7. Do you feel you trust the health workers?	
Yes	1
No	2

8. Do you have privacy during consultation and counselling?	
Yes	1
No	2
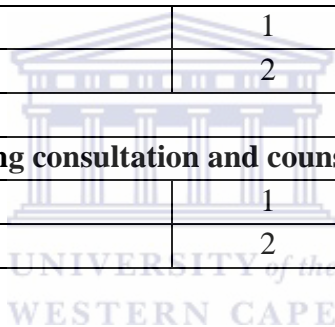
9.   How long did you spend altogether at the hospital when you last went for review?

10.   How long did you have to wait before being attended to?