DETERMINANTS OF EXCELLENT AND POOR ADHERENCE TO ANTIRETROVIRAL THERAPY IN BARBERTON

By

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DECLARATION

I declare that DETERMINANTS OF EXCELLENT AND POOR ADHERENCE TO ANTIRETROVIRAL THERAPY IN BARBERTON is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any other institution.

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Tariro Chikoka       Date

20 October 2015
ABSTRACT

Background: South Africa has a generalised HIV epidemic which is managed through free Antiretroviral Therapy (ART). Adherence to ART has emerged as a crucial issue in HIV/AIDS therapeutics.

Purpose: The aim of the study was to explore determining factors for poor and excellent adherence to ART for HIV positive patients residing in Barberton, a mining town in Mpumalanga Province.

Methodology: A generic qualitative research design was undertaken. Data was collected through in-depth qualitative interviews from a purposive sample of 13 ART patients. Qualitative interpretive analysis was employed.

Findings: The study found that excellent adherence to ART is significantly associated with the availability, effectiveness and comprehensiveness of HIV services, psychological support and medical advances. Side effects of ART, opportunistic infections and alcohol and drug use hinder adherence. However, longer duration on ART enhanced self-efficacy and facilitated adherence. Successful ART is dependent on taking ARVs as prescribed and executing necessary lifestyle changes.

Keywords: Adherence, patient, self-efficacy, opportunistic infections
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- Research participants, for taking time off their busy schedules to participate in the study.
- The Mpumalanga Province: Department of Health, for giving me permission to conduct the study.
DEDICATION

To my mother. You made me the woman I am.
### ABBREVIATIONS

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tbody>
<tr>
<td>AIDS</td>
<td>Acquired Immunodeficiency Syndrome</td>
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<tr>
<td>ART</td>
<td>Antiretroviral Therapy</td>
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<tr>
<td>ARVs</td>
<td>Antiretrovirals</td>
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<tr>
<td>ASSA</td>
<td>Actuarial Society of South Africa</td>
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<tr>
<td>ANC</td>
<td>Antenatal</td>
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<tr>
<td>FDC</td>
<td>Fixed-dose combination</td>
</tr>
<tr>
<td>GARPR</td>
<td>Global AIDS Response Progress Report</td>
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<tr>
<td>GFATM</td>
<td>Global Fund to fight AIDS, Tuberculosis and Malaria</td>
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<tr>
<td>HAART</td>
<td>Highly Active Antiretroviral Therapy</td>
</tr>
<tr>
<td>HBC</td>
<td>Home Based Care</td>
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<tr>
<td>HIV</td>
<td>Human Immuno-deficiency Virus</td>
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<tr>
<td>PEPFAR</td>
<td>United States President’s Emergency Program for AIDS Relief</td>
</tr>
<tr>
<td>PLWH</td>
<td>People Living With HIV/AIDS</td>
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<tr>
<td>STD</td>
<td>Sexual Transmitted Disease</td>
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<tr>
<td>TCE</td>
<td>Total Control of the Epidemic</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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CHAPTER 1

ORIENTATION TO THE STUDY

1.1 INTRODUCTION

Adherence to Antiretroviral Therapy (ART) has emerged as a crucial issue in HIV/AIDS therapeutics. Adequate drug potency and favourable pharmacologic properties of Antiretroviral (ARV) agents are essential for obtaining therapeutic benefit. However, behavioural aspects for proper adherence to medication often determine therapeutic outcome, (Brown & Bussell 2011:304). Nearly perfect adherence is necessary to build up an immune system, achieve viral suppression, and protect against the development of drug-resistant strains of the virus. ART scale-up in sub-Saharan Africa has made it possible to investigate the maintenance of adherence to HIV medications, (Roux, Kouanfack, Cohen, Marcellin, Boyer, Delaportw, Carrieri, Laurent and Spire 2011:S40).

The human immunodeficiency virus (HIV) pandemic continues to spread in the population making HIV disease one of the most important public health crisis in the world, (Monjok, Smesny, Okokn, Mgbere and Essien 2010:69). According to the HIV and Human Rights in Southern and East Africa Report [HHRSEAR] (2014:12) Sub-Saharan Africa continues to bear the brunt of the epidemic with nearly one in 20 adults (4.9%) is living with HIV and they account for 69% of all people living with HIV. In South Africa the prevalence of HIV among adults aged 15-49 stood at 18.1% in 2010, approximately one in every five adults, (World Health Report 2010:32). Initiatives by the government through the Department of Health, United States President’s Emergency Program for AIDS Relief (PEPFAR) and the Global Fund to fight AIDS, Tuberculosis and Malaria (GFATM) have responded to the HIV pandemic by expanding the provision of ART to the increasing number of affected patients including those in Barberton community. Barberton is a small mining town in Mpumalanga province with a population of 67 156 and 4 gold mines namely The Agnes, Fairview, New Consort and Sheba Reef gold mines, (www.sahistory.org.za). The town is ravaged by poverty, crime, unemployment, alcohol and substance abuse and HIV prevalence has exacerbated the people’s plight, (Umjindi Local Municipality Integrated Development Plan Report 2010:9-
10). Analysing the determinants associated with excellent or poor adherence to ART in Barberton is essential in addressing initiatives to HIV/AIDS management in the fight against HIV/AIDS.

1.2 BACKGROUND

According to a USAID report on HIV/AIDS health profile for Sub-Saharan Africa (2012:1), South Africa is among the countries with the highest prevalence of HIV infection in the world and one of the few countries providing free ART to patients with HIV sero-positivity. Mpumalanga is the second highest province in HIV-prevalence after KwaZulu Natal, according to Shisana, Rehle, Simbayi, Zuma, Jooste, Zungu, Labadarios and Onoya (2014:25).

A lot of research has been done thus far to determine ART patients’ adherence to ART from continental, national, provincial to district levels. However, a minimal number of researches have been done in Mpumalanga province. Skovdal, Campbell, Nhongo, Nyamukapa and Gregson (2011:296) did a research in Zimbabwe on adherence to ART but paying particular attention to contextual and psychological determinants to ART in the rural part of Zimbabwe. Other researches from South Africa have been conducted at national or provincial level, for example research by Yoder, Mkhize and Nzimande (2009:1) who’s focus area was KwaZulu Natal. This research not only focused on adherence to ART but also ART programmes available in that province, how the programmes are monitored, and importance and measurement of adherence. Participants of this study were ART patients and health care professionals. Another research focusing on KwaZulu Natal province again focused on adherence, information, motivation and behavioural skills of ART patients in public hospitals (Peltzer, Friend-du Preez, Ramlagan and Anderson 2010:1). The participants of the study were only those who had been on ART for at least six months. Other researches were conducted at district level, for example research done by Zungu (2009:3) which focused on Gert Sibande District in Mpumalanga. The research focused on adherence to ART in AIDS patients as well as how the adherence is measured at two hospitals, Bethal which is located in the urban area and Embuleni located in a rural area.
The current study focuses on Barberton community in Mpumalanga. Barberton is characterised by high prevalence of HIV and high levels of alcohol and substance abuse, crime and unemployment (Umjindi Local Municipality Integrated Development Plan Report 2010:9-10). The researcher has been exposed to the community through clinical work in alcohol and substance abuse prevention and treatment. Through work experience the researcher observed that most of the clients with drug dependency problems or drug addiction were on ART and the two (drug addiction and ART) have an effect and influence each other. Such observations sparked an interest in the researcher to explore the kind of effect such behaviours have on ART adherence.

In Barberton the government, in partnership with the private sector has rolled out programmes to assist HIV infected people in getting and adhering to treatment amongst which are the Total Control of the Epidemic (TCE) project and partnerships with number of Home Based Care Organizations. The South African Government is putting efforts through a number of home-based carers to ensure adherence to ART in Barberton. The home-based carers are trained and equipped to go around empowering HIV positive patients to adhere to their treatment and offer support to both ART patients and their families.

1.3 STATEMENT OF THE RESEARCH PROBLEM

Adherence to ART is a huge determinant of the success of the treatment, (AIDSinfo 2014:K1). ART patients face different challenges and situations, both positive and negative, as they continue with their medication which eventually influences them to either adhere or not adhere to ART. A lot of research has been done focusing on adherence and other related issues and such studies have been conducted at different levels ranging from continental level down to district levels, for example the researches done in Zimbabwe, KwaZulu Natal and Gert Sibande district as stated earlier. There has not been much research done in Mpumalanga province and not much research has been done at much local levels. Therefore this study sought to explore the factors that either hinder or encourage ART patients’ adherence to their treatment at a much local scale, Barberton community.
1.4 AIM OF THE STUDY

1.4.1 Research purpose

The purpose of the current research was to investigate the determining factors for excellent and poor adherence to ART for HIV positive patients on ART residing in Barberton, a mining town in Mpumalanga Province of South Africa.

1.4.2 Research objectives

In order to meet the purpose of this study the following objectives were made:

1. To explore and describe factors leading to adherence and or non-adherence to ART
2. To establish availability of services for ART services in Barberton

1.5 SIGNIFICANCE OF THE STUDY

The study has significance for patients on ART, health care providers as well as policy makers.

1.5.1 Significance to health providers and ART patients

The current study empowers ART patients with knowledge on adherence to their treatment as their participation did not only serve as a reflection on how they have been adhering to ART, but also reinforce basic ideas about adherence. For patients who did not receive adequate counselling and information, the study helped them in that they were identified and proper referrals to professional counsellors or professionals who deal with ART administration were made.

When health professionals dealing with ART patients are able to understand their patients and know how best to use their expertise to address their specific needs, it means a better functioning health practice for the communities and the country at large. This means the study benefits not only ART patients but the health professionals who assist them and the community as well, both HIV-infected and those who are affected.
1.5.2 Significance to policy makers

The knowledge generated from the study is valuable to programme managers involved in managing HIV/AIDS by giving an insight into not only what makes ART patients not adhere to treatment but also what makes them adhere to treatment. In this way they are able to plan interventions that directly address the raised issues or determinants and interventions that will be more responsive to the ART patients’ needs.

The results of this study will contribute to HIV/AIDS literature and advance the management of the epidemic.

1.6 DEFINITIONS OF TERMS

Adherence

Brown & Bussell (2011:304) quoted World Health Organization (WHO) and defined adherence as the extent to which a person’s behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider.

This study adopts the WHO definition as adherence is not limited to taking prescribed medication (ARVs) but also encompasses numerous health-related behaviours.

Patient

Oxford dictionary (2015:459) defines a patient as a person receiving or registered to receive medical treatment. In this study patient refers to an HIV positive adult person on ART who resides in Barberton.

Self-efficacy

Self-efficacy is defined by Bandura as a term that refers to an individual's belief in his or her capacity to execute behaviours necessary to produce specific performance attainments. It reflects confidence in the ability to exert control over one’s own
motivation, behaviour, and social environment, (Carey & Forsyth 2015). In the same context this study defines self-efficacy as ART patient's belief, ability and confidence in taking ART to manage HIV.

Opportunistic infection

An opportunistic infection is an illness caused by any one of various organisms that occur in people with weakened immune systems, including people with HIV/AIDS (www.aids.gov). Opportunistic infections that are common in people with AIDS include pneumocystis carinii pneumonia (PCP); cryptosporidiosis; histoplasmosis; toxoplasmosis; other parasitic, viral, and fungal infections; and some types of cancers.

Opportunistic infections in this study refer to any infections that ART patients suffered after commencing ART.

1.7 METHODOLOGY

This study used a generic qualitative research design which most authors argue as a design that is created by the researcher, is moulded (rather than dictated) by the method, and is responsive to the context and the participants, (Qualitative research 2006:74). Generic qualitative research allowed the research to gain rich understanding on factors which hinder or encourage HIV positive patient in taking their chronic medication.

The participant population was both male and female HIV positive patients on ART residing in Barberton at the time of the study. 13 participants were purposively sampled from the Barberton HIV register (sampling frame) based on the eligibility criteria of being above the age of 18 years, both genders and both employed and unemployed.

The research instruments used to gather information from the participants was the researcher and in-depth interviews. The researcher used a grand tour question, “Could you tell me about your experience with antiretroviral therapy?” and allowed the
participants the lead the interview. Probe questions were asked to meet the objectives to of study.

The collected data was analysed using interpretive data analysis which is oriented towards themes, Boeije (2010:94) followed by writing the report.

The detailed methodology of this study will be discussed fully in chapter 3.

1.8 TRUSTWORTHINESS

To ensure methodological validity or trustworthiness the logic of enquiry, procedures and measurement instruments must be valid and clearly described. Trustworthiness is the truth value of a piece of research, which a study has to meet for it to be trustworthy: credibility, transferability, dependability and confirmability, according to Holloway & Wheeler (2010:303).

1.8.1 Credibility

Credibility is when the participants recognise the meaning that they give to a situation or condition and recognise the truth of the findings in their own social context, according to Holloway & Wheeler (2010:303). This means that the researcher’s findings will be compatible with the perception of the people under study. This can be enhanced through peer debriefing where the researcher finds out whether colleagues arrive at similar interpretations when shown the data or the analysis. In this study the researcher performed member checks to verify emerging interpretations through feedback from the participants and to obtain their reaction. Probing of participants was done to ensure that the researcher understood the participants’ meanings of the experiences they shared.

1.8.2 Dependability

Dependability can be described as auditability. If other researchers can follow the investigator’s decisions throughout the study and come to the same conclusion, the study is auditable, Boswell & Cannon (2014:237). The study report has to be consistent
and accurate. This can be ensured by audit trails where the researcher provides detailed descriptions of the path of the research. Elaboration on the data collection, analysis and the methodological framework was done in this research to provide a clear audit trail. A description of the researcher’s role (research instrument), her training and more than 5 years’ experience in the field of HIV counselling and testing and therapeutic intervention also enhanced the dependability of the study. Electronic recording of each interview on a tape recorder was also done to enhance dependability of the study.

1.8.3 Confirmability

According to Boswell & Cannon (2014:237) confirmability is when findings of the research are not an outcome of the biases and subjectivity of the researcher (neutrality). It is the truth value of data and data analysis. Qualitative research is subjective in nature so to reduce chances of researcher bias or enhancing objectivity, the researcher has to uncover the decision trail for public judgment or be reflexive and show that the data can be traced back to its origins. An audit trail is reported and documented to enhance confirmability as it permits for external reviews of the research methods and the presented data. In this study the researcher kept good and clear records of the research process to enhance confirmability.

1.8.4 Transferability

Halloway & Wheeler (2010:303) describe transferability as when findings in one context can be transferred to similar situations or participants. For the findings on poor or excellent adherence to ART in Barberton to be transferable to the wider population, it required thick, accurate and detailed descriptions of the data. Purposeful sampling and the inclusion criteria were employed to give rich and specific information. Ensuring a wide range of variation on dimensions of participants’ age, employment status, marital status and social backgrounds helped enhance the transferability of the study findings.
1.9 STRUCTURE OF THE DESSERTATION

Chapter 1 Discusses the background of determinants of excellent or poor adherence to antiretroviral therapy, the problem statement in which the study purpose and objectives are outlined and key terms of the study were defined.

Chapter 2 Discusses the literature review on adherence and determining factors to adherence for HIV positive patients internationally, nationally, at district level down to community level.

Chapter 3 Discusses the research design and methodology including data collection, analysis and validity of the study.

Chapter 4 Presents data analysis and description of the research findings.

Chapter 5 Gives the conclusion to the study, interpretation of the research findings and recommendations.

1.10 CONCLUSION

Successful antiretroviral therapy is dependent on sustaining high rates of adherence, correct dosage, taken on time, in the correct way either with or without food coupled with necessary behavioural changes. None or partial adherence can lead to the development of drug-resistant strains of the virus. Through generic qualitative research, the research study explored the determinants of poor and excellent adherence to ART. Participants of the study were selected using non-probability sampling, particularly purposive sampling technique. Since the study involves humans there were measures put in place to ensure their safety, protection and upholding of their humanity. Participants had to meet the inclusion criteria to participate in the study which was being HIV positive, being on ART, residing in Barberton and being above 18 years of age. The resultant information from the participants was analysed using interpretive qualitative data analysis.
CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Sub-Saharan Africa continues to bear a disproportionate share of the global HIV burden. In mid-2010, about 68% of all people living with HIV/AIDS (PLWH) resided in sub-Saharan Africa, a region with only 12% of the global population (WHO 2011:24). While that is the case, antiretroviral therapy (ART) has been advancing in the Sub-Saharan Africa region and efforts are being enhanced to reach out to the 28.5million PLWH in the region. From 2009 to 2010, ART coverage increased more in sub-Saharan Africa than in any other region. During that time, the number of people receiving ART in sub-Saharan Africa grew by approximately 30 per cent from 3.9 million in December 2009 to 5.1 million 2010. Despite these increases, only 49 per cent of PLWHA in sub-Saharan Africa eligible for treatment under the 2010 WHO guidelines are receiving ART, (USAID 2012:4).

South Africa is habitat to one of the highest HIV prevalence in the Sub-Saharan region while Mpumalanga Province is the second most affected province in South Africa (Ige & Quinlan 2012:97). The government has put in place policies and interventions to manage the disease amongst which is the ART programme. However, the management of this pandemic through ART depends on adherence to the treatment. This study thus sought to understand the determinants of excellent and poor adherence to ART in Barberton, Mpumalanga. This chapter undertakes a literature review on the epidemiology of HIV/AIDS in South Africa and in Mpumalanga province, and how the pandemic has been managed through ART.

2.2 Epidemiology of HIV/AIDS in South Africa

HIV disease is a chronic and incurable condition in which progressive failure of the immune system predisposes one to life-threatening infections, if there is no treatment intervention, (www.aids.gov). HIV is spread through body fluids like blood, semen, cervico-vaginal secretions, rectal secretions and breast milk. The virus is transmitted
through unprotected sexual contact with someone who has HIV (anal, oral and vaginal sex), and having multiple sex partners or having other sexually transmitted infections can increase the risk of infection through sex (www.aids.gov). It is also transmitted through direct blood contact, including injection drug needles, blood transfusions, accidents in health care settings and from mother to child before or during birth, or through breast milk.

According to WHO (2011:24), South Africa’s HIV epidemic remains the largest in the world, with an estimated 5.6 million PLWH in 2009. Consequently, South Africa is one of the high-income countries in the Sub-Saharan region which has made ART widely available to PLWH. It has come a long way in providing comprehensive care and treatment for HIV infected people since 2003/4 when the roll out of antiretroviral (ARVs) began in public hospitals (Ige & Quinlan 2012:97). Ige & Quinlan (ibid) qualify the comprehensive care and treatment as the establishment of a minimum of one service point in every health district in the country where people receive ARVs, ARV-adherence monitoring and support, counselling, nutritional supplements and training on side effects, new health professionals and laboratory testing.

Statistics SA (2013:4) estimated that the overall HIV prevalence rate of South Africa increased from 9.3% in 2008 to approximately 10% in 2013. The total number of PLWH was estimated at approximately 5.26 million in 2013. For adults aged 15–49 years, an estimated 15.9% of the population is HIV positive. However, this data is less reliable for generating population level estimates as it is based primarily on the prevalence data collected annually from a select group of people, pregnant women attending public antenatal clinics since 1980. The data excludes pregnant women who use private health care, women who are not pregnant, and all men and children. Other researchers form Human Science Research Council estimated the HIV prevalence in adults aged 15-49 years at 16.9% in 2008, [Global AIDS Response Progress Report (GARPR) 2012:12]. Shisana et al (2014:25) share the same opinion and reported that in 2012, it is estimated that 12.2% of the population (6.4 million persons) were HIV positive, which is 1.2 million more PLWH than in 2008 (10.6%, or 5.2 million). According to Van der Linde (2013) the HIV prevalence in the country increased from 10.6% in 2008 to 12.3% in 2012. Although the statistics differ, what is common and what researchers agree on is the fact that HIV prevalence is high in the country.
While South Africa has a generalised HIV epidemic (pandemic common to all demographic groups), the pandemic has stabilised over the past four years at a national antenatal prevalence of around 30%, as stated by the Global AIDS Response Progress Report [GARPR (2012:12)]. Policies, medication and education have developed in an endeavour to lower the HIV prevalence to meet our millennium developmental goal number 6: Combat HIV/AIDS, malaria and other diseases. The government, working in partnership with the private sector to combat the epidemic has seen the number of people accessing ART in the public sector grow from 85 000 in 2005 to 100 000 in 2007 according to the AIDS Foundation of South Africa statistics and by mid-2012 it had increased to 2 million (Van der Linde 2013). Shisana et al (2014:27) argue that the epidemiological curve has shifted over the 4-year period between 2008 and 2012, presumably as a result of the effects of increased ART coverage. Peak HIV prevalence for females has shifted from the 25–29 year age group in 2008 to the 30–34 year age group in 2012, while for males it has shifted from the 30–34 year age group in 2008 to the 35–39 year age group in 2012. There has been a substantial downturn in AIDS related mortality in recent years, with the annual number of AIDS deaths reduced from about 257,000 in 2005 to about 194,000 in 2010, according to Actuarial Society of South Africa (ASSA) quoted in the GARPR (2012:12).

The South African government has been putting a lot of effort in making ART more accessible (GARPR 2012:28). However, it cannot be taken for granted that PLWH receive treatment but it is equally important to determine if they adhere to the treatment. An example of some of the research conducted in the country focusing on ART adherence is the qualitative study conducted by Yoder, Mkhize and Nzimande (2009:1) in KwaZulu Natal. The study focused on adherence to ART and the ART programmes available in that province, how the programmes are monitored, and the importance and measurement of adherence. Through individual interviews with ART patients health care professionals they found out that patients adhere better to ART with the help of a committed and informed treatment supporter who reminds them to take the medication or is there to discuss with them the necessary lifestyle changes; if they accept that treatment is for a lifetime and it will make them feel better; and disclosure to the people who know the patient. On the other hand adherence is hindered by dealing the side effects of the treatment, inadequate income for providing food and transport expenses and defaulting as treatment is a lifelong intervention.
Another research was conducted in KwaZulu Natal province and it focused on adherence, information, motivation and behavioural skills of ART patients in public hospitals, (Peltzer, Friend-du Preez, Ramlagan and Anderson 2010:1). It is a cross-sectional study of 735 HIV-positive patients who had been on ART or commencing the treatment. They were systematically sampled and interviewed from outpatient departments of three hospitals in UThukela health district.

While a lot has been done to offer ART extensively, a study prepared for the Congress of South African Trade Unions in 2008 estimated the number of people needing treatment but were not receiving to be 1.7 million in 2008, (Ige & Quinlan 2012:98). The HIV epidemic is severely hampering South Africa’s ability to achieve several MDGs, including the target of halting and reversing the spread of HIV and TB by 2015.

2.2.1 HIV in Mpumalanga

Mpumalanga is the second smallest provinces in the country measuring 79 490 square kilometres, which is a total of 6.5% of South Africa’s land area. It has a population of 67156, (www.statssa.gov.za). It is also the second highest province in HIV-prevalence with an estimated rate of 14.1% in 2008, behind KwaZulu Natal which recorded a 16.9%, according to Shisana et al (2014:25).

There is minimal published literature or researches conducted in Mpumalanga province. Most of the researches which have been conducted have focused mostly on one of the province’s districts, Gert Sibande due to its high HIV prevalence in the province. An example is the research done by Zungu (2009:3) which evaluated the determinants of ART in AIDS patients at two hospitals, Bethal which is located in the urban area and Embuleni located in a rural area and another research done by Pretoria researchers to identify factors that influence adherence to ARV prophylaxis by HIV positive mothers participating in the HIV prevention of mother to child programme, (Peltzer, Mlambo, Phaswana-Mafuya and Ladzani 2010:699). The high HIV prevalence has been attributed to high levels of migrancy with mining pulling people to seek employment in the district. Gert Sibande shares the border with Swaziland in the east, KwaZulu-Natal.
in the south-east, the Free State in the south-west and Gauteng to the west leading to high levels of to economic migrancy, (Health and Development Africa 2010:16). The district is also characterised by high unemployment particularly among women and alcohol use among other issues which are contributory factors to the high HIV prevalence. The 2008 antenatal (ANC) survey suggests that Gert Sibande district had the highest ANC prevalence of 40.5% in the province, according to Health and Development Africa (2010:16). Such a statistic has led to researchers seeking to find out more concerning issues around HIV in the district.

2.3 MANAGEMENT OF HIV/AIDS

2.3.1 ART and HAART

ART has been defined by a number of authors as treatment with a combination of at least three ARV drugs which maximally inhibit the ability of HIV to multiply in the body and stop the progression of the HIV disease.

Highly Active Antiretroviral Therapy (HAART) is the name given to aggressive treatment regimens used to suppress HIV viral replication and the progression of HIV disease. The HAART regimens have been proven to reduce the amount of active virus until it is undetectable by current blood testing techniques, (aids.about.com). The usual HAART regimen combines three or more anti-HIV drugs from at least two different classes. HAART has been in use since 1996 and has changed what was once a fatal diagnosis into a chronically managed disease, [National Institute on Drug Abuse (NIDA) 2012:2]

2.3.2 Importance of adherence to ART

HIV is the virus that causes AIDS and if not managed appropriately with ART can lead to death. Adherence is closely following (adhering to) a prescribed treatment regimen. It requires a patient to take the correct dose of a drug at the correct time, exactly as prescribed. Failure to adhere to an anti-HIV treatment regimen can lead to virology failure and drug resistance, (NIDA 2012:1). The World Health Organization defines adherence as “the extent to which a person’s behaviour—taking medication, following a diet, and/or executing lifestyle changes—corresponds to agreed recommendations from

For HIV infection to be transformed from a fatal condition to a manageable disease condition, high adherence is absolutely necessary. According to Hansana, Sanchaisuriya, Durham, Sychareu, Chaleunvong, Boonyaleepun and Schelp (2013:2), inadequate adherence results in antiretroviral agents not being maintained at sufficient concentrations to suppress HIV replication in infected cells to lower the plasma viral load. In addition, suboptimal adherence can accelerate development of drug-resistant HIV and mitigate ART’s role in reducing HIV incidence and transmission. Yoder, Mkhize and Nzimande (2009:14) are in agreement and noted that while high adherence is essential for positive outcomes in many domains; suboptimal adherence may lead to the development of viral strains that are resistant to the first-line drugs offered to ART patients. This possibility has both medical and economic implications, because second-line drugs are far more expensive, more complex, and may have greater side effects (AIDSinfo 2015:H6).

South Africa is one of the resource-limited countries which adopted the two sequential ART regimens for the public health approach to ART advocated by the World Health Organization. With the limited ART options available, it is particularly important for antiretroviral programmes to achieve high levels of adherence, (Maartens et al 2013:513).

2.3.3 ART interventions and policies in South Africa

In response to the epidemic new prevention efforts had to be established and similarly additional treatment strategies that would make the fight against HIV more sufficient, comprehensive and tailored to local epidemics. Strategies like stronger country surveillance systems, especially among key populations at higher risk of HIV infection, greater political commitment to implementing evidence-informed programmes and the development of improved tools to strengthen national responses and accelerate
progress towards achieving the Millennium Development Goals have been proposed (WHO 2011:62). Global efforts have been directed at scaling up select interventions for HIV prevention related to the health sector (male circumcision, blood safety and preventing sexually transmitted infections), addressing the role of ART and key emerging approaches for HIV prevention, such as pre-exposure prophylaxis and the use of ART for HIV prevention. Targeted preventative interventions at key populations at higher risk of HIV exposure and infection, particularly sex workers and men who have sex with other men as outlined by WHO (2011:62) have been considered to alleviate the impact of HIV prevalence.

With the focus on increasing universal access to free antiretroviral therapy, the South African government in partnership with non-governmental and business sectors has directed its efforts to combat the pandemic by targeting all demographic groups including pregnant women who are HIV positive, all persons with CD4 of less than 350 CD4 Cells/mm3 and all persons with TB who are co-infected with HIV, (GARPR 2012:2).

In 2000 the Department of Health initiated its HIV/AIDS/STD Strategic Plan for South Africa 2000-2005 with the goal of reducing the number of HIV infections and reducing the impact of HIV/AIDS on individuals, families and communities. The Plan focused only on the prevention and management of HIV/AIDS rather than on the treatment of PLWH. To address that the government initiated the roll-out for ART in 2003. A follow up Strategic Plan of 2007-2011 was an elaboration of the first Strategic Plan and it gave specific targets. It focused on reducing the number of new infections by 50% and reducing the impact of HIV on individuals, families and communities by expanding access to appropriate treatment, care and support to 80% of people diagnosed with HIV, according to Ige & Quinlan (2012:92&101).

Recommendations have been put forward to apply a holistic approach to ART to ensure more effective treatment. Lazarus, Christiansen, Ostergaard and Richey (2005:23) outlined the recommendations put forward by the department of Health as partnership of organizations; ensuring sustainability of ART; reducing dependency by making the recipients of the treatment pay part of the treatment so additional value is attached, and
removing any dichotomy between treatment and prevention because ARVs reduce the prevalence of opportunistic infections and reduce HIV transmission through reducing viral load and helping those who do not know their status to access health care facilities to get tested.

According to Shisana et al (2014:28), the country has managed to increase the number of people on ART, which has led to a decrease in AIDS mortality and an increase in life expectancy. There has been a dramatic increase of ART coverage in the country with over 2million PLWH having been reported to be on ART by mid-2012, (GARPR 2012:28).

The annual HIV surveys among pregnant women and household population surveys continue to show that the prevalence of HIV remains stable in the country and that the total number of persons living with HIV is still very high. This may be attributed to the impact of the ARV treatment programme, the largest in the world. Data are showing a reduction in HIV-related mortality particularly among women. In addition, mother to child transmission of HIV has declined from 8.5% in 2008, to 3.5% in 2010, a direct impact of the accelerated programme for the elimination of vertical transmission, as attributed by the GARPR (2012:2).

Although challenges remain, South Africa continues to monitor the epidemic and is continually assessing, strengthening and reviewing the response to the HIV and AIDS epidemic.

2.4 CONCLUSION

While sub-Saharan Africa continues to have the highest global HIV burden, there is evidence that strategies, policies and interventions put in place are to some extent responsive to the epidemic at country levels. South Africa has generalised HIV epidemic and continues to fight the impact of the epidemic on all demographic levels. Preventative and treatment interventions for HIV has yielded positive results and at the same time there are indications that more still has to be done especially in helping the
population groups who are at higher risk of exposure to HIV. ART has come a long way with more PLWH being reported to be on ART and at the same time more has to be done to manage how they take their treatment to ensure adherence and effective disease management.
CHAPTER 3

RESEARCH DESIGN AND SETTING

3.1 INTRODUCTION

Research methodology is what makes social science scientific making research design and method an essential guide on how a research study is done. This chapter discusses the research approach, design and methodological framework used to explore the research questions. It also explains in detail the sampling procedures, data collection and data analysis, as indicated in chapter 1.

3.2 RESEARCH APPROACH

This research used the qualitative research approach (naturalistic) which is defined by Polit, Beck and McGrath (2010:420) as the investigation of phenomenon, typically in an in-depth and holistic fashion, through the collection of rich narrative materials using a flexible research design. A qualitative research approach was the most appropriate for this study as Punch (2014:119) states that it is an approach whose philosophy is concerned with how behaviours and social processes are determined. It seeks to explore human complexity, putting emphasis on understanding everyday-life experiences of individuals, groups, societies and organisations through careful collection and analysis of qualitative materials that are narrative and subjective, in this case understanding factors around their adhere or non-adherence to ART. This approach allowed the researcher to utilize an interpretive or subjective approach focused on how the respondents experience and understand adherence to ART.

Qualitative research is research that usually takes places in the field, in real-world naturalistic settings which facilitates sustained contact. The researcher becomes a research instrument and can conduct studies in multiple sites (Polit & Beck 2014:269). Qualitative research is characterised by a holistic approach to questions. It recognises that ART experiences and realities for HIV positive patients are complex hence the approach strives for an understanding of the whole through in-depth interviews using mostly open questions to gather narrative information. Another characteristic of
qualitative research is that it is flexible and elastic. The researcher is capable of adjusting to what is being learned during the course of data collection. According to Polit & Beck (2014:259), this flexibility allows for evolving procedures to be used in the study. It therefore requires on-going analysis of the data to formulate subsequent strategies and to determine when fieldwork is done. Munhall (2011:114) qualifies this saying this flexibility is essential to the inductive approach of qualitative research.

3.3 RESEARCH DESIGN

This study used the generic qualitative research design. While there is a lot of debate going on as different authors try and outline what generic qualitative research is, most authors tend to agree that research design is created by the researcher, is moulded (rather than dictated) by the method, and is responsive to the context and the participants, (Qualitative research 2006:74). Lal, Suto and Ungar (2012:1) quotes Thorne who defines generic qualitative research as a non-categorical, highly interpretive approach that requires explication of theoretical influences, and an analytic framework that locates the interpretation within existing knowledge. On the contrary, Sandelowski (2010:78) suggests that generic qualitative research is categorical, less interpretive, and less abstract and has the goal of a straight descriptive summary of data. Merriam in Daymon & Holloway (2011:112) argue that basic or generic qualitative research are those studies that epitomise the characteristics of qualitative research but rather than focusing on culture as does ethnography, or the building of theory as does grounded theory, they simply seek to discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved. Caelli et al and Merriam are in agreement and in the same light define generic qualitative research studies as “those that exhibit some or all the characteristics of qualitative endeavour but rather than focusing the study through the lens of a known methodology they seek to do one of the two things: either they combine several methodologies or approaches or claim no particular methodological viewpoint at all. They go on to qualify this saying generic qualitative research design as “that which is not guided by an explicit or established set of philosophic assumptions in the form of one of the known qualitative methodologies.” This study adopts both definitions by Caelli et al and Mirriam. The generic qualitative research design allowed the researcher to develop a rich understand a phenomenon as it exists in the real world and as it is constructed by individuals in the context of that
world, in this case adherence to ART from the people who are taking the treatment, concerning factors that either hinder them from or encourage them to continuously take their chronic medication. The research design allowed one to address the research problem and objectives as they are non-experimental in nature and seek to understand why certain behaviours (adherence or non-adherence) occur.

3.4 RESEARCH SETTING

3.4.1 Population and sampling

According to Hissong, Lape and Bailey (2015:47) population consists of all subjects of interest. Polit & Beck (2014:393) define population as the entire aggregation of cases in which the researcher is interested, sometimes called universe. In the current study the participant population consists of all HIV positive patients on ART residing in Barberton community at the time of the study.

The accessible population, also known as the source population is the aggregate of cases that conform to designated criteria and that are accessible as subjects for the study. Halloway and Wheeler (2010:137) argue that the accessible population that has the particular experience or knowledge of the phenomenon which the researcher is seeking to explore is the target population. The study population consists of all the individuals whom the researcher can gain access to and who have the appropriate knowledge and experience while the sampling frame is the population from which the sample is chosen (Halloway & Wheeler 2010:137). Saks & Allsop (2013:186) argue that population and target population are terms which are used interchangeably referring to the same thing, Polit & Beck (2014:3393) goes on to define the target population as the entire population in which a researcher is interested and to which he or she would like to generalize the study results. The target population should be clearly defined in respect of person, place and time, (Banerjee & Chaudhury 2010:61).The target population for this study was both male and female HIV positive people on ART living in Barberton. The eligibility criteria was adults, (above 18 years of age), both employed and unemployed and who are on ART. The inclusion criteria are criteria that state what particular people are included in the research and it depends on the aim of the particular study Holloway & Wheeler (2010:144). For the current study the inclusion criteria is both
male and female HIV positive patients who are already on ART and residing in Barberton above the age of eighteen years.

Qualitative data sources consist mainly of people or conversations. Data sources utilised in the study are HIV positive patients on ART who reside in Barberton, the HIV coordinator for Barberton community to demarcate the study population, and home based care givers to locate research participants’ homes and introduce the researcher to the participants.

Polit & Beck (2014:391) define a sample frame as a list of all the elements in the population, from which a sample is drawn, and Gerrish & Lacey (2014:145) qualify it as a list or representation of the study population, either of individuals or of groups of individuals, depending on the specific type of random sampling used. The sampling frame for this study is the ART register from the Barberton HIV/AIDS coordinator listing all Barberton residents on ART.

Sampling according to Polit & Beck (2014:391) is the process of selecting a portion of the population to represent the entire population. Sampling enabled a study on a subgroup of HIV positive patients on ART living in Barberton to be done while being able to make generalisations to the entire population from which the group was drawn. This is supported by Faherty (2010:33) who argues that qualitative data is typically drawn from small samples.

The sampling method employed was non-probability sampling where each HIV positive patient on ART in Barberton did not have an equal chance of being included in the sample. According to Creswell (2014:158) a sample design is a definitive plan for obtaining a sample from a given population. It refers to the technique or the procedure the researcher would adopt in selecting items for a sample. Non-probability sampling ensured that the research samples were rich sources of data that generate in-depth conceptual understanding, (Gerrish & Lacey 2010:144).
The sampling technique used was purposive sampling. From the ART register a sample was selected using the purposive sampling technique also known as judgmental sampling, where sampling is based on the belief that the researcher's knowledge about the population can be used to hand-pick sample members, (Ritchie et al 2014:131). Based on the inclusion and exclusion criteria, the researcher together with the HIV/AIDS coordinator purposefully selected cases with a wide range of variation on dimensions of interest (maximum variation sampling), for example the age (to include adults only), both genders, employment status, diverse backgrounds, and the area of residence being Barberton. This is supported by Holloway & Wheeler (2010:138) when they state that the logic and power of purposeful sampling lies in selecting information-rich cases for in-depth study. Information rich cases are those from which one can learn a great deal about issues which are of central importance to the purpose of the research. Since the researcher does not personally know who constitutes the sample, the HIV coordinator for the Barberton community assisted in drawing up a list of possible participants of the study.

The purposive sample of this study consisted of a total of 13 HIV positive patients on ART and residing in Barberton.

Although the sampling method presents with a sampling bias from being rarely representative since some segment will be systematically under-represented, (leading to misleading results), it is convenient and affordable. Looking at the HIV topic in the context of our local communities, it still is a sensitive subject thus reducing numbers of willing participants. One has to subjectively utilise every possible participant until data saturation in order to make increased generalizability.

The sampling technique provided no external, objective method of assessing the typicalness of the selected subjects. To address these challenges presented by non-probability sampling and purposive sampling, the researcher utilised the maximum variation sampling strategy. According to Patton in Polit & Beck (2014:298), this is a strategy involving purposefully selecting cases with a wide range of variation on dimensions of interest, for example including both sexes, considering a range of social status, diverse backgrounds, different viewpoints, and so on. Sampling until data
saturation also helped to overcome the sampling challenges. It facilitated information adequacy and the resulting data was richly textured.

3.4.2 Data collection

3.4.2.1 Data collection approach and method

Data collection allows the researcher to understand how the subjects perceive their situation and their role within this context. This study used qualitative data collection approach and the data collection instruments used were the researcher and in-depth interviews.

Punch (2014:144) states that interviewing is the most prominent data collection tool in qualitative research and is a good way of accessing people's perceptions, meanings, definitions of situations and constructions of reality. According to Walker (2011:20), research interviews can be located along a continuum with structured and unstructured interview types representing opposite ends of the spectrum. While structured interviews include a fixed set of questions to be answered in a specified sequence and give participants limited opportunities to qualify their responses or explain the underlying meaning of their responses (Punch 2014:146), unstructured interviews are conversational and interactive, are a mode of choice when the researcher does not have a clear idea of what it is they do not know and the researcher lets the participants tell their stories (Punch 2014:147). The study used semi-structured in-depth interviews. The researcher had a topic guide, encouraged participants to talk freely about their experiences with the ART and participants could tell their stories in their own words. Gerrich & Lacey (2010:349) highlight that semi-structured interviews retain the flexibility necessary to follow issues raised by participants that had not been anticipated.

3.4.2.2 Characteristics of the data collection instrument

In qualitative research the researcher is the research instrument. Lincoln and Guba in Peredaryenko & Krauss (2013:2) introduced the concept of the human being as the research instrument to stress the uniqueness of the researchers’ role in the process of
scientific inquiry. This uniqueness lies in the notion that only people construct and bring meaning into the world through their qualities of sensitivity, responsiveness and flexibility, making them the most appropriate instrument for inquiries aiming to arrive at understanding, meaning, the promotion of critical awareness, emancipation, and movement toward deconstruction or decolonization, in this case understanding from ART patients the factors which promote or hinder their adherence to ART.

The researcher acted as the "human instrument" of data collection as outlined by Denzin & Lincoln in Chenail (2011:255). The researcher was the key person in obtaining data from participants. It is through the researcher's facilitative interaction that a context is created where respondents share rich data regarding their experiences and life world, (Chenail 2011:255), that is a context where ART patients were able to share their experiences around adherence and non-adherence to ART. The researcher ensured that the questions asked were understood by the participants in order to meet the objectives of the study. It was essential that the researcher created a safe and comfortable environment for the interviews to enhance participants' potential for full exploration.

Van Manen in Paterson & Higgs (2005:348) asserts that interviews have two purposes; as a means to explore and gather experiential narratives material that may serve as a resource for developing a richer and deeper understanding of human phenomenon (descriptive); and as a vehicle to develop a conversational relation with a partner (interviewee) about the meaning of experience (interpretive). The researcher engaged with research participants to try and describe and interpret the participants' experiences with ART and how such experiences facilitate or hinder their adherence to ART. Open-ended questions gave the research participants an opportunity to give in-depth responses of how they see and understand their experiences of ART.

3.4.2.3 Data collection process

The researcher sought permission to conduct the study from Mpumalanga Department of Health Ethics Committee. When permission was granted the researcher had a discussion with the HIV coordinator for Barberton concerning the study and coming up with a sampling frame. Participants were purposively selected from HIV register.
Appointments were made prior to meeting with the individual participants and the researcher personally approached the 13 participants individually to explain to them about the study, its importance, the participants’ role and all the ethical issues.

The researcher sought to ensure that the research participants felt comfortable and are able to open up especially given the sensitive and personalised nature of the research topic. Most of the participants opted to do the interviews in neutral locations and they chose the time when they felt most comfortable to conduct the interviews.

All participants who met the inclusion criteria, understood their participation in the study, agreed to participate in the study and gave their written consent were selected for the study. Interviewer directed semi-structured interviews were administered and the process was audio taped with the permission of the participants. Punch (2014:147) highlights semi-structured interviewing as effective since it gives the respondents the opportunity for personal exploration and detailed responses to enhance understanding of the subject which is essential in meeting the study objectives. In-depth interviewing as a form of discussion between the interviewer (the researcher) and the interviewee (the HIV patient on ART) on factors that determine the interviewee’s poor or excellent adherence to ART enabled much exploration on the subject resulting in rich data.

The researcher used a grand tour question in the interviews which allowed the participants to set the direction of the interview (Scaife 2013:36). The researcher then followed the leads that the participants provided. Probe questions were also used in order to meet the objectives of the study. The participants were asked, “Could you tell me about your experience with antiretroviral therapy?” as the grand tour question. Other questions asked were:

1. What was your experience when you learnt that you are HIV-positive? (Then probe)
2. What do you understand about the ART programme? (Then probe)
3. Tell me about the psychological support that you have. (Then probe)
4. What are your experiences of having been on ART? (Then probe)
5. What are some of the opportunistic infections you have suffered? What was it like to have those infections? (Then probe)
6. I appreciate you time. Is there anything else you would like to tell me that can help in this study?
7. Would it be alright to call you if I need more information?

The researcher then followed the leads that the participants provided. While using no-directive probes like “What else?” helped the researcher to get in-depth information it also enabled certain responses to be questioned in greater depth which facilitated in weighing up the credibility of responses from inconsistencies and exploring the underlying motives more directly. Clarity was sought from study participants on issues that were not understood or not clear to the researcher. Because the interviews were conducted with one respondent at a time, the individual focus allowed the interviewer to draw out the information in more detail. As this is an emotive issue (adherence to ART amongst HIV patients), individual focus facilitated a more conducive environment for full exploration.

All the interviews were conducted in a period of 6 weeks.

There is no total accuracy with semi-structured interviews since people have to report on their attitudes. Other challenges include boredom and fatigue on the researcher’s part leading to incorrect recording of responses, third party bias, and giving responses that respondents feel are more acceptable. Such challenges called on the researcher to schedule fewer interviews per day to enhance accurate data collection, conducting interviews where there is privacy and the interviewee is comfortable, and asking open ended questions in order to pick any inconsistencies in the interviewees’ responses, respectively.

In-depth interviewing can be an emotionally and physically exhausting process as it requires intense concentration. It was essential then for the researcher to collect data at a pace that minimised the emotional impact like conducting one interview per day and engaging in emotionally releasing activities (exercising and debriefing) between interviews.
3.4.2.4 Ethical considerations related to data collection

Mack, Woodsong, Macqueen, Guest and Namey (2005:9) argue that research ethics deal primarily with the interaction between the researcher and the research participants to ensure that the well-being of the participants is priority. The four ethical principles which guide research are respect for persons, beneficence, justice and respect for communities. Van der Walt & Van Rensburg (2006:31) support Mack et al when they state that ethical principles are based on human rights that need to be protected in research; but state the ethical principles as rights to self-determination, privacy, anonymity and confidentiality, fair treatment and being protected from discomfort.

To show respect for persons or participants the researcher had to uphold every participant’s dignity and treat them with respect. The research participants were given an indication that the researcher is competent to conduct research in sensitive areas like in this study, on HIV and adherence. Indication was given that the researcher is a qualified social worker, has been trained in the field of HIV/AIDS to do counselling and testing and that she has six years’ experience in practice. With the area of study being such a sensitive issue the researcher elaborated on beneficence. Mack, et al (2005:9) state that beneficence requires a commitment to minimize the risks associated with research, including psychological and social risks, and maximizing the benefits that accrue to research participants and Ehrlich (2007:33) highlights that beneficence captures the true moral essence of the professional responsibilities of health care professionals. The researcher indicated that no physical harm was foreseen in the study but that there was a possibility that research participants could suffer discomfort from exposing their sensitive information to the researcher. In the event that participants suffer discomfort from exposing sensitive information in relation to the study topic, or need emotional support to address and explore emotions that may arise, appropriate referral for professional help with a trained counsellor at their local clinic or at the hospital was discussed. Participants were also given an opportunity to voice their concerns or discomfort at any stage of the interview. The researcher made a commitment to support participants emotionally in the event that they were overwhelmed during the interviews or to reschedule the interview when necessary and participants were reminded of their right to withdraw from the study.
whenever they wanted to. In this way the researcher ensured that the possibility of harm was minimised.

**Justice** requires a commitment to ensuring a fair distribution of the risks and benefits resulting from research. Those who take on the burdens of research participation should share in the benefits of the knowledge gained. Or, to put it another way, the people who are expected to benefit from the knowledge should be the ones who are asked to participate, (Mack et al 2005:9). In this study there was not monetary or material benefits from participation but participants were empowered with knowledge on adherence to ART. Their participation did not only serve as a reflection on how they have been adhering to ART, but also reinforce basic ideas about adherence and necessary referral for further ART services where necessary.

Another principle the researcher upheld was **respect for communities**. This called on the researcher to respect the values and interests of the community in research and, wherever possible, to protect the community from harm. This was fundamental for the research process as it has implications on the research success. The researcher sought permission to conduct the research from the Provincial Research and Ethics committee of Mpumalanga Health Department and also worked with the Barberton HIV Coordinator in identifying research participants. It was essential to follow this protocol before entering the community to show respect for their values and structures.

The researcher clearly explained the information letter to each research participant in the language of their choice (English or SiSwati). The information letter outlined the nature and the purpose of the research, the role of research participants and the importance of the study. The researcher also explained how data was going to be collected using an audio tape. Each participant was therefore able to make an informed decision to take part in the research by signing a consent form which was clearly explained and a duplicate copy was given to each participant.

Issues of confidentiality and anonymity were addressed in this study. By maintaining anonymity on the participants’ names in the study the researcher ensured that
participants’ confidentiality was upheld. The researcher stored the names for the purpose of following-up and member checking.

The researcher recorded all the interviews conducted with the participants on a tape recorder. The tape recordings and the transcribed interviews were kept securely locked up in a place that was only accessible to the researcher and the study’s supervisor. The researcher and the study’s supervisor are the only people with access to the transcribed data which has been stored on a secure computer and protected by a specific password.

3.4.3 Data analysis

The purpose of data analysis is to organise, provide structure to, and elicit meaning from research data. According to Boswell & Cannon (2014:236) data collection and data analysis processed occur simultaneously in qualitative research. As new data evolves new questions emerge giving the interview less structure, allowing key areas to be drawn out to inform the data collection process. Data analysis is a non-linear or iterative process. It involves numerous rounds of questioning, reflecting, rephrasing, analysing, theorising and verifying after each interaction with participants.

Data analysis entails segmenting and reassembling the data in the light of the problem statement, with the aim of transforming the data into findings (Boeijie 2010:93). The current study used qualitative data analysis which is basically describing and summarising data generated in the study. Lacey & Luff (2009:6) argue that qualitative data analysis is an interpretive and subjective exercise and according to Faherty (2010:33) this is due to the individualism of the researcher and the uniqueness of the words that are studied. Punch (2014:169) states that there are no universal rules for analysing qualitative data and much depends on the purpose of the research. Qualitative data analysis process inolves indexing data, anonymising sensitive data, coding, identifying themes, re-coding, development of provisional categories, refinement of themes and writing the report.
The current study used interpretive analysis which is oriented towards themes present in the data, according to Boeije (2010:94). Stages in qualitative data analysis are interrelated rather than sequential. During data collection the researcher read data immersion and coded the data which is identifying emerging themes, sub-themes and patterns and attaching labels or codes to the texts that represent the themes. These themes were organized into coherent categories. Polgar & Thomas (2013:97) state that coding is used to organise data collected in an interview. They outline the stages of analysis for interview transcripts as follows: The researcher studies the interview transcript where concepts, themes and ideas are noted to form major categories; labels are attached to each category; coding and recoding is done to interpret meaning in the context in which the categories appear; then finally reporting which involves detailed description of the categories. Interpretation of the data is done at two levels, at all stages where the researcher searches for core meanings of thoughts, feelings, and behaviours described and overall, to identify how themes relate to each other, explain how study questions are answered and what the findings mean beyond the context of your study. The researcher had to identify the core meaning of the data, remaining faithful to the perspectives of the study participants but with wider social and theoretical relevance. The final stage of the data analysis was writing of the research report.

An attempt was made to conduct follow-up interviews with participants in order to weigh the appropriateness of each theme for congruency with their experience and reality. This brought the researcher to the writing up of the study data, which is the final phase of data analysis.

3.5 CONCLUSION

Generic qualitative research design was used to develop a rich understanding of a phenomenon as it exists in the real world and as it is constructed by individuals in the context of that world. That is, understanding what makes some ART patients adhere to treatment while others do not based on the patients’ personal experiences. The study population of 13 HIV positive people was purposively selected based on the inclusion criteria of being adults (above 18 years of age), both genders, both employed and unemployed and being on ART. Through in-depth interviews and semi-structured questions data was collected using an audiotape before it was analysed. The searcher
ensured that the rights of research participants were upheld throughout the process by considering all the ethical issues of the study.
CHAPTER 4

ANALYSIS, PRESENTATION AND DESCRIPTION OF THE RESEARCH FINDINGS

4.1 INTRODUCTION

The qualitative data in the current study consists of interviews, words and observations and the process of data analysis seeks to order and transform collected data into findings which can be understood. The process was guided by the purpose of the study which is to explore the determining factors for excellent and poor adherence to ART for HIV positive patients on ART residing in Barberton. As indicated earlier the current study used interpretive analysis which is oriented towards themes present in the data, according to Boeije (2010:94). This chapter will briefly look at data management and analysis before outlining emerging themes and sub-themes from what HIV patients participating in the study identified as factors that make them adhere or not adhere to ART.

4.2 DATA MANAGEMENT AND ANALYSIS

McNabb (2013:396) states that data management includes three important steps, namely: designing a system for retrieving data for comparative analysis, organising the collection process, and other interpretive activities. After conducting in-depth interviews the first step to data analysis was to prepare the data. The researcher transcribed verbatim the data obtained in the form of tape recordings. The tapes and transcribed data were kept securely locked up in a place only accessible to the researcher while soft copies were stored in a password protected computer.

The researcher listened to recorded interviews against transcribed text in order to gain understanding and get the whole picture of the phenomenon. This required the researcher to re-listen to the recordings and re-read the transcribed text.
Themes were developed by identifying sententious phrases that captured the fundamental meaning of the text as a whole, phrases that even if standing out of the context, would communicate sufficient information to provide a piece of meaning to the reader. The following themes were developed:

Table 4.1 Themes

<table>
<thead>
<tr>
<th>THEMES</th>
<th>SUB-THEMES</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Pre and post HIV test counselling</td>
<td>2.1: Benefits of ART</td>
</tr>
<tr>
<td>2. Pre ART counselling and training</td>
<td>2.2: Side effects of ART</td>
</tr>
<tr>
<td>3. Opportunistic infections</td>
<td></td>
</tr>
<tr>
<td>4. ART services in Barberton</td>
<td></td>
</tr>
<tr>
<td>5. Duration on ART</td>
<td></td>
</tr>
<tr>
<td>6. Psychosocial support</td>
<td></td>
</tr>
<tr>
<td>7. Alcohol and drug abuse</td>
<td></td>
</tr>
<tr>
<td>8. Self-efficacy</td>
<td></td>
</tr>
<tr>
<td>9. Medical advances</td>
<td></td>
</tr>
</tbody>
</table>

An attempt was made to do member checks with participants to enhance credibility by weighing the appropriateness of each theme for congruency with their shared experience and reality. This brought the researcher to the final stage of data analysis which is writing up of the research report.

4.3 RESEARCH RESULTS

4.3.1 Sample characteristics

The accessible sample met the inclusion criteria which is both male and female HIV positive patients; being on ART; residing in Barberton and being above the age of eighteen years. The sample was purposively selected to include a wide range of variation on age, including genders, marital status, diverse backgrounds and employment status. This is supported by Holloway & Wheeler (2010:138) when they state that the logic and power of purposeful sampling lies in selecting information-rich cases for in-depth study. Information rich cases are those from which one can learn a great deal about issues which are of central importance to the purpose of the research.
### 4.3.2 Socio-demographic characteristics of participants

**Table 4.2 Socio-demographic characteristics of participants**

<table>
<thead>
<tr>
<th>Name</th>
<th>Age (years)</th>
<th>Gender</th>
<th>Marital status</th>
<th>Period on ART</th>
<th>Highest educational level</th>
<th>Employment status</th>
</tr>
</thead>
<tbody>
<tr>
<td>Norman</td>
<td>43</td>
<td>Male</td>
<td>Separated</td>
<td>6 years</td>
<td>Grade 12</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Mandi</td>
<td>40</td>
<td>Female</td>
<td>Married</td>
<td>7 years</td>
<td>Grade 5</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Dorothy</td>
<td>46</td>
<td>Female</td>
<td>Married</td>
<td>4 years</td>
<td>Grade 11</td>
<td>Volunteer at HBC</td>
</tr>
<tr>
<td>Danish</td>
<td>41</td>
<td>Female</td>
<td>Single</td>
<td>5 months</td>
<td>Diploma</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Fortune</td>
<td>28</td>
<td>Female</td>
<td>Single</td>
<td>1 year</td>
<td>Grade 12</td>
<td>Waitress</td>
</tr>
<tr>
<td>Gordon</td>
<td>38</td>
<td>Male</td>
<td>Married</td>
<td>4 years</td>
<td>Grade 10</td>
<td>Plumber</td>
</tr>
<tr>
<td>Cole</td>
<td>33</td>
<td>Male</td>
<td>Divorced</td>
<td>3 years</td>
<td>Diploma</td>
<td>Artist</td>
</tr>
<tr>
<td>Brenda</td>
<td>30</td>
<td>Female</td>
<td>Divorced</td>
<td>5 years</td>
<td>Grade 3</td>
<td>Unemployed</td>
</tr>
<tr>
<td>Tumi</td>
<td>41</td>
<td>Male</td>
<td>Married</td>
<td>3 years</td>
<td>Degree</td>
<td>Teacher</td>
</tr>
<tr>
<td>Glory</td>
<td>46</td>
<td>Female</td>
<td>Widow</td>
<td>10 years</td>
<td>Grade 8</td>
<td>Volunteer at HBC</td>
</tr>
<tr>
<td>Solomon</td>
<td>37</td>
<td>Male</td>
<td>Divorced</td>
<td>3 years</td>
<td>Grade 12</td>
<td>Clerk</td>
</tr>
<tr>
<td>Sonny</td>
<td>26</td>
<td>Male</td>
<td>Single</td>
<td>5 years</td>
<td>Diploma</td>
<td>Bank teller</td>
</tr>
<tr>
<td>Sonia</td>
<td>28</td>
<td>Female</td>
<td>Single</td>
<td>2 years</td>
<td>Grade 12</td>
<td>Nurse</td>
</tr>
</tbody>
</table>

N.B * please note that names were changed to protect the identity of study participants.

HBC is an abbreviation for Home Based Care.

The table above shows the profile of the study participants who were interviewed for the purposes of collecting data for this research. It shows their age, gender, marital status, the period they have been on ART, their highest educational level and employment status. The average age for research participants was 36 years and the study was predominantly females with 54% females and 46% males. Married and single participants made up the majority (61%) of the participants (30.5% each), divorced participants were 23% of the participants while widowed and separated participants contributed 8% to the target population. Most of the participants attained a high school or a tertiary qualification (61.5%) while the rest (38.5%) did not complete their high school qualification. 70% was either employed or volunteering and 30% was unemployed. All participants were black Africans and they all resided in Barberton at the time of the study.
4.4 RESEARCH FINDINGS

Themes associated with adherence and non-adherence to ART

4.4.1 Theme 1: Pre and post HIV test counselling

Pre and post HIV test counselling is meant to provide more information, ensure that the person being tested is in the direction towards accepting his/her HIV result and to connect the person to necessary resources. HIV testing and counselling form the gateway to care, treatment and support for persons in need, (www.who.int). What was striking in all the interviews with the individual participants is how much the participants understood the information they received during their counselling sessions for their HIV tests as well as counselling on how to administer ART.

“…HIV is a life-time disease. It lowers the immune system.”
“…like cancer it cannot be cured…”
“…and it does not mean I cannot have a normal life”
“…they told me that the medication will lower my viral load.”

Counselling during the HIV test provided the necessary and essential information for the participants to help them have a better understanding that they are dealing with a chronic disease which cannot be cured and how they need to take care of themselves physically, sexually, psychologically and in terms of dietary needs.

“The counsellor emphasised that I have to condomise with my husband every time we get together, I should seek help from the clinic as soon as I don’t feel okay; I can have counselling if I feel I am not coping well and that I should eat a lot of fruits and vegetables.”

The counselling also prepared the participants by informing them that they are dealing with a life-long disease, and that necessary changes in their lifestyles will ensure that they have a normal and healthier future.
4.4.2 Theme 2: Pre ART counselling and training

Counselling and training on how to administer ART is essential and it enhances subsequent successful adherence. The counselling and training ensures that proper information and knowledge is passed to patients concerning HIV, ART, ART adherence, the purpose of ART (lower the viral load count and boost the CD4 cells), the benefits of ART, specific instructions on proper dosing (why the medication has to be taken at specific time intervals), duration of treatment (life-long treatment) and consequences of no-adherence.

The counselling and training empowers the patient and simultaneously makes the patient accountable and offers some form of supervision as the initial stages of the treatment can be challenging due to the body’s adjustment to the treatment.

“…when you are starting there is a chart you record on to remind yourself. When you go to fetch the pills the next time you take you tablets and they count them to see how many did you record and how many are left. On the next visit they do the same and on the third visit as well. When you pass that test then they can trust you and can give you tablets for 2 months or even 3 months and you don’t have to use the chart anymore.”

Counselling and training on ART administration offers patients guidance and information on why they have to adhere to all the health-related behaviours as adherence goes beyond taking ARVs as prescribed.

“I attended classes at MaAfrica clinic on how to take the tablets for 3 days…I was told not to drink alcohol; eat healthy, more fruits, vegetables, fish and 100% juices; not to mix the tablets with herbal medicines or traditional herbs and to be careful when I’m hurt and bleeding that I do not touch food.”

4.4.2.1 Sub-theme 2.1: Benefits of ART

Most participants believed in the life-prolonging power of ART. They have experienced tangible benefits of ART, while some were not optimistic about the expected end positive benefits.
“The ARVs stop the virus from multiplying and developing to the stage where it gets to full blown AIDS. They strengthen the immune system, they keep the balance.”

“It’s just that you have this virus and it’s no longer the same as before. It’s like when you walk uphill you can actually feel the body that you are not as strong as you were before. And on the other side if there was no medication it was going to be more difficult.”

“…it’s the same, no changes, I’m in pain. I do not know if this works.”

Some participants experienced additional benefits which they never expected,

“….I used to be very dark but now I look fresh.”

### 4.4.2.2 Sub-theme 2.2: Side effects of ART

Side-effects are actions or effects of a drug (or vaccine) other than the desired therapeutic effects. It is undesired or negative effects (adverse effects), such as headache, skin irritation, or liver damage, (AIDInfo 2008:124). Side effects interfere with adherence as they present with undesirable and uncomfortable experiences. Most participants tolerate side-effects because they have been informed.

“…lack of concentration and I feel like I’m drunk…for an hour to two only.”

“I used to vomit when I started the treatment. It was for 3 months but then then it got better.”

“When I started with the medication it was not easy to adhere because of the effects…I remembered what I was told … to take the tablets accordingly.”

“I got drugged a lot in the beginning which made it difficult to take the tablets. It was worsened by the fact that I struggled to eat…like they told me.”

Some participants came up with positive ways to address the side-effects while continuing with medication as prescribed,

“I decided to take the tablets 1 hour after eating food to avoid vomiting.”

On the other hand, insufficient information (no proper training and counselling for ART) and continuous uncomfortable side-effects caused some participants to adjust the medication dose or temporarily discontinue treatment,
“They just told me that I am positive and that I need to take medication after the CD4 count test. If only they had told me that it is this difficult to take this medication I would have prepared myself. Now my feet hurt, I struggle to eat, I can’t sleep at night and I’m very dark in complexion as you can see. This is not my skin.”
“When I needed to think clearly I would skip some doses.”

4.4.3 Theme 3: Opportunistic infections

Opportunistic infections are an illnesses caused by any one of the various organisms that occur in people with weakened immune systems, including people with HIV/AIDS, (www.aids.gov). Examples of opportunistic infections are tuberculosis, bacterial pneumonia, herpes (simplex and zoster), candidiasis and lymphoma. One of the goals of ART is to lower the risk of getting opportunistic infections. ART helps by increasing the number of CD4 cells, which help protect one from opportunistic infections.

Most participants have not suffered from opportunistic infections and those who did, did not have full understanding of what caused it to happen,
“…pneumonia and when I got to the doctors I was told that it was just a touch of pneumonia… It was summer that time and I don’t know if I was right to get pneumonia in summer around November or December.”

One participant was taking both ART and TB medication simultaneously. This proved to be a difficult experience for her as she was still trying to adjust to the idea that she just tested positive to HIV and that her immune system is heavily compromised. This was worsened by the side effects of ART and TB medication which presented as painful feet with a heat sensation, low appetite, night sweats, painful limbs and body weakness. Not having proper information on what side effects to expect caused her to miss some doses frequently.

4.4.4 Theme 4: ART services in Barberton

All participants access free ART services at their local clinics in Barberton. Below is a list of services participants’ access from the local clinics or the local hospital.
Table 4.3 list of services participants’ access

<table>
<thead>
<tr>
<th>Service</th>
<th>Frequency</th>
<th>Access point</th>
</tr>
</thead>
<tbody>
<tr>
<td>Collect ARVs</td>
<td>Monthly</td>
<td>Local clinics</td>
</tr>
<tr>
<td>CD4 cell count and viral load count</td>
<td>6 months</td>
<td>Local clinics</td>
</tr>
<tr>
<td>Pap smear</td>
<td>Every 6 months</td>
<td>Local clinics</td>
</tr>
<tr>
<td>TB screening</td>
<td>When presenting with symptoms</td>
<td>Local hospital</td>
</tr>
<tr>
<td>TB treatment and monitoring</td>
<td>During months of treatment</td>
<td>Local clinics</td>
</tr>
<tr>
<td>Other opportunistic infections screening and treatment</td>
<td>When presenting with symptoms</td>
<td>Local clinics</td>
</tr>
<tr>
<td>Support services (e.g. monitoring adherence, motivation etc.)</td>
<td>On-going</td>
<td>Local Home Based Care groups, local clinics</td>
</tr>
</tbody>
</table>

4.4.5 Theme 5: Duration on ART

Most participants have been on ART for longer than 3 years with three participants having been on ART for 2 years or less. For the participants who have been on ART for less than 3 years they expressed a lot of challenges with the treatment. They are not sure if they should believe the what they are told to be the long term benefits of ART (improved CD4 cells which means better health) or rather consider the side effects, changes in their wellbeing and the necessary changes they have to make in their lifestyle (eat more fruits and vegetables, always use condom with their partners, seek medical help immediately if they get sick and adhere to ART) as an indication of how difficult their lives will be.

“…You know what? I’m only 28 but since I got to know my status and started taking ARVs I can go out with my friends like before. It’s like I have to watch what I eat, where I go, whom I go with and what we do. You can’t have fun. If you need to sleep with someone you have to disclose your status and obviously that cannot be done too soon and who knows you might scare people away…”
Having been on ART for more than 3 years gave the participants enough time to get to know how the medication affects each of them individually. It provided them with time to see if what they are taught in ART counselling and training is the case and if so how to handle everything subjectively.

“…the treatment exposes all illnesses and deals with it.”

“It is about being conscious, knowing that the results will be better. For example my brother who passed away it was that. He absconded from his medication, he would fetch the tablets and then stop taking them and fetch them stop taking them again the same thing. He was in a bad state when he passed on.”

The longer the participants have been on treatment, the better their coping skills. One would have witnessed the effects of not adhering and decides otherwise or see the benefits and it reinforces the good behaviours. This is contrary to Andreo in Hansa et al (2013:8) whose observation was that being on ART for 31–60 months was significantly associated with non-adherence to ART. He found that where patients had been on ART medication for more than two years, increased non-adherence was observed. This could be because the longer patients are on treatment they become complacent and find it harder to follow the strict regimen.

4.4.6 Theme 6: Psychosocial support

Concurring with Skovdal et al (2011:306) ART adherence is heavily influenced by the social relationships that exist between ART patients and the people they interact with on a daily basis, including family and community members as well as service providers. Families, friends, therapists, care workers and nurses at local clinics played an important role in facilitating adherence. Psychosocial support in the study refers to the on-going psychological and social support aimed at accepting the participants without any stigma; reminding participants about taking their medication and clinic appointments; facilitating medical treatment when needed; creating a homely environment where participants can focus on getting better; providing healthy food; listening when the participants feel overwhelmed or stressed, responding to questions concerning ART and adherence as they presented and taking care of the children or the household. See the table below.
Table 4.4 Patient support

<table>
<thead>
<tr>
<th>Type of support</th>
<th>Person offering the support</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Acceptance, no stigmatization</td>
<td>Family, friends, care workers, nurses, therapists, the community</td>
</tr>
<tr>
<td>2 Reminder about taking treatment</td>
<td>Family, friends</td>
</tr>
<tr>
<td>3 Facilitating medical treatment</td>
<td>Family</td>
</tr>
<tr>
<td>4 Creating a conducive environment for effective treatment and recovery</td>
<td>Family, friends</td>
</tr>
<tr>
<td>5 Providing healthy food</td>
<td>Family</td>
</tr>
<tr>
<td>6 Providing answers to ART and adherence questions</td>
<td>Nurses, therapists, care workers</td>
</tr>
<tr>
<td>7 How to manage stress</td>
<td>Nurses, therapists, care workers</td>
</tr>
<tr>
<td>8 Taking care of children or household</td>
<td>Family</td>
</tr>
</tbody>
</table>

Most participants had their families and nurses at the local clinics as their support system and they have been actively involved in their treatment especially so in the beginning phases of treatment;

“...they treat me normal,”

And throughout the duration they have been on ART;

“...they support me unconditionally. You see, they even buy things that they don’t really want, things like lettuce.”

“If I am travelling or working long hours, my daughter reminds me to take my medication.”

Two participants have been working with therapists to help them cope better with the disease, treatment and the necessary adjustments and lifestyle changes they had to make;

“My therapist has been so helpful. She had hope for me before I saw it myself. She helped see my condition in better light, see that the treatment is not such a burden to take it daily but that it helps, and that it is all about how I choose to see the picture.”

Hansa et al (2013:8) identified that over time, family members who had initially played a supportive role in helping patients take their medication, assumed the PLHIV was taking
their medication as prescribed and followed up with the patient less regularly. This factor may also be a contributing factor in decreased adherence over time. Contrary to this, a significant number of participants in this study have their families actively involved in reminding them to take their medication. For example, Norman*. He has been on ART for 6 years and the family still assumes the supportive role as in the initial stages of treatment,

“...they do remind me, a lot, I would say above average. They ask always ask if I have taken your medication.”

One participant felt overwhelmed by the amount of support she received from her family. She took their support as a way of undermining her self-determination and instead of the support being a facilitator of adherence to ART in ended up being a barrier to adherence,

“If only they could give me space and see if I can’t do it. They treat me like a child; take your medication, wear a jersey its cold, take a walk, don’t work too hard…”

4.4.7 Theme 7: Alcohol and drug abuse

31% of the participants reported to be involved in active drug or alcohol use or at some point during their ART.

“…Things were not going so well in the beginning. It’s like you expect the medication to work right away yet it is another story. Back then I would drink just a few beers to ease my mind, here and there…”

“...it was hard to stop drinking because the drinking started before the treatment. But was I told to stop drinking. I had to but it was not easy.”

“Alcohol makes me forget my status, this medication and the stress from my family for a while.”

“…just a joint or two of dagga a day to help ease the mind, relax and feel normal for a while.”
The common drug of choice was alcohol and one participant was smoking dagga. In agreement with other research, active alcohol or substance abuse makes it more difficult for patients to adhere to treatment (Patel, Hirschhorn, Fullem, Ojikutu and Oser 2010:3).

“…I would forget to take the tablets…”
“…and maybe not stick to the time schedule for the tablets.”
“No matter how much alcohol I had, I would always take my tablets.”

While alcohol is legal drug, all drug and substance use or abuse presents challenges to ART: 1) an array of complicating comorbid medical and mental health conditions; (2) limited access to HIV care; (3) inadequate adherence to therapy; (4) medication side effects and toxicities; (5) the need for substance abuse treatment; and (6) drug interactions that can complicate HIV treatment (AIDSinfo 2012:14).

4.4.8 Theme 8: Self-efficacy
Self-efficacy is defined by Bandura as a term that refers to an individual's belief in his or her capacity to organize and execute behaviours necessary to produce specific performance attainments. It reflects confidence in the ability to exert control over one's own motivation, behaviour, and social environment, (Carey & Forsyth 2015). Some participants' belief, ability and confidence in taking ART to manage HIV was much higher than some of the participants.

“…like they told me, I knew the tablets would make me strong again. I have always been a strong person; I knew I could fight this. That is why it was easy for me to disclose my status to my family within a week.”

“It is about being conscious, knowing that the results will be better and you won't be in a state…my brother who passed away…He absconded from his medication…I want better.”

Such believe, ability and confidence stemmed from the knowledge some participants gained during their counselling and training for ART, in their field of work as one is a volunteer with a local Home-Based Care group and for another it stemmed from seeing how not adhering affected a close family member and eventually causing his death.
Some participants did not convey any belief in their capabilities to take the treatment as prescribed and this has been mainly caused by the effects of the drug they are currently experiencing.

“They can say what they want, treatment this treatment that, it’s good and what not. I know how it affects me. I tell you it’s not going to work for me. I just can’t go on like this. Besides we are all going to die anyway so what is the difference.”

Another participants was also struggling with side effects of ART and strongly felt that ART was limiting him from living a lifestyle of a youth as he is supposed to,

“I’m young and I tried this treatment but eish, I don’t know. All I know is I cannot continue like this…”

4.4.9 Theme 9: Medical advances

Advances in ART have seen the introduction of a fixed-dose combination (FDC) ARVs where more than one medicine is combined into a single tablet. For 3 participants who have been on ART for more than 4 years, the change of their ARVs from 3 tablets which were taken twice a day to a single dose of one tablet enhanced their adherence.

“I used to take 3 tablets. Now I take one since the beginning of this year. The tablet is less druggy and I eat better. I felt itchy though the first two months but now I’m fine.”

The new treatment presented with fewer effects and remedied the challenges presented by the previous treatment options, increasing participants’ adherence.

Some participants felt that a single dose a day of one tablet is more convenient and therefore made them take the treatment as prescribed.

“For example, let’s say I’m travelling or I am attending a funeral or a wedding somewhere. It is easier now because I take the tablet once which is better and I do not feel as sleepy as I did on the other tablets.
On the other hand, some of those who have started ART on the newly introduced single dose have not experienced such positive effects. The side effects of ART that they currently suffer overshadow the long term benefits of the treatment.

“This drug is not easy to take. You can't eat, you feel itchy and your feet feel hot. It is just a lot of things.”

4.5 CONCLUSION

Adherence to ART is a broad aspect which is not only limited to taking ARVs as prescribed but extends to a person’s behaviour including, following a diet and executing necessary lifestyle changes which support positive living. A number of factors hinder ART participants’ efforts of continuing on ART and most hindrances emanate from how they understand ART, perceived benefits and experience benefits of ART. Pre and post HIV test counselling and pre ART counselling and training are platforms where patients can be empowered with information, skills, support and necessary resources to use. Lack of such training or not comprehending such has an adverse effect on adherence to ART. Other factors which have been identified to either hinder or facilitate adherence to ART are opportunistic infections, support services, duration on ART, alcohol and drug use, self-efficacy and medical advances.
CHAPTER 5

CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

Effective and sustained benefits of ART in the management of HIV/AIDS can only be derived from high levels of adherence ART. This calls for HIV patients to manage and maintain their ART as prescribed. While excellent adherence is effective in viral load suppression, restoring the ART patients’ immune system and reversal of progression of HIV disease to AIDS, poor or non-adherence promotes the development of drug resistance mutations, necessitates the use of more complex ARV regimens, and increases the risk for life-threatening opportunistic infections and risk of transmitting HIV to others (Enriquez & McKinsey 2011:46). The negative impact of poor adherence not only affects the HIV patient but extends to the family, community and the country at large with social, psychological and economic effects. Getting a full understanding of what facilitates or hinders adherence to ART from ART patients will therefore help ART patients, their families, communities and the country as a whole when effective and responsive systems are put in place to facilitate adherence in the management of HIV/AIDS. This chapter seeks to report on conclusions concerning barriers and facilitators of adherence to ART in relation to the research questions and the problem statement. Thereafter, it indicates the recommendations, contributions and limitations of the study.

5.2 RESEARCH DESIGN AND METHOD

This qualitative study made use of the generic qualitative research design. The research design epitomizes the characteristics of qualitative research but rather than focusing on culture as does ethnography, or the building of theory as does grounded theory, it simply seeks to discover and understand a phenomenon, a process, or the perspectives and worldviews of the people involved, (Caelli et al in Daymon & Holoway 2011:112). In this case the phenomenon that sought to be understood was factors that promote or hinder adherence to ART from ART patients residing in Barberton. With this research
design the researcher was essentially the main research instrument (Punch 2014:117) and sought to gain an understanding on determining factors of ART adherence and non-adherence from ART patients. In-depth interviews were used to understand ART patients’ experiences and realities with adherence to their treatment.

The inclusion criteria was both male and female HIV positive patients who are already on ART and residing in Barberton above the age of eighteen years. The sampling technique used was purposive sampling, also known as judgmental sampling, where sampling is based on the belief that the researcher’s knowledge about the population can be used to hand-pick sample members, facilitating the selection of key individuals from the spectrum of interest. Since the researcher did not personally know who constitutes the sample, the HIV coordinator for the Barberton community assisted in drawing up a list of possible participants of the study.

Appointments were made prior to meeting at mutually acceptable places. The interviewer entered the field with the sole purpose of exploring participants’ understanding of ART adherence and establishing factors which either promote or hinder their adherence efforts guided by the grand tour question, “Could you tell me about your experience with antiretroviral therapy?” A grand tour question is an open ended question that allows the interviewee to set the direction of the interview (Leech 2006:667). The researcher then followed the leads that the participants provided. Probe questions were also used in order to meet the objectives of the study.

The current study used interpretive analysis which is oriented towards themes or categories present in the data, according to Boeije (2010:94).

5.3 SUMMARY AND INTERPRETATION OF THE RESEARCH FINDINGS

The objective of the study was to develop a rich understanding on the determining factors of excellent and poor adherence to ART based on ART patients’ experiences. The socio-demographic profile of the participants shows that the majority of participants are in the economically active age group where the median age of participants is 36
years and a female preponderance. This is consistent with findings of studies that identified people of this age group as most vulnerable to HIV/AIDS because they belong to the sexually active, reproductive age group (World Health Report 2010:32). This is a cause of concern as it has a negative impact on the long term socio-economic state of families, communities and the country at large if such trends are not addressed.

Demographic factors such as age, gender and marital status did not have significant associations with adherence level. This is consistent with findings of other studies which found that age, gender and ethnicity, alone do not seem to predict adherence (Patel, Hirschhorn, Fullem, Ojikutu and Oser 2010:3). The high proportion of females living with HIV in this study also supports other findings that HIV infection is more common in women than men due to socio-cultural and economic factors, (Skovdal et al 2011:304). On average, young females become HIV-positive about five years earlier than males, (GARPR 2012:53). Women are usually dependent on their partners economically, leaving them in a compromising situation where they struggle to inquire if their partners are having other sexual partners and to discuss condom use where they feel they are at risk of contracting HIV. Significantly such circumstances negatively impact their physical, reproductive, sexual, and mental health (GARPR 2012:71). Although women’s rights in most marriage situations are now protected by law, women in cohabiting relationships and religious marriages are still not fully protected and the country continues to experience high levels of gender inequality and gender-based violence, (HIV and Human Rights in Southern and East Africa Report 2014:114).

A great number of studies have explored the behavioural and structural barriers and facilitators to successful ART adherence. Patel, Hirschhorn, Fullem, Ojikutu and Oser (2010:4) identified lack of adequate food, transport costs, long waiting times, support services, side effects, dose frequency, stigma and lack of awareness as some of the barriers and facilitators to ART adherence while Goudge & Ngoma (2011:S63) identified gendered conflict, transactional sex, side effects and low self-esteem as determinants of ART adherence. This study found other additional factors which are pre and post HIV test counselling, pre ART training and counselling, duration on ART, self-efficacy and medical advances.
The themes below reflect on barriers and facilitators of ART adherence as captured from Barberton ART patients participating in the study.

5.3.1 Theme 1: Pre and post HIV test counselling

Pre-HIV test counselling is the process of providing a person with information on the biomedical aspects of HIV/AIDS and emotional support to any psychological implication of undergoing HIV testing and the test result itself he/she is subjected to. Post-HIV counselling is the process of providing risk-reduction information and emotional support to a person who submitted to HIV testing at the time the test result is released (420). Therefore pre and post HIV test counselling are fundamental in raising awareness (on HIV/AIDS and risk reduction), giving accurate information and offering the needed emotional support. (Shisana et al 2014:4). Awareness of one’s HIV status through HIV counselling and testing is pivotal to accessing prevention, care services, ARV treatment which mitigates the impact of HIV (Shisana et al 2014:81).

South Africa has been working on enhancing HIV counselling and testing. According to the GARPR (2012:78), there was a shift from patient-initiated towards provider-initiated HIV counselling and testing as one of the measures derived from the plan of the National Department of Health with the intention of providing Strategic Leadership for better health outcomes and accelerating implementation of the HIV & AIDS and Sexually Transmitted Infections National Strategic Plan 2007-11. While this has been a positive move, there has been challenges. Where health professional are not properly trained to offer HIV counselling or when it is not done effectively, the above intentions are not fully realised and HIV patients are not empowered with the rightful information which resultantly negatively impacts their adherence to ART.

This study found that proper pre and post HIV counselling was a facilitator for ART adherence because the counselling helped the participants understand better HIV as a disease and behavioural aspects that they need to take into consideration in order to have a better quality of life. Gaining such understanding of the disease and lifestyle that goes with it helped the participants to adhere to their treatment as they knew the benefits of taking the treatment (to lower the viral load and increase the CD4 cell).
5.3.2 Theme 2: Pre ART counselling and training

The most prevalent factor and facilitator to ART adherence was pre-ART counselling and training. This is a process where by HIV patients commencing ART access information and skills on ART administration through counselling and training sessions. Having greater knowledge about HIV, ARVs, treatment behavioural skills and not using herbal medicines are known facilitators of adherence (Peltzer et al 2010:7).

Pre ART counselling and training reinforced the information that participants received in the pre and post HIV test counselling and at the same time it served as information and awareness sessions for those participants who were not capable of comprehending the information during their pre and post HIV test counselling due to shock and distress. Pre ART counselling and training offered essential supervision and guidance to ART patients at a point when they were adjusting to life at physical, psychological, social and spiritual levels. Counselling and training helped participants focus and promote adhere knowing the benefits and being prepared for potential side effects.

For the participants who did not receive proper pre ART counselling and training it only showed how important this process is. Not receiving such counselling and training resulted in the participants being overwhelmed by all the changes in their bodies, how the disease affected their relationships, lifestyles and livelihood. The situation was worsened by the fact that they were not properly empowered with information and skills as to why there were so many changes, how to cope with all the changes and not knowing what to expect. All these caused a hindrance to ART adherence.

5.3.2.1 Sub-theme 2.1: Benefits of ART

The goal of ART is to achieve and sustain viral suppression. Most participants understood the benefits of ART and those who have been on ART for a number of years had experienced the benefits either from proper adherence since the commencement of ART, from previous personal mistakes related to non-adherence or from friends or family members who succumbed to death due to non-adherence to ART.
ART was responsible for keeping the patients healthy and for some participants it was coupled by the desire to stay alive to look after the well-being of their children.

Knowing about the benefits of ART alone was not enough to facilitate patients' adherence. Knowing about the benefits of ART coupled with either personal or a significant other’s experience and the need to fulfil parental roles to the family came up as a facilitator of adherence.

5.3.2.2 Sub-theme 2.2: Side effects of ART

Patients' perceptions of adverse effects contribute significantly to decisions regarding medication adherence. Non-adherence to medications secondary to adverse effects is termed rational non-adherence, which Garner (2010:1495-1501) defines as “the cessation of a prescribed therapy because of concern for, or the presence of, medication side effects.” Garner (2010:1498) further states that rational non-adherence “is nearly impossible to circumvent if a patient’s specific side-effect concerns are not substantially addressed.” Side effects experienced by participants upon commencement with ART ranged from skin rush, change in complexion, loss of appetite, nausea, vomiting, insomnia, lack of concentration, confusion to hallucinations.

For the participants who were informed and aware of side effects from ART, they managed to tolerate the side effects knowing that it was going to last for a phase only. In this way their adherence to ART was not hindered. Some participants came up with positive ways to work around minimising the side effects while adhering to treatment, for example, changing the medication time from before a meal to one hour after a meal in order to address the vomiting side effect. Not having proper and sufficient information on side effects presented as a hindrance to ART. This rational non-adherence was when participants decided on skipping doses, stopped taking ARVs for a period of time or stopped some of the behaviours which support their treatment like healthy eating habits and exercise. It is therefore critical that adverse effects of ARVs are considered and discussed with patients before they commence with ART to empower them on what to expect and how they can be handled.
5.3.3 Theme 3: Opportunistic infections

According to the HIV and Human Rights in Southern and East Africa Report (2014:12) almost two thirds (65%) of the estimated 1.1 million worldwide TB cases amongst PLWH in 2011 were in Southern and East Africa. Kenya, Mozambique, South Africa, Uganda, United Republic of Tanzania, Zambia and Zimbabwe together account for approximately 59% of the global burden of HIV-positive TB cases. TB continues to be a major public health problem and South Africa is one of the twelve TB high burden countries globally. The high proportion of TB-HIV co-morbidity in South Africa is currently estimated to be 73%, (GARPR 2012:65). Antiretroviral therapy (ART) results in a prompt and marked decrease in the incidence of TB disease. Even with the beneficial effects of ART, HIV-infected patients remain at higher risk of TB disease than the general population (AIDSinfo 2013:F1).

While this is a concerning statistic, a lot has been done to alleviate this challenge through prevention and treatment. South Africa has been a part of the internationally recognised concept of combination prevention. This is an understanding that no single intervention will address HIV and TB infection at a population level. Integrated interventions which were rights-based, evidence-informed, and community-owned programmes that use a mix of biomedical, behavioural, and structural interventions have been put in place to fight HIV, TB and STIs to have sustained impact, (GARPR 2012:77). On the treatment part the government introduced machines with new technology in a move that was endorsed by World Health Organisation for better screening of TB. The new GeneXpert machine had high sensitivity to detect multi-drug resistant TB (MDR), extremely drug resistant TB (XDR) and takes on average 35 days to give results after the sputum is taken, (GARPR 2012:66)

The impact of these government strategies and interventions could be the reason for the low rate of opportunistic infections in this study. The majority of participants reported to not have suffered from any opportunistic infection since they commenced ART. 2 out of 13 participants suffered from TB and pneumonia with one having pneumonia 4 years after commencing ART and the other being diagnosed with TB and HIV simultaneously. While ART patients may perceive opportunistic infections as a sign that their sickness is serious and cause them to adhere more to the treatment, this study found that
opportunistic infections are a barrier to ART adherence. One participant’s poor adherence to ART was due to the increased TB medication and ART side effects. For the other participant poor adherence was due to lack of information. Both cases indicate a lack of knowledge on side effects associated with taking both TB medication and ARVs at the same time, what opportunistic infections are, how they affect HIV positive people, how they can be treated and how all these relate to ART.

In as much as there has been advances in intervention strategies and technology, this study shows that to some extent sufficient information is not being fully disseminated to HIV patients when they test for HIV, when they receive ART counselling and training or when they go for their routine check-ups at medical facilities.

**5.3.4 Theme 4: ART services in Barberton**

All study participants accessed their ART and medical services from the local clinics. The study shows a significant association between free and easily accessible ART and high levels of adherence, similar to the findings of the research by Byakika-Tusiime, Polley, Oyugi and Bangsberg (2013:5) who found that receiving free HIV treatment was associated with better adherence among low income HIV-infected patients in a resource-limited setting. Most participants stay a walking distance from the local clinics where they access all the ART and medical services necessary with a few using local taxis (costing very minimal - R18-00/month) or their own transport. This means that the participants do not incur high medication costs, lack transport and high transportation costs to access treatment and medical, increasing their adherence levels.

The local clinics offer comprehensive services which include CD4 cell count and viral load count, pap-smear, TB treatment and monitoring and other OIs screening and treatment. Having to access a number of essential medical services from a single clinic for ART patients has been shown to be a predictor of adherence to ART. Comprehensive access points save the participants time, effort and money.
5.3.5 Theme 5: Duration on ART

This study found that being on ART for a long duration is significantly associated with excellent adherence contrary to the findings of previous researches conducted in the province, (Zungu 2009:41) and in People’s Democratic Republic (Hansa et al 2013:8) which observed increased non-adherence in patients who had been on ART medication for more than two years. The reason for the non-adherence was that patients became complacent as they had been on treatment for long and found it harder to follow the strict regimen. Another contributing factor to the non-adherence from these studies was that over time, family members who had initially played a supportive role in helping patients take their medication, assumed the patients were taking their medication as prescribed and followed up with the patient less regularly. Contrary to these findings, the current study found that the longer the participants had been on ART the better they understood HIV as a disease, the better they had developed lifestyles or behavioural changes which support ART, the better they had developed ways to deal with ART side effects, they had accepted their HIV status, were realising the life-prolonging benefits of ART and they knew where to access ART support services. All these factors facilitated their adherence to ART.

5.3.6 Theme 6: Psychosocial support

This study found that there were strong associations between psychosocial support and adherence, similar to previous studies, (Zungu 2009:41). Family members including children, friends, home-based care givers, therapists, nurses and community members helped participants integrate ART into daily life by providing practical support such as reminding participants to take their treatment as prescribed, keeping clinic check-up appointments, providing healthy food, cooking, cleaning and showing that they care. By offering acceptance, no stigmatization, providing answers to ART and adherence questions and helping manage stress the support network gave hope and created an environment conducive for treatment and recovery which facilitated participants’ adherence to ART.
Not only did psychosocial support enhance adherence to ART but it also emerged as an important enhancer of self-efficacy and sustained motivation. High levels of self-efficacy and motivation have proved to facilitate adherence.

While psychosocial support was essential and enhanced adherence for most participants it also became a predictor of non-adherence for a few participants who were overwhelmed by the level of care and support. Over supportiveness was taken as not being supportive, undermining the HIV patient’s self-determination and it diminished the HIV patient’s self-efficacy.

5.3.7 Theme 7: Alcohol and drug abuse

According to the Prevention of and Treatment for Substance Abuse Act 70 of 2008 substance abuse is the sustained or sporadic excessive use of substances and includes any use of illicit substances and the unlawful use of chemical, psychoactive substances that are prone to be abused, including tobacco, alcohol, over the counter drugs and prescription drugs. South African Council on Alcoholism and Drug Dependency (SANCA) Lowveld defines substance abuse as when repeated use of alcohol or other drugs leads to problems and stopping the drug leads to significant withdrawal symptoms, (SANCA sa:22). It is the consumption of a substance without medical supervision (prescription medication), for a purpose other than that which it is prescribed for, the consumption of a substance which has mind changing properties and has no legitimate medical or socially acceptable use (illegal drugs) or which is socially acceptable but can be used contrary to the acceptable norms or values of the community (legal drugs). Substance abuse leads to addiction. Addiction is defined as a chronic, relapsing disease characterized by compulsive drug seeking and abuse despite adverse consequences. It is associated with long lasting changes in the brain (NIDA 2012:10).

South Africa has put in place measures to address the link between HIV and substance abuse, particularly intravenous drug use. According to the GARPR (2012:58) South Africa addresses the inter-linkage between intravenous drug use and HIV as a component within a broader substance abuse strategy. South Africa also has approved substance abuse prevention and treatment models, a national drug master plan and it
recognises the International Day against Drug Abuse and Illicit Trafficking annually. Despite all these efforts, very little data is available in South Africa on intravenous drug use and HIV prevalence among intravenous drug use is unknown, (GARPR 2012:58). The focus on intravenous drug use has been due to the fact that the use of contaminated drug injecting equipment bears a high risk for transmitting HIV and intravenous drug use is often linked to other risky practices such as sex work or unsafe sexual practices. While this is so, unfortunately focus has been taken away from oral drug use and how it affects HIV transmission and ART adherence. This study found that alcohol and dagga are hindrances to ART.

A research by Hansa et al (2013:10) focused on illegal drug use only and they found a significant association between drug use and non-adherence to ART. This study considered both legal and illegal drug use because even legal drugs like alcohol, cigarettes, over-the-counter and prescription medication can be abused and have some impact on ART. From the current study, 4 out of 13 participants were drinking alcohol, 1 participant was taking illegal drugs (dagga and cat) and 2 participants were using both alcohol and dagga while on ART. Participants who started with drug use before getting infected with HIV and commencing with ART took drug use as a coping mechanism were not aware of its effects on their treatment effectiveness. For those who started taking drugs after commencing with ART, their decision was based on the need to cope better with the physical and psychological effects of ARVs even though they were informed and aware of the possible effects.

While GARPR (2012:53) highlights alcohol abuse as a major risk factor for HIV acquisition and transmission, the risk extends to management of HIV through ART. Illegal use and abuse of legal drugs stated above is associated with depression, anxiety, confused and irrational thinking and behaviour, loss of motivation, short term memory loss and impulsiveness either as part of the withdrawal process or because of repeated use. This is particularly relevant in the treatment of HIV because such effects are predictors of poor adherence and poor quality of life.
5.3.8 Theme 8: Self-efficacy

Self-efficacy in this study looked at individual participants’ willingness and perceived capacity concerning administering ART and perceived health beliefs and attitudes concerning the effectiveness of the treatment. Some study participants reported having experienced positive physiologic outcomes from treatment boosting perceived capacity to administer ART and this tended to increased willingness to stay on the treatment (adherence). Such participants trusted ARVs based on the positive physiologic benefits, felt a sense of personal responsibility over their treatment, and perceived themselves to be capable of meeting its requirements despite experiencing some side effects. Lack of motivation also affect the degree of medication adherence.

5.3.9 Theme 9: Medical advances

In April 2013, the health minister Dr Aaron Motsoaledi launched the fixed-dose combination (FDC) ARV to be given to newly diagnosed HIV positive people, HIV positive pregnant women and breast feeding mothers, (South Africa begins 2013). Not only did the launch of this single dose ARV benefit HIV positive people by reducing the pill burden and allowing allow patients to take their medication more discreetly if that is what they prefer to do, the benefits also extended to health workers and health systems. FDCs make prescribing, dispensing and monitoring treatment easier for nurses and pharmacists. Also, widespread use of FDCs makes ordering and monitoring ARV stocks simpler for clinics, medicine depots and government. FDC ARVs are simpler, more effective, cheaper than other regimens, more convenient, easier to take and has fewer side effects, (www.sanews.gov.za). Overly, these benefits improve adherence.

For the participants who were initially on multiple doses of ARVs, the change to the FDC ARV meant that the frequency of taking ARVs and the dosage were significantly reduced, improving their adherence. Adherence was enhanced by the low daily pill count, reduced side effects and the convenience of the drug, especially when prescribed either once or twice a day.
5.4 CONCLUSIONS

Adherence to ART is an important predictor of viral suppression and reversal of progression of HIV to AIDS. Non-suppressed HIV viral load is associated with drug resistance, increased morbidity and mortality, and a higher risk of person-to-person HIV transmission. A lot of factors facilitate or hinder ART patients’ adherence to ART and they range from behavioural to structural factors. This study found pre and post HIV test counselling, pre ART counselling and training, ART benefits, ART side effects, ART services, opportunistic infections, psychological support, self-efficacy, duration on ART and medical advances to be facilitators or hindrances to ART adherence among Barberton ART patients. While efforts and interventions have shown improvements on the HIV prevalence and an increase on the number of people on ART more still needs to be done to make ART patients stay on their treatment as prescribed. Collaborative efforts and interventions between government, community-based communities, the private sector and most importantly ART patients will go a long way to ensure impactful and sustainable interventions. The full benefits of ART and efforts to reduce the HIV pandemic require a thorough understanding of the adherence barriers and facilitators that are unique ART patients in order to make the programmes more responsive to patients.

5.5 RECOMMENDATIONS

- **ART services**

  Effective on-going individualised ART training for HIV patients commencing with ART. Such education will empower the HIV patients to ensure that they understand HIV as a disease, how to live with it, the necessary lifestyle changes, what is adherence, its benefits, side effects of ART and how to handle them. Ensuring that ART patients understand adherence not only as medication adherence but also that it includes behavioural or lifestyle changes. Government in partnership with communities and the private sector can work together and ensure that essential information reaches ART patients and those they comprehend and understand how to practically use the information. Using the teach-back approach which is asking patients to repeat the important points can confirm that patients understand all aspects of their new medication, which in turn increases adherence.
• **Support groups**

Use of community resources like libraries and clinics as support group venues where ART patients can meet to support each other, share their struggles and successes. This can be educational and help ART patients identify with each other, addressing the feelings of isolation, being overwhelmed and not knowing how to handle the disease.

• **Awareness**

In as much as the government has put in place combination strategies to fight HIV/AIDS, TB and STIs and there have been successful, it can be effective to add substance abuse to the combination strategy considering that all HIV, TB, STIs and substance abuse are interrelated, affect and influence each other and ultimately have an impact on ART adherence. In this way platforms like International Day against Drug Abuse and Illicit Trafficking can be utilized to empower the communities on the link between HIV and Substance abuse both as a preventative measure and during ART and substance abuse treatment. Close collaboration with substance abuse treatment programs and proper support and attention to this population’s special multidisciplinary needs are critical components of successful HIV treatment.

• **Training of HIV and ART counsellors**

Training on and use of motivational interviewing can be very essential in helping ART patients integrate ART and adherence into their daily lives. Motivational interviewing is a counselling technique originally developed to help treat addiction. It is a collaborative conversation style for strengthening a person’s own motivation and commitment to change. It is designed to help patients identify and overcome reasons they may be reluctant to change their behaviour which is critical to ART patients and their adherence to ART, (Miller & Rollnick 2013:12).

• **Recommendations for further study**

This study has shown facilitating and hindering factors towards ART adherence from ART patients in a small town in Mpumalanga called Barberton. One therefore recommends that future studies be conducted on determining factors of poor and
excellent adherence to ART in other towns of the province as well as in other provinces and that the study population be defined differently to be able to generalise the findings to the entire country.

5.6 CONTRIBUTIONS OF THE STUDY
Adherence to ART is crucial in HIV/AIDS management. Collaborative efforts between the governments, community based organizations, the private sectors, families and ART patients themselves will ensure an impactful strategies and interventions.

The study findings have captured how ART patients understand and experience ART and factors which facilitate or hinder their adherence to the treatment. The findings present an opportunity for programme managers involved in management of HIV/AIDS to use evidence-based knowledge in planning interventions that directly address the raised issues and interventions that will be more responsive to the ART patients' needs. The findings can also help the government have an insight on how effective their interventions have been from the grassroots level, (for example the combination prevention and the introduction of one tablet), the possibility of strengthening them and the need to put in place other strategies to improve impact on HIV/AIDS management.

There has not been much research done in Mpumalanga on determining factors of adherence to ART particularly from ART patients as compared to other provinces, yet the province is the second most affected province with the HIV/AIDS pandemic. Documented research in Mpumalanga has focused on big towns therefore the findings of this study make a significant contribution to evidence-based knowledge on HIV/AIDS management from the perspectives of ART patients residing in a small town.

The findings of the study could possibly give guidelines to future studies in the management of HIV/AIDS through ART.
5.7 LIMITATIONS OF THE STUDY

- Since the study utilised a small sample, its results and conclusions cannot be generalised to the entire country but can only be applied to the research setting in which it was conducted.

- Considering that HIV/AIDS is a sensitive and still a stigmatized issue, obtaining research participants proved to be a challenge despite the fact that the research was cleared by the Mpumalanga Department of Health Ethics Committee. The researcher had to approach a number of HIV patients to achieve data saturation and the process proved to be time consuming and took a lot of effort.

5.8 CONCLUSION

Adherence to ART is essential in effective HIV management. This research was aimed at exploring factors which either hinder or facilitate adherence to ART from ART patients from a small mining town, Barberton in Mpumalanga province. Most of the research done in the province has focused on bigger cities, therefore capturing the experiences of ART patients from a small town ravaged by social challenges like crime, unemployment, alcohol and drug abuse and HIV will provide significant evidence based knowledge to HIV and ART programme managers and policy makers in developing programmes which are more responsive to ART patients. This study found that there are a variety of factors which facilitate and hinder ART patient’s adherence to ART and these range from ART patient’s perceptions and understanding of HIV and ART; availability, effectiveness and comprehensiveness of HIV and ART services; family and psychological support; to medical advances. On-going education and support plays a major role is enhancing adherence to ART. The more ART patients understand the kind of disease they are dealing with for the rest of their lives, the more they know what to expect and resources that they can access to better the quality of their lives, the better their chances of adherence to ART. The study found that education empowers ART patients in making informed decisions, handling better the side effects of ART and in establishing and maintaining necessary behavioural changes which enhance quality of life. This education is received as early as when one accesses HIV testing services and it is enhanced and emphasised through ART counselling and training as well as during regular check-up sessions. Joint efforts between service providers, families, community
based organisations, government departments and the private sector will help provide an enabling environment for ART patients to adhere to their treatment.
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ANNEXURES

Annexure A: Information letter

Title of the study: Determinants of excellent and poor adherence to antiretroviral treatment in Barberton

Investigator:
Name : Ms Tariro Chikoka
Department : Health Studies University of South Africa
Address : P. O. Box 334 Nelspruit
Phone : 073 825 4467
Email : tarrychik@yahoo.com

You are invited to participate in a research study. The aim of the study is to explore the determinants of poor and excellent adherence to antiretroviral therapy (ART) amongst the Barberton community. As an ART patient, you are a very important source of information. Your participation in this study is entirely voluntary and you can withdraw from the study at any time. Your withdrawal will not affect your access to services. There are no incentives involved in participation.

Should you decide to participate in this study, you will be asked sensitive information about your experience with your ART. If you feel any discomfort as a result of this interaction, you will be referred to a trained counsellor or the clinic. There are no known risks involved in the study. All the information that you will provide will be treated confidentially.

Although you will not benefit directly from the study, the information you will give will help health professionals involved in HIV/AIDS management to render a better service in future.

Your participation will be highly appreciated.
1. What was your experience when you learnt that you are HIV-positive? (Then probe)
   - What are the circumstances that led you to get an HIV test?
   - Where and when were you tested?
   - What advice did you get when you received your results?
   - Who knows about your HIV status?

2. What do you understand about the ART programme? (Then probe)
   - How and when did you start with your ART programme?
   - What were your expectations from the programme?
   - How important is it for you to take Antiretroviral (ARVs) tablets?
   - How easily do you access ART services?
   - Are there any monetary costs involved in your accessing the ART programme?
   - How often do you collect your medication?

3. Tell me about the psychological support that you have. (Then probe)
   - How satisfied are you with the overall support you get from your family and friends?
   - How often does your family or friends remind you to take your antiretroviral treatment?

4. What are your experiences of having been on ART? (Then probe)
   - How do you feel about taking ARVs?
   - What effect do they have on your life (health, daily activities and relationships?)
   - What makes it easier to take your medication as you are prescribed to do?
   - What makes it difficult to take the medication regularly?

5. What are some of the opportunistic infections you have suffered? What was it like to have those infections? (Then probe)
   - What was it like to have those infections?
-How did that experience affect the way you take your medication?

6. I appreciate you time. Is there anything else you would like to tell me that can help in this study?

7. Would it be alright to call you if I need more information?

Thank you very much for your time.
Annexure C: Permission letter

Miss T. Chikoka
P. O Box 334
Nelspruit
1200

Mpumalanga Department of Health and Social Services
Health Ethics Committee

To whom it may concern

Re: Application for permission to conduct research in Barberton community, Ehlanzeni District, Mpumalanga Province on what determines HIV patients' excellent or poor adherence to antiretroviral therapy.

I wish to apply for permission to carry out a study on the determinants of excellent and poor adherence to antiretroviral therapy in the Barberton community. I am a Master of Public Health (MPH) student at the University of South Africa (UNISA), currently registered for the dissertation module.

My research topic is: “Determinants of excellent and poor adherence to antiretroviral therapy in Barberton.” Interest in this field was sparked by an observation from clinical work that some alcohol and drug using clients in Barberton are also taking antiretroviral therapy.

To facilitate adherence to antiretroviral therapy in HIV patients there is need to explore the circumstances around why people choose to adhere or choose not to adhere as well as finding the reasoning behind their choices.

It is my hope that the findings from this study will have potential to influence programme managers in the field of HIV/AIDS for a more responsive programme to facilitate more adherence to treatment and subsequently enhancing the lives of HIV positive patients. The study will provide evidence based information that could be used to support the effectiveness adherence programmes that are currently running.
Please find attached a copy of the ethical clearance certificate granted by the Higher Degrees Committee of the Department of Health Studies, UNISA. This indicates that the academic and ethical issues pertaining to this study were accepted by this committee.

Once permission has been granted from your office, permission will be requested from the Barberton HIV coordinator. Every HIV patient will be free to decide whether or not he/she wants to participate in this study without facing any coercion.

Thank you for considering this request.

Yours faithfully

Miss. T. Chikoka

Cell: 0738254467

Email: 46751203@mylife.unisa.ac.za
Annexure D: Letter of approval: Department of Health: Mpumalanga Province

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Ms. Tariro Chikoka
P.O Box 334
NELSPRUIT
1200

Dear Ms. Tariro Chikoka

APPLICATION FOR RESEARCH & ETHICS APPROVAL: DETERMINANTS OF EXCELLENT AND POOR ADHERENCE TO ANTIRETROVIRAL THERAPY IN BARBERTON

The Provincial Research and Ethics Committee has approved your research proposal in the latest format that you sent.

Kindly ensure that you provide us with the soft and hard copies of the report once your research project has been completed.

Kind regards

[Signature]

MR. MOLEFE MACHABA
RESEARCH AND EPIDEMIOLOGY

11 November 2014