

FACTORS THAT INFLUENCE TREATMENT ADHERENCE FOR PEOPLE LIVING WITH HIV
AND ACCESSING ANTIRETROVIRAL THERAPY IN RURAL COMMUNITIES IN MPUMALANGA

by

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DECLARATION

I declare that **FACTORS THAT INFLUENCE TREATMENT ADHERENCE FOR PEOPLE LIVING WITH HIV AND ACCESSING ANTIRETROVIRAL THERAPY IN RURAL COMMUNITIES IN MPUMALANGA** is my own work and that all the sources I have used or quoted have been indicated and acknowledged by means of complete references and that this work has never been submitted before for any other degree at any other institution.

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ABSTRACT

This study sought to investigate factors that influence adherence to treatment amongst rural people living with HIV and accessing antiretroviral therapy (ART) at Shongwe hospital in Mpumalanga. Both quantitative and qualitative methods were used. From patients' case files, a sample of twenty-eight respondents was recruited for the completion of questionnaires. A focus group discussion with nine participants was held, followed by qualitative interviews with three key informants. Findings indicated that a complex web of factors unique to each patient's social context plays a role in determining whether or not patients adhere to their regimens. Obstacles to adherence are poor social support, problems relating to disclosure, unemployment and economic hardship, traditional and religious beliefs, the quality and nature of adherence counselling and treatment side effects.

Key concepts: antiretroviral therapy, adherence, compliance, adherence counselling, loss to follow up

DEDICATION

This work is dedicated to my late father, Mr Sabimpi Joel Ndawonde, who always believed in my capabilities and always encouraged me to excel. 'Dad, how I wish you were around to see my achievements as I know you would have been so proud!'

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LIST OF ACRONYMS AND ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Therapy
ARV	Antiretroviral
ATLIS	AIDS Treatment for Life International Survey
CCMT	Comprehensive HIV and AIDS Care Management and Treatment
EGPAF	Elizabeth Glaser Paediatric AIDS Foundation
ETU	Education and Training Unit
HAART	Highly Active Antiretroviral Therapy
HCT	HIV Counselling and Testing
HCP	Health Care Provider or Professional
HIV	Human Immunodeficiency Virus
HBM	Health Belief Model
IDP	Integrated Development Plan
IMB	Information Motivation Behaviour Model
LTFU	Loss to Follow Up
NDOH	South African National Department of Health
NGO	Non-governmental organisation
NSP	National Strategic Plan
PEP	Post Exposure Prophylaxis
PHC	Primary Health Care
PLHIV	People Living with HIV
PMTCT	Prevention of Mother to Child Transmission
PTSD	Post Traumatic Stress Disorder
RTC	Right to Care
SA	South Africa
SASSA	South African Social Security Agency
SCT	Social Cognitive Theory
SSA	Sub-Saharan Africa
Stats SA	Statistics South Africa
STIs	Sexually Transmitted Infections

LIST OF ACRONYMS AND ABBREVIATIONS (continued)

TB	Tuberculosis
TRIAD	Training to Reduce the Incidence of AIDS-related Deaths
WHO	World Health Organization
UNICEF	United Nations Children's Fund
UNAIDS	United Nations Agency for International Development/Joint United HIV and AIDS Programme
UNGASS	United Nations General Assembly Special Session on HIV and AIDS
UNISA	University of South Africa

CHAPTER 1: OVERVIEW OF THE STUDY

1.1 INTRODUCTION

This study is an investigation and an exploration of factors that contribute to people living with HIV being non-adherent to their antiretroviral (ARV) treatment. This chapter presents a background to the study undertaken. It provides information on the focus area of the study; outlines the research problem and the history of the ARV rollout programme initiated by the South African National government. In addition, it outlines the aims and objectives of the study and the definitions of key terms are provided and a brief outline is given of the different chapters of this dissertation.

1.2 BACKGROUND TO THE STUDY

Sub-Saharan Africa is the region that is hardest hit by the HIV epidemic with approximately 60% of all people living with HIV and yet this region has only 10% of the world's total population (Hardon *et al* 2006:24). Globally, there is an estimated 34.2 million people living with HIV as at the end of 2011 and out of this an estimated 23.5 million (69%) of those people are in Sub-Saharan Africa (EGPAF 2012). This region alone had 1.9 million new HIV infections in 2011 compared to the 2.7 million new infections globally (UNAIDS 2011). According to the UNAIDS report the total number of people living with HIV and accessing ART in the region is estimated at 13.2 million (UNAIDS 2012). South Africa on the other hand, has only 0.7% of the world population but it is carrying 17% of the HIV and AIDS burden of the world (Motsoaledi 2011).

The advent and roll-out of the antiretroviral therapy (ART) programme which was initiated in South Africa in April 2004, was welcomed with trepidation and uncertainty by many quarters. According to Jones (2009:2), there were many clinicians, donors, governmental representatives and others who maintained that the expansion or general 'roll-out' of ART was politically and economically unworkable. This scepticism was the result of many factors such as lack of

adequate knowledge, a lack of economic resources, a lack of political will and leadership, and the fear that adherence would be a problem in resource-poor settings which would promote drug resistance and massive treatment failures (Jones 2009:2). At the level of the patient, the fear was that poverty, inequality and cultural or traditional habits would undermine the patient's ability to adhere to treatment. The South African National ART programme has, however, brought a great deal of hope to many people who otherwise would have faced serious morbidity and mortality. It has managed to initiate an estimated 1 163 522 people on ART as at the end of 2010 (Stats SA 2011) but the figure has recently been estimated to be at 1.7million as of July 2012 (Motlanthe 2012).

ARV drugs are currently the only available option for the suppression of the HI-virus to undetectable levels to an extent that the production of new viruses is stopped and the CD4 count is improved. When the replication of the virus is stopped, it allows the immune system to recover and be strong enough to fight opportunistic infections such as tuberculosis (TB) and pneumonia. ART is not a cure for HIV, but if administered well it helps prolong people's lives, decrease HIV and AIDS-related morbidity and mortality and generally improves the quality of life of those infected with HIV (Sunil & McGehee 2007:84). Haynes (2001:4) states that because this treatment does not cure the illness, patients must follow the treatment for as long as the illness persists which is for the rest of their lives. The prescription and adherence normally includes lifestyle changes such as adopting safer sexual practices, eating healthily and reducing or stopping the use of substances like alcohol, drugs and cigarettes.

The national ART roll-out programme has had its fair share of challenges which include non-adherence and poor retention of patients on treatment; the resultant high incidence of patients being lost to follow up or dropping out of the treatment programmes; epidemiological shift in the HIV disease burden and the scaling up of the number of people on ART. These will be discussed and elaborated on in chapter 2 of this dissertation. According to Leach-Lemens (2010) who carried out a cohort study in eight South African public treatment

programmes, almost 30% of patients initiated on ART were lost to follow up (LTFU) within three years. The study found that LTFU levels can reach 9% for the first six months after initiation and increase to 29% three years after initiation on ART.

For the ART programme to be successful and beneficial to the person on treatment, rigid and consistent adherence to the prescribed ART regimen is required. Adherence to treatment implies that the patient take at least 95% of the prescribed treatment to ensure complete suppression of viral replication, increase in the CD4 count, strengthening of the immune system and a general improvement in the quality of life (NDOH 2004:52). Good adherence to ART has the potential for turning HIV infection from an acute illness to a manageable chronic disease like other chronic diseases such as asthma and diabetes. The conversion of HIV infection to a chronic disease is due to the significant viral suppression achieved through ART and can only be realised with maximum levels of adherence by the patient (Frank & Duncan 2009:20).

Poor adherence refers to missing doses and taking medication inappropriately (Jean-Baptiste 2008:5). Inconsistent and less-than-expected adherence can result in treatment failure, rapid disease progression and in some cases in the development of drug resistant strains of HIV. Chesney (2000:171) attests that poor adherence to antiretroviral medication accelerates the development of drug-resistant HIV and states that '*without adequate adherence, antiretroviral agents are not maintained at sufficient concentrations to suppress HIV replication in infected cells and lower the plasma viral load*'. It is clear then that adherence is the cornerstone of a successful ART programme; it can promote retention of patients on ART for long periods and the attainment of optimal health. The National Strategic Plan (NDOH 2011:49) in emphasising the importance of adherence suggests having a communication strategy that includes daily adherence reminders and re-adherence counselling at every clinic visit.

Adherence to long-term medication for chronic conditions is reportedly at about 50% in developed countries and is even lower in developing countries (WHO 2003:xiii). According to Malangu (2008:49a), it is estimated in the case of ART that the average rate of adherence globally is approximately 70% although a 100% adherence is the ideal. This is also attested to by Bangsberg and Deeks (2002) as cited by Amico, Barta, Konkole-Parker, Fisher, Cornman, Shuper, & Fisher (2009:67) who, based on a number of studies using diverse measures of adherence, also set the average level of ART adherence at approximately 70%. In South Africa, adherence rates are estimated at between 40% and 50% as seen in a study conducted by Van Dyk (2011) using 450 ARV users. Only 40.1% reported a 90% level of adherence and almost 60% reported a between 70% and 90% level of adherence. From a cohort analysis done by Cornell, Grimsrud, Fairall, Fox, Van Cusem, Giddy, Wood, Prozesky, Mohapi, Graber, Egger, Boule and Myer (2010:2263) with adults initiating ART in 8 public sector programmes across South Africa, it was, however, found that 80% of patients initiated on ART were retained on treatment at 12 months and 64% at 36 months.

Because adherence is such an important part of the treatment of HIV and AIDS, it is important to identify, address and modify barriers to complete adherence as soon as possible when commencing ART (Bangsberg 2008: 272-278). A number of studies have been undertaken to determine the factors affecting and influencing adherence to treatment regimens. The individual-level factors that tend to be identified as barriers to adherence both in Sub-Saharan Africa and South Africa are:

- The high personal and household-related costs demanded by treatment costs, to afford a more nutritious diet or to pay for transportation to the clinic (Bangsberg, Ware & Simoni 2006: 140; Crane, Kawuma, Oyugi, Byakika, Moss, Bourgois & Bangsberg 2006:437-442; Hardon, Akurut, Comoro, Ekezie, Irunde, Gerrits, Kglatwane, Kinsman, Kwasa, Maridadi Moroka, Moyo, Nakiyemba,

Nsimba, Ogenyi, Oyabba, Temu & Laing 2007:658-665; Tuller, Bangsberg, Senkungu, Ware, Emenyonu & Weiser 2009)

- Fear of disclosing an HIV-positive status and stigma (Dahab, Charalambous, Hamilton, Fielding, Kielmann, Churchyard & Grant 2008:63-67; Hardon *et al* 2007; Nachega, Stein, Lehman, Hlatshwayo, Mothopeng, Chaisson & Karstaedt 2004: 1053-1056)
- Alcohol abuse (Dahab *et al* 2008:63-67; Reda & Biadgilign 2012: 1-8)
- Finding it difficult to follow complex drug regimens, poor self-efficacy in treatment adherence or an inability to tolerate the side effects of the treatment (Dahab *et al* 2008; Hardon *et al* 2007)
- Long waiting times at clinics (Hardon *et al* 2007)
- Sexual problems; decreased libido and satisfaction (Malangu 2008)

Some of the above-referenced studies focus primarily on biomedical and psychological factors contributing to non-adherence. The researcher wanted to focus on socio-economic factors that operate at the level of the individual and his or her social environment. In this regard Reda and Biadgilign (2012:3) state:

The patterns of infection have been shown to vary globally depending on the social and economic conditions of the country affected, with poverty having a significant role as a social determinant of HIV/AIDS and the spread of the virus as well as access and adherence to ART treatment.

These issues of socio-economic barriers to adherence are explored in greater detail in chapter 2 of this dissertation.

1.2.1 HIV and AIDS in South Africa

The HIV and AIDS pandemic has been one of the most challenging health issues that the South African government has had to deal with. In addition, HIV and AIDS pose a serious threat to the social and economic development of the country. HIV and AIDS are considered to be a threat to the economic well-being and social and political stability of many nations (UNAIDS 2004b:13).

UNAIDS (2004b:16) suggests that Southern Africa is the hardest hit region as it has the highest number of people living with HIV in the world. South Africa has only 0.7% of the world population but it is carrying 17% of the HIV and AIDS burden of the world (Motsoaledi 2011).

Amongst all the nine provinces in the country Mpumalanga, which is predominantly rural, is the second highest after KwaZulu-Natal in terms of the adult HIV prevalence rates (NDOH 2010:30). Shongwe Hospital, which is the chosen research site for this study, was the first facility to be accredited as a Comprehensive HIV and AIDS Care Management and Treatment (CCMT) site for the ARV roll-out programme in the Mpumalanga Province. It has, therefore, been regarded as a pioneer in terms of the ARV programme in the province and as a result has experienced a great number of challenges with the implementation of this programme, particularly in terms of ensuring adherence to ART regimens and retention of patients.

1.2.2 The chosen research site

The study was undertaken at Shongwe Hospital which falls within the catchment area of the Nkomazi Local Municipality which forms part of the Ehlanzeni District Municipality. According to the Integrated Development Plan (IDP) of the Nkomazi municipality, it has an estimated population of 338 095 people (IDP 2010/2011:19). The Nkomazi area is predominantly rural and approximately 24% of the population has no formal income. The rate of unemployment in 2008 was estimated to be at 24% (IDP 2010/2011: 24). The Nkomazi area is also close to the borders of Mozambique and Swaziland which contributes to the high rate of fluidity and mobility of most people accessing health care services in this district. The HIV prevalence rate of people infected with HIV in the Nkomazi local area was estimated to be 35.5% at the end of 2008 which was much higher than the national average of 11.4% (NDOH 2009).

1.3 THE RESEARCH PROBLEM

Shongwe Hospital was the first CCMT site in the Mpumalanga Province to be accredited for the roll-out of the ART programme. It was regarded as a pilot project for all the other sites within the province. The site has a cumulative number of 9 532 patients initiated on therapy and of these 3 791 have either been transferred or referred. The site has managed to retain 43% of patients on therapy excluding transfer-outs as at the end of September 2011 (Right to Care 2011). The problem the study focused on, therefore, was the factors influencing adherence and non-adherence to antiretroviral treatment by the persons living with HIV within the rural areas of Mpumalanga Province.

1.4 AIM OF THE STUDY

The aim of this study was to investigate individual-level and social factors that influence adherence to ART for patients attached to the Shongwe Hospital in Mpumalanga.

1.5 OBJECTIVES OF THE STUDY

From the aim described above, the following specific objectives were derived:

- To investigate the social context of patients on ART in order to identify possible factors related to adherence, non-adherence and fall out (that is, patients lost to follow-up)
- To identify the socio-economic factors that support adherence
- To identify the socio-economic factors that drive non-adherence and ultimately lead to fall out.

1.6 RATIONALE FOR THE STUDY

ART has the ability to turn HIV-infection from a terminal illness to a chronic disease. However, nearly perfect adherence is required to build up the patient's immune system, achieve viral suppression, and protect against the

development of drug-resistant strains of the virus (Yoder, Mkhize & Nzimande 2009:14). In terms of the mid-year population estimates from Stats SA (2011), South Africa has approximately 1 163 522 people who are currently on ART since the start of the roll out programme in April 2004. The South African Health Minister, following the launch of the HIV Counselling & Testing (HCT) campaign in early 2010, announced that the number of people on ART had increased significantly from 923 000 in February 2010 to 1.4 million in May 2011 (Motsoaledi 2011). The recent figures are currently estimated at 1.7 million people initiated on ART so far (Motlanthe 2012).

According to Rosen, Fox and Gill (2007:1-20), ART programmes in Africa have managed to retain approximately 60% of patients on therapy two years after initiation of therapy. The remaining 40% accounts for those who have either died owing to HIV- or AIDS-related illnesses, or those who are regarded as lost to follow-up. Retention of patients on therapy helps to reduce attrition and in many cases prevents death amongst patients. It is, therefore, crucial to gain an understanding of circumstances that either hinder or promote adherence to ART so as to develop programmes aimed at addressing this challenge. This study is intended to contribute to that body of knowledge. The findings of the study will contribute towards enhancing understanding of the phenomenon of adherence and also inform policy and programme development and implementation thereof.

1.7 ASSUMPTIONS

In this study interviews and a focus group were held with selected patients living with HIV who were initiated on ART and were either adherent or non-adherent to their treatment regimen so as to learn as much as possible about their experiences.

The assumptions in this regard were that:

- Not all patients initiated on ART are retained in the programme after 12 months of initiation on treatment

- Specific factors, such as the social and economic context of the patient, the quality of counselling concerning treatment and disclosure, play a significant role in determining whether individual patients adhere to treatment and, therefore, remain in the ART programme

1.8 RESEARCH METHODOLOGY

According to Mouton (2001:56), research methodology outlines the research process and the tools that are required to achieve the research objectives. The researcher used qualitative and quantitative research methodologies. This will be discussed in more detail in chapter 3 of this dissertation.

The study population comprised all patients who have been initiated on treatment at the Shongwe Hospital for a period of at least 12 months as on the last day of June 2011.

1.9 DEFINITION OF KEY TERMS AND CONCEPTS

1.9.1 ADHERENCE

Adherence can be referred to as *'the degree to which a client accepts an active role in following a treatment regimen which has been designed in a consultative partnership between the client and health care worker/ counsellor'* (NDOH 2010:6). It is the outcome of the patient's acceptance of his or her active role in his or her health care.

1.9.2 AIDS

Acquired immune deficiency syndrome is an infectious disease caused by the human immunodeficiency virus. It is characterised by the weakening of the immune system, which leaves the body ill-equipped to fight diseases (http://www.globalhealth.org/hiv_aids/glossary).

1.9.3 ART /ARV

This can be referred to as medication designed to suppress the replication of the HI-virus and thereby prevent or delay progression to the AIDS stage. It is the medication for people living with HIV that can work to inhibit the weakening of the immune system and to protect patients from developing opportunistic infections. (http://www.globalhealth.org/hiv_aids/glossary).

1.9.4 CD4 T-CELL

This refers to the white blood cells killed or disabled during an HIV infection (AIDSinfo 2011).

1.9.5 CD4 CELL COUNT

A CD4 cell count is a measurement of the number of CD4 cells in a sample of blood (AIDSinfo 2011).

1.9.6 COMPLIANCE

Compliance is the act of yielding, conforming, or acquiescing and, if compared with adherence, indicates a lack of sharing in the decision-making between the health care provider and the patient. (<http://www.hivguidelines.org/quality-of-care/best-practices-from-new-york-state/promoting-adherence-to-antiretroviral-therapy/>)

1.9.7 HAART

This is highly active antiretroviral therapy which refers to the use of combinations of various antiretroviral drugs with different mechanisms of action to treat HIV (<http://std.about.com/od/glossary/g/HAART.htm>)

1.9.8 HCT

This refers to the HIV counselling and testing process which consists of a pre-test, test and post-test counselling (NDOH 2010: 16-20).

1.9.9 HIV

Human immunodeficiency virus is a retrovirus that causes AIDS by infecting helper T cells of the immune system. It enters and destroys important cells which support the functioning of the immune system (Evian 2003:6).

1.9.10 LOSS TO FOLLOW-UP

This refers to the disappearance of the patient from the ART programme, for no reported reason (Rosen & Ketlhapile 2010:98). Depending on the different definitions some regard the patient as lost to follow-up when they have missed more than 90 days of clinic or pharmacy visit (Jordan, Bennett, Bertagnolio, Gilks & Sutherland 2008:17).

1.9.11 VIRAL LOAD

This refers to the amount of HIV virus in the circulating blood. It provides information about the number of cells infected with HIV and is an important indicator of HIV progression and of how well ARV treatment is working (AIDSinfo 2011).

1.10 OVERVIEW OF CHAPTERS OF THE DISSERTATION

The next section comprises of the review of all the chapters in order to familiarise the reader with the structure of the dissertation.

CHAPTER 1: INTRODUCTION AND BACKGROUND

The first chapter focuses on the overview and background to the study.

CHAPTER 2: LITERATURE REVIEW: HIV and AIDS; ARV TREATMENT; ADHERENCE AND THEORETICAL FRAMEWORK

The focus of this chapter is on HIV and AIDS in Sub-Saharan Africa, South Africa and the Mpumalanga province; the ART programme in South Africa and its challenges; the definition of the concept of adherence in relation to compliance; the identification and discussion of common patterns of non-adherence and how these can be measured; and an exploration of health-seeking behaviour models and their relevance to treatment adherence.

CHAPTER 3: RESEARCH METHODOLOGY

This chapter is dedicated to the review of the research methodology used in the research starting from the research design and the approach used; sampling, data collection, analysis and interpretation thereof. Ethical considerations and issues of rigour, trustworthiness in qualitative research and reliability and validity in quantitative research are outlined in detail. The process of gaining permission to access is also discussed.

CHAPTER 4: PRESENTATION AND DISCUSSION OF FINDINGS

This chapter focuses on the data analysis process and presentation of the findings from the research study. The demographic characteristics of the respondents are presented, their socio-economic circumstances and the patterns of adherence to their ARV treatment regimens.

CHAPTER 5: SUMMARY, RECOMMENDATIONS AND CONCLUSIONS

This chapter is a summary of the findings, conclusions and recommendations for both health authorities and for further research opportunities. The findings of the study and the conclusions thereof are discussed in relation to the objectives of the study as set out at the beginning. The researcher also outlines the identified strengths and weaknesses of the study.

1.11 CONCLUSION

In this chapter issues pertaining to adherence are introduced and background information is provided on the problem of adherence and the challenges of the ARV programme in South Africa. The research problem, aims and objectives of the study are also articulated. In the next chapter a detailed review of relevant literature and theoretical framework will be presented so that the basis of explanation of adherence can be understood by the reader.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

The purpose of a literature review is to enable the researcher to gain a better understanding of the complexity and extent of the research problem. The focus of this chapter is on HIV and AIDS in Sub-Saharan Africa, South Africa and the Mpumalanga province; the ART programme in South Africa and its challenges; the definition of the concept of adherence in relation to compliance; the identification and discussion of common patterns of non-adherence and how these can be measured and an exploration of health-seeking behaviour models and their relevance to treatment adherence.

2.2 HIV AND AIDS IN SUB-SAHARAN AFRICA (SSA)

The advent of ART has brought a great deal of hope to people living with HIV through improving the quality of and prolonging their lives. According to Levensky (2006:283) Highly Active Antiretroviral therapy (HAART) has been shown to reduce the rate of viral replication which often brings HIV to undetectable levels, decrease the incidence of opportunistic infections, delay progression to the AIDS stage and generally improve the quality of life of the client. The ARVs prevent HIV from multiplying rapidly and boost the immune system and in that way increase the length and quality of life and enable PLHIV to lead full and productive lives (Hardon *et al* 2006:24)

Sub-Saharan Africa is the worst hit region in the world with approximately 60% of all people living with HIV and yet this region has 10% of the world's total population (Hardon *et al* 2006:24). According to the Elizabeth Glaser Paediatric AIDS Foundation (EGPAF 2012) fact sheet, of the estimated 34.2 million people living with HIV worldwide in 2011 an estimated 23.5 million (69%) of those people are in Sub-Saharan Africa. This region alone had 1.9 million new HIV infections in 2011 compared to the 2.7 million new infections globally (UNAIDS 2011). It is, however, important to note at this stage that

there has been a 26% drop in the rate of new HIV infections in the Sub-Saharan region from 1997 to 2010. According to the UNAIDS report 2012, there has been a notable increase in the number of people accessing ART in Sub-Saharan Africa where it rose by at least 19% between 2010 and 2011 to a total of 13.2 million (56%) of people on ART currently. The prevalence rate of HIV amongst 15 to 49 year olds in SSA is estimated at 4.8% with some variations regionally (WHO/UNICEF 2010).

2.3 HIV AND AIDS IN SOUTH AFRICA

South Africa had approximately 5.38 million people living with HIV in a population of approximately 50.59 million people at the end of 2011, which translates to 10.64% of the total population (Stats SA 2011). An estimated 16.6% of the adult population between the ages of 15 and 49 consists of people living with HIV. South Africa has nine provinces and according to the 2010 *National Antenatal Sentinel HIV and Syphilis Prevalence Survey* each province is affected to a different degree by the HIV epidemic with the Mpumalanga Province, which is the focus of this study, being ranked second after the KwaZulu-Natal Province (NDOH 2011:39).

Of those living with the HI-virus, an estimated 1.6 million people needed ART in South Africa by the end of 2009 (AVERT 2011) but this picture has changed dramatically. The South African ART programme managed to initiate an estimated 1.2 million people on ART by the end of 2010 (Stats SA 2011) but the figure has recently been estimated to be at 1.7 million (or close to 2 million) as of July 2012 (Motlanthe 2012). South Africa has thus made great strides in achieving universal access to ART with the total number of people receiving treatment reaching 80% of all in need of treatment by October 2012 (AVERT 2012).

According to Rosen *et al* (2007:1-20), ART programmes in Africa have managed to retain approximately 60% of patients on therapy two years after initiation of therapy. Despite reaching the 80% mark (which is higher than the

60% average for Africa estimated by Rosen *et al* (2007: 1-20) in terms of initiation on treatment, retention on treatment is still a major challenge for the ART programme. The South African National Department of Health (NDOH) has put in place programmes such as adherence counselling, buddy systems and peer support programmes to ensure treatment adherence and retention of patients on treatment. Despite all these programmes and the many advantages of being on ART, some patients still experience challenges with respect to adherence to treatment and remaining on treatment. As a result of non-adherence, patients drop out of the treatment programme and some even end up being lost to follow up completely. This is a serious challenge as the objective of the ART Programme is to have at least 95% adherence to therapy for treatment success to be realised (WHO 2005:12). The main aim of the South African ART roll out programme is also to initiate and retain HIV infected people on treatment to reduce morbidity and mortality.

2.4. HIV AND AIDS IN MPUMALANGA

According to the 2010 *National Antenatal Sentinel HIV and Syphilis Prevalence Survey*, Mpumalanga Province is second-highest in terms of HIV prevalence in the country, after KwaZulu-Natal (NDOH 2011:39). The report further states that Mpumalanga is amongst the few provinces that have shown an increase in the overall prevalence rate, that is, from 34.7% in 2009 to 35.1% in 2010. This current prevalence rate is even higher than the national prevalence rate of 30.2%. A noted increase was evident in the National HIV prevalence rate in the general population from 29.4% in 2009 to 30.2% in 2010 (NDOH 2011:40).

In the Ehlanzeni District (under which the chosen research site falls), a significant increase in the HIV prevalence rate was noted from 33.8% in 2009 to 37.7% in 2010 (NDOH 2011:43). According to a report by the Triad Trust (2010:6), a non-profit organisation operating in the Nkomazi Municipality, this area has an HIV rate of approximately 50%. These estimates may, however, only be based on the number of people that the organisation deals with and

may not necessarily be a true measure of the HIV prevalence rate in the area in question.

2.5 THE ART PROGRAMME IN SOUTH AFRICA AND ADHERENCE

The South African government, with the assistance of international funders and non-governmental organisations (NGOs), has managed to roll out a very effective ART programme since 2004 free of charge to the people living with HIV (PLHIV). South Africa has the largest ART programme in the world and it has made significant strides in improving ART coverage (UNAIDS 2012). At the end of 2009, an estimated 37% of infected people were receiving treatment for HIV (WHO 2010). In mid-2011, following the launch of the HIV Counselling and Testing (HCT) campaign by the SA National Department of Health in early 2010, it was announced that the number of people on ART had increased significantly from 923 000 in February 2010 to 1.4 million in May 2011 (AVERT 2011). Recently it has, however, been reported that South Africa has reached a target of universal access to treatment with 2 million people initiated on ART by October 2012.

The introduction of the new treatment guidelines which prescribed that HIV-infected individuals be initiated on ART at a CD4 count of 350 and less has an impact on the attainment of this (NDOH 2010). This directly promotes the strategy of using 'treatment as prevention' which espouses the notion that putting people on ART earlier will positively impact on the lowering of the overall number of new HIV infections and therefore result in fewer people needing treatment (Van Dyk 2011; WHO 2011:6-7). With the inability of various countries to control the HIV epidemic and the increasing number of new HIV infections, the treatment as a prevention strategy was introduced. ART has been shown to be effective in preventing the acquisition of HIV infection when given as a prophylaxis before or after exposure to HIV to prevent transmission from HIV infected persons (WHO 2011:7). This has shown well with the Prevention of Mother to Child Transmission (PMTCT) and the Post Exposure Prophylaxis (PEP) programmes which prevent transmission

to an uninfected person who has been exposed. A recent shift proposed in the approach to curbing the scourge of HIV is the 'test and treat' strategy. This is the model of universal voluntary HIV testing with immediate commencement of ART for those diagnosed HIV positive (WHO 2011:31). It is proposed as another form of using treatment as a preventative measure for HIV infection. The model is likely, however, to have its own challenges relating to adherence and needs to be explored further as a prophylactic model for HIV.

The provision of ART to persons living with HIV and requiring treatment in South Africa has brought hope to people who otherwise would not have survived. It has led to improved quality of life, reduced morbidity, mortality and the number of deaths resulting from AIDS-related illnesses and has generally prolonged the lives of many people living with the virus. According to the UNAIDS fact sheet (2012), there is a noted decline in the number of AIDS-related deaths by at least 24% since 2005 and in 2011 there were 1.7 million deaths reported. Despite these advantages, though, the ARV roll out programme has had its fair share of challenges such as non-adherence or poor adherence to ART and the resultant high incidence of patients being lost to follow up or dropping out of the programme. Rosen and Ketlhapile (2010: 98) state that although public sector programmes for providing ART in the Sub-Saharan region have matured tremendously, a high rate of patient attrition is still evident. They further note that while much of the attrition is due to mortality, loss to follow up or disappearance of patients from treatment, with no apparent reason, is very common. In a review of cohort studies conducted by Fox and Rosen in facilities around Johannesburg and published between 2007 and 2009 it was found that approximately 59% had disappeared from the system and could not be accounted for in the first year of being initiated on treatment (Rosen & Ketlhapile 2010:98).

Non-adherence can also have dire social consequences for people living with HIV and on ART at an individual, family and a societal level. This is attested to by Silva, Ximenes, Filho, Arraes, Mendes, Melo and Fernandes (2009:136) when they state that '*non-adherence to the proposed ART regimen is*

considered as one of the greatest dangers to the response to treatment on an individual level and the dissemination of resistant viruses on the community level'. Research has shown that the likelihood of transmitting HIV is greatly reduced if the individual takes his/her medication well and adheres fully. HIV-infected individuals with a high viral load are more likely to transmit the virus than those with an undetectable viral load (HIV Prevention Trial Network 2009). On an individual level, non-adherence can result in the person being very ill and, therefore, dependent on other people for daily upkeep; may experience loss of dignity, social rejection and isolation; displacement and loss of social support; and this may affect their ability to support themselves and their families financially if they can no longer work (Heyer & Ogunbanjo 2006: 6-8; Mukherjee, Ivers, Leandre, Farmer & Benforouz 2006:124).

In Shongwe hospital where the study was undertaken, the researcher became aware of the challenge posed by high numbers of patients who fall out of the ART programme. The ARV clinic has a cumulative number of patients commencing therapy of 9 532 patients and has transferred or down referred 3 791 patients. The site has managed to retain 43% of patients on therapy excluding transfer outs as at the end of September 2011 (Right to Care 2011). These statistics reveal that there are some challenges in terms of adherence and, therefore, retention of patients on treatment. This study was undertaken in order to gain an understanding of factors that may be either hindering or promoting treatment adherence within this facility.

2.6 LEGAL FRAMEWORK INFORMING THE SOUTH AFRICAN ART PROGRAMME

There are two important strategic documents informing the NDOH ART programme in SA: namely, the National Strategic Plan (NSP) and the National Antiretroviral Treatment guidelines to assist with the implementation of the programme. These two documents are discussed briefly below.

2.6.1 National Strategic Plan on HIV, STIs and TB 2012-2016

One of the key objectives of the NSP is the significant reduction in deaths and disability as a result of HIV and tuberculosis (TB) infection through universal access to accessible, affordable and good quality diagnosis, treatment and care (NDOH 2012:48). The NSP focuses specifically on expanding the quality and reach of health and wellness and is geared to addressing the gaps identified in the previous NSP of 2007-2011. The gaps identified include the ART programme reach, early diagnosis, follow up, support to adherence and retention in care. The NSP suggests that these gaps be addressed through annual HIV testing for everyone in South Africa, initiation of every HIV-infected individual on ART when their CD4 count is 350 and less and the strengthening of adherence counselling programmes to ensure retention on treatment.

2.6.2 National Antiretroviral Treatment Guidelines 2004 and 2010

The first National Treatment Guidelines (2004: 52-57) focused on defining adherence and formulating strategies to support and improve adherence to ART, clearly defining roles and responsibilities of the Health Care Team. In these guidelines, the approach focused on providing the patient with a comprehensive treatment plan and on-going monitoring to ensure adherence. In 2010 the treatment guidelines were reviewed and a new set introduced which re-emphasised the importance of adherence and support so as to ensure positive treatment outcomes for patients and the identification of issues that impact on adherence. There was also a shift in the approach used as the NSP emphasises negotiating the treatment plan and allowing the person to commit to the plan. It further identifies main factors that have an impact on adherence and these are personal and environmental factors (NDOH 2010: 17-18). These are listed below.

In terms of personal factors, the following issues are listed: 'internalised stigma and external discrimination; denial of diagnosis; unresolved grief

reaction; lack of disclosure; guilt; alcohol and other substance abuse and/or addiction; mental illness and dementia’.

Environmental factors include things like pill burden and side effects; income and food insecurity; negative staff attitudes; lack of training of staff; perceived lack of caring by health facility and staff; shift work and time off work to attend appointments.

The focus of the guidelines, therefore, is on the treatment of the patient in a holistic manner which takes into account all factors that may either promote or inhibit adherence to antiretroviral treatment.

2.7 CHALLENGES OF THE ART PROGRAMME

The South African ART programme is one of the biggest programmes in the world and has brought a great deal of hope and improvement to the quality of lives of many people living with HIV and AIDS (UNGASS 2010). Despite the success of the programme, it is not devoid of challenges. A brief discussion of some of the identified challenges that may have an impact on adherence to ART in the long term follows.

2.7.1 Retention of patients on treatment

The biggest challenge facing the ART programme in Sub-Saharan Africa and South Africa specifically is the ability to initiate and retain people living with HIV on their treatment regimens (NDOH 2012; Rosen, Fox and Gill 2007: 1-20). There is strong evidence that many patients with chronic illnesses such as asthma, hypertension, diabetes and those living with HIV have difficulty adhering to their recommended regimens (WHO 2003:xiii). According to Paul Cook (as cited in Donohue & Levensky 2006:183) the summary of results from many years of research demonstrates that across many medical conditions 50% or more of all patients stop taking their prescribed long-term medication within the first year of initiation. This could be due to a number of reasons

including the fact that patients have to submit to treatment for the rest of their lives, the number of tablets taken daily and co-infection with other chronic illnesses (WHO 2003:11). Geng, Nash, Kambugu, Zhang, Braitstein, Christopoulos, Muyindike, Bwana, Yiannoutsos, Petersen and Martin (2010) cite reasons such as stigma, ancillary costs associated with being on treatment and the fact that health care behaviours may be competing with other priorities that take precedence in the patient's life. All these are likely to lead to non-adherence and ultimately poor retention. From studies conducted by DiMatteo (as quoted in WHO 2006:28) over a period of 50 years on adherence to treatment for chronic conditions, adherence levels ranged from as low as 4.6% to 100%. Of all these studies, only 8 studies focused on adherence to ART and the mean adherence level in those was 88% in Sub-Saharan Africa which is below the 95% adherence rate as recommended by the World Health Organization (WHO 2005:12).

The National Strategic Plan 2012-2016 (NDOH 2012) has as one of its main objectives ensuring that 80% of all eligible patients commence ART and that 70% of those initiated be alive and still on treatment at the end of five years. According to Rosen, Fox and Gill (2007:1-20), ART programmes in Africa have only managed to retain approximately 60% of patients on therapy two years after initiation on therapy. In South Africa, the issue of retention on ART also remains a major challenge as evidenced in the following studies:

- Thirty-two studies by Rosen, Fox and Gill (2007) in which the retention rate at two years of treatment is at 62%
- Analysis of 33 studies by Fox and Rosen (2010) also reveals a retention rate of 72% at 3 years of treatment
- A study conducted by Cornell (2010) in Khayelitsha, South Africa, in which 3,595 adults enrolled in HAART over 5 years were analysed, revealed that the cumulative proportion of patients remaining in care at 54 months after initiation on treatment was 78% (Geffen 2009)

2.7.2 High levels of loss to follow up and attrition

Directly linked to the poor retention of patients on ART is the high rate of patients lost to follow up and attrition for various reasons. LTFU is particularly high within the public health system especially when referral to another facility is indicated (NDOH 2011:49). According to Bärnighausen (2008:141), attrition is measured as the proportion of patients who are lost to follow up, who die or stop ART whilst in care. From the two studies carried out in facilities around Johannesburg by Rosen, Fox and Gill (2007:1-20), it is evident that the largest contributor to attrition is loss to follow up with 56% of patients being lost as a result of attrition and 40% to death. Rosen and Ketlhapile (2010:98) also established in a cohort study carried out from 2007 to 2009 that loss to follow up accounts for 59% of all reported attrition in the first year of treatment. Such a high rate of patients lost in care is an indication of challenges regarding non-adherence to treatment which result in patients dropping out of the treatment programme.

2.7.3 Epidemiological shift in the HIV disease burden

Another major challenge facing the ART programme in South Africa and other developing countries is the changing nature of the disease prevalence. According to WHO (2003:23), the epidemiological shift in the HIV disease burden from an acute to a chronic illness has made the current health care models obsolete and ineffective in meeting the needs of those living with the HI-virus.

With the launch of the ART rollout programme in 2004 according to the CCMT Operational Plan, the South African government aimed to provide comprehensive HIV care in an integrated manner so as to achieve universal access for all those eligible for ART (NDOH 2003). Despite the aim to deliver the programme in an integrated manner it was implemented as a vertical and a stand-alone programme (Uebel, Timmerman, Ingle, Van Rensburg & Molentze 2010:589). It was not implemented as part of the Primary Health Care package

with all the other diseases attended at a clinic level. This may have given rise to what is referred to as HIV exceptionalism which promotes treating HIV infected people differently and the disease as being different from other chronic diseases (Cameron 2010:6). Uebel *et al* (2010:589) also contend, in their study conducted in the Free State, that this vertical approach may have contributed to the programme not achieving universal access to treatment for people living with HIV and eligible for ART as is evident.

The vertical approach or model used to deliver health care services has the potential to affect the patients' adherence to their treatment regimens with special reference to the following areas:

(i) Availability of adequately trained staff

Health care providers are an integral part of a successful ART programme and with relevant training they can promote an efficient and effective ART programme. Vawda and Variawa (2012) identify and attribute the challenge facing the ART programme to the shortage of adequately trained healthcare personnel. This can negatively impact on the patients' ability to adhere to their treatment if they do not receive the desired support and guidance from health care providers.

(ii) Level of on-going communication with patients

Lack of or poor communication between health care providers and patients can have an effect on the interaction and the treatment outcomes if patients feel that they are not supported. According to Van Dyk (2011) and Moola (2010: 16-17), one of the key challenges that people on ART are experiencing is the inability of or difficulty with communicating with health care professionals. This impacts on their adherence to their treatment. The NSP 2012-2016 (NDOH 2011:49) advocates on-going communication as it has been shown that for adherence to be achieved fully, there needs to be constant adherence messaging through various means such as daily adherence sessions at

a clinic level, community structures and the media playing a significant role in this.

2.7.4 Scaling up of the number of people on ART

ART is now recognised as a critical HIV and TB prevention intervention strategy. Evidence suggests that ART can help reduce the risk of HIV transmission sexually to an HIV negative partner (NDOH 2011). It also helps to minimise the likelihood of contracting TB whilst on treatment and this results in lowered TB incidence on the whole. To be able to achieve this, NSP 2012-2016 (NDOH 2011:48) advocates the early initiation of HIV-infected people by 'scaling up the uptake and increase(ing) the number of people on ART by initiating at least 80% of eligible patients on ART and that at least 70% of those initiated on ART are alive and on treatment at the end of five years'. The strategic focus of the current NSP, compared with the previous one, is more on expanding the quality and reach of health and wellness, particularly on ensuring support to adherence and retention in care. Increasing quality, reach and the number of people on treatment also has its own challenges including the need for recognition of the value of testing and subsequent treatment and life-long commitment to ARVs. This is likely to have an impact on the process of initiating patients on treatment including adherence counselling and other important steps necessary to prepare, encourage and ensure adherence to ARV treatment. The proposed 'test and treat' strategy may also further influence adherence levels as more people will be initiated on ART without any counselling done if this is implemented.

2.8 ADHERENCE VIS-A-VIS COMPLIANCE

Adherence is the cornerstone of a successful ART roll-out programme. It can be defined as 'the degree to which a client accepts an active role in following a treatment regimen which has been designed in a consultative partnership between the client and health care worker/ counsellor (NDOH 2010:6). According to Heyer and Ogunbanjo (2006:5), 'close to perfect adherence is required to suppress a patient's viral load to undetectable levels and prevent

the development of drug resistant viruses'. The South African ART Guidelines (NDOH 2004:53), on the other hand, state that ideal adherence means that patients must take more than 95% of their prescribed doses. This is equivalent to missing no more than three doses per month.

WHO (2003:3) broadens the definition of adherence by referring to 'the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds to agreed recommendations from a health care provider'. This definition encompasses not only the act of taking the tablets but also the availability of an appropriate diet to complement the treatment regimen; the ability to adapt one's eating patterns/habits and the practising of safer sex for the prevention of re-infection with the HI-virus. In terms of the South African ART Guidelines (NDOH 2004:53), if a person takes less than 95% of their doses, they are at a risk of developing virological resistance to the treatment and if they take less than 80% it is highly unlikely that the treatment will have successful outcomes.

Sometimes the term adherence is used interchangeably with compliance and it is taken to mean the same thing. According to Donohue and Levensky (2006:4), the term adherence is now used more frequently than the term compliance. They assert that this shift came as a result of insights from health care professionals suggesting that compliance suggests passivity and obedience on the part of the patients whereas adherence implies patient-provider collaboration and an active role of patients in developing their treatment programme. Compliance implies subservience by the patient and it constitutes some kind of blaming of the patient in case of non-compliance (Haynes 2001:4). Munro, Lewin, Swart and Volmink (2007:104) assert that the term adherence is 'a more neutral term than compliance which can be construed as being judgemental'. Compliance assumes that the patient is a passive participant who is not capable of making valuable inputs regarding his or her treatment. At the same time, compliance regards the health care professional as the expert in as far as treatment is concerned.

It is, therefore, important to differentiate between compliance and adherence for the purposes of this study. The main difference is that adherence requires the patient's agreement with the recommendations from the health care provider (WHO 2003:4). Adherence implies that the patient is actively involved in the development of his or her treatment plan. It entails more than simply remembering to take one's medication at the recommended time and considers the role played by social, cultural, economic and personal factors in adherence (Chabikuli, Datonye & Nachega 2010: 351). Adherence also implies that the patient is actively involved in the decisions regarding the issues such as whether to disclose his or her HIV status, the appropriate time to disclose and to whom, the appropriate and convenient time for taking medication, change of lifestyle and generally committing to lifelong treatment. In adherence, therefore, the patient has an opportunity to own the process, determine how it will progress and ensure positive treatment outcomes with the assistance of health care professionals.

2.9 COMMON PATTERNS OF NON-ADHERENCE AND/OR POOR ADHERENCE

Non-adherence to treatment involves 'not taking medication at all, self-adjusting doses so as to modulate side effects, prematurely terminating treatment, not honouring clinic appointments and not filling prescriptions' (Kagee 2006:414). Poor adherence on the other hand refers to missing doses and taking medication inappropriately (Jean-Baptiste 2008:5). It implies not taking the treatment in the recommended dosage, at the recommended time and in the recommended way. Non-adherence may also involve not making other recommended behavioural changes and lifestyle adjustments like practising safer sex and stopping alcohol drinking and smoking. Non-adherence to ART regimens may take many forms ranging from not initiating treatment when it is indicated; stopping treatment soon after initiation for no known reason; skipping some dose(s) and taking what is normally referred to as 'medicine holidays' when treatment is completely stopped, which may happen on a regular basis such as on weekends or holidays, to reducing or

increasing doses (Dunbar-Jacob 2004:8). In addition, Levensky and Donohue (2006:4) state that non-adherence includes instances in which the patient does not attend or comes late for clinic appointments and does not complete behavioural change recommendations. It is further stated that non-adherence also includes sharing of medication with other people which could be a spouse or other family members (Levensky & Donohue 2006:184). In this way the patient may end up running short of his/her medication and therefore become non-adherent. According to WHO (2003:118), some patients may self-adjust regimens because they experience side effects, toxicity or because of their personal beliefs. A number of factors may contribute to these different types of non-adherence which all have detrimental effects on treatment outcomes.

2.10 FACTORS INFLUENCING ADHERENCE TO ART

A wide variety of factors play a role in determining treatment adherence amongst patients who are on chronic medication, particularly ART. Enrolment in the ART programme is a lifelong commitment on the part of the patient which presents many challenges that may ultimately have an impact on treatment adherence. Sunil and McGehee (2007:84) assert that adherence to treatment is important as it decreases morbidity and mortality rates related to any chronic illness including HIV- and AIDS-related illnesses. Non-adherence, therefore, can result in the development of treatment resistance and ultimately treatment failure (Erlen, Mellors & Lehman-Trzynka: 2004).

South Africa is currently facing a major challenge in terms of maintaining and retaining patients on ART for a period after initiation (Rosen, Fox & Gill: 2007: 1-20). In Africa the retention rates are estimated at 60% two years after initiation on treatment whilst studies conducted in South Africa in 2007 and 2010 indicate a retention rate of 62% after two years of treatment and 72% after three years of treatment respectively. There is a close link between adherence and poor retention of patients on ART and this makes it necessary to develop an insight into the factors impacting on the phenomenon of treatment adherence.

A wide range of factors may contribute to patients being non-adherent regarding their medication and these could include psychological, social, cultural and economic factors. The National Strategic Plan (NDOH 2011:17-18) group the factors that can impact on adherence into personal and environmental factors. WHO (2003: 27) and Simoni, Amico, Pearson and Malow (2009:192), group the factors affecting adherence into the following categories:

- health care-related factors, including the patient-provider relationship
- socio-economic factors
- condition-related factors, including factors related to the specific treatment regime
- patient-related factors. These factors are discussed in greater detail below.

2.10.1 Health system or care team-related factors

These are factors that relate to the health care services provided, the health care system and the relationships between the patient and the health care professionals. In South Africa the identified factors impacting on adherence are the negative attitudes of staff, a perceived lack of caring by health facility and staff and lack of training of staff (NDOH 2011:17). The factors related to poor adherence include:

- Poor communication between provider and patient. According to Oldridge (2001:337), improving provider communication skills is very important because patient adherence and outcomes depend to a considerable extent on good provider-patient communication. NSP 2012-2016 (NDOH 2011:17) identifies negative staff attitudes and a perceived lack of caring by health facility and staff as factors that impact on adherence to treatment. The relationship between a patient and a health care provider is regarded as a crucial adherence mediator as it directly influences how the patient views the illness and how this will be treated (Frank & Duncan 2009:21)

- Exclusion of patients in decision making. In a study conducted with 18 HIV-positive participants from two large clinics in Kansas City by Amico, Barta, Konkle-Parker, Fisher, Cornman, Shuper & Fisher (2009:66-75), it was found that adherence information exchange in a caring patient-provider relationship is a critical component for adherence mastery. Giving of adherence information alone is not enough to encourage behaviour change but showing positive regard and respect for the patients and their opinions can play a significant role in influencing adherence.
- Inadequate follow-up and monitoring. For patients on ART, retention in care is crucial to ensure prevention of treatment interruptions, prevent development of drug resistance and to enable the monitoring of treatment efficacy (Geng *et al* 2010: 234-244). Evidence suggests that lack of adequate follow up and monitoring of patients on treatment can impact on retention in care and ultimately on treatment adherence levels. This is attributed to the high number of patients initiated on ART mainly and the shortage of staff within the public health sector (NDOH 2007:21). According to a study conducted by Cornell (2010) in Khayelitsha, South Africa, the number of patients on ART affected the ability of clinics to monitor and follow up on the non-collection of pills. This five-year study of the ARV treatment programme found that the rapidly growing number of patients on ARVs had put extra pressure on the health care system.
- Inadequate training of health care providers (HCP). NSP 2012-2016 (NDOH 2011:17) identifies lack of training of staff as one of the key challenges that impact on adherence to ART in South Africa. In a study conducted, 20% of ARV users even complained about not being adequately prepared for commencement of treatment by health care providers which could be due to lack of necessary skills and training on the part of HCP (Van Dyk: 2011). Vawda and Variawa (2012) also report that HCP experience high stress levels owing to their demanding

working circumstances. A study cited in Vawda and Variawa (2012) found many reasons for the high levels of stress including the lack of support for and training of health care providers. This situation is even more serious in rural and informal settlements where there is a dire shortage of skilled personnel. Adequate training of staff is important to ensure that appropriate education and imparting of up-to-date information to patients is achieved.

According to Chesney (2000:171), these system-of-care-related factors may be greatly influenced by dissatisfaction caused by past experiences of the health care system which may result in the avoidance of future encounters.

2.10.2 Socio-economic factors

According to Kagee (2006:415), social and economic factors may combine to yield poor adherence outcomes in South Africa especially for those living in poverty in circumstances in which there are limited or no financial resources to meet treatment requirements. On the contrary, however, Heyer and Ogunbanjo (2006:8) state that socio-economic factors are not consistently predictive of adherence. They assert that in studies carried out in India and South Africa no association was found between adherence and the patient's economic status.

A number of investigators relate the costs of accessing treatment at the level of the individual and his or her family to poor adherence outcomes. For example, Roura, Busza, Wringe, Mbata, Urassa and Zaba (2009:48) regard cost such as transport and waiting times as important barriers in addition to stigma, family pressures and religious beliefs. Hardon, Davey, Gerrits, Hodgkin, Irunde, Kgatlwane, Kinsman, Nakiyemba and Laing (2006), in a review of studies conducted in Tanzania, Uganda and Botswana conclude that although patients are highly motivated to adhere to their medication as prescribed, constraints such as transport costs, user fees, long waiting times, hunger, stigma and discrimination, lack of social support, side effects and lack

of appropriate counselling all undermine such intentions. Mukherjee *et al* (2006:124) also confirm that costs such as payment for transportation to and from clinics serve as a deterrent to ART adherence. They further state that the lack of adequate food has also been associated with poor adherence to ART.

Socio-economic factors reported to have a significant impact on adherence are poor socio-economic status, poverty, illiteracy, low levels of education, unemployment, lack of effective social support networks, unstable living conditions, long distance from treatment centres, high costs of transport and medication, changing environmental situations, cultural and/or traditional beliefs about illness and treatment and family dysfunction (WHO 2003:28). Heyer and Ogunbanjo (2006:5-9), however, state that educational levels, literacy, income and housing status are not predictive of adherence. They report that from the 22 studies conducted; only 5 demonstrated an association between socio-economic factors and adherence. A study in Cape Town also found no association between socio-economic status and ART adherence (Orrell, Bangsberg, Badri & Wood 2003). WHO (2003:28), however, maintains that the socio-economic status of the patients is associated with adherence to treatment, because 'in developing countries low socio-economic status may put patients in the position of having to choose between competing priorities'.

Poverty can influence adherence because access to the financial means to travel to and from the ART clinic, to pay for child-minders during a parent's absence to access treatment and to attend to several, competing needs and responsibilities all come into play (Simoni *et al* 2009:192; Kagee 2006:416). For the poor and the unemployed, lack of financial resources to pay for the kind of food stuffs required to be taken alongside medication may be of particular concern. Nevertheless, studies from several resource-poor countries demonstrate that high levels of adherence can be achieved, for example, in Rwanda (Demeester, Omes, Karasi, Schneider, Mugabo, Maliboli & Arendt 2005:113-114), Haiti (Koenig, Leandre & Farmer 2004: 521-525), and Uganda (Weidle, Wamai, Solberg, Liechty, Sendagala, Were, Mermin, Buchacz, Behumbiize & Ransom 2006:1593).

According to the NSP (NDOH 2010:9) in SA, poverty is one of the major contributors to poor health and treatment outcomes through food insecurity in as far as HIV and TB acquisition and treatment adherence are concerned. The SA government, in order to support adherence through its social development department, introduced a chronic disease grant assistance for those HIV infected who cannot support themselves and their families (NDOH 2007:114; ETU 2012). The qualification criterion for the grant is that an HIV-infected person must be too sick to work and when their health improves the grant is terminated (SASSA 2012). From a study conducted in the Cape Peninsula, South Africa with 29 patients it was found that in order to keep their CD4 counts low, some manipulated the treatment so that their viral loads remained high (De Paoll, Mills & Gronningsaeter 2012: 6). This is further attested to by Van Dyk (2011) as she reports that a commonly cited reason for non-adherence is the fear of losing one's grant and that this results in some patients 'managing' their CD4 counts by skipping some doses. This ensures that the viral load is not completely suppressed and this enables them to continue receiving the grant as long as there is no improvement in the CD4 count. This can have devastating effects in terms of developing treatment resistance and treatment failure in the long run and the patient may end up with fewer treatment options.

As far as social factors are concerned, WHO (2006:28) suggests that positive attitudes of the community towards people living with HIV play a significant role in influencing adherence. Adults on ART and receiving community-based support have been reported to be less likely to be lost to follow up. This was evident in a prospective cohort study which compared those receiving community-based adherence support and those not receiving the support. It was found that of the 19,668 patients only 6% of those receiving community-based adherence support were lost to follow up compared with 9% of those not receiving any community-based adherence support (AIDSmap 2012).

According to Campbell and Murray (2004:189), many key determinants of individual health are of a social nature, and as such the challenge facing the

health practitioners is that of changing not only individual patterns of behaviour but also that of the community and the social context that help sustain ill-health. To create a health-enabling environment, therefore, requires participation in collective action that promotes community networks and collaborations capable of serving as a good source of social support, buffering individuals from the health-damaging effects of everyday stressors which may impact on the individual's health. The emphasis is on creating a safe environment for marginalised social groupings such as those living with HIV and on ART and are, therefore, more susceptible to having adverse social conditions undermining their health. One such initiative was the introduction of lay counsellors and patient advocates which is an effective alternative to creating health-enabling communities for ART users (Campbell & Murray 2004:189-190; Kagee 2006:416). The clinic based community outreach adherence support programme also introduced treatment advocates who helped with the scaling up of ART access, on-going adherence counselling and psychosocial support at a community level (AIDSmap 2012).

A study conducted by Yoder, Mkhize and Nzimande (2009:70) in five different sites in KwaZulu-Natal on the experience of patients on antiretroviral therapy findings suggests that challenges such as the availability of a treatment supporter, adequate household income and side-effects are all determinants of adherence, non-adherence and/or ultimate drop-out from treatment. Another important social factor which is associated with adherence is the support of significant others in a patient's life as they provide support and understanding for the patient. Heyer and Ogunbanjo (2006:6-7) confirm this by stating that the presence of social support systems such as supportive family members, friends and treatment supporters have been consistently associated with good adherence to treatment.

2.10.3 Condition-related factors

Condition-related factors are the illness-related demands placed on the individual patient which require behaviour change (WHO 2003:30). These

include factors such as the severity of the illness, the rate of progression of the disease, level of disability if any, and the availability of treatment for such an illness. All these factors are likely to have an impact on the patient's perception of the risk and therefore influence adherence or non-adherence to their treatment regimens.

Co-infection with other illnesses also needs to be identified and treated as this may possibly affect adherence. It has been established that a high number of HIV-infected individuals will most likely be co-infected with TB because of compromised immune systems. South Africa is ranked as the third highest country in the world in terms of the TB burden which makes all HIV-infected individuals more susceptible to contracting this disease (NDOH 2012:13). STIs such as herpes simplex can also play a significant role in the acquisition of HIV which puts anyone with this infection at a high risk of contracting HIV. Co-infection is, however, not only limited to STIs and TB but may include even depression, anxiety and other psychological illnesses. According to Brief *et al* (2004, as cited in Frank & Duncan 2009:21), post-traumatic stress disorder (PTSD) and depression have been generally associated with poor levels of adherence. Being afflicted with these illnesses at the same time may have an impact on adherence and may lead to pill burden or may even lead to fast progression in illness if adherence is not good.

The fact that there is no cure for HIV and AIDS may also impact on the perceptions of the individual of the illness and the significance of taking antiretroviral therapy which may in turn impact on adherence levels. According to Mehta, Moore and Graham (1997:1669), patients' knowledge of their diagnosis and acceptance thereof, and the expected course of the illness and treatment associated with increased adherence levels.

2.10.4 Therapy-related factors

These are factors that relate to the type of regimen that the patient is on and the factors associated with the regimen like side effects, schedule and other

requirements. According to Kagee (2006:415), regimen-specific factors include dosage, the requirement of eating specific foods, toxicity and the side effects. Mehta *et al* (1997:1667) suggest that therapy-related factors include the form of medication, the complexity of the prescribed regimen and the side effects. According to Van Dyk (2011), the most common regimen-related reason for non-adherence is the treatment's side effects. This is evident in her study of patients on ART in which 60% of the patients studied experienced side effects at different points of their treatment span. Heyer and Ogunbanjo (2006:6) emphasise the importance of dealing with side effects effectively so as to prevent discontinuation of treatment. They further state that the more complex the prescribed regimen, the more difficult it is for patients to adhere and incorporate it into their daily routine. The imminent introduction of the new triple fixed dose combination pill of ARV treatment from April 2013, however, will help to simplify the treatment regimen and greatly improve adherence levels for patients (Motsoaledi: 2012). This will mean that patients do not have to take three tablets a day but can now take one tablet once a day.

Understanding of one's treatment regimen has also been associated with good adherence to treatment. Heyer and Ogunbanjo (2006:6) state that patients on ART who do not have a good understanding of the relationship between adherence, viral load and disease progression adhere significantly more poorly than those who understand these matters. It is crucial that patients understand how the treatment works and the impact that non-adherence or poor adherence will have on the viral load and treatment outcome.

It is important to view the issues discussed here as therapy-specific factors in conjunction with the other factors that affect adherence and to understand that these factors are interrelated and may amplify the impact each has on adherence. In this respect Oldridge (2001:337) identifies factors such as waiting times at the health care facility, frequency of appointments and the continuity of care including issues of accessibility of the health care facility as having an impact on adherence to treatment. According to Simoni *et al* (2009: 192), therapy-related factors extend to the dietary restrictions that may be

necessary for effective adherence to treatment, for example, having to take medication on an empty stomach or avoiding certain foods when taking medication. According to Kagee (2006:415), food required to be taken alongside medication may not even be easily affordable and money for purchasing adherence supporting tools such as alarms and diaries may not be available. In a comparative study conducted by Van Dyk (2011), it was found that 37% of non-adherent ARV users and 21% of adherent ARV users reported having insufficient food and this impacted on their ability to take their treatment fully.

In South Africa poverty and food insecurity is still an issue of concern as it contributes largely to poor health which in turn promotes the acquisition of HIV and TB and poor treatment adherence (NDOH 2012: 37). The situation that the majority of people live under is such that there is little or no household income and they are faced with many competing responsibilities and priorities such as providing food for the whole family instead of directing the limited money to travel fares to the clinic. This may hinder the acceptance and acknowledgement of the importance of adhering to treatment regimens for positive health outcomes.

2.10.5 Patient-related factors

In many studies undertaken on adherence, it seems that the most important factors affecting adherence are those that operate at the level of the individual patient (Chesney 2000:173). The most common patient-related factors include substance abuse/addiction (alcohol and drugs), mental illness and dementia, internalised stigma, feelings of guilt, denial of diagnosis and lack of disclosure (NDOH 2010:17). Chesney (2000:172) further identifies other factors relating to the individual patient like active substance abuse or addiction, active depression and anxiety, lack of self-efficacy and the age of the individual.

According to Simoni *et al* (2009:192), patient-related factors include socio-demographic factors and psychosocial factors such as active substance

abuse, active or acute psychological and/or psychiatric conditions and the level of social support they receive from their significant others. WHO (2003:30) states that patient-related factors represent the resources, knowledge, attitudes, beliefs, perceptions and expectations that the patient may have. The following five patient-related issues are discussed in greater detail below: substance abuse, active mental illness, self-efficacy, health literacy and general factors.

(i) Substance abuse

Alcohol and drug abuse has been directly linked to the inability to adhere to treatment regimens as it can affect the ability to remember taking one's treatment when under the influence. According to Kalichman and Rompa (2003 as cited in Frank & Duncan 2009:21), substance abuse is perceived as a correlate of sexual risk practice in HIV-infected individuals and may serve as an indicator of health compromising behaviour including poor treatment adherence.

(ii) Active mental illness

Certain psychological states have been perceived as affecting the person's level of adherence and these include high levels of emotional distress, depression, anxiety and psychotic episodes (Frank & Duncan 2009:21). A person suffering from depression normally has no interest in or desire to engage in any important life activities, let alone having to commit to taking medication on a regular basis for a life time.

(iii) Self-efficacy

Self-efficacy is the belief in one's ability to successfully execute behaviour required for positive outcomes (Martin, Harskard-Zolnieriek & DiMatteo 2009:4). It has been found that higher measures of self-efficacy, that is, confidence in one's ability to take all or most of one's medication, predict high levels of adherence (Chung *et al* cited in Frank & Duncan 2009:21). Linked to this is the feeling and belief that one has no control over the illness which may seriously hamper adherence. This is evident in a study

conducted by Van Dyk (2011) in which 44% of respondents believed that their health was in the hands of other people who were more powerful than they like their sexual partners and health care professionals.

(iv) Health literacy

The amount of knowledge and understanding that a patient has about his or her illness and the treatment has an impact on the level of adherence to the treatment regimens. According to Mehta *et al* (1997:1669), patients' lack of knowledge of their diagnoses and the expected course of illness and treatment has been associated with decreased levels of adherence.

(v) General patient-related factors

Other factors identified as impacting on adherence include:

- Treatment fatigue and pill burden. According to Van Dyk (2011), having to take a number of pills as a result of co-infection with other illnesses such as TB and hypertension can result in fatigue and pill burden. This can result in patients adhering sub-optimally to their treatment. Some patients may also develop 'treatment or pill fatigue' after being on treatment for a long time and they may suddenly find it difficult to adhere to their recommended treatment regimens. Several research studies have reportedly shown adherence declining over time for people on long-term treatment and even with people who have been very successful in taking their medication (AIDSinfonet 2012).
- Lack of disclosure, fear of stigma and discrimination (Van Dyk 2011; Kagee 2006:419). People living with HIV are often subjected to a great deal of stigma and discrimination which may result in their not being willing to disclose their HIV status for fear of being discriminated against.

- Cultural and religious beliefs (Kagee 2006:422) play a very significant role in shaping and determining beliefs and values which may directly influence attitudes to treatment and adherence.
- Forgetfulness and lack of planning (NDOH 2010:18; Van Dyk 2011). These factors may be manifest when the patient attends social functions on weekends or is away from home and no provision has been made in terms of having adequate treatment available.
- Lack of adequate financial resources and food insecurity (NDOH 2010:18) is cited as one of the major problems experienced in South Africa. This may result in the lack of money for transport to attend clinic, money for food to take with the medication and this can affect adherence.

Over and above all of these factors, the individual's motivation, determination and an ability to manage his or her illness, available resources and support systems, understanding of possible consequences of non-adherence and expectation of positive treatment outcomes all interact to impact on adherence.

2.11 ASSESSMENT AND MEASUREMENT OF ADHERENCE

Adherence to ART can be measured in two ways: namely, through subjective and objective assessments. Accurate measurement of adherence can be very difficult and can only be estimated by use of indirect measures (WHO 2006: 27). Subjective measurements include self-reported adherence by patients (Levensky & Donohue 2006:5). Objective measurements are done through pill counting, tests such as CD4 count, viral load and clinical presentation of the patient.

2.11.1 Subjective assessment

Subjective assessments mainly refer to patients' self-report of adherence during their clinic appointments or visits. According to WHO (2003:96), the main shortfall of this method of adherence measurement is that patients tend to over-exaggerate their self-reported adherence. This could be due to both a recall bias and a desire to please the health care provider or to avoid criticism. Consequently, this may lead to a significant underestimation of the adherence levels within a particular population. Dunbar-Jacob (2004:9) states that a number of issues influence patients' self-reporting of adherence. These include factors such as the structure of the self-report measure; the tendency to report only what is regarded as 'good behaviour' and a failure to remember certain events.

2.11.2 Objective assessment

Objective assessment or measurement includes methods such as pill counting, audits of pharmacy refill records, tests such as CD4 count and viral load and the clinical presentation of the patient. Methods like pill counting can sometimes be an inadequate measurement tool as some patients have been known to dispose of their medication prior to a scheduled appointment or clinic visit in order to appear adherent (WHO 2003). The CD4 count and viral load are also referred to as biological indicators of the level of adherence as they test the blood to determine levels of adherence. According to Dunbar-Jacob (2000:9), the biological indicators may also prove to be inadequate as a measure for adherence. The ineffectiveness of biological indicators in measuring adherence could be due to the influence that the adequacy of the treatment regimens, treatment interactions with other drugs, metabolism of drugs and other individual characteristics may have on them.

2.12 MODELS OF HEALTH-SEEKING BEHAVIOUR

A wide variety of theoretical approaches are used to explain and predict patients' health-seeking behaviour patterns in as far as taking of medication for chronic illnesses such as HIV is concerned. These theoretical approaches largely originate in the fields of social psychology and sociology and they explain factors that may promote adherence or non-adherence to ART. According to Haynes (2001:13), theories from psychology can provide a basis for understanding why certain behaviour change strategies work and others do not. He further states that adherence interventions can be broadly categorised into three categories, that is, cognitive, behavioural and social support.

In this study, the researcher adopted three theoretical models based on this categorisation: namely, the Health Belief Model (HBM), Social Learning or Cognitive Theory and the Information Motivation and Behaviour (IMB) Model. These approaches all attempt to offer explanations for what motivates patients to seek health-promoting behaviours and to adhere to their treatment regimens. These models enabled the researcher to identify the factors that are potential barriers to treatment adherence. According to Simoni *et al* (2009: 193), these theoretical models seek to identify a collection of constructs that influence adherence and assist in understanding the manner in which all these constructs co-exist and influence one another. These models are discussed in detail hereunder.

2.12.1 The Health Belief Model (HBM)

The HBM was first introduced in the 1950s by a group of American social psychologists in order to understand human behaviour in relation to health matters. It was updated in the 1980s. It attempts to explain and predict health behaviours through examining and understanding attitudes and beliefs of individuals regarding long-term treatment. HBM has also been used to explain change and maintenance of desired health-related behaviour changes (Janz *et al* 2002 as cited in Moola 2010:30). According to Masokoane (2009:21), the

HBM posits that the perceived benefits of a healthy lifestyle will more likely encourage people to follow positive health regimens so as to achieve positive treatment outcomes.

The HBM focuses primarily on beliefs as motivators of health behaviour (Martin *et al* 2009:3). The model is based on four key tenets that are discussed below.

(i) Perceived benefits of the recommended health action

This refers to those aspects of an action that the individual perceives as a possible benefit should he or she follow a recommended health action. The perceived benefits can be of a physical, social or a psychological nature. According to Hayden (2009:32), this is the person's opinion of how valuable or useful a new behaviour can be in reducing the risk of likely infection, morbidity or mortality from a disease. It is the belief in the effectiveness of strategies designed to reduce the threat of illness and the benefit that can be derived from engaging in recommended behaviours. The premise here is that people who are on ART and have a good understanding of what positive changes the treatment will bring about physically and otherwise are more likely to adhere to their regimens. This can be an incentive for them to be adherent so as to achieve the possible positive health outcomes like an improved CD4 count, decrease in viral load and a general improvement in their health. The basic principle is that for the behaviour to be undertaken the patient must evaluate the benefits of the recommended change as more valuable than the action required.

(ii) Perceived barriers to the recommended health action

This refers to the perceived negative and detrimental circumstances that will prevent the patient from taking the recommended health action. These negative consequences may include social, psychological, economic and even physical expectations or demands on the individual. This is an individual's

evaluation of the perceived obstacles that can prevent them from adopting a new behaviour (Hayden 2009:33). The recommended action may not be taken even if a person believes that the benefits of taking action will yield positive outcomes if there are perceived barriers. Barriers are regarded as those situations that prevent or discourage the patient from taking recommended action. The recommended behaviour change may be perceived as inconvenient, painful or unpleasant and may be even costly for the patient to undertake. In ART adherence over and above taking all dosages in the recommended manner, patients are required to practise safer sex and to adopt a healthier lifestyle. Adopting a healthier lifestyle may require that the patient at least have the financial resources to be able to meet this and it may be a barrier if he/she is unemployed and has no other source of income (NDOH 2010:18). Practising safer sex requires that the patient understand the link between infection and hyper-infection and unsafe sex and be sufficiently motivated to change his or her behaviour accordingly. In addition, it may also depend on the individual's bargaining power in intimate relationships to negotiate for and adopt safer sex practices.

(iii) Perceived susceptibility to the disease or the consequences of not adhering to treatment

This refers to the perceived vulnerability to or risk of being infected with a particular illness or disease and the consequences that may come about as a result of not taking the recommended health action. The individual's subjective belief that they may be vulnerable to contracting a certain disease may deter them from engaging in certain behaviours or spur them on to actively seek healthier behaviours like adhering to their treatment if already infected (Kagee 2006:420). In ART adherence the belief that the risk of non-adherence may result in treatment failure, development of drug resistance and a possible progression from being infected with the HI-virus to the AIDS stage may be a deterrent to the patient engaging in unhealthy behaviours (Evian 2011:465). In a study by Chung *et al* (2002: 301-310 as cited in Frank & Duncan 2009:21) it

was observed that a strong belief in the development of resistant HIV strains as a result of non-adherence served as a positive motivator for adherence.

(iv) *Perceived severity of the disease*

This refers to the feelings that individuals may have regarding the seriousness of having or contracting a particular disease and the seriousness of consequences that may result from not adhering to their treatment (Rosenstock, Strecher & Becker 1988:177). These negative consequences can be either physical, that is, deterioration in health condition (Kagee 2006:420) or social consequences which may mean being unable to perform one's social tasks like holding a job and providing for one's family as a result of ill-health.

Although positive perceptions of benefits and a minimisation of the barriers to healthy behaviours induce the preferred health action, an individual still requires some triggers or stimuli which will promote taking action. These are referred to as 'cues to action' and 'self-efficacy'. Hayden (2009:33) states that cues to action can be people, events or things that move people to take action so as to change their behaviour. Wekesa (2007:8) explains the cues to action as '*internal and external factors which influence action e.g. mass media, family and symptoms of illness*'. Self-efficacy, on the other hand, is the belief in one's ability to successfully execute behaviour required for positive outcomes (Martin *et al* 2009:4).

In terms of ART adherence the basic assumption of HBM is that a person who believes that HIV and AIDS are severe diseases, sees more benefits in being on treatment than barriers and has confidence in his or her ability to take medication even under difficult circumstances (Wekesa 2007:8). The researcher included questions about the perceived benefits and barriers of the recommended health action, cues to action and self-efficacy in the instruments used in the study.

The major shortfall of HBM is that it places greater emphasis on the individual's perceptions and feelings about the illness and the recommended health action at the expense of other factors such as the environment, social and economic factors. Moreover HBM portrays individuals as social economic decision makers, making its application to health issues related to sexual behaviour limited (Sheeran & Abraham 1996). For example, condom promotion for safer sex that is only directed at women will have a minimal impact as women do not have autonomous control over their sexual encounters (MacPhail & Campbell 2001:1614).

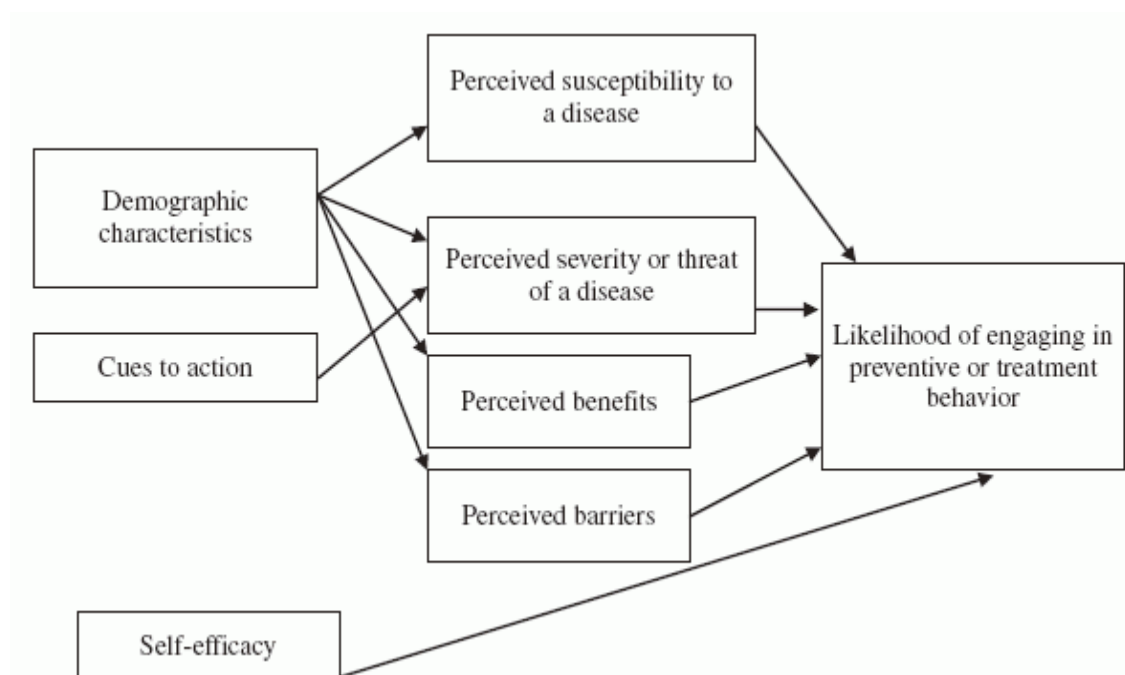


Figure 2.1: A depiction of the major tenets of the Health Belief Model
(Adapted from Martin *et al* 2009)

2.12.2 Social Learning or Social Cognitive Theory

According to the social cognitive theory, human behaviour can be defined as a three dimensional interaction of three significant factors: namely, personal factors, behaviour, and the environment. In other words, behaviour change can be influenced largely by any one of the three factors. People learn by observing others, with the environment, behaviour, and cognition all as the chief factors in influencing development.

Martin *et al* (2009:16) state that social learning theories posit that both personal expectancies and environmental factors (e.g. reinforcements) determine behaviour, and that modifying either of these two factors can result in behavioural change. According to Rosenstock, Strecher and Becker (1988:176), social cognitive theory, which has been relabelled as social learning theory, holds that behaviour is determined by expectancies and incentives. Expectancies include three main components: namely, expectancies about environmental influences, expectancies about the consequences of one's actions and expectations about one's competence to perform the behaviour needed to influence the outcome. Incentives on the other hand refer to the '*value of a particular object or outcome*' (Rosenstock *et al* 1988:178). This can be referred to as the gain or benefit derived if a particular behaviour is performed.

The key principle of the social cognitive theory is the concept of self-efficacy. This implies that a person has to believe that they have the ability to perform a particular behaviour and expect to have a positive and desired outcome as a result of the behaviour. In addition there must be a perceivable incentive and benefit for the person to perform the behaviour. Self-efficacy can be improved upon in several ways, amongst them by providing clear instructions, providing the opportunity for skill development or training, and modelling the desired behaviour. Rosenstock *et al* (1988:180) cite two major ways of improving or increasing self-efficacy: namely, through vicarious experience and verbal persuasion. In vicarious experience the person observes successful and unsuccessful behaviours of others and learns from those performances. This is equivalent to peer counselling amongst patients and the support groups that patients attend in order not only to support one another but also to learn from other patients' experiences. Verbal persuasion is mostly used in health education programmes to teach a person the best action to take for behaviour change. In ART programmes this can refer to the adherence counselling process through which patients are taught about the treatment, possible side

effects, expected outcomes of the treatment and strategies and techniques that can be applied so as to ensure adherence to treatment regimens.

The Social Learning Theory attempts to predict health behaviour by assuming that health is influenced by behaviour and that behaviour is modifiable (Conner & Norman 1996). Such assumptions imply that individuals are rational decision makers who are able to systematically review available information to derive intentions from this. This renders health decision making a cognitive process whilst ignoring the role played by the complex social contexts in moulding people's decisions and behaviour.

2.12.3 The Information Motivation and Behavioural Skills (IMB) Model

According to Martin *et al* (2009:19), the basic principles underlying the Information Motivation Strategy Model (IMB) are that before a person can achieve health behaviour change, that person must know the change that is necessary (*information*); have the desire to change (*motivation*); and have the necessary tools to achieve and then maintain the change (*strategy*). The IMB model suggests that having the necessary health-related information and knowledge, the motivation and appropriate skills to apply the information gained will largely determine whether the health behaviour will be performed or not. This model of adherence addresses information about adherence and the motivation to maintain adherence that includes personal and social motivations and the necessary behavioural skills for adhering to ART. According to Simoni *et al* (2009:194), the IMB model

proposes that ARV adherence is a function of one's fund of accurate regimen-specific information, social and personal motivation, and adherence related behavioural skills, which is further considered in relation to the relative presence of moderating factors such as homelessness, or depression.

The information component of the model may include health knowledge, beliefs and the ability to remember what to do to ensure adherence. Motivation on the other hand refers to attitudes, feelings, confidence and expectations, amongst others. Finally, the strategies refer to both physical and social tools such as time, financial resources and the social support of family and friends (Martin *et al* 2009:20).

This model also considers situational and individual characteristics such as the ease or difficulty of access to medical care that can affect the relationship between IMB model constructs and adherence behaviour (Amico, Barta, Konkle-Parker, Fisher, Cornman, Shuper & Fisher 2009:67). In terms of ART, this model holds that people living with HIV who are well informed, motivated to act and possess the necessary behavioural skills that enable them to act effectively, will adhere to the ART programme (Fisher, Fisher, Amico & Hamann 2006). There are, however, other factors such as personal and situational factors which may have a bearing on whether the patient adheres to treatment or not. An individual's unique experiences, beliefs and personal attributes influence his or her responses to new information, to environmental reinforcements, to motivational messages, and to all of the other things that are potential triggers for behavioural change. There is always an interaction between personal factors and environmental factors which determine whether behaviour change happens or not. Despite having the knowledge or information, the motivation and skills necessary to perform the behaviour, the individual and situational factors such as disclosure of one's status, one's beliefs and past experiences and the support of family members, accessibility of the health facility, reliable transport system and/or affordability thereof can all have a bearing on whether the patient adheres to his or her treatment. The implication for health care professionals is that developed health care intervention programmes should be such that they take into account even personal and situational factors for them to be effective. Figure 2.2 illustrates how the four factors can lead to treatment adherence.

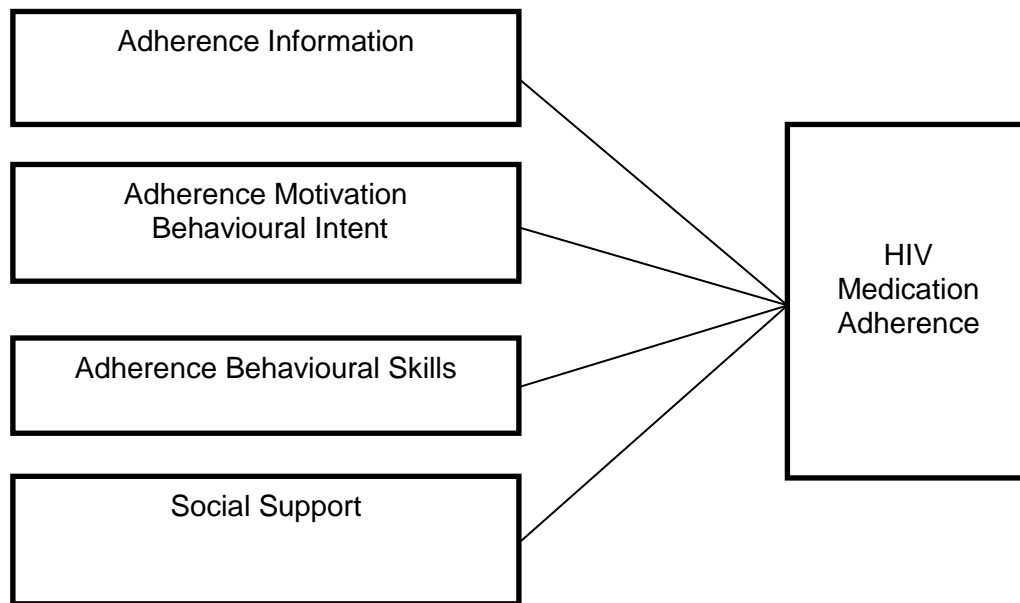


Figure 2.2. A depiction of the major tenets of the Information Motivation Strategy Model
(Adapted from Pomeroy *et al* 2007)

2.13 CONCLUSION

In this chapter, HIV and AIDS both in Sub-Saharan Africa and South Africa as well as the ARV programme in SA and its challenges were discussed. The concept of adherence was also defined in relation to compliance. The common patterns of non-adherence were also identified and discussed and how these can be measured. An overview of the different theoretical approaches to health behaviour change was presented. In the next chapter the research methodology and design utilised in this research will be discussed in detail.

CHAPTER 3: RESEARCH METHODOLOGY

3.1 INTRODUCTION

This chapter is dedicated to the description of the research methodology used in the research starting from the research design and the approach used; sampling, data collection, analysis and interpretation thereof. Ethical considerations and issues of rigour, trustworthiness in qualitative research and reliability and validity in quantitative research are all outlined in detail. The process of gaining permission to access is also discussed.

3.2 RESEARCH DESIGN

The researcher used a two-phased research design in which the first phase was a quantitative survey design and the second phase a qualitative focus group discussion design. According to Mouton (2001:55), research design can be defined as *‘a plan or blueprint of how one intends to conduct research’*.

Babbie and Mouton (2001:80-81) identify three most important purposes that different researchers may have when undertaking research and these are exploration, description and explanation. The approach adopted in this study was the use of both a qualitative and a quantitative research design and it had two distinct phases. In the first phase of the study the researcher collected data through the survey interviews with patients identified through their case files. The second phase entailed the use of qualitative methods such as focus group interviews and face-to-face interviews with key informants that included lay counsellors, a pharmacist assistant and a social worker. In both phases the orientation was to obtain data that would meet the goals of description and exploration of the topic. Each of the two phases is discussed in greater detail below.

3.2.1 The quantitative phase

Quantitative research is aimed at determining the extent of something or detecting the relationship between variables within a particular population by managing and presenting data numerically. Taylor (2005:235) states that it is designed to provide objective descriptions of phenomena and how these can be controlled. According to Grinnell (2001:91), quantitative studies seek to answer research questions about quantity. In this study the researcher utilised two sources of data: namely, the patients' case files and survey questions posed to a sample of patients in a face-to-face interview. The case files were studied in order to obtain demographic details such as age, gender, level of education and employment status with the aim of gaining a clear profile of the units of observation and this was, therefore, descriptive in nature.

3.2.2 The qualitative phase

Monsen and Van Horn (2008:65) define qualitative research as any data-gathering technique that generates open-ended, narrative data or words rather than numerical data or numbers. It tends to be exploratory and descriptive in nature and is designed to develop an understanding of individuals in their natural environment. According to Dawson (2002:14), this method explores attitudes, behaviour and experiences through such methods as open-ended, face-to-face interviews and focus groups. In this study of socio-economic factors influencing adherence to treatment, data were collected using a focus group which built on the information collected from the survey interviews. Qualitative research typically focuses on having smaller samples owing to the nature of data that are rich in description collected (Crabtree & Miller 1999:34).

3.2.3 A descriptive study

Descriptive studies seek to '*define and describe social phenomena of interest*' (Grinnell 2001:28; Rosnow & Rosenthal 2005:1). The aim of this type of study is to describe a social phenomenon, the factors associated with that

phenomenon and to state the nature of those factors or actions. In this study the aim was to describe who the patients were; what their social circumstances were; capture their understanding of adherence; and the factors that lead to non-adherence.

3.2.4 An exploratory study

According to Babbie & Mouton (2001:790), the main goal of exploratory studies is to explore a new area of interest or topic so as to gain an insight and familiarity with it. Exploratory studies usually lead to greater insights and comprehension of the phenomenon but may not necessarily provide '*detailed, accurate and replicable data*' (Babbie & Mouton 2001:80).

3.3 THE STUDY POPULATION

The target population for this study comprised of people living with HIV and meeting the following eligibility criteria for the survey part of the study:

- Participants had to receive treatment from Shongwe Hospital, Mpumalanga
- Participants should have been on ART for a period of at least 12 months prior to commencement of the study
- Participants had to reside within the catchment area of Shongwe hospital

3.4 SAMPLING STRATEGIES FOR THE STUDY

According to Grinnell (2001:207), '*sampling is defined as the selection of some units to represent the entire population (set) from which the units were drawn*'.

With non-probability sampling, the probability for the participant to be selected cannot be estimated and is therefore not known (Grinnell 2001:215). There is very little or no assumption that the sample will be representative of the larger population and as a result the findings cannot be generalised. In purposive

sampling the researcher uses his/her own judgements when selecting possible participants for the study (Grinnell 2001:216).

3.4.1 Sampling strategies for the quantitative phase

A non-probability, purposive sampling technique was chosen. The researcher undertook a retrospective review of 50 patients' case files to find those cases already identified as defaulting on treatment, or having missed one or more clinic appointments, or as having a high viral load despite having been on treatment for the past 12 months. This formed a sampling frame of potential defaulters. From these case files it was possible to identify characteristics such as the ages, genders, marital status, employment status, and disclosure status of these patients. Using this method the researcher could, out of the 50 case files, identify 35 patients that fitted the eligibility criteria as listed under sub-heading 3.3 above and who were traceable for inclusion in the survey part of the study. Of the 35, only 28 patients were willing to participate in the study. Igumbor, Scheepers, Ebrahim, Jason and Grimwood (2011) also used retrospective patient files to conduct their study on ART adherence, but they used only the patients' records as their primary data and did no additional data-generation.

3.4.2 Sampling strategies for the qualitative phase

The participants for the focus group interviews were purposefully chosen as two groups of patients fitting the eligibility criteria listed earlier in the chapter and visiting the hospital on two separate days. The researcher identified and approached those attending the clinic and only nine participants volunteered to participate in the two focus group discussions. The participants for the key informant interviews were purposefully chosen as the key staff rendering services to the patients.

3.5 INSTRUMENTATION

The development of the research instruments was largely informed by the reading and preparation done during the research proposal writing phase. The first draft of the questionnaire was submitted to the supervisors for their comments after which amendments and revision of the same were done accordingly. The instrument was also pre-tested with five patients from the Thembaletu Clinic (which is outside of the study area). Because these five respondents did not fit the eligibility criteria, their responses were only used to test the questionnaire and were not included in the analysis. The final questionnaire (see Annexure 3) has three distinct sections which focus on:

Section A: Biographical information (the veracity of this was checked against the patients' files)

Section B: Socio-economic factors

Section C: Treatment and adherence factors

The questionnaire comprised closed and structured questions in sections A and B of the questionnaire and open-ended questions in section C.

The qualitative phase of this research involved the conducting of focus group discussions in order to collect contextual data about the meanings that patients attach to adherence (Walliman 2011). Babbie and Mouton (2001:292) state that focus group discussions can be used to obtain information that one would not otherwise be able to access. According to Liamputtong (2011:5) focus group discussions are an ideal way of exploring people's stories, experiences, points of view, beliefs, needs and their concerns. This method allows the participants to interact with others who are in a similar situation and can share their own views in their own way without necessarily agreeing with them. The researcher developed a guide for the discussions that was informed by the questionnaire used in the quantitative phase of the study. In particular, the researcher guided the respondents to explain the conditions and/or circumstances they thought could either promote and encourage or discourage adherence to treatment.

3.6 DATA GENERATION STRATEGIES

For the quantitative phase of the study, the researcher opted for a survey approach using a structured questionnaire applied to 28 face-to-face interviews. This phase took place from 5 to 9 September 2011 and each interview lasted 20 to 30 minutes. The researcher explained in detail the objectives of the study, issues of confidentiality, privacy and anonymity; voluntary participation and the need to record all the proceedings. Formal and written consent was obtained from eligible patients before they were interviewed. Interviews were held with individual participants in an office that the researcher was allocated by the facility. The interviews were conducted in English and siSwati and IsiZulu for those respondents who were not conversant in English.

The second phase of the study was the focus group discussion in which nine participants were involved. Babbie and Mouton (2001:292) suggest that it is always a good idea to over-recruit at least by 20% to compensate for those participants who do not show up. The researcher learned a valuable lesson as for the first focus group discussion only two persons arrived and the planned group meeting had to be cancelled and rescheduled. Eventually two focus group discussions could be conducted, consisting of four and five members respectively.

The researcher also conducted interviews with the three different informants who work closely with the patients on a daily basis and could provide valuable insight into the issue of non-adherence. These discussions were held on 6 September 2011.

(i) Social worker

The social worker is tasked with the responsibility of tracing all patients who are either defaulting and/or are non-adherent regarding their treatment. It was,

therefore, logical for the researcher to interview her so as to gain more insight into the phenomenon from a service provider perspective.

(ii) Lay counsellors

The researcher also interviewed two lay counsellors who were allocated to do adherence counselling at the ARV clinic. They were in a position to provide insights into what they considered to be factors influencing non-adherence.

(iii) Pharmacist assistant

Every patient on ART has to go to the pharmacy at each regular clinic visit to receive their medication. The treatment refill records are normally a good indicator of adherence or non-adherence to treatment. The pharmacist or pharmacist assistant usually interviews patients to find what the reasons for their non-adherence are. The researcher conducted an interview with the pharmacist assistant as there was no pharmacist at the hospital during the time of data-gathering.

3.7 ETHICAL CONSIDERATIONS

The basic considerations when conducting social research involve recognising and making ethical choices, making principled decisions, ensuring confidentiality and obtaining informed consent from participants whilst maintaining research integrity (Babbie & Mouton 2001:520-528). This is done in order to minimise any possible harm and distress that may be caused through participating in the survey (Curtis & Curtis 2011:160). Ethical considerations in this study included gaining permission to access research participants' and patients' case files from the Mpumalanga Provincial Department of Health Research and Ethics Committee, The Higher Degrees Committee of the Department of Sociology, University of South Africa (UNISA) and obtaining consent from the participants.

3.7.1 Permission to access the study population

It is very important for a researcher to obtain permission to access any study population. In many cases the researcher will have to negotiate access to the facility or the participants with a number of gatekeepers (Henn, Weinstein & Foard 2006: 178). It is even more crucial when the subjects of the study are patients and ethical issues may potentially arise during research study. Prior to conducting this research, the researcher sought ethical clearance from the Department of Sociology; University of South Africa and it was obtained on 11 March 2011 (see Annexure 6).

The researcher then proceeded to request permission from the Mpumalanga Provincial Department of Health Research and Ethics committee and Shongwe Hospital where the study was to be undertaken. The hospital was not in a position to grant permission and the researcher was referred back to the Mpumalanga Provincial Department of Health. The application was made in April 2011 and was only granted on 24 June 2011 (see Annexure 7).

3.7.2 Informed consent

Informed consent implies that the researcher makes participants aware of what the research study is all about and the processes that will be followed so that they are in the best position possible to make informed decisions regarding participation (Curtis & Curtis 2011:16). In this study informed consent was obtained from each respondent prior to conducting the survey interviews, the focus group discussions and the individual interviews with the key informants. The process involved the researcher explaining verbally to each respondent and participant the objectives of the study and assuring them of anonymity and confidentiality, emphasising that participation was voluntary. Consent forms were signed for this study by both the respondents and the researcher (see Annexure 2).

3.7.3 Voluntary participation

The researcher explained and emphasised that participation was voluntary and participants could choose to withdraw at any point with no penalty or even decide not to participate at all without any repercussions for them. During this study seven of the patients selected for the survey opted not to participate in the study.

3.7.4 Confidentiality

Confidentiality refers to protecting and not sharing any personal information of the respondents without their consent (Henn, Weinstein & Foard 2006:85). In this study the names and identity of all participants were kept confidential. Instead of names, the researcher used codes in order to link each completed questionnaire with the correct patient file. The list of codes was kept under lock and key and only the researcher had access to it. The patients' files were returned to the hospital. The completed questionnaires and the notes taken during the focus group interviews and the key informant interviews and all signed consent forms were kept in a locked cupboard by the researcher. This material will be shredded five years after the degree has been conferred.

3.8 RELIABILITY AND VALIDITY IN QUANTITATIVE RESEARCH

According to David & Sutton (2011:266), reliability is '*the degree to which the indicator or test is a consistent measure over time*'. On the other hand, validity refers to '*the degree to which a measuring instrument actually measures and describes the concept it was designed to measure*' (David & Sutton 2011: 268).

3.8.1 Reliability

Reliability is the extent to which observations when repeated under the same circumstances still produce similar findings. This means being able to obtain

consistent results from the same measure over time (Babbie 2010:155). To ensure reliability in this study the researcher pre-tested the data collection instrument so that when it was used in the main study it was more appropriate and reliable. The coding of the responses was checked by the supervisors who also verified the accuracy of the data entry on the computer. The biographical details of each of the 28 respondents were verified against the patients' case files.

3.8.2 Validity

According to Galofshani (2003:599), validity refers to whether the means of measurement are accurate and whether they are actually measuring what they are intended to measure. It means getting the results that accurately reflect the concept it was intended to measure in the first place (Babbie 2010:155). The goal of this particular study was to investigate the social context of people living with HIV who are on ART so as to identify contributing factors to adherence or non-adherence. The question items included in the survey questionnaire were developed from a review of the literature. This instrument was pre-tested at the Thembaletu clinic, Johannesburg.

3.9 TRUSTWORTHINESS OF THE DATA GATHERING FOR THE QUALITATIVE PHASE OF THE STUDY

According to Babbie and Mouton (2001:276), the key principle of good qualitative research is found in the trustworthiness of its findings. According to Dzindza (2007:76), four aspects need to be considered to ensure trustworthiness of research findings and these are credibility, transferability, dependability and confirmability.

3.9.1 Credibility

This refers to the extent to which the researcher has established confidence in the findings of his/her study. According to Babbie and Mouton (2001:277),

credibility asks whether there is any correlation between the constructed realities in the respondents' minds and what is being attributed to them by the researcher. A researcher can ensure credibility in different ways and in this study the researcher used prolonged engagement through spending as much time with respondents as possible and establishing a trusting relationship with them as proposed by Padgett (1998:94); audio recording the focus group and key informant interviews and triangulating different data sources to ensure credibility of findings (Dzindza 2007:76).

3.9.2 Transferability

According to Babbie and Mouton (2001:277), transferability refers to '*the extent to which the findings can be applied in other contexts or with other respondents*'. In this study the sample size was small and, therefore, it cannot be claimed that it was representative of the total population. The researcher ensured transferability through the use of thick description of data collected and reported it accordingly. The researcher also used purposive sampling so as to maximise the nature and range of information that can be obtained (Babbie & Mouton 2001: 277)

3.9.3 Dependability

According to Dzindza (2007:77), dependability considers whether the findings would be consistent if the inquiry were to be replicated with the same subjects or in a similar setting. Grinnell (2001:533) states that dependability refers to the '*soundness of both the steps taken as qualitative data analysis and the conclusions reached*'. To ensure dependability in this study both key informant interviews and focus group discussions were employed for triangulation purposes. Data was recorded using both the digital recorder and detailed notes were also taken. Babbie and Mouton (2001:278) further state that there can be no dependability without credibility in as much as there is no reliability without validity in quantitative research.

3.9.4 Confirmability

This refers to the extent to which the research results can be corroborated or confirmed by others and the extent to which the results of the study are an objective reflection of the study and not the subjective biases of the researcher. Babbie and Mouton (2001:278) state that '*confirmability is the degree to which the research findings are a direct result of the inquiry and not the perceptions and prejudices of the researcher*'. Lincoln and Guba (as cited in Babbie & Mouton 2001:278) suggest the use of a confirmability audit trail which will enable the auditor to see if the interpretations and conclusions arrived at are in line with the available inquiry data. This chapter is a full disclosure of the steps taken to generate record, analyse and interpret the data.

3.10 DATA ANALYSIS

Data analysis is the process by which all data is arranged and reduced from its raw form to a point at which it is more manageable and can yield meaningful findings. The two research approaches adopted in this study have different ways of analysing data and these will be discussed hereunder.

3.10.1 Data analysis strategies for the quantitative phase

Walliman (2011:112) states that quantitative data analysis manages data numerically and uses mathematical operations to investigate its properties. The data collection method used in this instance was the review of case files and face-to-face interviews in a survey using a questionnaire.

In this study the researcher used descriptive statistics to analyse the data collected in the quantitative phase. According to Babbie and Mouton (2001:459), descriptive statistics implies presenting numerical data in a manageable form. For the survey, the researcher gave numerical codes to all of the answer options. A respondent code linked the interviewee with his or her

respective case file to enable the cross-checking of the biographical data. The list of codes was checked by the supervisors who also adjudicated the accuracy of the coding and the entering of the data into the computer. SPSS 18 was used to generate descriptive tables.

3.10.2 Data analysis strategies for the qualitative phase

According to Walliman (2011:132), qualitative data analysis involves data reduction through a coding process, categorisation and summarising of the data collected. Liamputtong (2011:165) states that the first most important step in analysing focus group data is the transcription of data. In this study the researcher used a recording device to tape record the focus group discussions and the interviews with the key informants. In addition, she took detailed notes of group interactions and discussions. The audio-recordings were personally transcribed by the researcher.

In thematic analysis the researchers are predominantly interested in the emergence of themes from the collected data. Liamputtong (2011:173) defines this as a *'method of identifying, analysing and reporting patterns (themes) within the data'*. The transcribed interviews and notes taken during the interviews and focus group discussions were first read several times and checked for accuracy against the recordings. The researcher then searched for repeated themes that emerged from the data to draw up a list of themes. These themes were given codes and the codes applied to the printed text.

3.11 INFERENCES: SYNTHESIS OF THE DATA

The researcher needed to integrate the data obtained for the various data-generating approaches in a meaningful way. According to Bazeley (2009:204), integration happens when *'qualitative and quantitative components can be considered integrated to the extent that these components are explicitly related to each other within a single study and in such a way as to be mutually*

illuminating, thereby producing findings that are greater than the sum of the parts’.

In this study both the data collection methods used could be regarded as related to each other as the second phase built on the information and insights of the initial phase. The researcher also adopted a similar approach during the analysis phase as the first phase was about describing the sample profile and the second phase focused on gaining meaning from the participants’ experiences but in their own words. The reporting of the data analysis and interpretation thereof will be done in an integrated manner for each identified theme in the next chapter.

3.12 SUMMARY

This chapter was dedicated to the review of the research methodology and design used in this research study. The study was both descriptive and exploratory in nature in that it was aimed at describing and exploring the social context of people living with HIV and AIDS and receiving ART.

The measures taken to ensure reliability and validity in the quantitative research phase and trustworthiness in the qualitative research phase were also outlined. The ethical considerations taken during this research were also explained.

CHAPTER 4: PRESENTATION AND DISCUSSION OF FINDINGS

4.1 INTRODUCTION

This chapter focuses on the presentation of the findings from the research study. The demographic characteristics of the respondents are presented and their socio-economic circumstances as well as the patterns of adherence to their ART regimens are outlined.

4.2 BACKGROUND CHARACTERISTICS OF THE RESPONDENTS

The demographic data on the sample of patients receiving ART is presented in terms of age, gender, marital status, level of education, employment status and current place of residence.

Table 4.1 shows the distribution of the respondents by age. From this information it is clear that the largest proportion of respondents falls within the age category of 30 to 39 years of age, that is, 39.3%. Those 40 years and older account for 32.1% of the sample and those younger than 30 years comprise 28.6% of the sample. The mean age of the respondents for this study is 36.93 years. This was also similar in the qualitative data where at least 44.4% of respondents fall within the 30 to 39-year-old categories. The majority of the respondents (71.4%) fall into the category of between 30 years and older. According to the developmental psychologist, Erik Erikson (Harder 2002), these life stages are characterised by a need to form meaningful relationships, start families and develop careers as personal developmental milestones. It is, therefore, anticipated that most of the people in this category would be concerned about their health and well-being as it has a bearing on their ability to form meaningful relationships, start a family and be able to develop and keep a fulfilling career.

Table 4.1: Age group of respondents (N=28)

AGE RANGES	FREQUENCY	%
Younger than 30 years	8	28.6
30-39 years	11	39.3
40 years and older	9	32.1
Total	28	100.0
Mean age 36.93 years		

Table 4.2 indicates an equal distribution between the sexes of the respondents which is at 50% (n=14) each (see Table 4.2). The researcher used the qualification criteria as outlined in section 3.5 of this dissertation to select the respondents and coincidentally it was a 50-50 gender distribution. This is not consistent with the normal trends in terms of gender distribution of people that are living with the virus and also the general population where there tend to be more females than males (Stats SA 2009). It is, however, important to take into cognisance that this study sample is very small and cannot be generalised to a wider population. In the qualitative phase though there were more females in the group than males at 66.7% compared to 33.3% of males.

Table 4.2: Gender of respondents (N=28)

GENDER	FREQUENCY	%
Female	14	50.0
Male	14	50.0
Total	28	100.0

Table 4.3 indicates that 50% of the respondents were single whilst only 7.1% were married, 17.9% cohabiting, 10.7% widowed and/or divorced and those married but having an extra-marital partner as well 7.1%. This was also evident in the qualitative phase of the study in which 77.8% of the respondents in the focus group were single and 22.2% were either married or cohabiting.

Table 4.3: Marital status of respondents (N=28)

MARITAL STATUS	FREQUENCY	%
Single	14	50.0
Married	2	7.1
Divorced	2	7.1
Co-habiting	5	17.9
Widowed	3	10.7
Married plus a co-habiting girl/boyfriend	2	7.1
Total	28	100.0

Table 4.4 depicts the level of education amongst the study respondents. It shows that 67.9% of the respondents had at least a secondary school level of education whilst 17.8% had primary school education and 14.3% no education at all. The fact that the majority of respondents had a secondary level of education might be indicative of the respondents' ability to know their treatment well, understand and recognise its importance and the possible consequences of not adhering to treatment in the long run. There has, however, not been any correlation between illiteracy and non-adherence in terms of literature on adherence and in fact the contrary has been established (Heyer & Ogunbanjo 2006: 5-9).

Table 4.4: Educational level of respondents (N=28)

EDUCATIONAL LEVEL	FREQUENCY	%
None	4	14.3
Primary	5	17.8
Secondary	19	67.9
Total	28	100.0

The respondents' places of residence were evenly distributed throughout the 11 villages which fall within the catchment area of the Shongwe hospital (see Table 4.5). Table 4.6, on the other hand, depicts that the majority of the

respondents (92.9%) resided in a predominantly rural area and only 7.1% in an urban area which is closer to the town of Malelane. The study area is predominantly rural and this profile is indicative of that fact.

Table 4.5: Current place of residence (N=28)

PLACE OF RESIDENCE	FREQUENCY	%
Bosfontein	2	7.1
Driekoppies	1	3.6
Emangweni	1	3.6
Jeppes Reef	3	10.7
Kamhlushwa	4	14.3
Langeloop	4	14.3
Magogeni	3	10.7
Magudu	2	7.1
Mgobodzi	1	3.6
Middelplaas	1	3.6
Schoemansdal	6	21.4
Total	28	100.0

Table 4.6: Respondents' residences in a rural or an urban area (N=28)

PLACE OF RESIDENCE	FREQUENCY	%
Urban	2	7.1
Rural	26	92.9
Total	28	100.0

4.3 SOCIAL AND ECONOMIC BACKGROUND VARIABLES

Kagee (2006:415) suggests that social and economic factors may combine to yield poor adherence outcomes. This assertion is, however, disputed by Heyer and Ogunbanjo (2006:8) who state that socio-economic factors are not consistently predictive of adherence. They further assert that in studies carried out both in India and South Africa no association has been found between adherence and the patient's economic status. This study aimed at establishing whether the socio-economic factors of these respondents had any bearing on their adherence to treatment.

4.3.1 Employment status

Table 4.7 shows that 53.6% of the respondents were employed whilst 46.4% were unemployed. Of the 53.6% of respondents who were employed at the time, the data reveals that they held positions across a wide spread of economic sectors such as security, construction, agriculture, general labour, assistants, the beauty industry, education and traditional healing (See Table 4.8). The 46.4% who were unemployed included one person who was still at high school and another person who had been medically boarded and was no longer employed. Qualitative data on the other hand showed that 33.3% of the nine respondents in the focus group were unemployed whilst 66.7% were employed which is slightly higher than the percentages in the quantitative data.

Table 4.7: Respondents' current employment status (N=28)

EMPLOYMENT STATUS	FREQUENCY	%
Yes	15	53.6
No	13	46.4
Total	28	100.0

Table 4.8: Current employment positions (N=28)

CURRENT EMPLOYMENT STATUS	FREQUENCY	%
Unemployed*	13	46.4
Security guard	3	10.7
Teacher	1	3.6
Hairdresser	2	7.1
Cleaner	1	3.6
Secretary	1	3.6
Miller	1	3.6
General assistant	1	3.6
Plumber	1	3.6
Gardener	1	3.6
Welder	1	3.6
Traditional healer	1	3.6
Irrigator	1	3.6
Total	28	100.0

*(including a scholar/student and a person medically boarded)

4.3.2 Main source of income

The findings of this section of the study showed that the main source of income for the respondents was a salary/wage in line with the number of people employed and this was estimated to be 53.5% as shown in Table 4.9. It also revealed an equal distribution between those who were dependent either on parents or grandparents' pensions or on their own pensions at 3.6% each. About 7.1% were dependent on spouses' incomes for survival. Those with absolutely no source of income were at 28.6% which is quite a substantial number of people with no income. In the qualitative data percentages, the number of people who were unemployed and dependent on a spouse or another person numbered three respondents out of nine. This is very likely to have an impact on adherence to their treatment in terms of regular attendance at the clinic, ensuring that they have adequate food to take with treatment and money to cover transport and other related costs.

Table 4.9: Main source of income of the respondents (N=28)

MAIN SOURCE OF INCOME	FREQUENCY	%
Salary/wage	15	53.5
Solely dependent on parents	1	3.6
Pension after having been medically boarded	1	3.6
Dependent on grandmother's pension	1	3.6
Spouse's income	2	7.1
No income	8	28.6
Total	28	100.0

4.3.3 OTHER SOURCES OF INCOME

Table 4.10 and 4.11 indicate that some of the respondents had other sources and means of income besides those indicated in Table 4.9. Table 4.10 indicates that 35.7% of respondents had other sources of income besides those mentioned in Table 4.9. Table 4.11 shows these additional sources of income as 21.4% being dependent on the disability grant, 10.7% dependent on child maintenance which was sometimes not paid at all and 3.6% relying on their spouses for survival.

Table 4.10: Households' possible other sources of income besides the respondents' salaries (N=28)

OTHER SOURCES OF HOUSEHOLD INCOME	FREQUENCY	%
Yes	10	35.7
No	18	64.3
Total	28	100.0

Table 4.11: Source of other income besides salary (N=10)

SOURCES OF INCOME	FREQUENCY	%
Disability grant	6	21.4
Spouses' incomes	1	3.6
Fathers sometimes paid maintenance	3	10.7
Total	10	35.7

4.3.4 FINANCIAL LOSSES INCURRED DUE TO CLINIC ATTENDANCE

Table 4.12 indicates that about 92.8% of the respondents incurred transport expenses as they had to travel various distances to the clinic to obtain their medication. Of the respondents, 10.7% had to take sick leave from work which affected their wages; 7.1% either lost income through having to buy food when attending the clinic or lost income-earning opportunities as they could not actively look for a job whilst they were attending the clinic. Only one person (3.6%) in the group had to pay a child-minder when attending the clinic (see Table 4.12). The total number of responses exceeds the number of respondents as more than one response was applicable for some. Poverty and lack of financial resources can influence adherence as sometimes patients have to prioritise other family needs over treatment when faced with the many daily needs competing for limited resources (WHO 2003).

Transportation costs have been identified as a factor that impacts on adherence in different studies conducted in the past (WHO 2003; Mukherjee *et al* 2006; Hardon *et al* 2006; Kagee 2006 & Simoni *et al* 2009). The findings of this study also show a similar trend as 92.8% of respondents indicated that the major costs incurred were those of transportation to the clinic. Lack of financial means to pay for transport to the clinic, paying a childminder or even to buy food whilst at the clinic may result in the patient not attending clinic appointments. Long waiting times at the clinic may also be a possible barrier to attending a clinic appointment when a patient is faced with not receiving a

salary on the day and having to spend money on food whilst waiting. Some respondents (10.7%) reported having to take sick leave when attending clinic which they stated affected their wages. The likelihood of sometimes not honouring clinic appointments in order to receive full salaries is always there and may ultimately impact on adherence.

Table 4.12: Type of financial losses incurred due to clinic attendance

FINANCIAL LOSSES DUE TO CLINIC ATTENDANCE	FREQUENCY	%
Taxi fare	26	92.8
Had to take sick leave	3	10.7
Lost income-earning opportunities	2	7.1
Cost of food	2	7.1
Had to pay child-minding fees	1	3.6
Total	28	*

* As respondents could give more than one answer here, the percentages summate to more than 100%.

4.3.5 CONSTITUTION OF RESPONDENTS' HOUSEHOLDS

Just below a third of respondents, that is 32.1%, lived with their extended families whilst 28.6% lived with a spouse and children. Smaller proportions of respondents (7.1%) either lived with children under the age of 18 years or with their parents. Table 4.13 shows that 17.9% of the respondents lived with people who were not relatives whilst 3.6% lived with children older than 18 years and a further 3.6% lived with a spouse. A recent study by Jury and Nattrass (2012) in Khayelitsha reveals that household compositions of people who are initiated on ART tend to include family members (especially parents) to a greater extent than people who are not HIV positive. Over time, as ART restores the health of the patient, the household compositions change so that the household compositions of people on ART and the general population

become indistinguishable. This suggests that family members act as caregivers in the early stages of ART. Whereas it is not possible to deduce this from Table 4.13, the researcher found it interesting that, although half of the respondents were single in terms of marital status, none of the 28 respondents were living completely on their own.

Table 4.13: Constitution of respondents' households (N=28)

CONSTITUTION OF HOUSEHOLDS	FREQUENCY	%
Extended family	9	32.1
Spouse and children	8	28.6
Other non-kin	5	17.9
Children under 18 only	2	7.1
Parents	2	7.1
Spouse only	1	3.6
Children older than 18 only	1	3.6
Total	28	100.0

4.3.6 SIZE OF RESPONDENTS' HOUSEHOLDS

The average size of the households of the 28 respondents was 4.89 people. A sizeable proportion (28.8%) of the respondents' households consisted of five people whilst a quarter (25%) had households comprising four people. Another 25% had 6 or more people living in the same household. The rest of the respondents (21.4%) had small households comprising 3 members.

Table 4.14: Size of respondents' households

SIZE OF HOUSEHOLDS	FREQUENCY	%
3 people	6	21.4
4 people	7	25.0
5 people	8	28.6
6 or more people	7	25.0
Total	28	100.0
Mean household size 4.89 people		

4.3.7 NUMBER OF LIVING CHILDREN

Table 4.15 indicates that the average number of living children per respondent was 2.11. Half of the respondents had two children; 28.6% had three or more children and 7.1% had only one child. A small percentage (14.3%), however, had no children at all. This implies that 85.7% of the respondents had progeny that would be affected by the health status of their mothers or fathers.

Table 4.15: Number of living children of respondents (N=28)

NUMBER OF CHILDREN	FREQUENCY	%
None	4	14.3
1 child	2	7.1
2 children	14	50.0
3 or more children	8	28.6
Total	28	100.0
Mean number of children 2.11		

4.3.8 AGES OF YOUNGEST CHILDREN LIVING WITH RESPONDENTS

The mean age of the youngest child living with a respondent was 10.33 years as indicated in Table 4.16. Nearly half (45.8%) of the respondents had children younger than 6 years of age. Read in combination with Table 4.15, it can be deduced that a large proportion of the respondents had minors who might have been dependent on their care, making the issue of adherence for the survival of these parents a matter of crucial importance.

Table 4.16: Ages of youngest living children of respondents (N=24)

AGES OF CHILDREN	FREQUENCY	%
Up to 1 year old	4	16.7
2- 5 years old	7	29.1
6-9 years old	3	12.5
10-15 years old	4	16.7
16-18 years old	3	12.5
19 years and older	3	12.5
Total	24	100.0
Mean age of youngest child 10.33 years		

4.4 HIV DIAGNOSIS AND DISCLOSURE

This section discusses the results of data-gathering concerning the experiences of each of the 28 respondents, their HIV-positive diagnosis and their disclosure behaviour. Some of the factors identified as having an impact on adherence to treatment include the diagnosis with HIV, reaction to that diagnosis and the decision whether to disclose or not. Denial of HIV diagnosis and a lack of disclosure to significant others have been identified as factors that determine the level of adherence to treatment (NDOH 2010:17). According to Mehta *et al* (1997:1669), patients' knowledge of their status and acceptance thereof and the expected course of the illness and treatment have all been

associated with increased levels of adherence to treatment. The IMB model also proposes that having adequate health-related information and knowledge may motivate the person to make the necessary health behaviour changes (Martin *et al* 2009:19). According to Van Dyk (2011) and Kagee (2006:419), lack of disclosure, fear of stigma and discrimination have also been associated with non-adherence to treatment. People living with HIV are often subjected to a great deal of stigma and discrimination which may result in lack of disclosure of their HIV status for fear of being discriminated against. The Social Learning theory posits that personal expectancies and environmental factors determine behaviour (Martin *et al* 2009:16). This may negatively impact on their ability to adhere to their treatment regimens.

4.4.1 Initial reaction to HIV diagnosis

The respondents' responses to how they reacted when they first tested HIV positive indicate that 39.3% claimed to have accepted their status immediately; 32.1% did not feel afraid whilst 21.4% felt very upset upon receiving the news. Only one respondent (3.6%) indicated that he/she did not think that he/she was at risk of being infected and was shocked by the results and one more respondent indicated that he/she was not upset at all as he/she had seen other people living with HIV (see Table 4.17) . On the whole, the quantitative data thus revealed an overall positive response to an HIV-positive result. The qualitative data revealed that of the nine respondents, three initially reacted with sadness, fear and anger but later accepted their HIV status whilst one respondent reported being shocked as he/she did not expect to test HIV positive at all. The rest of the group reported that they just accepted their status. These findings should be seen in the context of these respondents' encapsulation in current ART care and cannot be generalised to all persons who have tested positive.

Table 4.17: Respondents' initial reactions upon receiving an HIV positive diagnosis (N=28)

INITIAL REACTION TO TESTING HIV POSITIVE	FREQUENCY	%
Not afraid	9	32.1
Accepted	11	39.3
Very upset	6	21.4
Did not think I was at risk	1	3.6
I was not upset as I have seen other people living with HIV	1	3.6
Total	28	100.0

4.4.2 Disclosure

The information received from the respondents indicated that all of them had disclosed their HIV status albeit to different people (see Table 4.18). A quarter of the respondents (25%) had disclosed to everyone whilst 17.9% had only disclosed to their mothers followed by those that had disclosed to their spouses (14.3%). The rest had disclosed to their children, parents, siblings, friends and colleagues respectively. From the qualitative data it is evident that of the nine respondents, eight had disclosed their status either to spouse, family and/or friends. It is, however, important to point out that only one respondent in the quantitative phase and none in the qualitative phase disclosed at their workplaces which affects adherence to some extent when at work.

Table 4.18: People to whom respondents disclosed (N=28)

PERSONS RESPONDENTS DISCLOSED TO	FREQUENCY	%
To children and parents	2	7.1
To eldest child	1	3.6
To mother	5	17.9
To everyone	7	25.0
To sister and boyfriend	1	3.6
To children	1	3.6
To mother and boyfriend	1	3.6
To sister	2	7.1
To a friend	1	3.6
To a spouse	4	14.3
To father	1	3.6
To a grandparent	1	3.6
To a work colleague	1	3.6
Total	28	100.0

4.4.3 Reaction to respondents' disclosure

The data in table 4.19 shows that the majority of people that the respondents disclosed to were supportive (71.4%) compared with the 14.3% of those who found it hard to accept the status of the respondents. A small percentage (7.1%) reported, however, that they just accepted the fact that the person was HIV positive whilst 3.6% expressed fear that the respondent might die as a result of being HIV positive. Only one respondent (3.6%) reported being blamed for testing HIV positive. It has been reported in literature that a large number of people do not disclose their status for fear of being blamed and in some cases discriminated against. The AIDS Treatment for Life International Survey (ATLIS) conducted in 2010 found that 35% of people in a sample of 2 035 did not disclose for fear of being stigmatised and discriminated against. (AVERT 2011). In the qualitative phase the researcher also found that two

thirds of the respondents reported positive responses upon disclosure, although some cases of emotional abuse and rejection by partners were reported.

**Table 4.19: People's reaction/s when respondents disclosed to them
(N=28)**

REACTION TO DISCLOSURE	FREQUENCY	%
They were supportive	20	71.4
They accepted the fact	2	7.1
They were afraid that I would die	1	3.6
They found it hard to accept	4	14.3
I was blamed	1	3.6
Total	28	100.0

4.4.4 Respondents' feelings about benefits of disclosure

The information below indicates that all respondents found that disclosing their HIV status to significant others was beneficial for different reasons (see Table 4.20). A third (35.7%) of respondents felt that disclosing made it possible for them to receive the support they needed; 28.6% felt that their significant others gained a better understanding of what was happening in their lives; 17.9% gained a better perspective of their own illness and 14.3% felt that a burden had been lifted from their shoulders when they disclosed. One respondent stated that although he/she was blamed initially, this reaction to disclosure encouraged him/her to seek medical help in order to live a longer and meaningful life.

Table 4.20: Respondents' feelings about benefits of disclosure (N=28)

WHETHER DISCLOSURE WAS BENEFICIAL TO RESPONDENTS	FREQUENCY	%
Yes, receive support now	10	35.7
Yes, loved ones now understand what is happening	8	28.6
Yes, I gained perspective	5	17.9
Yes, a burden has been lifted	4	14,3
Yes, encouraged to seek medical help	1	3.6
Total	28	100.0

4.5 TREATMENT AND ADHERENCE FACTORS

The provision of ART to people living with HIV and AIDS has led to improved quality of life, reduced morbidity, reduced mortality rates and the number of deaths due to HIV- and AIDS-related illnesses and has generally prolonged the lives of many people living with the virus. To attain treatment success the patients have to adhere to their treatment at least 95% of the time in order to ensure complete suppression of the virus (NDOH 2004). A wide range of factors influence adherence to ART and this is the subject of the current study. The following sections focus on the findings relating to aspects of treatment and adherence.

4.5.1 Year of commencement of ART

The largest proportion of respondents in this study (46.4%) commenced treatment in 2010 whilst 21.4% began in 2008; 14.3% in 2009 and 10.7% in 2011. The remainder of the respondents (3.6%) began ART in 2000 and 2006 respectively (see Table 4.21). It is also noted from the findings that 92.8% of respondents had been on treatment for a period of fewer than five years whilst the rest (7.2 %) had been on treatment for over ten years. Being on treatment for a long time can also impact on adherence as patients may develop what is

referred to as ‘treatment or pill fatigue’ resulting in their being unable to adhere to the recommended treatment (AIDSinfonet 2012; Van Dyk 2011). Several research studies have reportedly shown adherence declining over time for people on long-term treatment and even with people who have been very successful in taking their medication (AIDSinfonet 2012). In this study the findings indicate that at least 7.2% of the respondents in the quantitative phase had been on treatment for over ten years and they might require more support to ensure that they remained adherent to their treatment regimens.

In the qualitative phase of this study, findings show that eight of the nine focus group respondents had been on ART for fewer than five years as they were initiated between 2009 and 2011. One discussant had been on treatment for ten years after initiation in 2006.

Table 4.21: Year in which respondents commenced ART (N=28)

YEAR OF INITIATION ON TREATMENT	FREQUENCY	%
2000	1	3.6
2006	1	3.6
2008	6	21.4
2009	4	14.3
2010	13	46.4
2011	3	10.7
Total	28	100.0

4.5.2 Treatment regimen

In terms of the South African Treatment Guidelines (NDOH 2010) only three categories of regimens are available to patients at this point, that is, the 1st line, 2nd line and the salvage line. Health care professionals aim to maintain their patients on the 1st line as long as possible so that they do not run out of treatment options. Remaining on the first line regimen requires at least 95% of adherence to treatment and no adverse reactions on the part of the patient.

The data in Table 4.22 indicates that 75% of the respondents were on the first line regimen. This is a positive finding in terms of long-term adherence and the success of treatment. A small proportion (7.1%) of respondents were already on the second line regimen which left them with fewer options in the long run. The rest of the respondents (17.9%) did not know their treatment regimen and, therefore, could not provide information in this respect. The fact that 5 of the 28 respondents did not know their regimen is disconcerting as it is preferable that the patient be informed about and understand his/her treatment as this encourages adherence. In the qualitative phase the researcher found that 5 of the 9 respondents were on the first line regimen, one was already on the second line regimen and 3 were on the salvage regimen.

Table 4.22: Treatment regimen respondents were currently on (N=28)

TREATMENT REGIMEN	FREQUENCY	%
1st line	21	75.0
2nd line	2	7.1
Don't know	5	17.9
Total	28	100.0

4.5.3 Meaning of adherence to respondents

Adherence can be defined as *'the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds to agreed recommendations from a health care provider'* (WHO 2003:3). From table 4.23 it is evident that half of the respondents (50%) understood adherence to refer to taking their medication correctly. Whilst 7.1% understood it to refer to taking medicines correctly and practising safe sex, 7.1% stated that it referred to self-care and 3.6% asserted that it meant eating regular meals. It is, however, of concern to note that 32.1% of the respondents did not know what adherence means. This may have a serious impact on

adherence as the person may not understand what is expected of them and as a result will not adhere very well to their treatment regimen.

Table 4.23: The value of treatment adherence to respondents (N=28)

THE VALUE OF TREATMENT ADHERENCE TO RESPONDENTS	FREQUENCY	%
Taking medicines correctly (as prescribed)	14	50.0
Do not know	9	32.1
Taking medicines and using condoms	2	7.1
Self-care	2	7.1
Eating regular meals	1	3.6
Total	28	100.0

4.5.4 Perceived benefits of adherence counselling

All 28 respondents confirmed that they attended adherence counselling sessions prior to commencing treatment. The respondents in the qualitative phase also reported that they all attended adherence counselling although one of them felt that the quality of counselling was not good. The findings of this study show a wide range of responses, some of which are positive and others negative (see Table 4.24). The largest proportion of respondents, (42.8%) reported that they found the adherence counselling sessions to be very good and informative whilst 28.6% reported that the sessions helped them to learn more about their medication, diet and living positively; how to deal with side effects, fear and stigma; helped with planning for the family; found it to be an enjoyable experience and it helped them make friends. A small percentage (3.6%) reported that attending the counselling sessions helped her see that she was not the only one who was living with HIV and that was very helpful. The rest of the respondents either reported that they were late for their sessions (3.6%); they found it confusing at first (10.7%); could not remember

what was discussed (3.6%) or could not even answer the researcher when interviewed (7.1%).

Table 4.24: The perceived benefits of attending adherence counselling sessions (N=28)

PERCEIVED BENEFITS OF ADHERENCE COUNSELLING	FREQUENCY	%
It helped me with my fears about side effects	2	7.1
I learnt about diet and how to live positively	1	3.6
I found it informative	9	32.1
It was very good	3	10.7
I learnt how to take the medication	2	7.1
It helped me to deal with my fear of stigma	1	3.6
I was late for some of my counselling appointments	1	3.6
I could see that I'm not the only one living with HIV	1	3.6
It was a good experience and I made friends	1	3.6
I found it confusing at first	3	10.7
Cannot remember	1	3.6
No answer	2	7.1
Helped me with planning my family despite being HIV+	1	3.6
Total	28	100.0

4.5.5 Treatment supporter

This question relates to the person that was a treatment supporter for the respondents whilst attending adherence counselling sessions. The first SA National Treatment Guidelines (NDOH 2004:52-57) advocated ensuring that patients have adequate support systems including treatment supporters on initiation of treatment so as to improve adherence to their ART regimens. From a study conducted by Yoder, Mkhize and Nzimande (2009:70) in five different sites in KwaZulu-Natal on the experiences of patients on antiretroviral therapy, findings suggested that challenges such as the availability of a treatment supporter were determinants of patients' adherence, non-adherence and/or

ultimate drop-out from their treatment. This can be a beneficial resource for patients especially those who may be extremely ill when initiating treatment and may have difficulty understanding and/or remembering all the information given. In this study, 71.4% of the respondents reported having no supporters during that stage whilst 17.9% were supported by their relatives and 10.7 % were supported by their spouses (see Table 4.25).

Table 4.25: Respondents' treatment supporters (N=28)

RESPONDENTS' TREATMENT SUPPORTERS	FREQUENCY	%
Spouse	3	10.7
Other relatives	5	17.9
No one	20	71.4
Total	28	100.0

4.5.6 Travelling time between respondents' homes and the ARV clinic

The majority of the respondents (71.4%) spend between 30 minutes to an hour travelling to the clinic for their appointments. Only 17.9% of the respondents spend fewer than 30 minutes and these are the ones that live in close proximity to the clinic. A small number (10.7%) travels for more than an hour to get to the clinic for their appointments (see Table 4.26). It would thus seem that the clinic was accessible to all of the respondents albeit with varying degrees of travel involved.

Table 4.26: Travelling time between respondents' homes and the ARV clinic (N=28)

TRAVELLING TIME TO THE CLINIC	FREQUENCY	%
Fewer than 20 minutes	2	7.2
20-29 minutes	3	10.7
30 minutes	10	35.7
45 minutes to an hour	10	35.7
More than an hour	3	10.7
Total	28	100.0

4.5.7 Mode of transport

The majority of respondents (92.9%) relied on taxis for transport to the clinic for their ARV appointments. One respondent used company transport and another walked to the clinic (see Table 4.27).

Table 4.27: Type of transport respondents relied on to visit the ARV clinic (N=28)

TYPE OF TRANSPORT	FREQUENCY	%
Taxi	26	92.9
Company car	1	3.6
Walk	1	3.6
Total	28	100.0

4.5.8 Respondents' experience of first commencing treatment

Table 4.28 indicates the different experiences of respondents when they were first initiated on ARVs. Respondents reported both negative and positive experiences in this regard with the majority (85.7%) reporting positive

experiences and 14.3% reporting negative ones. It is notable that some respondents reported experiencing both positive and negative reactions.

4.5.8.1 Positive experiences

The most common changes reported in this category were the improvement in health, sleeping better, being able to stop drinking, an increased appetite and feeling generally happy. A third (38.3%) of the respondents reported that there was notable improvement in their health and general well-being as a result of being put on ART. It is also important to note that 14.3% of the respondents stated that even though they had no positive things to report they, however, did not experience any problems either. In the qualitative phase, the researcher found that all of the nine respondents reported a great improvement after treatment.

4.5.8.2 Negative experiences

The kinds of negative experiences reported pertained mostly to side effects such as diarrhoea, pins and needles and dandruff. Side effects are common in patients in the first six weeks after commencing ART and the data in this study is consistent with that information (Evian 2011:175). These side effects should, however, subside within the first six weeks of being on treatment. In the qualitative phase, the researcher found that of the nine respondents, only one reported having experienced some side effects which made him unable to cope with his schoolwork. These were his sentiments regarding side effects:

The treatment has affected my schooling ... when I take the tablets I can't concentrate and feel like sleeping all the time [Respondent 3].

Table 4.28: Respondents' experiences on commencement of ART (N=28)*

EXPERIENCES ON INITIATION OF ART	FREQUENCY	%
<i>Positive experiences</i>	24	85.7
Improvement in health	11	38.3
Felt happy/had hope for the future	3	10.7
Slept better	1	3.6
Good experience	3	10.7
No problems	4	14.3
Increased appetite	1	3.6
Helped me to quit drinking	1	3.6
<i>Negative experiences</i>	8	14.3
Dandruff and sores on scalp	1	3.6
Pins and needles in hands	1	3.6
Powerlessness/decreased libido/sexual impotency	3	10.7
Many side effects	1	3.6
Diarrhoea	1	3.6
Stopped menstruating	1	3.6

* As respondents could give more than one answer here, the percentages summate to more than 100%.

4.5.9 Changes respondents noticed after commencement of ART

The changes noticed by respondents after commencement of ART were both positive and negative. As will become clear in the next section, most respondents became acutely aware of corporeal changes that were experienced as negative (side effects of medication) and positive (weight gain and feeling better). Amongst the positive experiences cited was weight gain, starting to feel stronger and a general improvement in health. On the other hand, the negative changes noticed and reported were decrease in sexual interest and libido, body aches, skin problems, asthma and swollen feet. Three quarters (75%) of the respondents experienced positive changes with 50% of them reporting weight gain, 14.3% reporting feeling stronger after starting

treatment and 10.7% reporting a general improvement in health (see Table 4.29).

Being infected with HIV and being at stage four of the Aids disease is characterised by a loss of weight of more than 10% of body weight, wasting and a general deterioration in health and well-being (AVERT 2011). It is, therefore, encouraging that 75% of respondents reported weight gain, feeling stronger and a general improvement in health after starting treatment as it implies that treatment was working. A quarter (25%) of the respondents reported noticing negative changes after commencing treatment including one who reported a decreased libido; 10.7% reported skin problems and the rest of the respondents reported body aches, swollen feet and asthma. This is also consistent with findings from other studies in which people report experiencing side effects as a result of commencing treatment (Evian 2011:175; Van Dyk 2011).

According to Van Dyk (2011), the most common treatment-related reason for non-adherence is the treatment side effects. This is evident in her study of patients on ART in which 60% of the patients studied experienced side effects at different points of their treatment span. Heyer and Ogunbanjo (2006:6) emphasise the importance of dealing with side effects effectively in order to prevent discontinuation of treatment and non-adherence. According to Simoni *et al* (2009:194), the IMB model proposes that ARV adherence is a function of one's fund of accurate regimen-specific information and understanding. It is important for patients to understand how their treatment works and the possible complications that may arise in order to take appropriate and timely action. Without this understanding, the side effects may be experienced as a threat or barrier to health as espoused in HBM and may result in premature termination of treatment.

Table 4.29: The changes respondents noticed when they commenced ART (N=28)

CHANGES SINCE COMMENCEMENT OF TREATMENT	FREQUENCY	%
<i>Positive changes</i>	21	75.0
Weight gain	14	50.0
Starting to feel stronger	4	14.3
General improvement in health	3	10.7
<i>Negative changes</i>	7	25.0
Sexual interest has decreased	1	3.6
Whole body aching	1	3.6
Skin problems	3	10.7
Asthma	1	3.6
Swollen feet	1	3.6

4.5.10 respondents' major challenges adhering to ART

The major challenges as reported by respondents were mainly associated with medication side effects. It is important to mention at this point that respondents reported more than one challenge and as a result the percentages summate to more than 100%. In Table 4.30, 89.4% of respondents reported that the side effects had an impact on their adherence to treatment (this includes the responses to various side effects, diarrhoea, fever, hallucinations and nightmares). Only 10.7% attributed non-adherence to forgetfulness and/or mental disturbances, whilst 3.6% 'felt sick' which made it difficult to continue treatment and another 3.6% reported that she found it difficult to take her treatment on time. The latter respondent also included worries about medication, that men attending the clinic were disruptive, pressure at work made side effects worse and extreme poverty.

It is interesting to note that in the focus group interviews, barriers to adherence included matters of a more intimate nature between the patients and their spouses, partners or significant others. In the qualitative phase of data collection, the nine participants told the researcher that their major challenges regarding adherence included a lack of support from significant others; an inability to negotiate condom use with spouses and to practise safer sex; domestic violence; unemployment and lack of financial resources; homelessness and displacement; traditional and religious beliefs; forgetfulness; and irregular working hours. A third of the respondents told the researcher that they were forced to have unprotected sex despite both partners being HIV positive. Three participants also spoke of a lack of financial support as they were unemployed and had to depend on other people for daily upkeep. These issues are discussed in greater detail under sub-heading 4.8 in this chapter.

The findings between the qualitative and quantitative phases of this study differed in terms of the factors that lead to the difficulty in adhering to ART regimens. In the quantitative phase the major reason cited for non-adherence was side effects – 89.4% of respondents reported this. This is consistent with the findings of another study conducted in which 60% of respondents reported experiencing side effects at some point of their treatment span (Van Dyk 2011). In terms of HBM, the side-effects can be perceived as a barrier as their severity discourages patients from continuing taking treatment (Hayden 2009:33).

In the qualitative research though the findings showed that lack of cooperation and support from significant others; an inability to negotiate condom use with spouses and practise safer sex; and an inability to take treatment owing to irregular working hours were major factors impacting on adherence. In terms of the social learning theory, individual actions are largely determined by both personal and environmental factors which is consistent with the emerging picture from these findings (Martin *et al* (2009:16; Rosenstock *et al* 1988:177). The social circumstances and experiences of these patients determined their

actions as far as adherence to treatment was concerned. Four of the nine respondents reported difficulty in negotiating for safer sex and three of the nine reported irregular working hours and fear of being seen taking treatment by colleagues as impacting on their adherence to their treatment. The difference in these findings could be owing to the fact that the focus group participants were different from those in the face-to-face interview. In the focus group, prolonged engagement with participants resulted in the establishment of a good rapport and a safe environment in which to be open. This resulted in their being able to discuss more intimate reasons affecting their adherence. The common reasons cited in the two phases were the following: working irregular hours including night shift, forgetting to take treatment until much later than prescribed and having to hide their medication.

Table 4.30: Major challenges experienced by respondents when trying to adhere to ART (N=28)*

RESPONDENTS' MAJOR CHALLENGES WHEN TRYING TO ADHERE TO ART	FREQUENCY	%
Diarrhoea	1	3.6
Forgetfulness or mental disturbances	3	10.7
Feeling feverish	1	3.6
Finds it difficult to take the medicine on time	1	3.6
Pressure at work makes side effects worse	1	3.6
Hallucinations and nightmares	5	17.9
Extreme poverty	1	3.6
Worries about medication	1	3.6
Various side effects	18	64.3
The men at the clinic are noisy and disruptive	1	3.6
Sleeps too much	1	3.6
Total	28	*

* As respondents could give more than one answer here, the percentages summate to more than 100%.

4.5.11 Specific side effects experienced by respondents on ART

Table 4.31 shows what the specific side effects were as experienced and reported by respondents whilst on ART. It indicates that 39.3% of respondents reported rashes, swollen feet and feeling cold, followed closely by those who experienced drowsiness (32.1%) and those who suffered from hallucinations (7.1%). Other side effects reported were a distended stomach, swollen breasts and weight gain. One respondent (3.6%) reported experiencing all the side effects mentioned here and another 3.6% also had side effects but sought help at the clinic and these then subsided.

It is very common for patients to experience side effects within the first two weeks of starting treatment but these should subside within the first six weeks. The majority of these side-effects are short-lived and self-limiting (Evian 2011:175) and some may need to be reported to the health care professional so that they can be attended to in good time. One respondent (3.6%) reported experiencing none of the side effects. This is supported by literature as not every person experiences side effects on treatment (Evian 2011:175). In the qualitative phase of the study only one respondent cited experiencing some side effects which made it hard to cope at school. This is what he had to say:

The treatment has affected my schooling ... when I take the tablets I can't concentrate and feel like sleeping all the time'.

**Table 4.31: Specific side effects experienced by respondents on ART
(N=28)**

SPECIFIC SIDE EFFECTS EXPERIENCED ON ART	FREQUENCY	%
Rash, swollen feet, feels cold	11	39.3
Distended stomach	1	3.6
None	1	3.6
Had side effects, but was treated at clinic	1	3.6
Drowsiness	9	32.1
Swollen breasts	1	3.6
Everything (all possible side effects)	1	3.6
Weight gain	1	3.6
Hallucinations	2	7.1
Total	28	100.0

4.5.12 Specific problems related to taking medication on time

Patients may experience a wide range of problems relating to the taking of medication which may impact on adherence. According to Kagee (2006) and Mehta *et al* (1997), these may include factors such as the complexity of the treatment regimen, dosages, schedules, food requirements, toxicity and side-effects. Table 4.32 shows that 82.1% of respondents reported having no problems relating to taking their medication whilst 17.9% cited various reasons that made it difficult for them to adhere to their treatment. These findings should, however, also be seen against the reported rates of missed dosages commented on later in this chapter.

Two respondents (7.1%) reported having difficulty taking their medication whilst at work as no one knew about their HIV status; one (3.6%) reported having no money to buy the kind of food needed when taking his/her medication. Of the remaining two respondents, each (3.6%) reported having difficulty taking medication when fasting and when having her menstrual period respectively. This was attributed to religious and traditional beliefs respectively

by the respondents. In terms of the reports in this aspect it seems that most respondents were able to take their medication as prescribed at least most of the time. But when this finding is compared with the results on missed dosages in the previous section, the findings show that most patients have difficulty adhering to their regimens as 64.3% reported missing a dose some time during their treatment span.

It is, however, important also to view the treatment specific problems in conjunction with other factors that may interact with these and amplify the impact on adherence. These may include issues such as disclosure and fear of discrimination as evidenced by the two respondents who reported being unable to take their medication whilst at work. This was as a result of both lack of disclosure and the treatment schedules and times. According to the NSP (NDOH 2010:9), in SA poverty is one of the major contributors to poor health and treatment outcomes through food insecurity in as far as HIV and TB acquisition and treatment adherence are concerned. In this study, however, only one respondent reported food as a factor which contributed to non-adherence and the others ensured adherence in one way or another. The SA government, in order to reduce the impact of poverty, introduced a chronic disease grant assistance for those living with HIV who could not support themselves and their families so as to encourage adherence (NDOH 2007:114; ETU 2012). The qualification criterion for the grant is that the PLHIV must be too sick to work and when their health improves the grant is terminated (SASSA 2012).

Table 4.32: Specific problems related to taking medication on time (N=28)

SPECIFIC PROBLEMS RELATED TO TAKING MEDICATION ON TIME	FREQUENCY	%
No problems	23	82.1
Cannot take medication while menstruating	1	3.6
No money for food one has to eat whilst taking medication	1	3.6
Cannot take medication while fasting	1	3.6
Finds it difficult to take it when at work	2	7.1
Total	28	100.0

4.5.13 Specific problems related to following a prescribed diet

It is necessary for every human being to follow a healthy balanced diet but even more important for an HIV positive person because of their compromised immune system. A balanced diet is integral to the success of ART and patients are encouraged to follow a diet consisting of all the five basic food groupings: namely, carbohydrates; proteins; fruits and vegetables; milk and dairy; fats and oils (Evian 2011:137). This prescribed diet is in no way different from the diet required by every other human being. A healthy diet helps delay the progression from HIV infection to Aids, helps improve the performance of the immune system, protects the body against opportunistic infections and illnesses and helps develop and repair cells and tissues. Good nutrition also helps the body tolerate medical treatments more easily and improves one's sense of well-being (Health24:2009). The specific problems relating to diet reported by respondents were mainly poverty and an inability to buy the necessary food (See Table 4.33). Of the total number of respondents, 46.4% reported that they simply could not afford to buy all the necessary food whilst another 46.4% stated that it was rather difficult but somehow they coped. The rest of the respondents (7.1%) reported having initiated food gardens and these had provided much needed relief as they also could not afford to buy basics such as vegetables and fruit. With unemployment and poverty levels

being high these food gardens can only be a worthwhile supplementation alternative.

Investigating the local shops, the researcher found that one needs at least R250 per week to buy basics such as vegetables, fruit and bread in order to meet the daily dietary requirements. This amount increases significantly when other basic necessities like proteins are included. This can be a challenge for people with no reliable source of income or with no income at all. In SA, poverty is one of the major contributors to poor health and treatment outcomes through food insecurity in as far as HIV and TB acquisition and treatment adherence are concerned (NDOH 2010:9). The unavailability of these basic foods can be regarded as a barrier to good adherence as some patients may not take their treatment when they have no food at home. Literature also shows that there is a strong association between poverty and lack of food and poor adherence to ART (WHO 2003:28; Kagee 2006:415; Hardon *et al* 2006:10; Mukherjee *et al* (2006:124). The SA government has put resources in place such as the chronic disease grant, social relief and food parcels but all these are temporary and sometimes may promote non-adherence when these measures are terminated as mentioned in chapter 2 of this dissertation.

Table 4.33: Specific problems related to following a prescribed diet whilst taking medication (N=28)

SPECIFIC PROBLEMS RELATED TO FOLLOWING A PRESCRIBED DIET	FREQUENCY	%
Cannot afford food	13	46.4
Poverty is a problem, but we cope	13	46.4
Have enough food, because we have a food garden at home	2	7.1
Total	28	100.0

4.5.14 Specific problems related to receiving support whilst taking medication

The study shows that all respondents disclosed their status to someone and as a result almost all had someone to support them through this process. Table 4.34 shows that 96.4% of respondents reported having someone who was a source of support; someone they confided in and someone who helped them adhere to their treatment. It is, however, important to note that one respondent reported having no one to discuss the HIV with. Despite having disclosed and received support from significant others, the findings here show that the majority of respondents were still having difficulty achieving optimal adherence to their regimens.

The SA National Treatment Guidelines (NDOH 2004) stipulate that whilst disclosure is not a requirement for a person initiating ART, it is highly recommended that they disclose to at least one family member or a trusted friend and join a support group. Disclosure is important for those diagnosed with HIV in order for them to obtain support and help them reduce the stress of coping on their own; it can also help them to protect themselves and their sexual partners (NDOH 2010:17; Evian 2011:467). It, however, needs to happen when the patient is ready and counsellors can assist with preparation for disclosure (Norval 2012). When people disclose their status they become vulnerable to negative responses such as discrimination, rejection, abandonment and even antagonism which may result in isolation for those disclosing (Norval 2012). According to Van Dyk (2011), stigma, discrimination and lack of social support are often the main reasons for people on ART hiding their HIV status and treatment-taking from colleagues, friends and family. Adherence counselling can, therefore, play a significant role in assisting with disclosure as much as possible.

Literature also shows that clients who have not disclosed their status and are required to take their treatment in secret have a poorer chance of adhering to their regimens (Evian 2011:467; NDOH 2010:17; Van Dyk 2011; Kagee

2006:419). It has, however, been shown from practical experience that not all patients disclose their HIV status for fear of being discriminated against as HIV as a disease carries a great deal of stigma. This is not the case with this current study as the majority have disclosed. In the qualitative phase it was discovered that eight of the nine participants had disclosed to their significant others and seven of them were being supported by their loved ones. However, one of them disclosed to her partner and he was not supportive towards her, and instead allegedly acted in an abusive way towards her.

Table 4.34: Specific problems related to receiving support whilst taking medication (N=28)

SPECIFIC PROBLEMS RELATED TO RECEIVING SUPPORT WHILST ON MEDICATION	FREQUENCY	%
Has no one to discuss HIV with	1	3.6
Mother is very supportive	3	10.7
Confides in sister	2	7.1
Spouse/girlfriend/boyfriend helps me adhere	20	71.4
Family member helps me adhere	1	3.6
I have sufficient support	1	3.6
Total	28	100.0

4.5.15 Specific problems related to adherence

Table 4.35 shows that more than three quarters of all the respondents (78.5%) have no problems adhering to their ART. The specific problems relating to adherence to medication cited by the remaining 21.5% of respondents, that is, six respondents, included the inability to purchase all necessary food like fruit and vegetables; being unable to take medication when at work; forgetting; and feeling depressed. Half of those with a challenge, that is three of the six respondents who reportedly had difficulty adhering to their treatment, cited being unable to be adherent whilst at work. Factors identified as playing a role

in adherence include '*internalized stigma and external discrimination, lack of disclosure, shift work, time off work to attend clinic appointments*' (NDOH 2010:17-18). This is consistent with the findings of this study in which patients cited inability to take their treatment when at work and that working irregular hours impacted on their treatment adherence in both qualitative and quantitative phases. The common specific problems mentioned during the qualitative phase of the study were unemployment, lack of food, working night shift and forgetting to take treatment at times.

Table 4.35: Specific problems related to adherence (N=28)

SPECIFIC PROBLEMS RELATED TO ADHERENCE	FREQUENCY	%
No problems	22	78.5
Unable to buy fruit and vegetables	1	3.6
Very depressed	1	3.6
Finds it difficult to adhere when at work	3	10.7
Forgets when favourite TV programme starts	1	3.6
Total	28	100.0

4.5.16 Respondents who missed a single dosage

Table 4.36 indicates that just under two thirds (64.3%) of the respondents reported that they had missed a dose of treatment. Only 35.7% reported not missing a single dose of their treatment. Ideal adherence means that patients must take more than 95% of their prescribed doses, which is equivalent to missing not more than three doses per month (NDOH 2004: 53). Non-adherence, on the other hand, means '*not taking medication at all, self-adjusting doses so as to modulate side-effects, prematurely terminating treatment, not honouring clinic appointments and not filling prescriptions*' (Kagee 2008:414). It also extends to not making the recommended behavioural changes and lifestyle adjustments such as practising safer sex

and stopping alcohol usage. Being adherent with taking medication but still engaging in unprotected sexual intercourse with an HIV positive person may expose the patient to possible re-infection with the virus and, therefore, insufficient suppression of the HI virus.

According to Jean-Baptiste (2008:5), poor adherence implies '*missing doses and taking medication inappropriately*'. The findings clearly indicate that almost three quarters of the respondents were adhering poorly to their treatment as suggested in the above definition of what poor adherence is. This is a cause for concern for long-term treatment outcomes as with missed dosages viral suppression is limited owing to insufficient medication taken (Van Dyk 2011). These gaps in treatment provide the virus with a chance to replicate which may result in the immune system becoming weak again and unable to fight any opportunistic infections. Literature has, however, shown that subjective reporting of adherence can sometimes be under- or over-estimated as patients may tend to over-exaggerate their self-reported levels of adherence (WHO 2003:96). The probability of a higher percentage of non-adherence amongst the respondents in this study exists.

Table 4.36: Respondents who missed a single dosage (N=28)

WHETHER RESPONDENTS HAVE EVER MISSED A DOSAGE	FREQUENCY	%
Yes	18	64.3
No	10	35.7
Total	28	100.0

4.5.17 Number of times a dosage has been missed

Table 4.37 shows a mixed picture of instances when a dosage was missed. From the 28 respondents interviewed, 10 reported never missing a single dose and 18 reported having missed a dose during their treatment span as shown in table 4.37. About a third (33.3%) of the 18 who had missed a dosage did so

rarely, followed by 22.2% who missed a dosage once a week; 22.2% who missed a dosage once a month; 16.7% who missed a dosage once in three months and one respondent who had completely stopped taking ARVs for the two months prior to the interview.

If one takes into account the definitions of adherence, non-adherence and poor adherence as cited in paragraph 4.5.16 above, the findings clearly depict a mixed picture of both non-adherence and poor adherence. Fewer than a quarter (22.2%) of the respondents reported missing a dose at least once a week, which is equivalent to four times a month and that clearly shows poor adherence as ideal adherence is equivalent to missing no more than three doses per month. At least one person also reported stopping treatment completely two months prior to these interviews which is in essence non-adherence to treatment as it was prematurely stopped. The rest of the respondents had either missed a dose once a month, once in three months or very rarely and this can be considered being adherent as 95% of the treatment was reportedly taken but nevertheless it was poor adherence. This is, however, a subjective report of adherence and according to WHO (2003:96) patients may tend to over-exaggerate their self-reported level of adherence. This could be owing to a recall bias, a desire to please the health care provider or to avoid criticism from HCP. A third (33.3%) of those who missed a dose reported rarely missing one and the researcher is of the view that the probability of under- or over-reporting of adherence in this instance exists. The findings in this study nevertheless give a clear indication of poor adherence levels albeit at different levels.

In the qualitative data one respondent reported completely stopping treatment owing to religious beliefs as he/she believed God would heal him/her. This is what he/she had to say:

I do not see the need to be on treatment as I believe God has the power to heal. I know my health improved when I was started on treatment but God was still responsible for my health improvement even then.
[Respondent 3]

Table 4.37: Number of times a dosage was missed (N=28)

HOW OFTEN A DOSAGE HAS BEEN MISSED	FREQUENCY	% OF TOTAL	% of those who have missed
Once a week	4	14.3	22.2
Once a month	4	14.3	22.2
Once in three months	3	10.7	16.7
Rarely	6	21.4	33.3
Never	10	35.7	-
Stopped for 2 months	1	3.6	5.6
Total	28	100.0	100.0 N=18

4.5.18 Circumstances that lead to respondents missing a dosage

Patients normally cite various reasons for missing a dosage of their treatment. As shown in Table 4.38, the major reasons cited by the 18 respondents who missed a dosage, are the respondent attending a funeral (22.1%) or being away from home (27.8%). Other reasons cited were respondents forgetting to take their treatment (5.6%); no food at home (11.1%); attending a soccer match (11.1%); having severe financial problems at home which impacted on travelling cost and availability of food (5.6%); and respondents having difficulty taking medication at work when there was no privacy (11.1%) The findings in this study indicated that the majority of respondents (61%) found it difficult to adhere when they were not at home attending some kind of social function. One respondent also reported forgetting to take his/her medication. This is consistent with the literature as forgetfulness and lack of planning are patient-related factors associated with non-adherence (NDOH 2010:18; Van Dyk

2011). These manifest when patients attend social functions on weekends or when they are away from home and when no provision has been made to have adequate treatment in their possession. This is an important issue to be addressed during adherence counselling sessions to ensure that patients are empowered and skilled to plan accordingly. On the other hand, lack of adequate financial resources and availability of food were also reported to have an impact on the ability to adhere (NDOH 2010) which is consistent with the findings of this study. This is evident as 5.6% and 11.1% of respondents reported experiencing severe financial problems at home and having nothing to eat respectively.

Table 4.38: Circumstances that lead to respondents missing a dosage (N=18)

CIRCUMSTANCES THAT LEAD TO RESPONDENTS MISSING A DOSAGE	FREQUENCY	%
When attending a funeral	4	22.1
When I forget	1	5.6
When I had nothing to eat	2	11.1
When away from home	5	27.8
When playing soccer/attending/watching a soccer match	2	11.1
When having severe financial problems at home	1	5.6
When working/earning an income	2	11.1
When I have no privacy to take my medication	1	5.6
Total	18	100.0

4.5.19 Factors that encourage adherence

Respondents cited various reasons that encourage and promote adherence to their treatment regimens. Almost a third (32.1%) reported that being aware of the benefits of ART encouraged them to adhere, whilst 18% noticed improvement in their well-being and 7.1% were grateful to be alive as a result of being on ART. Another category of respondents (32.1%) reported that having support from loved ones played a very significant role in their

adherence and 10.7% felt that having accepted their HIV status also encouraged them to adhere to their treatment (see Table 4.39).

According to Heyer & Ogunbanjo (2006:6), understanding the treatment regimen plays a very significant role in encouraging adherence. They state that patients on ART who do not have a good understanding of the relationship between adherence, viral load and disease progression adhere significantly more poorly than those who understand. In terms of HBM, the perceived benefits of a recommended health action can serve as an incentive for patients to follow positive health regimens so as to achieve positive treatment outcomes (Masokoane 2009:21) The premise here is that people on ART who have a good understanding of what positive changes the treatment will bring about physically and otherwise are more likely to adhere to their regimens. This implies that for the behaviour to be undertaken the patient must evaluate the benefits of the recommended change as more valuable than the action required. This seems to be consistent with the findings here as 32.1% of respondents felt that awareness helped them with adherence.

Denial of HIV diagnosis and a lack of disclosure to significant others have also been identified as factors that determine levels of adherence to treatment (NDOH 2010:17). According to Mehta *et al* (1997:1669), patients' knowledge of their status and acceptance thereof, the expected course of illness and the treatment have all been associated with increased levels of adherence to treatment.

Lack of effective social support networks has also been reported to have a significant impact on adherence (WHO 2003:28). Findings from studies carried out in Sub-Saharan Africa indicate that although patients may be motivated to adhere to their regimens, lack of support undermines their good intentions (Hardon *et al* 2006). In this study the findings are consistent with this information as respondents reported social support as playing a very significant role in their adherence.

Table 4.39: Factors that encourage adherence (N=28)

FACTORS THAT ENCOURAGE ADHERENCE	FREQUENCY	%
Because I'm aware of the benefits	9	32.1
Support from spouse/loved ones	9	32.1
It improves my well-being	5	18.0
To have accepted my status	3	10.7
I am grateful to be alive	2	7.1
Total	28	100.0

4.5.20 Perceptions of the service received at the clinic

The majority of respondents (67.9%) felt that the service offered at the wellness clinic was generally good. They, however, cited varying feelings regarding the service which ranged from some feeling free when they were at the clinic and feeling that they were treated equally with no discrimination whilst others felt that the health care professionals were sometimes strict with them. Further to this, 3.6% of the respondents felt that the waiting times were too long at the clinic and others (3.6%) felt that some nurses were rude to them. It is important to point out that at least 14.3% of the respondents had no answer to this question and did not want to commit themselves (see table 4.40). Negative staff attitudes and a perceived lack of caring by health facility staff (NDOH 2012:17) impact on how the service is viewed and received by patients. Long waiting times at the clinic (Roura *et al* 2009:48; Hardon *et al* 2006:9) have also been associated with poor adherence and in this study it emerged that some respondents felt that this affected the service offered at the clinic. The possibility is great that this was a perceived reality but it was how the respondents experienced the interaction with staff and the service offered.

Table 4.40: Perceptions of the service received at the clinic (N=28)

PERCEPTIONS OF THE SERVICE	FREQUENCY	%
Generally a good service	19	67.9
Good, but strict	1	3.6
Felt free	1	3.6
Treated the same	1	3.6
Long waiting times	1	3.6
No answer	4	14.3
Some of the nurses are rude to patients	1	3.6
Total	28	100.0

4.5.21 Perceptions of the attitudes of the health care professionals at the clinic

Table 4.41 indicates that 85.7% of respondents did not want to respond to this question whilst 10.7% stated that it did not matter what they thought about the health care professionals' attitudes. Only 3.6% (n=1) felt that the HCP were supportive towards their adherence. Negative staff attitudes; a perceived lack of caring by health facility and staff (NDOH 2012:17); poor communication; and provider-patient relationship (Oldridge 2001:337) were all identified as factors that impact on the provider-patient interaction and ultimately adherence to treatment. The majority of the respondents (85.7%) were not willing to express their opinions on this and the researcher is of the opinion that they feared possible victimisation from staff if they expressed negative sentiments. It is also possible that the researcher was associated with the clinic staff as she had worked in that clinic before and they did not feel at ease discussing the issue with her. It is also interesting to note that 67.9% of the respondents (see Table 4.40) felt that the service was generally good but at the same time the majority at 85.7% seemed afraid to talk about the attitude of the staff towards them.

Table 4.41: Perceptions of the attitudes of the health care professionals at the clinic (N=28)

PERCEPTIONS ABOUT ATTITUDES OF HCP	FREQUENCY	%
It doesn't matter	3	10.7
They are supportive of my adherence	1	3.6
No answer	24	85.7
Total	28	100.0

4.5.22 Respondents' rating of the service received at the clinic

The respondents rated the service at Shongwe hospital wellness clinic as either good or very good with more than half of the respondents (57.1%) rating the service positively (see Table 4.42).

Table 4.42: Respondents' rating of the service received at the clinic (N=28)

RATING OF SERVICE AT THE CLINIC	FREQUENCY	%
Good	16	57.1
Very good	12	42.9
Total	28	100.0

4.6 A SYNTHESIS OF THE QUANTITATIVE PHASE

The quantitative phase of the study provided an overview of the respondents as being of potential wage-earning ages; however 46.4% of the respondents were unemployed at the time of the interview despite the fact that 67.9% of them have at least a secondary school level of education. Many had young children that could potentially lose a parent if the patient did not adhere to the treatment.

Although only 21.5% of the respondents reported that they have had difficulty adhering to their treatment regimens, a staggering 64.3% of them admitted to having missed a dosage. Those who cited specific difficulties in adherence named finding it difficult to take their treatment whilst at work; being forgetful; a shortage of food; and depression as reasons for failing to adhere to their treatment.

Nearly two thirds (64.3%) of respondents also reported having missed a dose of their treatment with 14.3% of them missing at least a dose per week. In terms of adherence, a patient should be adherent at least 95% of the time which is equivalent to missing three doses per month. It is an issue of concern when such a large percentage of respondents miss at least four doses per month as this may result in treatment failure in the long run.

The major reason cited for missing a dose is being away from home for reasons including attending a funeral. Half (50%) of the respondents reported that the reason for missing their dosages was being away from home, either attending a funeral or visiting family. This was in most cases because they did not bring enough tablets for fear of being seen by others taking treatment.

The majority of respondents reported having no problems adhering to their treatment. At least 78.5% reported that they did not experience any problems relating to treatment adherence. In terms of the Health Belief Model and the Information Motivation Behaviour Model, it is possible for patients to attain adherence to their treatment if they have the relevant knowledge; motivation to see positive changes in their health status; skill to bring about the change; and the belief in their ability to bring about this change. Social support of the spouses and loved ones and a supportive network in the community can serve as motivating factors for people living with HIV and receiving treatment.

The two major reasons cited for encouraging adherence among the respondents was being aware of the benefits of being on treatment and receiving the support of family and friends. Nearly a third of the respondents

(64.2%) cited these two reasons as encouraging them to adhere, followed by the improvement brought about by ART in their health and having accepted their status. The majority of respondents received enough support from their significant others with 80% reporting positive and consistent support. In terms of HBM, the support of the family can serve as a cue to action for a patient who can be influenced by the support from family to take the recommended health action in order to bring about positive health outcomes.

The three health-seeking behaviour models emphasise that for patients to adhere to their ART regimens there must be perceived benefits to taking the recommended treatment as proposed by HBM; positive expectancies about consequences of their actions in terms of the Social Cognitive Theory; and having the knowledge, motivation and skill to bring about change as espoused by the IMB model.

4.7 RESULTS OF THE FOCUS GROUP DISCUSSIONS

The researcher adopted a thematic analysis method to analyse data from focus group interviews. From the transcripts it was possible to identify main themes and these became the basis for the analysis of the data obtained. These identified themes were categorised under the following themes that affect adherence, that is, patient-related, socio-economic, therapy-related factors and health care provider-related factors. This section reports on the findings of the data analysis in terms of the themes identified. Each of the themes will be introduced briefly and described and then followed up with a direct quotation from the respondents' utterances to support the identified theme. It should be noted that some of the salient findings from the focus group discussions that either corroborated or contradicted the findings from the quantitative survey were mentioned under sub-headings 4.2 to 4.6.

4.7.1 Theme 1: Patient-related factors

4.7.1.1 Feelings regarding receiving an HIV-positive diagnosis

It is normal for people to experience strong feelings and emotions on receiving an HIV positive diagnosis. In this study, the respondents also expressed varied feelings after testing HIV positive. Feelings such as shock, guilt, fear, denial and/or acceptance of an HIV diagnosis have been reported to affect adherence (NDOH 2010:17). These determine responses and attitudes to the disease and the available treatment and readiness to engage in the long-term commitment of ART.

Fear, sadness, shock and upset

Three of the nine respondents reported that they initially felt very afraid, sad and upset but had since accepted their statuses.

‘When I was told I am HIV positive I felt very sad and afraid as I thought I will die.’ [Respondent 1]

‘I felt sad and upset when I tested positive but I have accepted.’
[Respondent 2]

‘I discovered that I am HIV positive when I was tested during my second pregnancy. I was shocked as I was not expecting it. To make matters worse the quality of counselling I received was not good but I have been exposed to good counselling in recent years.’ [Respondent 9]

Acceptance

Acceptance of an HIV-positive status is an important factor in the person’s readiness for treatment adherence. Enriquez (2002:12) defines readiness as *‘a conscious awareness, on the part of an individual, based on free will, that he/she has considered and determined that a particular behaviour change (i.e., taking his/her anti-HIV medication as prescribed) will be beneficial’*. It implies

that a person realises that the status quo is not likely to change and therefore he or she needs to accept and learn ways of living with it meaningfully. It is also evident in the statements of these three respondents who initially felt angry, afraid and upset but had to accept and move on with their lives.

Stress

Two participants reported experiencing a great deal of stress after losing their jobs owing to absenteeism when attending the clinic, losing their homes and as a result being displaced.

Respondent 4 reported losing his job because of taking time off work to attend the clinic. He used to work as a petrol attendant and the employer did not understand that he had to attend clinic at least once a month. This was also compounded by the fact that he had not disclosed his status. He was then fired and as a direct result of this lost his rented home and became displaced. He stated:

'I was fired from my job as I used to take time off for clinic visits. Being unemployed and having no food and depending on other people who do not even know my status put pressure on me and as a result I feel really stressed.'

Respondent 9 reported being separated from her partner and the father of her children as a result of being diagnosed with HIV. The respondent said that she was financially dependent on her partner for survival and that they had shared a home. When the relationship ended, she and her children became homeless and displaced as a result.

'When my relationship broke down I lost someone who was taking care of me and my children. I lost my home and now have no source of income but have to depend on other people for everything.'

4.7.1.2 Irregular working hours and forgetfulness

Two of the nine focus group discussants reported working irregular hours that included night shift or late shifts. These irregular working hours made it difficult for the discussants to take their treatment properly as this coincided with either the time when still busy at work or when travelling back home. Practical and environmental factors like working odd hours have been associated with an inability to take treatment properly (Van Dyk 2011). This is consistent with the report by discussants that sometimes it is practically not possible to take treatment when working such hours. In terms of the social learning theory it is also postulated that environmental factors play a significant role in determining action. The fact that a person is busy at work may result in his/her being unable to take time off in order to take treatment as required or even forgetting to take the treatment. This was reported by two participants in the focus group but was not established in the quantitative phase of the study and cannot therefore be generalised to the wider population. This is what they said in this regard:

‘My work schedule ...working night shift make it difficult to take my treatment. I even forget to take my treatment when I am working at night.’ [Respondent 2]

‘I work very irregular hours ... sometimes I work an early morning shift and sometimes it’s a late afternoon shift. This affects my daily routine and I have not been able to find a suitable time to take my treatment properly.’ [Respondent 6]

4.7.2 Theme 2: Socio-economic factors: social support factors

This section is aimed at discussing themes categorised under socio-economic factors that influence adherence. These include factors such as attitude of family and significant others towards HIV; religious and traditional beliefs;

transport costs; long waiting times; lack of food; stigma; discrimination; and lack of social support.

4.7.2.1 Denial of HIV by a sexual partner and condom use

Four of the nine respondents reported having sexual partners who were in denial regarding the respondents' status and their own had a bearing on their adherence. All four of these respondents were female and they reported that their spouses were also HIV positive but they were not practising safe sex. This is what they had to say:

'We are both HIV positive, but my partner refuses to use a condom. This has affected our sexual relations. I just feel like he doesn't care about me at all and I do not have much say in this.' [Respondent 1]

'My partner is not co-operative and he refuses to use a condom when we have sexual intercourse. He also does not want me to take my ARV medication and I have to hide it from him ... it is so difficult because we are staying together.' [Respondent 5]

'I currently live with my boyfriend and he is supporting me as I am unemployed. Sometimes we use the condoms and sometimes we don't. It is just difficult.' [Respondent 7]

'My partner is also HIV positive but he refuses to use a condom. He uses traditional medicines and do not want to take ARVs.' [Respondent 8]

4.7.2.2 Support system and disclosure

People affected by and infected with HIV and Aids are often subjected to discrimination and rejection by their friends, family, sexual partners and work colleagues (Evian 2011:464). Even though they may be motivated to adhere to

their ART for personal reasons, lack of or poor support from their loved ones, or feelings of being discriminated against or stigmatised as a result of being HIV positive may negatively impact on adherence. Of the nine respondents only one respondent reported that he had not disclosed to anyone his HIV status. His reasons for not disclosing his status were that he did not see any benefit and was also afraid of disclosing to the wrong person. This is what he had to say:

'I have not disclosed to anyone as I see no need for that ... I also fear that I might tell a wrong person. I always have a problem though since I now have a new partner to whom I have not disclosed. When she is around I have to hide my tablets and take them in secret and sometimes it is not easy.' [Respondent 2]

The rest of the respondents reported having disclosed their status to different people. Some disclosed only to their partners, others to family and friends and yet others to their parents. The reasons for disclosing to particular people and not to others also varied within this group of respondents. Here are some of the examples of reasons cited by respondents:

'I disclosed to my sister because she is also HIV positive and I thought we can be in a position to support each other.'
[Respondent 1]

'I have only disclosed to my partner and not the whole family as I am not sure how they will respond.' [Respondent 4]

'I have disclosed to my partner but it has not helped me in any way. He is not supportive of me taking my treatment and is very abusive towards me. Sometimes I wish I had just kept it from him because maybe things could have been better now.' [Respondent 5]

'I have told everyone ... my partner, family and friends. I have not told anyone at work and it is difficult for me to take my medication when I am at work as no one knows about my illness.'

[Respondent 6]

'I have told everyone and they are all very supportive.'

[Respondent 7]

'I decided to tell everyone so that everyone knows what I am going through. Everyone has been very supportive except for partner who decided to leave me to suffer with my kids.'

[Respondent 8]

'My partner knows my status since we tested together and he is also HIV positive. I haven't told anyone at work though as I am scared I might be discriminated or victimised.' [Respondent 9]

The last respondent had a different story to tell as he was born HIV positive and therefore did not have to disclose. He was only tested in 2009 when he became very sick having herpes zoster which is one of the common opportunistic infections for people at a stage four of the disease (Evian 2011:39). This information was also corroborated by the patient's father and the health care professionals at the clinic. This is what he had to say:

'I was told by my dad that I got the virus from my mother who passed away when I was very young. I have accepted the fact that I am HIV positive though I do not want any HIV medication.' [Respondent 3]

4.7.2.3 Belief system

An individual's belief system plays a major role in determining how he/she perceives situations and it largely determines attitudes, behaviour and actions (Kagee 2006:423). This is also true for people living with HIV who may have

their own beliefs regarding the HIV disease which may have an impact on whether they believe ARVs will help them or not.

In this section the researcher considered traditional beliefs that participants might use to understand their illness and traditional ways of coping with the illness. It emerged from the discussion that these traditional beliefs sometimes may lead to non-adherence. Of the nine respondents, only one respondent reported that her partner believed in traditional medicine and as a result he did not want her to take ARVs. Although she did not stop taking medication, it affected her adherence levels as she had to take it in secret. The researcher found it interesting that no other person reported belief in or use of traditional medicines amongst the respondents who reside in a rural area where traditional and cultural beliefs still significantly influence health seeking behaviour. Literature suggests that traditional healers are the primary health care providers in rural areas for at least 80 to 85% of rural people both in Tanzania and South Africa (Mustapher 2012; AIDS Foundation 2010). This is what one participant had to say:

‘He does not want me to take my ARV medication and I have to hide it from him ... it is so difficult because we are staying together. He is taking his traditional medicine which he believes will cure him.’
[Respondent 5]

The researcher explored how religious beliefs might affect adherence with the focus group participants. One participant claimed to being a born again Christian who started treatment in 2009 when he was very sick. He has, however, stopped taking his ART as he strongly believes there is no need for treatment as God will heal him of the disease. These are his sentiments:

‘I do not see the need to be on treatment as I believe God has the power to heal. I know my health improved when I was started on treatment but God was still responsible for my health improvement even then.’ [Respondent 3]

4.7.2.4 Unemployment and financial dependence

Unemployment plays an important role in whether patients are able to adhere to their treatment regimens or not. It relates to factors such as costs that patients incur when they attend clinic like transport costs and ensuring they have sufficient food in order to take their medication well (NDOH 2010; WHO 2003). Of the nine respondents, three reported being unemployed and having to depend on other people like spouses and relatives.

‘Unemployment, having no food, being stressed can have an effect on one’s ability to adhere; being homeless and living with people who are not even aware of your HIV status ... It’s really tough!’ [Respondent 4].

‘Dependence on your spouse for everything you need can be very difficult especially if that person is not very supportive towards you and your taking of ART. You find yourself agreeing to everything that they tell you just to keep the peace.’ [Respondent 5]

‘Being unemployed and having no source of income makes it really hard to cope. I am under so much stress but despite all that, I make sure that I take all my treatment regularly.’ [Respondent 9]

4.7.3 Theme 3: Therapy-related factors: side effects

The majority of people when initiated on ART tolerate some discomfort resulting from side effects as these usually present as mild and self-limiting symptoms such as headaches, nausea and abdominal discomfort (Evian: 2011:175). In instances of more serious side-effects such as diarrhoea and leukopenia, some patients might then stop taking their medication or adjust their dosages so as to decrease the severity of the side effects. This has also been found to be true in a study of mentally ill patients who discontinued treatment owing to the fear of side effects (Mehta *et al* 1997:1668-1669). Of the nine respondents, one reported having experienced some side effects which made

him unable to cope with his schoolwork. These are his sentiments regarding side effects:

‘The treatment has affected my schooling ... when I take the tablets I can’t concentrate and feel like sleeping all the time.’ [Respondent 3]

4.7.4 Theme 4: Health care provider-related factors

This refers to those factors related to the health care providers, the services provided and the relationship they have with patients which may impact on adherence. These include factors such as poor communication between provider and patient (Oldridge 2001:337) and the relationship between the HCP and patient (Frank & Duncan 2009:23).

4.7.4.1 Adherence counselling

One of the most important components of patients’ commencement of ART is adherence counselling as it prepares the patient for the long-term commitment required. It is essential that patients be provided with a comprehensive treatment plan to support adherence and this is negotiated during adherence counselling sessions with all the relevant players involved (NDOH 2004). NSP 2012-2016 further advocates that adherence counselling be offered at each clinic visit to increase patients’ understanding and ensure that they are retained in care (NDOH 2011:49). The emphasis is on the fact that adherence counselling is not a once-off event but it should be an on-going process aimed at ensuring that patients do not fall out of the programme unnecessarily (Van Dyk 2011)

Some patients attend adherence counselling sessions when they are already very sick and have difficulty understanding what is happening. This is likely to have an impact on whether the patients understand the treatment and what is expected of them in terms of diet and behaviour change. The introduction of treatment advocates or supporters nominated by patients is advocated when

initiating treatment as it helps provide support to the patient (NDOH 2004). All of the nine respondents in this focus group discussion stated that they attended adherence counselling and eight respondents found it to be of good quality. These are examples of their responses:

‘The quality of counselling I received when I first discovered I was HIV positive in 1999 was not good but I have since been exposed to good counselling in recent years.’ [Respondent 9]

‘I received good counselling from the counsellors. It really helped me understand my medication and side effects.’ [Respondent 2]

In the quantitative phase it was noted that all of the 28 respondents reported attending adherence counselling but that 32.1% of them stated that they did not know what adherence was all about and could not remember what had been discussed. This is an issue of concern as adherence counselling is the basis of an effective ART programme.

4.8 RESULTS OF THE FACE-TO-FACE INTERVIEWS WITH KEY INFORMANTS

Interviews were held with the social worker, lay counsellors and the pharmacist assistant. The main findings are reported below.

4.8.1 Lay counsellors

The lay counsellors stated that the main reasons cited by patients as barriers to treatment adherence were side effects, belief in traditional medicine as an alternative to ART and alcohol abuse which resulted in their forgetting to take their treatment. In the literature it has been established that side effects are the most commonly cited factors impacting on adherence (Van Dyk 2011; Evian 2011:175). Active substance and alcohol abuse or addiction has also been

associated with poor adherence to treatment (Chesney 2000:172) although this was not evident in this study. This is what the lay counsellors had to say:

'Most patients, when we ask them, they tell us that side effects make them to stop taking their treatment. They say that sometimes it feels like these tablets are going to kill them. So, what do they do ... they stop taking them!'

'During counselling we tell the patients that they cannot take their ARV's with traditional medicines. But then you see them not getting any better and the viral load going up. When you are doing re-adherence with them, they will admit to consulting and taking traditional medicines. Most people around here believe in those things and it is not easy to change them. That's how they live.'

'I just think that some patients drink too much and when they are drunk, they forget about their treatment, especially on weekends and during holidays.'

There are some similarities between what the lay counsellors reported and the findings in the quantitative phase in which 89.4% of the respondents reported experiencing side-effects which influenced their adherence. In the focus group discussion only one participant reported belief in traditional medicine by a partner which indirectly impacted on her adherence. No evidence of the effect of alcohol abuse could be established in all the phases of this study and this could have been anticipated as it is not easy to admit abusing alcohol or any other substances readily.

4.8.2 Pharmacist assistant

The two biggest factors identified by the pharmacist assistant as the reason for less-than-perfect adherence were lack of disclosure and side effects. Disclosure is seen as a major challenge in that patients are afraid to disclose

their status for fear of being stigmatised and discriminated against. This, therefore, makes it difficult for them to take their medication in front of other people. This is in sharp contrast to the findings of this study which showed that all respondents during the quantitative phase had disclosed to different persons in their lives and in the qualitative phase only one participant had not disclosed. It is, however, important to point out that the findings of this survey cannot be generalised because of the small sample size.

The second most significant factor mentioned by the pharmacist assistant impacting on adherence was side effects which sometimes caused patients to stop or adjust their treatment in order to minimise the side-effects. The findings of the current study were consistent with this as 89.4% of respondents reported experiencing some side effects at one point of their treatment life span. One had this to say:

'The biggest challenge here is that patients don't disclose their status and as a result, they refuse to be down-referred to their local clinics as they fear being known in their local communities. When you talk with them you discover that some even have difficulty taking their medication in front of people who are not aware of their status.'

'Side effects also pose a serious problem and you will find them complaining that the tablets make them sleepy and they can't function properly. Some even decide to stop the treatment or take it at night only even though we advise them to come back if the side effects are severe!!'

4.8.3 Social worker

The social worker identified two major barriers to adherence, with lack of food being the highest, followed closely by lack of transport money to attend the clinic. She reported that since many patients were unemployed, some ran out of money for transport to the clinic. This has not been established as a major

problem in the study even though 92.8% of respondents incurred transport-related costs when attending the clinic. In addition, the social worker said that many patients dropped out of the programme during the initiation phase. These included patients who started with adherence counselling in preparation for ART but then dropped out fearing an inability to commit to lifelong therapy. In terms of HBM, this can be regarded as lack of self-efficacy which may impact on the ability to adhere if the patient does not believe he/she can do it. This aspect is not relevant to this study as all respondents had already commenced ART.

Patients, who remained on the programme after initiation, reportedly stated that it was difficult to take tablets without any food as taking the abrasive medication on an empty stomach caused nausea. Lack of adequate financial resources and food insecurity have been identified as major factors associated with poor adherence to treatment (NDOH 2010). In this study, 92.8% of respondents reported experiencing financial difficulties but only half of them (46.4%) admitted being unable to afford food owing to lack of financial resources. The other half reported coping somehow despite the difficulties.

At the service level, the social worker identified 'down-referral' of patients as a challenge as most of the patients refused to be referred back to their local clinics. This was not established during this survey so no comparisons can be made. This is what she had to say:

'Most patients complained of having no food and feel they cannot take tablets on an empty stomach as the tablets are harsh and abrasive in the stomach.'

'Patients always complain of having no money for transport to come to the clinic when referred for re-adherence after defaulting. They however refuse to be down-referred to their local clinics as they will be known to be taking ARV's. Some even tell me that they want a disability grant!!'

'Some patients drop out of adherence counselling as they are scared to start ARV because they cannot stop any more. I guess they are just afraid of this long term commitment.'

4.9 A SYNTHESIS OF THE QUALITATIVE PHASE

The objective of the qualitative phase of the study was to gain an understanding of the respondents' experiences in their own words. This information was obtained through the use of a focus group interview held with nine participants.

Factors cited as affecting adherence were the stress and fear associated with the HIV diagnosis; the uncooperativeness of sexual partners in terms of condom use and the taking of antiretroviral medication; unemployment and financial dependence on partners; homelessness and displacement; traditional and religious beliefs; irregular working hours; and forgetfulness.

Factors that were cited as promoting adherence were having accepted one's HIV status; receiving support from loved ones; a desire to see children grow up and be there for them; and living a good quality of life.

The Health Belief Model emphasises that for adherence to happen there must be a perceived benefit of the recommended health action and a perceived susceptibility to the consequences of not adhering to the recommended health action. The Social Cognitive Theory, on the other hand, espouses that behaviour is largely determined by incentives and expectancies. There must be a perceivable incentive for changing one's behaviour and expectancies about consequences of one's actions.

From the qualitative phase the belief that following a recommended health action would be beneficial in reducing the perceived threat was very evident. The respondents reported that they believed that taking their treatment would enable them to continue having a good quality of life; give them an opportunity

to see their children grow up and be an example to their families and friends for them to see that one can live positively with the virus for many years.

4.10 CONCLUSION

In this chapter the findings of the research study were presented and discussed and integrated with the theoretical models of health behaviour. This study used a mixed research design and as a result both qualitative and quantitative data were presented in this chapter. Conclusions and recommendations arising from the findings will be the focus of the next chapter.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

The previous chapter presented all the data and findings of both the quantitative and qualitative phases of the study. In this chapter the researcher discusses a summary of the findings, conclusions and recommendations for both health authorities and for further research opportunities. These are discussed in relation to the objectives of the study as set out at the beginning. The researcher also outlines the identified strengths and weaknesses of the study.

5.2 SUMMARY OF FINDINGS ACCORDING TO THE OBJECTIVES

The main aims of the study were to investigate the social context of patients on ART living in rural Mpumalanga so as to identify the major factors that affect adherence to ART, identify factors that support adherence as well as those factors that drive non-adherence amongst rural people living with HIV and Aids.

5.2.1 Objective 1: social context of patients on ART

The first objective of the study was to investigate the social context of patients on ART so as to identify the main contributing factors to adherence, non-adherence and fall out (that is, patients' loss to follow-up, LTFU) from the treatment programme. From the study it emerged that a great many factors within the person's social context play a role in determining whether they adhere to their regimens or not. This is supported by the social learning theory which suggests that personal, behavioural and environmental factors largely determine one's actions (Martin *et al* 2009:16). On the other hand, HBM suggests that one's actions and behaviours are influenced by perceptions and beliefs which are regarded as primary motivators of health behaviours (Martin *et al* 2009; Masokoane 2009:21). The patients' view of their circumstances, the

support they receive both from significant others and the health care providers may influence their behaviour and the decisions they make. It is not only individual factors that are important but also the interaction between those individual factors and the social factors such as the belief systems; support systems that exist; attitudes and reactions of significant others towards PLHIV; attitudes of health care professionals and the available resources such as transport infrastructure and accessibility of the clinics.

The belief system entails the values, cultural and religious beliefs that dictate people's perceptions of situations and their behaviour. Belief systems can impact on issues such as disclosure; the nature of the relationship with partners which may affect issues of safer sex practices; roles and expectations of women specifically; and even the taking of ART instead of traditional medicines. In this study, only one respondent cited the issue of traditional beliefs as having an influence on their treatment adherence. It is very interesting to note that in a rural area where traditional and cultural beliefs still significantly influence health-seeking behaviour, only one participant admitted to this belief affecting their adherence to some extent. Literature suggests that traditional healers are the primary health care providers in rural areas for at least between 80 and 85% of rural people in Tanzania and South Africa (Mustapher 2012; AIDS Foundation 2010). It would seem that almost all the respondents had internalised the importance of not mixing ART medication with traditional medicine as suggested in the South African ART guidelines (NDOH 2010:18) which is a great achievement for the ART programme. This might not be an indicator for general trends in this community since this is a small sample size but the progress made in raising awareness on the use of traditional medicine for PLHIV is worth acknowledging. Support systems include the availability of support from family members and friends and support groups where available. All of these factors within the patients' social environments interact in a way that will either promote or inhibit proper adherence to treatment.

The prominent factors identified in this study were that all the respondents except for one disclosed their status with positive outcomes as 78.5% of them were being supported by family and friends. This is a positive success indicator for the ART programme in terms of HIV status disclosure as only one person was not able to disclose to anyone. This high rate of disclosure has reportedly impacted positively on their adherence as a result as they are supported by significant others. The rest of these respondents did not obtain the support they expected after disclosure and they consisted of those who were either blamed (3.6%), their family were afraid the respondent might die (3.6%) or families finding it difficult to accept the HIV diagnosis and the respondents' status (14.3%). This percentage of non-disclosure is negligible when one compares it with the information on the study conducted by ATLIS in 2010 which found that 35% of people in a sample of 2 035 did not disclose for fear of being stigmatised and discriminated against. This is a very positive finding as a large number of people do not disclose their status for fear of being blamed and in some cases being discriminated against (AVERT 2011). It was, however, also noted that of all those respondents who were employed, three had not disclosed at work and all of them reported difficulty in taking their treatment whilst at work.

In the qualitative phase, the following factors were reported as having a negative bearing on adherence: being unemployed; homeless and displaced; dependency on spouses and the inability to negotiate for safer sex practices; and difficulty of taking medication at work. In the quantitative phase 46.4% of respondents reported having no income and poverty as having an impact on their ability to adhere properly as sometimes there was no food and no money for transport to honour clinic appointments. In the qualitative phase three of the nine respondents were unemployed and had to depend on someone else for survival but had managed to be adherent with medication despite the unfavourable financial circumstances.

5.2.2 Objective 2: Factors supporting adherence

The second objective was to identify those socio-economic factors that support adherence amongst rural people living with HIV (PLHIV) accessing ART. The following factors were cited as encouraging for respondents to take their treatment.

5.2.2.1 Social support

Having solid support systems is very important for people living with HIV and Aids as it plays a significant role in ensuring adherence to their treatment regimens (WHO 2003:28; AIDSmap 2012). Social support from family, friends and the community at large has been associated with increased and better adherence to treatment in many instances in which patients are on long term treatment (Heyer & Ogunbanjo 2006:6-7). This support system is there to buoy up the patients emotionally and to motivate them to take the recommended health actions. Social support of significant others can also serve as 'cues to action' as espoused in the Health Belief Model where patients can be influenced by external factors such as family to take action (Hayden 2009:33). Support does not only refer to social and emotional support but in many cases it includes financial support from significant others.

In this study, the two main reasons cited as encouraging adherence among the respondents were being aware of the benefits of being on ART and receiving the support of family and friends. Nearly two thirds (64.2%) of the respondents cited these two reasons as encouraging them to adhere, followed by the improvement brought about by ART in their health. Having accepted their HIV status also helped as it meant the status quo had been accepted and the patient was dealing with the situation positively.

5.2.2.2 Knowing and understanding the benefits of ART

Having a good understanding of how ART works and the benefits the patients can derive from being on treatment may encourage patients to take their treatment as recommended. From a review of many studies on adherence, Heyer and Ogunbanjo (2006:6) have established that patients who receive inadequate information about ART or have difficulty understanding medication schedules adhere less than those who have a good understanding of the purpose of ART. This understanding is crucial for patients to appreciate the importance of the treatment and the required adherence for it to work optimally and produce positive outcomes. Two of the reasons cited by respondents for encouraging adherence were appreciating how it works and understanding the benefits obtained from taking treatment as recommended. Some of the benefits cited by respondents were being able to live a better life; live long enough to see their children grow up; have an opportunity to plan for their family's future; be an example to other people and show that it is possible to live a good life even with HIV.

5.2.3 Objective 3: Factors driving non-adherence and loss to follow up

The objective here was to identify those socio-economic factors that drive non-adherence and ultimately fall out amongst rural PLHIV accessing ART. Hardon *et al* (2006:7) in their studies conducted in three African countries, that is, Tanzania, Uganda and Botswana, review constraints such as transport costs, user fees, long waiting times, hunger, stigma and discrimination, lack of social support, side effects and lack of appropriate counselling. All undermine adherence to therapy. It is important to indicate at this point that the majority of respondents (78.5%) reported having no problems adhering to their ART whilst 64.3% of the respondents agreed but admitted to having missed some doses of treatment at some point at varying degrees. The findings clearly indicate that almost three quarters of the respondents were not adhering to their treatment as recommended. This is a cause for concern for long-term treatment outcomes.

Taking into account the definitions of adherence, non-adherence and poor adherence as cited in paragraph 4.5.16, the findings clearly depict a mixed picture of both non-adherence and poor adherence. Nearly a quarter (22.2%) reported missing a dose at least once a week, which is equivalent to four times a month and that clearly shows poor adherence. The patient can still be considered adherent if no more than three doses per month have been missed as the treatment will still suppress the virus sufficiently (NDOH 2004:53). At least one person also reported stopping treatment completely two months prior to these interviews which is in essence non-adherence to treatment as it was prematurely stopped. The rest of the respondents had either missed a dose once a month, once in three months or very rarely and this can be considered as being adherent as 95% of the treatment was reportedly taken. The findings nevertheless show that there is generally poor adherence to treatment regimens in this study. This is, however, a subjective report of adherence by respondents and generally patients have been found to have a tendency to over-exaggerate their self-reported levels of adherence for various reasons (WHO 2003:96).

The following factors were identified as having an impact on adherence in this study.

5.2.3.1 Lack of social support

The presence of social support for people living with HIV and Aids has been associated with good adherence to treatment. Conversely the lack of this support can have a negative impact on patients' ability to adhere to their treatment regimens. This was also confirmed in a review of many studies done by Heyer and Ogunbanjo (2006:8) in which they discovered that lack of support, specifically social and familial support, and fear of stigmatisation are generally associated with non-adherence to treatment.

One respondent in this study reported having no one to discuss and share their feelings about HIV status and treatment. In the qualitative phase of the

study three respondents reported not getting any cooperation and the necessary support from their spouses despite both partners being reportedly HIV positive which made adherence difficult to achieve as they were unable to negotiate the practice of safer sex.

5.2.3.2 Unemployment and lack of financial resources

Mukherjee *et al* (2006:124) state that studies undertaken in several different settings show that costs such as payment for transportation to and from clinics serve as a deterrent to ART adherence. They further affirm that the lack of adequate food has also been associated with poor adherence to ART. In this study, 46.4% of respondents in the quantitative phase and three of the nine respondents in the qualitative phase were unemployed and had to depend on significant others for financial support. In instances in which this financial support was discontinued, patients' lives were destabilised. This may result in displacement and homelessness but in this study only two focus group participants reported being homeless. This was not reported as a factor affecting adherence for them. From a review of many studies, Heyer and Ogunbanjo (2006:8) have established that a lack of support from significant others, homelessness and displacement are all generally associated with poorer adherence.

The majority of respondents (92.8%) reported incurring transport expenses as they had to travel various distances to the clinic to obtain their medication but this was not regarded as a problem as they were nevertheless able to attend clinic regularly. Poverty and a lack of financial resources to provide themselves with food was reported by at least 46.4% of respondents who could not afford to buy food and another 46.4% who reported financial difficulties but they somehow found ways to cope. Some respondents reported missing a dose as a result of having no food at home. This was also one of the reasons cited by key informants as contributing to patients missing their appointments but this was not correlated by the findings.

5.2.3.3 Traditional and religious beliefs

Traditional beliefs and religion shape and determine our actions and it can impact on the acceptance of one's HIV status; the willingness to disclose; fears about stigma and discrimination and ultimately willingness and preparedness to enrol on the ART programme (Kagee 2006:422; Hardon *et al* 2006:68). Our responses and actions with respect to these beliefs are more than likely to impact on adherence to treatment. In a study conducted in Tanzania by Zou, Yamanaka, John, Watt, Ostermann and Thielman (2009:79) it was discovered that 80.8% of respondents believed that prayer could cure HIV and a correlation between refusal to take treatment and lack of knowledge about ART was established amongst this group. In this study there was evidence of this belief when one respondent stopped treatment as he believed that God would cure him of HIV even though he had been on treatment for two years and was doing well. In this instance religious beliefs had a negative impact on treatment adherence. No respondent reported believing in traditional or alternative medicine *per se* but some reported that the spouse did not believe in ART and as a result did not want them to take the treatment.

5.2.3.4 Irregular working hours and lack of disclosure

People infected with and affected by HIV and AIDS are often subjected to discrimination and rejection by their friends, family and partners and even work colleagues (Evian 2011:464). Many people who have disclosed their HIV status to someone are often met with mixed responses and reactions. Whilst most literature advocates disclosure of one's status, it is important to point out that disclosure may not be good for everyone. Hence many people decide not to disclose especially at the workplace where there are no guarantees of unconditional acceptance and support. The disadvantage with disclosure is that the reaction to it cannot be predicted. Once a patient has disclosed to someone and the reaction is negative, it cannot be taken back or withdrawn. Even though disclosure may sound like a good thing to do and patients may be motivated to adhere to their ART, if there is a slight sense of discrimination and

stigmatisation as a result of having disclosed this may negatively impact on their adherence. Three of the nine discussants in the focus group reported having difficulty taking their treatment when they were at work and when they were working irregular shifts. The main reason cited was being unable to take treatment when working late or on night shift as it sometimes clashed with work routines or coincided with travelling times. One respondent also mentioned fear of discrimination and victimisation.

5.2.3.5 Adherence counselling

The role of health care professionals, particularly lay counsellors is to help prepare patients for initiation on ART. This is done through adherence counselling mainly and if this process is not handled efficiently it can impact on adherence in the long run. Adherence counsellors should consider whether patients are in a position to fully comprehend the discussions and can apply this knowledge in their day-to-day situations.

In this study it emerged that although all respondents reported attending adherence counselling sessions before starting treatment, some of them reported that they were confused, did not understand what adherence was all about and some even cited poor quality of counselling offered. According to Heyer and Ogunbanjo (2006:6), patients who have difficulty concentrating, have received inadequate information about ART or are struggling to understand how treatment works will adhere poorly to their treatment. The importance of adequate counselling when preparing patients for initiation and ensuring that the patients gain adequate insight is of great importance and it cannot be over emphasised. From the findings, 50% of the respondents reported having difficulty with adherence when they were away from home either attending a funeral or some other social function. The researcher is of the opinion that there could be a link between this and with the nature of counselling received. The aim of adherence counselling is to help prepare patients for initiation on treatment and assist them with developing strategies to overcome such challenges. In this instance, it seems that the respondents

were not adequately coping with the challenges and hence the inability to devise strategies to ensure adherence even when they were not in their natural environment. From the interview with the social worker it emerged that she does not play any role with regard to adherence counselling; only the lay counsellors render this service. The researcher is of the opinion that the social worker can and should play a significant role in rendering of adherence counselling. It is also very important to emphasise that adherence counselling is not a once-off event but should be on-going to ensure that patients do not fall out of the programme unnecessarily (Van Dyk 2011). NSP 2012-2016 (NDOH 2011:49) advocates that adherence counselling be offered at each clinic visit to increase patients' understanding and ensure that they are retained in care.

5.2.3.6 Side effects

It is very common for patients to experience side effects within the first two weeks of starting treatment but these normally subside within the first six weeks. Some can be short term and self-limiting and others need the attention of health care providers like fat redistribution from one body part to another. Patients are always encouraged to seek help as soon as possible if this happens (Evian 2011:166). A high percentage (89.4%) of respondents in the quantitative phase of this study reported experiencing different side effects and that these had a direct impact on their adherence to treatment. In the qualitative phase of the study only one respondent cited experiencing some side effects which made it hard to cope at school. This is also consistent with the information obtained from the key informants who reported side effects as one of the major problems identified as leading to non-adherence.

5.2.3.7 Treatment regimens

In the quantitative phase of the study 75% of the respondents were on the first line regimen which is a good thing in terms of long-term adherence and the success of treatment whilst 7.1% of the respondents were already on the

second line regimen which leaves them with fewer options in the long run. The rest of the respondents (17.9%) did not know their treatment regimen and could not provide information in this respect. This is a worrying factor as it is ideal for the patients to know and understand their treatment as this encourages good treatment adherence. Qualitative data showed that five of the nine focus group participants were on the first line regimen, one was on the second line regimen and three were on the salvage regimen. This is a concern as these three individuals may run out of treatment options soon if adherence levels do not improve. These are indicative of serious challenges in terms of treatment adherence which may be as a result of lack of adequate knowledge of treatment, side effects or circumstances which are not conducive to adherence.

5.3 STRENGTHS AND WEAKNESSES OF THE STUDY

5.3.1 Strengths of the study

(i) The study was able to meet the objectives as set out in the beginning of the study which was to describe the social context of people living with HIV and Aids in rural Mpumalanga and explore factors that support adherence and those that encourage non-adherence to treatment.

(ii) The study contributes to the existing body of knowledge in relation to understanding of adherence and non-adherence of people living with HIV and receiving ART. Previous studies focused more on the psychosocial factors leading to non-adherence but this study focused more on the socio-economic factors. It has emphasised the role played by side-effects in adherence; the importance of adherence counselling with respect to long-term treatment adherence; and the impact of disclosure and social support on the patient's adherence.

5.3.2 Weaknesses of the study

(i) The researcher had a very limited budget when undertaking this study and as a result could not choose a very large sample. A relatively small sample was chosen owing to budgetary constraints and this small sample size means that the findings of the study cannot be generalised to a larger population.

(ii) Non-probability sampling was used in the selection of respondents which implies that the probability of being chosen to participate was unknown. The findings of the study, therefore, are not representative.

(iii) Another shortcoming in this study was the language barrier as the respondents predominantly spoke SiSwati and the researcher is an IsiZulu speaker. Although both these languages are Nguni languages and there are similarities in some instances it still posed a challenge in communication which may have impacted on the responses. Where a difficulty was identified the researcher explained further in English when the respondent was able to understand and also explained and clarified it further in SiSwati.

(iv) The interviews were conducted at the CCMT site for the convenience of both the interviewer and some respondents and as a result the researcher was viewed as part of the staff and this could lead to over-reporting of adherence to appease the researcher.

(v) The researcher also had challenges regarding gaining permission to access the health facility to conduct research owing to the delays in the granting of this consent. This impacted negatively on the progress of the study itself and it resulted in delays in starting and completing the study.

(vi) Further delays were also experienced when the researcher had no personal laptop to do her work and this had a major impact on the

progress of the study. This was overcome with the assistance of the Postgraduate Financial Assistance Programme from UNISA.

5.4 RECOMMENDATIONS STEMMING FROM THE FINDINGS

(i) The importance of adherence counselling when preparing patients for initiation on ART and its association with non-adherence if not done properly has been positively established. The findings of the study showed that there may be gaps in terms of adherence counselling and this needs to be addressed to ensure better counselling quality. Adequate training of the relevant personnel may assist in ensuring that counselling is done efficiently. It is also recommended that the social worker be actively involved in ensuring that adherence counselling is consistently of a higher quality and that social worker renders in-service training where necessary.

(ii) The findings also depicted that 92.8% of respondents incur transport costs in order to attend clinic which is far from their residential localities. It is recommended that the down-referral to local primary health care clinics of those patients who are stable on treatment be explored further and strengthened for easy accessibility of services for patients at no extra cost.

(iii) At least four of the nine participants in the focus group discussion indicated that their partners were not cooperative with respect to issues such as condom use, taking ART and traditional practices. This cannot be generalised as a big problem since the sample size was small but the issue is significant enough to be explored. It is recommended that the involvement of partners in the development of a treatment plan for the patient, especially if both partners are HIV positive, be ensured as far as possible.

5.5 RECOMMENDATIONS FOR FURTHER RESEARCH

(i) The researcher was not able to do an extensive research on the socio-economic factors owing to budgetary limitations and there might be a need to explore this aspect further. It is recommended that further studies be carried out on these factors in order to gain a better understanding of the impact they can have on adherence.

(ii) It seems as if down referral of patients from hospitals to local clinics might go a long way in alleviating problems of non-adherence as a result of lack of money to attend clinic appointments. This aspect needs to be explored and strategies relevant to localities developed for proper implementation.

(iii) Adherence counselling in order to prepare patients for ART is very important and if it is not done effectively it can have an impact on the adherence to treatment and outcomes thereof. It is recommended that the role of adherence counselling in ART initiation be explored with the objective of developing improved implementation strategies.

5.6 CONCLUSION

The aim of this study was to describe and explore factors that influence adherence amongst people living with HIV and Aids in the rural Mpumalanga province. It is envisaged that the findings will assist health care professionals to develop intervention programmes that will assist in identifying those patients most at risk of and vulnerable to being non-adherent to their regimens. The factors affecting adherence can be divided into five categories, that is, treatment-related, condition-related, patient-related, health care team-related and socio-economic factors.

The most commonly cited reasons affecting adherence in this study were being away from home for social events like funerals; inability to take treatment whilst at work owing to irregular working hours; fear of stigmatisation and/or

victimisation; treatment side effects; and forgetting their treatment. A very clear picture that emerged from the study was the inability of women respondents to negotiate safer sex practices like condom use which made them non-adherent with their treatment regimens.

The study revealed how the individual factors interacted with other factors in the respondents' social environment to impact and influence treatment adherence. It indicated that the majority of women experience difficulty in gaining the cooperation of their spouses in terms of condom use and taking of treatment in case of concurrent HIV positive diagnosis of both partners. Another issue that was evident is the financial dependence of female partners on their spouses which in most cases makes it difficult to negotiate safer sex practices. In this study, three respondents from the focus group reported being financially dependent on partners and felt a sense of obligation which made it difficult to negotiate condom use. The issue of adherence counselling and the quality thereof was another factor identified as possibly having an impact on the ability to adhere to treatment regimens. The significant role that adherence counselling can play in promoting adherence by all cannot be over emphasised.

'Access- to-all' campaigns are no longer acceptable without adding the important 'adherence-by-all' message – Van Dyk 2011

LIST OF SOURCES

- AIDSinfo. 2011. *Glossary and HIV/AIDS-related terms*. Available at http://aidsinfo.nih.gov/contentfiles/GlossaryHIVrelatedTerms_English.pdf. (Accessed on 15/08/2011).
- AIDSinfomap. 2012. *Community-based support, aids retention, adherence and treatment response*. Available at <http://www.aidsmap.com>. (Accessed on 01.11. 2012).
- AIDSinfonet. 2012. *How much adherence is enough?* Available at http://www.aidsinfonet.org/fact_sheets/view/405#FATIGUE. (Accessed on 10.01.2013)
- AIDS Foundation SA. 2010. *Traditional medicine, culture and health*. Available at <http://www.aids.org.za>. (Accessed on 10.01.2013).
- Amico, KR, Toro-Alfonso, J & Fisher, JD. 2005. An empirical test of the Information, Motivation and Behavioural Skills model of antiretroviral therapy adherence. *AIDS Care* 17 (6):661-673.
- Amico, KR, Barta, W, Konkle-Parker, DJ, Fisher, JD, Cornman, DH, Shuper, PA & Fisher, WA. 2009. The information–motivation–behavioural skills model of ART adherence in a Deep South HIV+ clinic sample. *AIDS Behaviour* 13 (1):66-75.
- AVERT. 2011. *HIV and AIDS treatment*. Available at <http://www.avert.org/aidssouthafrica.html>. (Accessed on 20.04.2011).
- AVERT. 2012. *Antiretroviral treatment in South Africa*. Available at <http://www.avert.org/aidssouthafrica.htm>. (Accessed on 10.01.2013).

- Babbie, ER. 2010. *The practice of social research*. Belmont: Wadsworth, Cengage Learning.
- Babbie, E & Mouton, J. 2001. *The practice of social research*. Cape Town: ABC Press.
- Bangsberg, DR. 2008. Preventing HIV antiretroviral resistance through better monitoring of treatment adherence. *The Journal of Infectious Diseases* 197:S272-278.
- Bangsberg, DR, Ware, N & Simoni, JM. 2006. Adherence without access to antiretroviral therapy in Sub-Saharan Africa? *AIDS* 20:140-141.
- Bärnighausen, T. 2008. Reasons for loss to follow-up in antiretroviral treatment programs in South Africa. *Future HIV Therapy* 2(2):141-145.
- Bazeley, P. 2009. Integrating data analyses in mixed method research. *Journal of Mixed Methods Research* 3(3):203-207.
- Burke, LE & Ockene, IS. 2001. *Compliance in healthcare and research*. Armonk, New York: Futura Publishing.
- Cameron, E. 2010. Stigma, human rights, testing and treatment – time for action. *The Southern African Journal of HIV Medicine* 37:1- 45.
- Campbell, C & Murray, M. 2004. Community health psychology: Promoting analysis and action for social change. *Journal of Health Psychology* 9(2):187-195.
- Chabikuli, O, Datonye, DO & Nachega, J. 2010. Adherence to antiretroviral therapy, virologic failure and workload at the Rustenburg Provincial Hospital. *SA Family Practice* 52(4):350-355.

- Chesney, MA. 2000. Factors affecting adherence to antiretroviral therapy. *Clinical Infectious Diseases* 30 (2):S171-176.
- Conner, M & Norman, P. 1996. *Predicting health behaviour. Search and practice with social cognition models*. Buckingham: Open University Press.
- Cornell, M. 2010. *ARV dropouts exacerbate epidemic*. Available at www.timeslive.co.za. (Accessed on 20.11.2012).
- Cornell, M, Grimsrud, A, Fairall, L, Fox, MP, Van Cusem, G, Giddy, J, Wood, R, Prozesky, H, Mohapi, L, Graber, C, Egger, M, Boule, A & Myer, L. 2010. Temporal changes in programme outcomes among adult patients initiating antiretroviral therapy across South Africa 2002-2007. *AIDS* 24(14): 2263-2270.
- Crabtree, BF & Miller, WL. 1999. *Doing qualitative research*, 2nd edition. London: Sage Publications.
- Crane, JT, Kawuma, A, Oyugi, JH, Biyakika, JT, Moss, A, Bourgois, P & Bangsberg, DR. 2006. The price of adherence: qualitative findings from HIV positive individuals purchasing fixed-dose combination generic HIV antiretroviral therapy in Kampala, Uganda. *AIDS Behaviour* 10(4):437-442.
- Curtis, B & Curtis, C. 2011. *Social Research. A Practical Introduction*. London: Sage.
- Dahab, M, Charalambous, S, Hamilton, R, Fielding, K, Kielmann, K, Churchyard, GJ & Grant, AD. 2008. "That is why I stopped the ART": Patients' & providers' perspectives on barriers to and enablers of HIV treatment adherence in a South African workplace programme. *BMC Public Health* 8:63-67.

- Dawson, C. 2002. *Practical research methods*. Wiltshire: Cromwell Press.
- Demeester, R, Omes, C, Karasi, JC, Schneider, S, Mugabo, J, Maliboli, MJ & Arendt, V. 2005. Adherence to first-line antiretroviral regimens in Rwanda. *Journal of Acquired Immune Deficiency Syndromes* 40:113-114.
- De Paoll, MM, Mills, EA & Gronningsaeter, AB. 2012. The ARV roll out and the disability grant: A South African dilemma? *Journal of the International AIDS Society* 15(1):6
- Donohue, WT & Levensky, ER. 2006. *Promoting treatment adherence: A practical handbook for health care providers*. Thousand Oaks: Sage.
- Dunbar-Jacob, J. 2004. Adherence to treatment regimens. *Encyclopaedia of Health and Behaviour*. Available at http://www.sage-reference.com.oasis.unisa.ac.za/behaviour/Article_n2.html. (Accessed on 19.11.2010)
- Dzindza, I. 2007. Perceptions and beliefs of physicians about adherence to antiretroviral treatment by patients in the South-East District of Botswana. Master of Public Health. Department of Health Studies. Pretoria: University of South Africa.
- Elizabeth Glaser Paediatric Aids Foundation. 2012. *Fact Sheet and Issue Briefs*. Available at <http://www.pedaids.org>. (Accessed on 10.11.2012).
- Enriquez, M. 2002. An examination of the index of readiness as a predictor of adherence and an adherence intervention in HIV-positive males who repeatedly failed anti-HIV treatment regimens. PhD thesis. Kansas City: University of Missouri.

- Erlen, JA, Mellors, MP & Lehman-Trzynka, ES. 2010. AIDS and HIV: Adherence to medications in persons with HIV infection. *Encyclopaedia of Health and Behaviour* 1:19-24
- ETU. 2012. *How to deliver care for people with HIV and AIDS and their families*. Available at www.etu.org.za. (Accessed on 10.11.2012).
- Evian, C. 2003. *Primary HIV clinical care for adults, children and pregnant women*, 4th Edition. Melville, Johannesburg: Jacana Media.
- Evian, C. 2011. *Primary HIV clinical care for adults, children and pregnant women*, 5th Edition. Melville, Johannesburg: Jacana Media.
- Fisher, J, Fisher, W, Amico, RK & Hamann, JF. 2006. An information-motivation-behavioural skills model of adherence to antiretroviral therapy. *Health Psychology* 25(4):462-473.
- Frank, J & Duncan, N. 2009. Speaking to experts and patients: Recommendations for improving antiretroviral therapy (ART) adherence. *Health SA Gesondheid* 14(1):20-28.
- Galofshani, N. 2003. Understanding reliability and validity in qualitative research. *The Qualitative Report*. 8(4):597-607.
- Geffen, N. 2009. *ARV Programme results reports at IAS*. Available at <http://i-base.info/htb-south/184>. (Accessed on 10.11.2012).
- Geng, EH, Nash, D, Kambugu, A, Zhang, Y, Braitstein, P, Christopoulos, KA, Muyindike, W, Bwana, MB, Yiannoutsos, CT, Petersen, ML & Martin, JN. 2010. Retention in care among HIV-infected patients in resource-limited settings: Emerging insights and new directions. *Current HIV/AIDS Reports* 7:234-244.

Global Health. 2010. *HIV and AIDS glossary*. Available at <http://www.globalhealth.org>. (Accessed on 15/08/2010).

Grinnell, RM. 2001. *Social work research & evaluation: Quantitative & qualitative approaches*, 6th Edition. Belmont CA: Thomas Learning.

Harder, AF. 2002. *The developmental stages of Erik Erikson*. Available at <http://www.learningplaceonline.com/stages/organize/>. (Accessed on 02.05.2012).

Hardon, AP, Akurut, D, Comoro, C, Ekezie, C, Irunde, HF, Gerrits, T, Kgatlwane, J, Kinsman, J, Kwasa, R, Maridadi, J, Moroka, TM, Moyo, S, Nakiyemba, A, Nsimba, S, Ogenyi, R, Oyabba, T, Temu, F & Laing, R. 2007. Hunger, waiting time and transport costs: time to confront challenges to ART adherence in Africa. *AIDS Care* 19(5):658-665.

Hardon, A, Davey, S, Gerrits, T, Hodgkin, C, Irunde, H, Kgatlwane, J, Kinsman, J, Nakiyemba, A & Laing, R. 2006. *From access to adherence: The challenges of ART*. Available at <http://www.who.int/medicinedocs/pdf/s13400e/s13400e.pdf>. (Accessed on 20.11.2010).

Hayden, J. 2009. *Introduction to health behaviour theory*. Washington DC: Jones & Bartlett Publishers.

Haynes, RB. 2001. Improving patient adherence, in *Compliance in health care and research*, edited by LE Burke & IS Ockene Armonk, New York: Futura Publishing.

Health24. 2009. *HIV/AIDS and Nutrition*. Available at http://www.health24.com/medical/Condition_centres/777-792-814-1769,22097.asp. (Accessed on 20.11.2012).

- Henn, M, Weinstein, M & Foard, N. 2006. *A short introduction to Social Research*. London: Sage.
- Heyer, A & Ogunbanjo, GA. 2006. Adherence to HIV antiretroviral therapy Part I: A review of factors that influence adherence. *South African Family Practice* 48(8):5 --9.
- HIV Clinical Resource. 2001. *Promoting adherence to antiretroviral therapy*. Available at <http://www.hivguidelines.org>. (Accessed on 10.01.2013).
- HPTN. HIV Prevention trials network. 2012. *A randomized trial to evaluate the effectiveness of ART plus HIV primary care versus HIV primary care alone to prevent the sexual transmission of HIV-1 in sero-discordant couples*. Available at http://www.hptn.org/research_studies. (Accessed on 29.11.2012).
- IDP. 2010. *Nkomazi Local Municipality Integrated Development Plan*. Available at www.nkomazi.gov.za. (Accessed on 30.06.2011).
- Igumbor, JO, Scheepers, E, Ebrahim, R, Jason, A & Grimwood, A. 2011. An evaluation of the impact of a community-based adherence support programme on ART outcomes in selected government HIV treatment sites in South Africa. *AIDS Care* 23(2):231-236.
- Jean-Baptiste, R. 2008. *Factors associated with adherence to antiretroviral therapy in Rwanda: A multi-site study*. Bethesda, MD: University Research.
- Jones, PS. 2009. *AIDS treatment and human rights in context*. New York: Palgrave Macmillan.

- Jordan, MR, Bennett, DE, Bertagnolio, S, Gilks, CF & Sutherland, D. 2008. World Health Organization surveys to monitor HIV drug resistance prevention and associated factors in sentinel antiretroviral treatment sites. *Antiviral therapy* 13(2):15-23.
- Jury, C & Nattrass, N. 2012, *Parental presence and the impact of antiretroviral treatment on household composition in Khayelitsha*. Centre for Social Science Research Working Paper Number 318. Cape Town: University of Cape Town.
- Kagee, A. 2006. Adherence to antiretroviral treatment in the context of national rollout in South Africa: Defining a research agenda for psychology. *South African Journal of Psychology* 38(2):413-428.
- Kip, E. 2008. Factors influencing patients' adherence to antiretroviral therapy in four selected health facilities in Botswana. Doctor of Literature & Philosophy. Department of Health Studies. Pretoria: University of South Africa.
- Koenig, SP, Leandre, F & Farmer, PE. 2004. Scaling-up HIV treatment programmes in resource-limited settings: the rural Haiti experience. *AIDS* 18: S21-S25.
- Leach-Lemens, C. 2010. *Loss to follow up high in South African public sector ARV programmes*. Available at www.aidsmap.com. (Accessed on 15.10.2012).
- Levensky, ER. 2006. Adherence to HIV/AIDS treatment, in *Promoting treatment adherence: A practical handbook for health care providers*, edited by WT Donohue & ER Levensky. Thousand Oaks: Sage Publications.

- Liamputtong, P. 2011. *Focus group methodology: Principles and Practice*. New York: Sage Publications.
- MacPhail, C & Campbell, C. 2001. 'I think condoms are good but, aai, I hate those things': condom use among adolescents and young people in a Southern African township. *Social Science and Medicine* 25(11):1613-1627.
- Malangu, NG. 2008. Self-reported adverse effects as barriers to adherence to antiretroviral therapy in HIV infected patients in Pretoria. *SA Family Practice* 50(5):49a-49b.
- Martin, LR, Harskard-Zolnieriek, KB & DiMatteo, MR. 2009. *Health behaviour change and treatment adherence: Evidence based guidelines for improving health care*. New York: Oxford University Press.
- Masokoane, KQ. 2009. Adherence and non-adherence to antiretroviral treatment in HIV positive people in Port Elizabeth. MA dissertation in Counselling Psychology. Department of Psychology. Port Elizabeth: Nelson Mandela Metropolitan University.
- Mehta, S, Moore, RD & Graham, NMH. 1997. Potential factors affecting adherence with HIV therapy. *AIDS* 11(14):1665-1670.
- Monsen, ER & Van Horn, L. 2008. *Research: Successful approaches*, 3rd edition. Chicago: American Dietetic Association.
- Moola, S. 2010. A qualitative analysis of the communication process between HIV-positive patients and medical staff: A study at Stanger Regional Hospital's antiretroviral therapy clinic. MA dissertation in Sociology. Department of Sociology. Pretoria: University of South Africa.

- Mouton, J. 2001. *How to succeed in your master's and doctoral studies. A South African guide and resource book*. Pretoria: Van Schaik.
- Motlanthe, K. 2012. *Address at the opening of the X1X International AIDS conference in Washington DC, USA*. Available at www.doh.gov.za. (Accessed on 10.10.2012).
- Motsoaledi, A. 2011. *How we're re-engineering the health system: Health budget vote policy speech presented at the National Assembly on 31.05.2011*. Available at www.politicsweb.co.za. (Accessed on 20.11.2011).
- Motsoaledi, A. 2012. *Statement on the announcement of the new ARV tender ahead of the World AIDS Day*. Available at <http://www.doh.gov.za>. (Accessed on 15.01.2013).
- Munro, S, Lewin, S, Swart, T & Volmink, J. 2007. *A review of health behaviour theories: how useful are these for developing interventions to promote long-term medication adherence for TB and HIV/AIDS*. Available at <http://www.biomedcentral.com>. (Accessed on 20.08.2010).
- Mukherjee, JS, Ivers, L, Leandre, F, Farmer, P & Benforouz, H. 2006. Antiretroviral therapy in resource-poor settings. Decreasing barriers to access and promoting adherence. *Journal of Acquired Immune Deficiency Syndrome* 1 (43): S123-126.
- Mustapher, S. 2012. *Tanzania: Traditional Medicine excels where science fails*. Available at <http://allafrica.com/stories/201211020138.html>. (Accessed on 10.01.2013).

- Nachega, JB, Stein, DM, Lehman, DA, Hlatshwayo, D, Mothopeng, R, Chaisson, RE & Karstaedt, A. 2004. Adherence to antiretroviral therapy in HIV-infected adults in Soweto, South Africa. *AIDS Research and Human Retroviruses* 20:1053-1056.
- NDOH. South African National Department of Health. 2003. *Operational plan for comprehensive HIV and AIDS care, management and treatment for South Africa*. Pretoria: NDOH.
- NDOH. South African National Department of Health. 2004. *National Antiretroviral treatment guidelines*. Pretoria: NDOH.
- NDOH. South African National Department of Health. 2007. *National HIV and AIDS & STI Strategic Plan for South Africa 2007-2011*. Pretoria: NDOH.
- NDOH. South African National Department of Health. 2009. *National antenatal sentinel HIV and Syphilis prevalence survey in South Africa*. Pretoria: NDOH.
- NDOH. South African National Department of Health. 2010. *National antenatal sentinel HIV and Syphilis prevalence survey in South Africa*. Pretoria: NDOH.
- NDOH. South African National Department of Health. 2010. *National HIV counselling and testing (HCT) Policy Guidelines*. Pretoria: NDOH.
- NDOH. South African National Department of Health. 2010. *Clinical guidelines for the management of HIV & Aids in adolescents and adults*. Pretoria: NDOH.
- NDOH. South African National Department of Health. 2011. *National strategic plan for HIV and AIDS, STIs and TB (2012-2016)*. Pretoria: NDOH.

- Norval, R. 2012. *"To tell or not to tell? – Disclosure and you"*. Available at <http://www.health4men.co.za/resources/entry/>. (Accessed on 10.01.2013)
- O'Donohue, WT & Levensky ER. 2006. *Promoting treatment adherence: A practical handbook for health care providers*. California: Sage Publications.
- Oldridge, N. 2001. Future directions: What paths do researchers need to take: What needs to be done to improve multi-level compliance? in *Compliance in healthcare and research*, edited by LE Burke & IS Ockene. Armonk, New York: Futura Publishing.
- Orrell, C, Bangsberg, DR, Badri, M & Wood, R. 2003. Adherence is not a barrier to successful antiretroviral therapy in South Africa. *AIDS* 17: 1369-1375.
- Padgett, DK. 1998. *Qualitative methods in social work research: Challenges and rewards*. Thousand Oaks: Sage Publications.
- Pomeroy, EC, Thompson, S, Gober, K & Noel, L. 2007. Special Issue: Predictors of Medication Adherence among HIV/AIDS Clients. *Journal of HIV/AIDS & Social Services* 6(1-2):65–82.
- Pope, C, White, RT & Malow, R. 2009. *HIV/AIDS: Global frontiers in prevention/intervention*. New York & London: Routledge.
- Reda, AA & Biadgilign, S. 2012. Determinants of adherence to antiretroviral therapy among HIV-infected patients in Africa. *AIDS Research and Treatment* 2012: 1-8.
- Right to Care. 2011. *Programmatic performance report*. Available at www.righttocare.org (Accessed on 06.06.2011).

- Rosen, S, Fox, MP & Gill, CJ. 2007. Patient retention in antiretroviral therapy programs in Sub-Saharan Africa: A systematic review. *WHO Bulletin* 85(7):1-20.
- Rosen, S & Ketlhapile, M. 2010. Cost of using a patient tracer to reduce loss to follow-up and ascertain patient status in a large antiretroviral therapy program in Johannesburg, South Africa. *Tropical Medicine and International Health* 15(1): 98-104.
- Rosenstock, IM, Strecher, VJ & Becker, MH. 1988. Social Learning Theory and Health Belief Model. *Health Education & Behaviour* 1988 15:175.
- Rosnow, RL & Rosenthal, R. 2005. *Beginning behavioural research: A conceptual primer*, 5th edition. New Jersey: Pearson Prentice Hall.
- Roura, M, Busza, J, Wringe, A, Mbata, D, Urassa, M & Zaba, B. 2009, Barriers to sustaining antiretroviral treatment in Kisesa, Tanzania: A follow-up study to understand attrition from the antiretroviral program. *AIDS Patient Care and STDs* 23(3):203-210.
- SASSA. South African Social Security Agency. National Department of Social Development. 2011. *You and your grant*. Available at www.sassa.gov.za. (Accessed on 10.11.2012).
- Sheeran, P & Abraham, C. 1996. The Health Belief Model, in *Predicting health behaviours: Research and practice with social cognition models*, edited by M Conner & P Norman. Buckingham: Open University Press.
- Silva, MC, Ximenes, RA, Filho, DB, Arraes, LW, Mendes, M, Melo, AC & Fernandes, PR. 2009. Risk factors for non-adherence to antiretroviral treatment. *Rev Inst Med Trop Sao Paulo* 51(3):135-139.

- Simoni, J, Amico, KR, Pearson, C & Malow, R. 2009. Overview of adherence to antiretroviral therapies, in *HIV/AIDS: Global frontiers in prevention/intervention*, edited by C Pope, RT White & R Malow. New York: Routledge.
- Stats SA. Statistics South Africa. 2009. *Mid-year population estimates*. Available at: www.statisticssa.gov.za. (Accessed on 19.03.2010).
- Stats SA. Statistics South Africa. 2011. *Mid-year population estimates*. Available at: www.statisticssa.gov.za. (Accessed on 31.10.2012).
- Sunil, TS & McGehee, MA. 2007. Social and religious support on treatment adherence among HIV/AIDS patients by race and ethnicity. *Journal of HIV/AIDS and Social Services* 6: 83-99.
- Taylor, GR. 2005. *Integrating quantitative and qualitative methods in research*, 2nd edition. Maryland: University Press of America.
- Triad Trust. 2010. *Media kit*. Available at <http://www.triadtrust.org>. (Accessed on 10.01.2012).
- Tuller, DM, Bangsberg, DR, Senkungu, J, Ware, NC, Emenyonu, N & Weiser, SD. 2009. *Transportation costs impede sustained adherence and access to HAART in a clinic population in south western Uganda: A qualitative study*. Available at: <http://www.ghdonline.org>. (Accessed on 10.01.2012).
- Uebel, KE, Timmerman, V, Ingle, SM, Van Rensburg, DHCJ & Mollentze, WF. 2010. Towards universal ARV access: Achievements and challenges in Free State Province, South Africa. *South African Medical Journal* 100(9):589–593.

UNAIDS. 2004b. *Combating AIDS in the developing world - UN Millennium project*. Geneva: UNAIDS.

UNAIDS. 2006. *Report on the global AIDS epidemic*. Geneva: UNAIDS.

UNAIDS. 2008. *UNAIDS' Terminology Guidelines*. Geneva: UNAIDS.

UNAIDS. 2010. *AIDS epidemic update*. Geneva: UNAIDS.

UNAIDS. 2011. *UNAIDS World AIDS Day Report. How to get to zero: Faster. Smarter. Better*. Geneva:UNAIDS.

UNAIDS. 2012. *The global AIDS epidemic – key facts*. Available at www.unaids.org. (Accessed on 30.10.2012).

UNICEF. 2012. *Child information: Monitoring the situation of children and women*. Available at www.childinfo.org. (Accessed on 31.10.2012).

UNGASS. 2010. *Country progress report on the declaration of commitment on HIV/AIDS*. Available at www.unaids.org. (Accessed on 20.10.2012).

Van Dyk, AC. 2011. *Antiretroviral treatment in South Africa: Are we burning our bridges?* Available at <http://uir.unisa.ac.za>. (Accessed on 30.10.2012).

Vawda, YA & Variawa, F. 2012. Challenges confronting health care workers in government's ARV rollout: Rights and responsibilities. *Potchefstroom Electronic Law Journal*. Available at <http://www.saflii.org/za/journals/PER/2012/30.html>. (Accessed on 30.10.2012).

Walliman, N. 2011. *Research methods: The basics*. New York & London: Routledge.

- Weidle, PJ, Wamai, N, Solberg, P, Liechty, C, Sendagala, S, Were, W, Mermin, J, Buchacz, K, Behumbiize, P, Ransom, RL & Bunnell, R. 2006. Adherence to antiretroviral therapy in a home-based AIDS care programme in rural Uganda. *Lancet* 368:1587-1594.
- Weiser, S, Wolfe, W, Bangsberg, D, Thior, I, Gilbert, P, Makhema, J, Kebaabetswe, P, Dickenson, D, Mompoti, K, Essex, M & Marlink, R. 2003. Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *Clinical Science Journal of Acquired Immune Deficiency* 34(3):281-288.
- Wekesa, E. 2007. *ART adherence in resource poor settings in Sub-Saharan Africa: A multi-disciplinary review*. Available at <http://uaps2007.princeton.edu>. (Accessed on 02.05 2011).
- WHO. World Health Organization. 2003. *Adherence to long-term therapies: Evidence for action*. Geneva: WHO.
- WHO. World Health Organization. 2005. *Introducing ARV therapy in the public sector in Botswana*. Geneva: WHO.
- WHO. World Health Organization. 2010. *Guidelines on antiretroviral treatment*. 2010. Available at <http://www.who.int/>. (Accessed on 15.08.2010).
- WHO. World Health Organization. 2011. *ART in prevention of HIV and TB. Frequently asked questions*. Geneva: WHO
- WHO/UNAIDS. 2006. *Progress on global access to HIV antiretroviral therapy: A report on '3 by 5' and beyond*. Geneva: World Health Organization/United Nations Joint Programme on AIDS.

WHO/UNICEF. 2010. *Towards universal access: Scaling up priority HIV/AIDS interventions in the health sector*. Available at <http://www.who.int/>. (Accessed on 15.08.2010).

Yoder, PS, Mkhize, S & Nzimande, S. 2009. *Patient experiences in antiretroviral therapy programmes in KwaZulu-Natal, South Africa*. Calverton: Health Systems Trust and Macro International.

Zou, J, Yamanaka, Y, John, M, Watt, M, Ostermann, J & Thielman, N. 2009. Religion and HIV in Tanzania: Influence of religious beliefs on HIV stigma, disclosure and treatment attitudes. *BMC Public Health* 9:79.

LIST OF ANNEXURES

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Provincial Department of Health

ANNEXURE 1

7 Eagle Creek
Rugby Road
Weltevreden Park
1709
11 April 2011

The Hospital Chief Executive Officer
Shongwe Hospital
Private Bag. X301
Shongwe Mission
1331

For Attention: Mrs. M.T. Themba

Dear Madam,

RE: REQUEST FOR ACCESS TO CONDUCT RESEARCH AT SHONGWE HOSPITAL

I am a student registered for Master's Degree (Social Behaviour Studies in HIV/Aids) with the University of South Africa. I intend doing research in your area and would like to request permission to access information on your patients' files for the purposes of conducting this research and interviewing individual patients for more detailed information. The title for my dissertation is:

“Factors that influence treatment adherence for people living with HIV and accessing antiretroviral therapy in rural communities in Mpumalanga”.

The objectives of this study are to:

- Investigate the social context of patients on antiretroviral therapy (ART) so as to identify the main contributing factors to adherence and fall out (that is, patients lost to follow-up, LTFU)
- Identify the socio-economic factors that support adherence amongst rural PLWH and accessing ART
- Identify the socio-economic factors that drive fall out (LTFU) amongst rural PLWH and accessing ART

The proposed research design is a mixed-method research design. As patients lost to treatment may be particularly hard to trace and interview, the researcher intends to use a mixed design in which the background information on patients as noted in their case files are used in addition to in-depth, face-to-face interviews with adherent and non-adherent patients. The goal is to compare and describe the socio-economic contexts of these two groups so that the socio-economic factors that either support or hinder adherence can be discovered.

The proposed data sources are thus patient records and interviews conducted according to an interview schedule. Given the nature of confidentiality, the researcher will rely on non-random sampling and ask for volunteer research participants from the case files. Although this limits generalizability, the nature of the topic means that voluntary participation in the study is essential.

I will ensure that:

- The patients' consent is obtained prior to commencement of research interview
- The patients' well-being and dignity is not harmed or compromised in any way
- The participation of patients is completely voluntary and that they can withdraw from participation at any point should they wish to without any penalty
- The anonymity of the respondent, privacy and confidentiality of the session is maintained at all times
- The information obtained from this study will be analysed using relevant data analysis tools and be reported as part of the research report of this study and submitted as part fulfilment of the academic requirements at Unisa

Attached please find the ethical clearance letter from the Mpumalanga Provincial Department of Health for your information. Should you wish to contact me urgently my contact details are as follows:

Email: mildred.sithole@righttocare.org

Cell: 084 588 6322 Tel: 011- 7107143

Thanking you in anticipation of a positive response.

Yours faithfully

Mrs. B. M. Sithole

ANNEXURE 2

“FACTORS THAT INFLUENCE TREATMENT ADHERENCE FOR PEOPLE LIVING WITH HIV AND ACCESSING ANTIRETROVIRAL THERAPY IN RURAL COMMUNITIES IN MPUMALANGA”

CONSENT FORM

Dear research participant,

My name is Bongani Mildred Sithole and I am currently completing a Master's degree in Social Behaviour Studies in HIV/AIDS at the University of South Africa (UNISA). As a requirement for the degree, I have to conduct a research study about the response to HIV and AIDS in Africa.

The purpose of the study is to investigate the social and economic context of patients on antiretroviral therapy (ART) so as to identify the main contributing factors to adherence and fall out (that is, patients loss to follow-up, LTFU). For this reason, I will interview both adherent and non-adherent patients so as to compare and describe the socio-economic contexts of these two groups so that the socio-economic factors that either support or hinder adherence can be discovered.

This is therefore an invitation to participate in this study. If you agree to do so, it is important to take note of the following:

- You will be asked to respond to questions about you and your experiences in an interview that will take approximately two hours.
- Your participation is voluntary and you will not be penalised in any way should you decide not to participate. However, without your kind co-operation, we cannot gather scientific data that will help us understand the problems experienced and improve service delivery. This is therefore an urgent appeal to you to please participate.
- No personal particulars or identifying details such as names will be documented on the research guide. This is because nobody outside the research team has to know who answered what.
- Everything we discuss during the interview will be kept confidential i.e. between you and the person asking the questions. So you can feel free to answer the questions as honestly as possible without fear that someone will

know what you said.

- You will be asked to sign the consent form and the signed forms will be kept separate from the questionnaires in a locked safe and destroyed 3 years after the study has been completed.
- You have the right to withdraw from participating in the study at any time should you feel you do not want to be part of the study anymore. If, however, you want to be part of the study, the interviewer will discuss a possible date and time for the interview and ask you to sign this document in two copies: one will remain with you and the other one will be kept by the interviewer.
- Other participants in the community will also be asked to participate in this study.
- Should you need to contact the researcher for support she can be contacted on 0845886322.

I have read and understood this consent form, and I agree to participate in this study.

Participant's signature:

Interviewer's name:

Signature

Signature

Date

Date

ANNEXURE 3

INTERVIEW SCHEDULE

SECTION A: DEMOGRAPHIC INFORMATION

1. Age :

2. Gender :

F		M	
----------	--	----------	--

3. Marital Status

Single	
Married	
Divorced	
Cohabiting	
Widowed	
Separated	

4. Educational Level

No schooling	
Primary School	
Secondary School	
Tertiary Institution	

5. What is your place of residence?

6. Is this an urban or rural area?

7. Are you currently employed?

Yes		No	
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8. If yes, what type of job do you do?

9. If not, what is the major source of income for your family?

SECTION B: SOCIAL AND ECONOMIC FACTORS

10. Do you have any other source of income besides a salary?

Yes		No	
-----	--	----	--

11. If yes please specify, nature of income.

12. Do you incur any losses in terms of income as a result of attending the clinic?

Probe: Transport cost to attend clinic

Probe: Time lost to search for job, if unemployed

Probe: Do you have to take leave

Probe: Do you have to pay a child minder

13. Who do you stay with at home? (Answer all options)

	Yes	No
Spouse		
Children under 18 years		
Children 18 years and older		
Parents		
Extended family		
Any other (Please specify)		

14. How many people stay in your house?

15. Do you have any children? What are their ages?

16. How did you feel when you were told that you were infected with the HIV?

17. Did you disclose your HIV status to anyone?

18. If yes, how did they respond towards you after the disclosure?

19. If not, what were your reasons for not disclosing?

20. Looking back do you think disclosing was of any benefit to you?
Probe: How have you benefitted?

SECTION C. TREATMENT AND ADHERENCE FACTORS

21. Can you remember when exactly did you start taking your antiretroviral treatment?

Date: _____

22. Which regimen of treatment are you currently on?

TREATMENT REGIMEN	TICK
1 st line	
2 nd line	
Salvage	

23. What does treatment adherence mean to you?

24. Did you attend any adherence counselling sessions before starting treatment?

Yes		No	
-----	--	----	--

25. How was that experience for you?

26. Who was your treatment supporter during adherence counselling sessions?

TREATMENT SUPPORTER	TICK
Spouse	
Children	
Relative/Family	
Friend	
Any other	

27. How often do you normally attend clinic to get your treatment?

28. When was the last time you attended the clinic to get your ARV treatment?

29. How long does it take you to come to the clinic? Here I refer to the travelling time between your departure point (home or work) and the clinic.

30. How do you get to the clinic and what transport do you use per trip?

31. Tell me about your experiences of being on ARV's?

32. Can you share with me the changes you have noticed after being initiated on treatment, if any?

33. What are the major challenges or difficulties you face as a result of being on ARV treatment?

Probe: Side effects – have you experienced any; what did you do when you experienced those.

Probe: Taking medicines on time – are you able to take your medicines on time. If not, what are the major barriers to taking your medicines timeously?

Probe: Diet – do you normally have sufficient food to take with your medications and how does this impact on adherence.

Probe: Support – do you have anyone to discuss your challenges with regarding treatment?

Probe: Adherence – would you be able to share your experiences as far as adherence is concerned?

34. Have you ever missed a dosage of your treatment?

Yes		No	
-----	--	----	--

35. How often does this happen

MSISSED DOSAGE	
Once a week/often	
Once a month	
Once in three months	
Rarely	
Never	

36. Under what circumstances do this normally happen?

37. What are the things or circumstances that make it difficult for you to take your treatment as prescribed by the health care worker?

Probe: Personal (time, memory, adherent, intrinsically)

Probe: Interpersonal (stigma, hide, pressure, non-support)

38. What are the things or circumstances that encourage or make it easier for you to take your treatment as prescribed by the health care worker?

Probe: Personal versus interpersonal issue

39. How do you feel about the service that you receive at the clinic?

Probe whether experience of service enables or hinders adherence. How do you think the attitude of health care professionals impacted or contributed to your treatment adherence?

40. If you were to rate the service, on a scale of 1 to 5 with 1 being very poor and 5 being very good what score would you give them in terms of service ?

1	Very Poor	
2	Poor	
3	Average	
4	Good	
5	Very good	

THANK YOU FOR YOR PATICIPATION.

ANNEXURE 4

FOCUS GROUP QUESTIONS

1. LEARNING ABOUT HIV STATUS

Can you tell me about the circumstances that led you to getting an HIV test for the first time: where and when, and how it happened?

PROBES

- What were the circumstances that made you decide or motivated you to take the test
- Where and when were you tested
- How do you feel about the counselling received when you were given your results
- Who did you share your results with or disclosed your status to.
- What were your reasons for disclosing to that particular individual(s)
- Looking back do you think disclosing was of any benefit to you?
- If so how have you benefitted?

[illegible]

2. TREATMENT AND ADHERENCE FACTORS

2.1 ARV Regimen

Could you please tell me about the ARVs that you take: which ones, how often, where you get them, etc?

PROBES

- Specifics of taking the medications
- Who knows about their taking ARVs
- How they learned, why they were told
- How and how often they collect the drugs
- Meeting with counsellors or health care providers at clinic

This image shows a single sheet of white paper with horizontal blue ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

2.2 Effects on them of taking the drugs

Once you started taking the drugs regularly, how did the ARVs affect you and your life?

Probes

- Health
- Daily routine/schedule
- Interpersonal and/or social relations
- Sexual relations

[illegible]

2.3. Who can tell us what they think they have benefitted from being on ARV therapy.

This image shows a single sheet of white paper with horizontal ruling lines. The lines are evenly spaced and run across the width of the page. There are no margins, text, or other markings on the paper.

2.4. Circumstances or things that has encouraged or enabled you to take your treatment well?

I am interested in hearing about how people find ways to keep taking their drugs or don't take them anymore. How has this been for you?

PROBES

- What are the ways that you have found helpful in taking your drugs?
 - Other people who assist them
 - Getting the food necessary
 - Hiding from others that they take ARVs
 - Things they have tried to help themselves that have failed

This image shows a full page of blank, lined paper. It features approximately 28 horizontal blue or grey lines spaced evenly apart, typical of notebook paper. The lines extend across the entire width of the page, leaving small margins at the top and bottom. There are no vertical lines, text, or other markings on the page.

2.5. Circumstances that make it difficult to take your treatment as prescribed.

What kinds of things make it difficult for you to take the treatment regularly?

PROBES

- Having others know they take drugs
- Remembering the right time
- Finding the right food to eat

This image shows a full page of blank, lined paper. It features approximately 28 horizontal blue or grey lines spaced evenly apart, typical of notebook paper. The lines extend across the entire width of the page, leaving small margins at the top and bottom. There are no vertical lines, text, or other markings on the page.

ANNEXURE 5

INTERVIEW QUESTIONS FOR HEALTH CARE PROFESSIONALS

HCP: _____

Knowledge of how patients manage to take their medication or not

I would like to hear about experiences of patients who have done well with taking their treatment and those who have done poorly.

PROBES:

- Examples of patients who have done well
- Examples of patients who have struggled
- Strategies you think work well for patients
- Circumstances that make it difficult for patients to take their medication
- Experiences with patients who miss treatment
- Contacts with patients who have missed taking their drugs

[illegible]

ANNEXURE 6: UNISA ETHICAL CLEARANCE LETTER

ANNEXURE 7:

PERMISSION TO ACCESS RESEARCH SITE FROM DEPARTMENT OF HEALTH.