AN INVESTIGATION INTO THE MANAGEMENT OF ADHERENCE TO ANTIRETROVIRAL TREATMENT: A CASE STUDY OF MURCHISON DISTRICT HOSPITAL

Junaid Sader  
Graduate of the Regent Business School, Durban, Republic of South Africa

T. Kazi  
Academic and Dissertation Supervisor, Regent Business School, Durban, Republic of South Africa

Anis Mahomed Karodia  
akterodia@regent.ac.za  
Professor, Senior Academic and Researcher, Regent Business School, Durban, Republic of South Africa

Abstract

The Human Immunodeficiency Virus and Acquired Immune Deficiency Syndrome constitute one of the major diseases that affect society since the first known cases in the early 1980’s. Recent statistics have indicated that South Africa has the largest and highest profile HIV/AIDS epidemic in the world with an estimated 5.7 million of its 48.3 million citizens being infected with HIV. As antiretroviral medicines become increasingly available and affordable for the treatment of eligible patients, more attention is rightly being focused on issues related to the rational use of these medicines, with one of them being adherence. One of the major challenges surrounding the management of ART programmes is the adherence of patients to their ART as non-adherence of patients to their ART not only has a host of negative consequences for the patient but also a number of significant effects on the organisation and the management thereof.

Key Words: Adherence, Anti – Retroviral Treatment, Immunodeficiency, HIV/ AIDS, Epidemic, Treatment, Patients, Medicines, Infected, Management

Introduction

The Human Immunodeficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS) constitute one of the major diseases that affect society since the first known cases in the early 1980’s (Vella, Govender, Dlamini, Taylor, Moodley, David and Jinabhai, 2008:3). Sub-Saharan Africa bears the brunt of this pandemic with current measures still being based on prevention, in particular the ABC strategy of Abstinence, Being Faithful and the use of Condoms (Vella et al., 2008:3). Despite this, many attempts have been made to prolong patient’s lives as well as providing patient’s living with this disease with more productive years (Vella et al., 2008:3). One of these attempts is the rapid expansion and early access to antiretroviral treatment (ART) services. However, the current courses of therapy are a life-long requirement of strict compliance by patients in order that they may achieve success in their treatment (Tran, Nguyen, Hoang and Hwang 2013:1). In resource-scarce areas, such as South Africa, where second line and third line ART regimens and viral load monitoring are limited, routine assessment of and interventions for patients’ adherence have become one of the biggest priorities in delivering ART services (Tran et al., 2013:1). Little is known about factors associated with suboptimal ART adherence among...
patients in the South African setting, therefore the purpose of this study is to determine the reasons of ART non-adherence and effects thereof in Murchison District Hospital, a hospital based in Kwa-Zulu Natal, South Africa.

Aim of the Research
The aim of this study is to assess the reasons for non-adherence of patients to Antiretroviral Treatment at Murchison District Hospital and its implications on the organisation.

Objectives of the Study
- To identify as well as examine the reasons as to why patients on ART are not adhering to their treatment.
- To provide an overview of the theoretical models of adherence and their applicability to the reasons for non-adherence.
- To assess the effects of non-adherence to ART on the organisation.
- To investigate the current adherence management strategies of patients receiving ART at Murchison District Hospital and to recommend a range of effective and efficient adherence management strategies.

LITERATURE REVIEW

Introduction
According to Dawidowicz (2010:6), a literature review is an examination of scholarly and research-based information on a specific topic and its aim is therefore to create a complete and accurate representation of the knowledge and research-based theory that is available. This chapter will firstly review the existing literature on HIV and AIDS and its global impact, Antiretroviral treatment, adherence as well as the consequence of non-adherence. Secondly, the four objectives as per the aim will be discussed using existing literature and finally a conclusion will be drawn based on the facts and opinions noted.

Overview of HIV/AIDS, ART and Adherence

Definition of HIV/AIDS
HIV is a virus that attacks the body’s natural way of fighting diseases and illnesses (Ababio, 2005:4-5). The virus was first identified in the 1980’s in the United States of America and since then it has spread globally causing one of the most dreaded pandemics of modern times (Famoroti, Fernandes and Chima, 2013:2). The virus gradually weakens the body’s ability to fight diseases by destroying the cells in the body that control the body’s immune system (known as CD4 cells) (Famoroti et al., 2013:2) (Ababio, 2005:4-5). An individual that is infected by HIV may appear to be fine for many years, but eventually the virus causes so much damage to the immune system that the individual begins to get ill from a host of life threatening opportunistic infections, tumours and diseases. In South Africa the most important opportunistic infections are Tuberculosis (TB), serious skin infections, fungal infections of mouth and oesophagus, Pneumonia, and Fungal Meningitis (Ababio, 2005:4-5). When an individual is infected with HIV and develops opportunistic infections, the victim has developed what is called Acquired Immune Deficiency Syndrome, or AIDS (Famoroti et al., 2013:2) (Ababio, 2005:4-5). The causes and subsequent spread of HIV/AIDS vary and may include the following (Famoroti et al., 2013:2) (Ababio, 2005:4-5):

- Sexual contact with an infected person during unprotected sex (heterosexual/ homosexual)
Mother to child transmission during the birthing process or through breastfeeding
Sharing of needles by drug abusers who inject drugs
Transfusion of infected blood or blood components
Violence accompanying sex (e.g. rape, women abuse, child abuse)
Health care professionals that injure themselves with a needle that has been used to take a blood sample from an HIV infected person

HIV/AIDS: Summary of Global Epidemic
HIV/AIDS has become one of the world's leading infectious killers, claiming more than 25 million lives over the past three decades (Shigdel, 2012:1). Based on the 2013 statistics released by the World Health Organisation (WHO) and UNAIDS (Figure 1), it can be seen that there are 35 million people living with AIDS across the globe. The number of people newly infected with HIV has fallen to the lowest level in over two decades. According to the latest available data, the estimated 2.1 million people globally who acquired HIV for the first time in 2013 were 15% fewer than the 2.5 million who acquired the virus in 2009 which was the baseline for the WHO Global Health Sector Strategy on HIV/AIDS. In addition, this was 38% fewer than the estimated 3.4 million people who acquired HIV in 2001 (World Health Organisation, 2014:8-11). The estimated 1.5 million people dying from HIV globally in 2013 were 22% fewer than in 2009 and 35% fewer than when the number peaked in 2005. Children (younger than 15 years) in 2013 had 31% fewer deaths from HIV compared with 2009 and 40% fewer deaths compared with 2005 (World Health Organisation, 2014:8-11).

Figure 2.1: Global summary of the AIDS epidemic 2013

<table>
<thead>
<tr>
<th>Global summary of the AIDS epidemic</th>
<th>2013</th>
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<tbody>
<tr>
<td>Number of people living with HIV in 2013</td>
<td>Total 35.0 million [33.1 million – 37.2 million]</td>
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<tr>
<td></td>
<td>Adults 31.8 million [30.1 million – 33.7 million]</td>
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<tr>
<td></td>
<td>Women 16.0 million [15.2 million – 16.9 million]</td>
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<tr>
<td></td>
<td>Children (&lt;15 years) 3.2 million [2.9 million – 3.5 million]</td>
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<tr>
<td>People newly infected with HIV in 2013</td>
<td>Total 2.1 million [1.9 million – 2.4 million]</td>
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<tr>
<td></td>
<td>Adults 1.9 million [1.7 million – 2.1 million]</td>
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<td></td>
<td>Children (&lt;15 years) 240 000 [210 000 – 280 000]</td>
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<tr>
<td>AIDS deaths in 2013</td>
<td>Total 1.5 million [1.4 million – 1.7 million]</td>
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<tr>
<td></td>
<td>Adults 1.3 million [1.2 million – 1.5 million]</td>
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<td></td>
<td>Children (&lt;15 years) 190 000 [170 000 – 220 000]</td>
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(Source: WHO-HIV Department, 2014)

This report supports the fact that the global response to AIDS has demonstrated tangible progress toward the achievement of Millennium Development Goal 6, which is to combat HIV/AIDS malaria and other diseases (Shigdel, 2012:1)

HIV/AIDS prevalence in Sub-Saharan Africa, South Africa and Kwa-zulu Natal
Sub-Saharan Africa is the global epicentre of the AIDS pandemic and remains the region worst affected with countries in the region registering some of the highest HIV/AIDS prevalence rates in the world (Hardon, Davey, Gerrits, Hodgkin, Irunde, Khatwane, Kinsman, Nakiyemba and Laing, 2006:25-26) (Famoroti et al., 2013:2). Although it has little over 12% of the world’s population,
the region is home to more than 70% (24.7 million) of people living with HIV (35 million) (Hardon et al., 2006:25-26). The predominance of HIV/AIDS in Africa is due to the causal factors that emerge from general underdevelopment. Whilst people of all ages are affected by HIV, most of those infected are between the ages of 25-45 (Hardon et al., 2006:25-26). This age group is particularly important not only in terms of economic productivity but also as parents and providers. On a more positive side, recent statistics has shown that in Sub-Saharan Africa, 1 million fewer people acquired HIV in 2012 which is an almost 40% drop since 2001 (UNAIDS, 2013:8): 2001-2.6 million, 2012-1.6 million. There has also been a 22% drop in AIDS-related deaths in sub-Saharan Africa between 2001 and 2012, with 300 000 fewer deaths (UNAIDS, 2013:10): 2001-1.5 million, 2012-1.2 million. South Africa bears a huge burden of the HIV/AIDS epidemic. About 6.3 million people were estimated to be living with HIV in South Africa in 2013, which is 25% of the population infected in Sub-Saharan Africa (24.7 million) (World Health Organisation, 2014:10). An estimated 18.8 percent of the adult population (15-49) are affected (Steel, Nwokike and Joshi, 2007:1). The effects of the dreaded disease are severe as the estimated average life expectancy being likely to fall from 60 to 40 years (Ababio, 2005:1). With an estimated population of 10,819,130, Kwa-Zulu Natal is the second most populous province in the country and accounts for 21.4% of the country’s population. The province has the highest burden of disease associated with underdevelopment and poverty in the country which includes HIV and AIDS. The HIV prevalence in South Africa, according to 2011 statistics, places KwaZulu-Natal Province at the top of the other provinces with 15, 8% (1,622,870) HIV prevalence. More than half (54%) of the adult HIV patients in the country live in Kwa-Zulu Natal (Office of the premier, 2012:4-5).

Anti-Retro Viral Treatment (ART)
Currently, there is no known cure for HIV/AIDS although current treatment with antiretroviral drugs (ARVs) has led to an increase in life expectancy and an improved quality of life. The availability of ARVs has changed the course of HIV/AIDS from a rapidly fatal disease to a chronic and more manageable disease which invariably improves the quality of life of people living with HIV/AIDS (Famoroti et al., 2013:2). The first Anti-retroviral drug to be developed was Zidovudine, which was licensed in 1987; thereafter several other antiretroviral drugs were developed. These drugs are presently being utilised in different combinations (Vella, Govender, Dlamini, Taylor, Moodley, David and Jinabhai, 2008:1).

Outcomes of ART
The introduction of ARV’s has brought new hope to people living with HIV and the increased availability of treatment has dramatically improved survival rates and lowered the incidence of opportunistic infections in people living with HIV (Hardon et al., 2006:24). Improved access to ART is resulting in major increases in life expectancy. In South Africa, for example, data from ART programmes in three provinces indicate that the life expectancy of adults receiving ART is about 80% of the normal life expectancy, provided they do not start treatment late (World Health Organisation, 2013:9). The provision of ART has accelerated with about 12.9 million people receiving ART globally at the end of 2013 (37% coverage), with 11.7 million of them in low- and middle-income countries. The additional 2 million people who started ART in 2013 marked the largest-ever annual increase in ART provision. At current trends, the target of placing 15 million people on ART by 2015 in low and middle income countries will be exceeded (World Health Organisation, 2014:9-12). This 11.7 million people on ART represent 36% of the 32.6 million people living with HIV in low- and middle-income countries (World Health Organisation, 2014:12-13). From this 11.7 million people on ART in low and middle income countries, 9.1 million people are from the African region (78%) compared to 2002, where only 300 000 people were receiving ART in low to middle income countries and of that 50 000 were from the African region (World Health Organisation, 2013:7).
ART continues to expand dynamically in the WHO African Region, especially in Eastern and Southern Africa. At the end of 2013, an estimated 37% of all people living with HIV in the Africa Region were receiving ART. Furthermore it is also stated that from the 6.3 million people infected with HIV/AIDS in South Africa, 42% of that population are receiving ART (2 623 271 people) (World Health Organisation, 2014:9-12). What is also important is the need to identify people living with HIV early and then to link them with and retain them in care so that they may gain the full benefits of ARV drugs (World Health Organisation, 2014:14).

**Challenges of ART programmes**

The ART programme offers many benefits in managing a patient’s disease progression but as with all medical treatment, with these benefits comes challenges. The first challenge for patients on ART is the side effects of the drugs. All the ARV drugs that have been developed have different side effects and these can have a great impact on how the medicines will be used as well as how patients take them (Do, 2011:10). The most frequently reported side effects are constipation, diarrhoea, nausea, vomiting, lethargy, metallic taste in mouth, allergies and general numbness and tingling sensations (peripheral neuropathy). The side effects of ART have been seen to pose a barrier to ART adherence (Do, 2011:10). The second challenge for patients is dietary restrictions and lifestyle adjustments. ARV drugs are required to be taken with strict dietary guidelines in order for optimal results and thus it can interfere with a patient’s lifestyle. Patients are required to take their medication at specific time intervals and with specific meal requirements for the different formulations. This requirement also poses a huge barrier to ART adherence (Do, 2011:11).

Development of resistance to ART is the third and final challenge of ART programmes because the virus is extremely susceptible to developing resistance to ARV when it is exposed to reduced concentrations of the drug. These resistant strains could then be transmitted to other persons via a variety of ways as discussed earlier, thereby decreasing treatment options and worsening the HIV epidemic. The most important lesson from these studies is that poor adherence in advanced stages of the disease leads to resistance and thus carries a high risk of mortality. (Adefolalu and Nkosi, 2013:21). It can thus be concluded that if adherence to prescribed treatment is maintained, the challenges to ART programmes can be minimised or even overcome in some cases. Adherence to ART is therefore a challenge surrounding the management of ART programmes.

**Definition of Adherence**

The treatment of the disease extends beyond knowledge development among people infected with HIV; a partnership between the patient and healthcare provider is required, with the HIV-infected person assuming the major responsibility of self-care that will result in a good clinical outcome (Adefolalu and Nkosi, 2013:1-2). Adherence is thus described as the extent to which the individual’s behaviour (including: taking medication, following a diet, executing lifestyle changes and keeping clinic dates), corresponds to the prescribed medical advice of the health care provider. It has also been extended to include any referrals and need for further investigation (Adefolalu and Nkosi, 2013:1-2).

**Percentage Adherence Required for Optimal Results**

It is well understood and documented that HIV/AIDS requires near perfect adherence to obtain successful treatment outcomes. Recent studies have estimated the required level of adherence for sustained virological suppression to be about 95% (Steel et al., 2007:4). Therefore any adherence below 95% in ART has been linked to treatment failure. The risk of developing resistance to ARV
is also shown to be highest between the 80–90% level of adherence (Adefolalu and Nkosi, 2013:21).

**Consequences of Non-Adherence**
Non-adherence to ART results in inadequate suppression of viral replication in the body which allows the virus to continuously replicate and deplete the T-Helper cells. This destroys the immune system and allows the disease to progress at a faster rate. Therefore, the consequences of non-adherence are (Adefolalu and Nkosi, 2013:21): repeated hospital admissions, development of opportunistic infections, development of ART resistance, poor quality of life, loss of productivity and premature mortality.

**Measuring Adherence**
Adherence to treatment is critical to obtain the full benefit of ART and thus adequate monitoring of adherence is vital in preventing treatment failure and development of resistance to antiretroviral drugs. Furthermore, it is necessary for effective and efficient treatment planning (Steel et al., 2007:8-9). The measuring of adherence is difficult to assess among patients due to there being no standard method of measurement. The currently available methods for adherence assessment can be grouped into the following two categories (Steel et al, 2007:8-9):

**Direct measures**
- Directly observed treatment (DOT)
- Therapeutic drug monitoring (TDM)
- Biological Markers

**Indirect measures**
- Pharmacy records
- Self-report
- Pill count (PC)
- Visual analogue scale (VAS)
- Pill identification test (PIT)
- Electronic Device Monitoring (EDM)

Adherence is best measured by direct observation; however this is not practical for daily therapy which has to be taken for the patient’s entire life. Indirect methods are therefore commonly and widely used (Chalker, Andualem, Tadeg, Gitau, Ntaganira, Obua and Waako, 2009:4-6). Some of the more common direct and indirect methods of measurement will be summarised below:

**Patient Self-Report**
Patient self-report remains the main measure of adherence globally although other techniques have been used widely as it is relatively inexpensive and feasible in a wide variety of settings (Chalker et al., 2009:4-6). It involves asking patients to report their adherence via exit-interviews or questionnaires. The major drawback of this method is overestimation of adherence by patients due to desirability bias. The accuracy of adherence self-report could be achieved if patients are approached in a nonjudgmental way during assessment (Shigdel, 2012:10) (Chalker et al., 2009:4-6) (Adefolalu and Nkosi, 2013:23-26).

**Pill Counts Method**
Pill Counts can be carried out during a patient’s visits to health facilities or unannounced at patients’ home. It is a measure of adherence that involves counting the number of pills that a
patient comes to visits with. This technique is cheap but its major drawback is the manipulation of pills by the patient. Patients can throw away pills before hospital visits which will result in overestimation of adherence for the patient. Unannounced pill count is more reliable but it has the tendency to negatively affect the trust between the patient and health care provider which may then hinder adherence (Shigdel, 2012:10) (Adefolalu and Nkosi, 2013:23-26).

Pharmacy Based-Records
Pharmacy record is a simple and effective tool for monitoring adherence in ART and has been proven to be useful in adherence monitoring in a resource-limited setting. This method employs pharmacy records to monitor adherence among patients when collecting their medication at the pharmacy and those collecting their medication regularly are said to be adherent. Adequate record keeping is necessary for this measure to be useful; the drawback here is that the method only assumes that patients are adherent based on their empty pill containers and the regular collection of their medication, it does not measure actual medication intake (Mombasa, 2004:21) (Adefolalu and Nkosi, 2013:23-26).

Biological Markers Monitoring
Viral load is regarded as the main indicator of the risk of therapeutic failure and can also be used in measuring adherence. A low viral load and an increase in CD4 count are suggestive of good adherence although some patients may have a high viral load despite taking the ART regularly. The limitation here is the cost and availability in resource limited settings (Steel et al., 2007:8-9) (Mombasa, 2004:21). The measuring of adherence is not a simple task and therefore no single measure is appropriately designed for all settings. Therefore the use of more than one measure of adherence allows the strengths of one measure to compensate for the limitations of the other and therefore attain more accurate information that will determine the adherence level (Steel et al, 2007:8-9) (Adefolalu and Nkosi, 2013:23-26). Pill counts, self-report and pharmacy records are still the mainstay of measuring adherence in resource-limited settings. The current research therefore uses patient self reports as well as pharmacy based records as a measure of adherence.

Objective 1: Reasons for Non-Adherence to Antiretroviral Treatment
Many centuries ago, it was noticed by Hippocrates that patients pretended to have taken their medication. The growth in the number of effective medications forced attention on the problem of non-adherence with long-term therapies having the most problems. By the end of the 1970s, it was clear that determinants of adherence and non-adherence were complex and poorly understood (Vermeire, Hearnshaw, Van Royen and Denekens 2001:3). In order to determine the reasons as to why patients on ART do not adhere, one needs to understand that patients often do things for reasons that are not understood or cannot be explained. Therefore, being familiar with certain major determinants of poor adherence can help Health Care Professionals identify those patients who might have more potential to struggle with adherence. Nonetheless adherence is a challenge across the patient population and something that health care professionals should be mindful of with all patients (Duggan 2006:38). According to Masokoane (2009:9-20), the principal factors associated with non-adherence appear to be patient-related, including substance abuse, alcohol abuse, depression and psychiatric illness. However, other factors may also contribute such as inconvenient dosing frequency, dietary restrictions, pill burden, side effects, patient-health-care provider relationships, patient support structure and the system of care. It can thus be seen that many reasons for non-adherence to medical regimens exist and these can be placed into four broad categories that attempt to determine why patients might fail to adhere to their ART regimen. These categories are (KZN Health Research and Knowledge Management, 2015:2-5):
Patient and Family-Related Factors

Patient-related factors of adherence to ART include: demographic factors, perceptions of treatment, changes in health status, misinformation and misconceptions about HIV and ART, disclosure to family members, low health literacy, stressful life events, high levels of alcohol consumption, substance abuse, homelessness, poverty stigma, inconsistent access to medication and forgetfulness (KZN Health Research and Knowledge Management, 2015:2). Family-related factors include family member or caregiver illness, psychological factors, caregiver financial challenges and expenses incurred on their own treatment as well as perceived family support (KZN Health Research and Knowledge Management, 2015:2). In a South African study, it was reported that pervasive gender inequalities make it likely that the effects of the other structural barriers on adherence are different for women and men. Women are said to experience higher levels of poverty and encounter greater barriers to accessing care than men because of multiple work and child-care burdens, restricted mobility, and economic dependence upon men (Kagee, Remien, Berkman, Hoffman, Campos and Swartz, 2011:5).

However, in a study in Botswana, researchers noticed that being male and having a history of failure to refill ART at a pharmacy were significant risk factors for suboptimal adherence among HIV/AIDS-infected patients in this study population (Ndiaye, Nyasulu, Nguyen, Lowenthal, Gross, Mills and Nachega 2013:1). In yet another study, it was reported that due to socio-cultural and economic restrictions placed upon women in Nepal, women found it far more difficult to adhere to their ART medication than their male counterparts did. Most of the health-care providers mentioned that men had better adherence than women (Wasti, Simkhada, Randall, Freeman, and Teijlingen 2012:7). In a study conducted in Nepal, it was reported that most demographic data of patients had no effect on adherence levels though a higher educational level had been associated with increase adherence (Bam, Karki, Shyam, Lohani, Thapa, Aryal and Pathak 2011:10).

Due to the high rate of unemployment in many low income countries like South Africa, many patient’s that do not have regular employment make themselves available as day workers to employers. Often, the need for a day’s wages eclipses the potential benefit of a clinic visit (Kagee et al., 2011:3). Moreover, frequent absences from work create conditions under which employers may terminate employment if they do not know the reason for such absences, thus the threat of losing employment for this reason often impedes clinic attendance and adherence to treatment (Kagee et al., 2011:3). Inadequate public health care services, and familiarity with and belief in the cultural framework within which traditional healers work, make these service providers an attractive option for many patients. Although in many instances the interventions rendered by traditional healers may complement those of biomedicine, in some cases these may preclude full adherence to ART by unwittingly creating uncertainty among patients about their effectiveness (Kagee et al., 2011:5). In many resource-constrained countries, health literacy is low and vigorous efforts are needed to ensure adequate knowledge about the trajectory of HIV and the need for sustained treatment. Many patients consider medication only as a tertiary measure following the onset of symptoms, rather than as a prophylactic intervention. Health literacy is linked to education level, and in many low and middle income countries is inferior among non-elite segments of the population (Kagee et al., 2011:5).

In a study conducted in Khayelitsha, Cape Town, alcohol use emerged as the most cited reason for failure. It affected adherence in two ways: Firstly, patients often forgot to take their medication when drinking. Secondly, as with the timing of medication, patients understood that they could not drink and take their ART and therefore stopped their treatment altogether (Barnett, Patten, Kerschberger, Conradie, Garone, Van Cutsem and Colvin 2013:172-173). Perception is concerned
with people’s beliefs that they can exert control over their own motivation, thought processes, emotional states and patterns of behaviour. Therefore, negative perceptions as to the efficacy of ART and its effects could act as barriers and thus prevent adherence (Wasti et al., 2012:1-9). In a study in Brazil, it was concluded that psychosocial factors like anxiety and depression can contribute to non-adherence to antiretroviral therapy which, consequently, lowers immunity and increases virological response and the progress of AIDS, and thus deteriorates quality of life. Studies have shown that people with depression, anxiety or generalised panic responses were approximately twice as non-adherent as those without a psychological disorder (Calvetti, Giovelli, Gauer and De Moraes, 2014:8-15). The results of this study reveal a correlation between social support, quality of life and adherence to treatment. Psychological aspects, such as anxiety, depression and perceived stress, are shown to have an inverse correlation with health improvement of patients living with HIV/AIDS (Calvetti et al., 2014:8-15).

In a South African setting, it was seen that the onset of depression in HIV-positive patients is negatively associated with ART adherence. The successful treatment of depression with an antidepressant or psychotherapy was associated with improved ART adherence, independent of the type of treatment and socio-demographic factors. It is thus necessary to identify HIV-positive patients at risk of depression, to initiate antidepressant treatment which may prevent ART non-adherence, and subsequent disease progression and increased morbidity (Moosa and Jeenah 2012:148). Patients that have a cognitive impairment such as forgetfulness have been seen to not take their pills. This was often cited with various reasons, ranging from patients being busy with work or family obligations, travelling without medication, and the lack of a plan for treatment adherence (alarm or friend/family to remind them) (Barnett et al., 2013:172-173). In a study conducted in South Africa, it was found that forgetting to take ART during the weekend was one of the reasons for poor adherence among 22% of participants who default treatment. Some of the participants in this study regarded weekends as treatment holidays (KZN Health Research and Knowledge Management, 2015:2). Non-disclosure of HIV status was regarded to be a barrier to adherence, as patients find it difficult to maintain ART without support at home. Many of the patients felt the need to hide their medication and would often not take it when travelling or if others were present at work or at home (Barnet et al., 2013:172-173). Lack of family support acted as a barrier to adherence and family arguments stopped them from taking medication. Thus, the combination of difficulty of accessing hospital and an unhelpful family can negatively affect adherence whereas family support enhance adherence (Wasti et al., 2012:1-9).

Medication-Related Factors
Patients who take once-daily regimens have shown higher rates of adherence than those patients that take more than once daily regimens (KZN Health Research and Knowledge Management, 2015:3). Characteristics of regimens such as taste, size of pills, and availability of liquid formulations, low pill burden, without food requirement and few side effects or toxicities are known to be associated with higher adherence levels (KZN Health Research and Knowledge Management, 2015:3)

According to Barnett et al, (2013:172), in a study conducted in Cape Town, one-third of patients identified side-effects as a reason for treatment failure, citing nausea, vomiting, stomach pains and cramping.

Side effects have also contributed in no small measure to the decreased adherence in patients in a study undertaken in Nigeria. ARV medication usually has temporary side effects including transient reactions such as diarrhoea and nausea as well as longer lasting effects such as
lipodystrophy and neuropathy. Lipodystrophy, according to the author affects between 30% and 60% of persons on treatment (Ayenigbara, 2012:3).

In yet another study, most participants had experienced side-effects, which increased non-adherence. Doctors agreed that side-effects led some patients to stop taking ART. These common side-effects included vomiting, diarrhoea, body pain, skin rashes and reduced body fat (Wasti et al., 2012:1-9).

Non-adherence may also be caused by non-availability of ARV drugs. In Nigeria, the Federal Government dispenses out intermittently disrupted drug supplies and when the available drugs are exhausted the HIV/AIDS patients cannot continue their treatment and this may result in non-adherence (Ayenigbara, 2012:3).

At the time of ART initiation, counsellors instruct patients to take their pills twice daily at exactly the same time in the morning and evening. This is laid out as one of the ‘rules’ of ART adherence and is presented in a concrete format, allowing very little scope for the patients when times clashed with their schedule. One-third of patients stated that they had difficulty taking their medication because of the large pill size (Barnett et al., 2013:172).

Non-adherence to ART like many other drugs may be caused by a number of factors. For instance, as complexity of regimen for many chronic diseases such as Tuberculosis, Leprosy and HIV/AIDS (i.e. the number of pills per dose and number of doses per day) increases, adherence decreases (Ayenigbara, 2012:3).

Regimens that involve close monitoring and severe life style alteration together with side effects may lead not only to frustration and treatment fatigue, but also ultimately to non-compliance. Regimens requiring fewer alterations in lifestyle pattern are likely to have a positive influence on adherence to medication (Ayenigbara, 2012:3).

Participants who were satisfied with their treatment, who were not taking co-medications and never had a regimen switch were found to be more adherent to ART treatment than to the corresponding comparison groups (Demessie, Mekonnen, Amogne and Shibeshii 2014:1-10)

**Health Care Delivery Systems-Related Factors**
The limited availability and accessibility of ART, health care providers, counsellors and facilities leads to longer waiting times, restricted opening hours and inconvenient appointment schedules. Additionally, the presence of judgemental health care workers and limited privacy could lead to non-adherence (KZN Health Research and Knowledge Management, 2015:3)

In one study, interviews with patients revealed difficulties with healthcare delivery, with some patients citing missing medical records and clinic staff shouting at patients. Staff identified a lack of continued counselling support following ART initiation and insufficient education for patients as key obstacles. One clinician identified counselling as a critical but under-utilised component as counsellors are being overlooked but they are a critical part of the whole process (Barnett et al., 2013:173). Many facilities in Southern African countries have long patient waiting times, inadequate infrastructure and facilities, and insufficient staff. Severe staff shortages have necessitated only cursory exchanges between patients and their providers. When personnel are available, they may find themselves poorly prepared for the demands of ongoing relationships with patients who may be chronically ill (Kagee et al., 2011:5).
Mental health problems, particularly mood, anxiety, and substance use disorders, have been associated with compromised adherence levels due to inadequate services existing for the diagnosis, treatment and management of mental health problems associated with HIV patients in many resource-constrained settings (Kagee et al., 2011:5).

In an effort to alleviate the burden placed on professional health care workers, lay counselors have been employed to assist with pre- and post-test HIV counselling. Yet, insufficient emphasis is often placed on adequate training, ongoing supervision and support for such personnel and thus counselling is reduced to the dissemination of information, rather than processing of patients’ emotions to alleviate distress and alter long-standing behaviour patterns, like non-adherence (Kagee et al., 2011:5).

Social and Environmental-Related Factors

The living conditions of patients, having multiple caregivers, financial problems and structural social support are factors that can affect adherence. Stigma and discrimination may further lead to non-adherence of ART (KZN Health Research and Knowledge Management, 2015:3)

Poverty is likely to affect adherence to care, as financial resources may need to be directed elsewhere, funds for travel to a medical facility that provides ART may not be available, and childcare may not be readily accessible for parents who attend appointments. The combined stresses associated with poverty, such as inadequate housing, community violence and unemployment tend to increase non-adherence (Kagee et al., 2011:3-5).

Low and middle income countries are characterised by several deficits in environmental infrastructure, notably inadequate transport. As most patients who attend public health facilities do not have private transport they rely chiefly on public means, which are in many cases expensive, unsafe and in some areas, unavailable. The limited incomes characteristic of patients in low income countries may in some cases preclude even using public transport. Thus, if clinics are located far from residential townships, patients often have to walk, which may require considerable effort and thus may cause non-adherence to treatment (Kagee et al., 2011:3-5).

In a qualitative study conducted among ART users in Uganda, Tanzania and Botswana, participants reported that they were unable to afford food needed to satisfy their increased appetites following commencement of treatment, especially in the early stages of treatment when their bodies needed extra nutrition to regain lost weight and strength. Food insecurity may affect the regularity of ART doses, as some patients have reported taking their medication only when they have food available (Kagee et al., 2011:3-5).

Positive social and family support has been shown to be associated with good medication adherence. However, difficult living circumstances in low income countries, contributed to by residence in informal settlements, the absence of basic amenities, high rates of migration, overcrowded living conditions, family violence and substance abuse, often create conditions under which the quality of social support to patients is poor. Also, the desire for privacy due to HIV stigma can be a barrier to accessing social support from within a patient’s social network (Kagee et al., 2011:3-5).

Money also emerged as a common mentioned barrier to adherence, as most studies report economic worries related to the cost of (a) transport, (b) prescription, (c) diagnosis, and (d) food. Transport costs emerged as a key theme and patients often did not have enough money to go to the health facility to get their repeat prescription. Health care providers also concurred with this. This
may remain a major reason why some individuals may not be able to come to the health facility to refill their prescriptions (Wasti et al., 2012:6).

In yet another study, most participants had experienced some form of discrimination, and HIV-related stigma (or fear of stigma) was identified by the majority of interviewees as influencing adherence behaviour especially among women. Due to the fear of being victimised and/or rejected by their family or community, this generated a fear of exposure, which in itself affected adherence (Wasti et al., 2012:6).

Globally, stigma and discrimination are major obstacles leading to treatment seeking behaviour and effective HIV/AIDS prevention and care, especially in Sub-Saharan Africa. Stigma is rooted in deviance from the values and social norms of a community and known as a risk factor of lower levels of adherence to treatment especially, ARVs. Because of stigma and discrimination, patients often tend to miss their doses as a result of fear of being identified as HIV positive (Kheswa, 2014:452).

Addressing the problem of non-adherence involves targeting these four factors to the extent that they compromise efficient, effective service provision, and the adoption and maintenance of therapeutic behaviours. To accomplish this requires a shift from an acute care model of treatment that has traditionally overemphasised the role of the patient-related factors as a determinant of adherence (Sabaté, 2001:9).

**Objective 2: Theoretical Models of Antiretroviral Treatment Adherence**

There are a number of social cognitive theories that have been developed to gain an understanding of health behaviours in general. These include the Health Belief Model, the Theory of Planned Behaviour, and the Informational–Motivational–Behavioural Model. A brief overview of these models will be provided below together with their applicability to ART adherence management (Kagee, 2008:8).

**2.3.1. Health Belief Model**

The Health Belief Model is a psychological model that attempts to explain and predict health behaviours by focusing on the attitudes and beliefs of individuals. It was first developed in the 1950’s by social psychologists Hochbaum, Rosenstock and Kegels working in the American Public Health Services in response to the failure of a free tuberculosis health screening programme. Since then, it has been adapted to explore a variety of long- and short-term health behaviours, including sexual risk behaviours and the transmission of HIV/AIDS (Masokoane, 2009:13).

The conventional wisdom that is associated with the way ART adherence is currently viewed in South Africa is that, given the facts and presented with alternatives, people will adhere to treatment (Kagee, 2008:8). In a large measure this approach is encapsulated by the Health Belief Model which states that health-related action depends on the simultaneous occurrence of four factors namely; susceptibility, severity, barriers and cue to action. These factors interact as follows:

While the perceived susceptibility and severity to a disease constitutes a perceived threat, the perceived barriers and perceived benefits influence the perceived effectiveness of medication adherence. A high perceived threat with low barriers and high perceived benefits promote healthy
behaviour. The model also adds cues to action which can be either internal such as symptom perceptions or external such as health communication (Unni, 2008:17). For persons receiving ART, HIV positive status, CD4 count, and quality of life constitute the health concern; the prospect of deterioration in health status, leading ultimately to death, is the perceived threat; and factors such as stigma may be the perceived barriers (Kagee, 2008:8). The perceived benefit of ART prolonging life along with cues to action such as a strong patient-provider relationship could assist in overcoming the barrier and thus promoting healthy behaviour. In addition, the model also added self efficacy as a construct to explain the need to feel competent to be medically adherent. The major limitations of the model are its failure to take into account the influence of social relationships and the inability to address behavioural coping skills (Unni, 2008:17)

**Theory of Planned Behaviour**

This theory was developed by Ajzen and Fishbein in 1980 and regards the intention to be adherent with medications being influenced by constructs such as attitudes towards the behaviour, subjective norms, and perceived behavioural control (Unni, 2009:18). Numerous successful HIV/STD prevention research efforts and interventions have been partially or completely based on this theoretical framework.

Behavioural intention is considered as the strongest predictor for the behaviour. While attitudes comprise both positive and negative beliefs as well as the evaluation of outcomes of the behaviour, subjective norms include the perceived expectations of significant others and the individual’s motivation to comply with their expectations. Perceived control is a function of the perceived ease or difficulty in performing behaviour (Unni, 2009:18).

Attitudes towards treatment adherence are a person’s evaluative opinions, both positive and negative, of the outcome of a behaviour which in this case is ART adherence (Kagee, 2008:8-9). With regard to adherence to ART, negative attitudes toward ART have been shown to be associated with non-adherence which was related to concerns about adverse effects and perceptions of the necessity of the medication. To the extent that attitudes are modifiable, it is possible that interventions directed at increasing positive attitudes towards ART may result in higher treatment adherence (Kagee, 2008:8-9).

Subjective norms refer to a person’s evaluation of others’ (usually family and friends) expectations of a specific behaviour. The concept of subjective norms is based on the assumption that social pressure encourages people to behave in a socially desirable manner and that people are in turn motivated to comply with these social expectations (Kagee, 2008:8-9).

Perceived behavioural control on the other hand refers to an individual’s belief that he or she is able to engage in a specific behaviour, taking into account internal and external control factors. Internal control factors refer to the abilities, skills, or information that he or she possesses, while external control factors refer to the opportunities or barriers that he or she may experience. Both internal and external control factors are influenced by past behaviour or experiences. Perceived behavioural control is seen here as the ability to take a proactive role in one’s health (Kagee, 2008:8-9). However, this theory is based on the assumption that individuals behave rationally and thus does not consider the impacts of affective beliefs in medication adherence. (Unni, 2009:18).

**The Informational–Motivational–Behavioural Model**

This model states that information, motivation, and behavioural skills are the fundamental determinants of behaviour which, in the present instance, is adherence to ART (Kagee, 2008:9-10).
Initially, information that is related to the role of ART adherence in leading to optimal health outcomes is necessary for HIV preventive behaviour. A motivation to engage in the adherence behaviour is then necessary and includes personal motivation and social motivation (Kagee, 2008:9-10).

Both information and motivation tend to influence whether an individual will be inclined to engage in adherence-related behaviours, such as clinic attendance and regular pill-taking. Therefore the behavioural skills associated with adherence, such as being able to go to the hospital and remembering to take medication, as well as a sense of self-efficacy for caring out these acts, comprise the third prerequisite of ART adherence (Kagee, 2008:9-10). In terms of this model, these behavioural skills determine whether well-informed and well-motivated persons will indeed adhere to their medication regimens (Kagee, 2008:9-10).

The advantage of this theory is its simplicity and it is said to be moderately effective in promoting behaviour change. It has also been shown to have predictive value for ART adherence (Munro, Lewin, Swart, Volmink, 2008:8).

**Objective 3: The Effects of Non-Adherence to Antiretroviral Treatment on the Organisation**

Cost of care is the most important effect that non-adherence has on the institution as an increase in non-adherence is seen to be proportional to the associated costs for the institution.

Medication non-adherence is a very important issue in medical care as it imposes a considerable financial burden upon health care systems (Vermeire, Hearnshaw, Van Royen and Denekens, 2001:1). Non-adherence causes medical and psychosocial complications of diseases: it reduces patients’ quality of life and wastes health care resources. Together, these direct consequences impair the ability of health care institutions to achieve population health goals (Sabaté, 2003:11). Furthermore, it leads to poor outcomes, which then increases health care service utilisation and overall health care costs (Iuga and McGuire, 2014:37). It can therefore be regarded as a significant contributor to avoidable health care costs. While impact on disease outcome and cost is more pronounced in some illnesses than others, stakeholders agree that increasing medication adherence would improve health outcomes and save a considerable portion of an institutions budget (Iuga and McGuire, 2014:37).

Adherence to ART on the other hand has positive effects on the health status of patients with chronic illnesses and it confers economic benefits. These are direct savings generated by less use of sophisticated and expensive health services caused by disease exacerbation, crisis or relapses of patients due to non-adherence (Sabaté, 2001:9).

Estimates of costs and outcomes are often expressed in hospitalisation costs, which do not include medical costs that happen outside hospital, such as ambulatory care and nursing home care. This often results in an underestimate of the true cost of non-adherence and its impact on society. To fully understand the impact of non-adherence and the benefit of adherence with proper intervention, it is appropriate to estimate the full cost of non-adherence. This may include (Schilling, Kaye-Blake, Allen and Zeng, 2012:6-7):

**Direct Costs**

Hospital Costs: These are health care and medicine costs that occurred due to increased morbidity and hospital visits as a result of non-adherence to medical instructions and recommendations. In the case of HIV/AIDS, the costs for hospitalisation events are due to opportunistic diseases as a direct result of non-adherence.
Treatment Costs: These are changes in the costs of treating the disease due to non-adherence where patients have to be put on second line therapy which comes at a higher cost on average as compared to first line therapy.

Hospital-Related Costs: These are costs outside the hospital setting that are caused by non-adherence, which include: ambulatory care costs, nursing home care costs, laboratory tests costs and so on.

Indirect Costs
Productivity Costs: These include costs incurred by the patient and society because of lost or impaired ability to work or engage in leisure activities due to morbidity and lost economic productivity due to early death.
Social Welfare Costs: These are costs to the social welfare system given an individual’s inability to work
Personal Costs: These are costs to the patient due to loss of health and subsequent loss of income as a result of non-adherence.
Costs to the patient’s family and friends: These are costs to family members and other associates, such as time associated with caring for the patient
Other Associated Costs: These include all other negative externalities not covered above. For example, non-adherence with infectious diseases may cause public health problems if other patients are infected.

The direct costs are those that have an effect on the organisation. An online search for studies that reported on the costs associated with non-adherence to ART yielded limited results for South Africa as well as Sub-Saharan Africa. The two studies found are discussed below.

With regard to the direct hospitalisation costs, in a study conducted by Ellis, Smit and Laubsher (2003:16-17), it was reported that the financial strain on the public health sector was severe, not only as a result of the sheer number of people seeking health care, but also because health care for AIDS patients is more expensive than for most other conditions. In 2003 the estimates suggested that the average annual cost to the public sector of treating an AIDS patient was between R3 000 and R4 500 per patient. Furthermore, this analysis explored the impact of providing public health care at a cost of R16 900 per full-blown AIDS case. With 75% of all the AIDS victims who are not employed in the skilled and highly skilled sectors looking towards publicly funded hospitals for medical care, this would have amounted to roughly R6 billion of extra public sector spending on health care by the year 2005 and R11.7 billion by 2010.

It was assumed that 60% of this extra health expenditure would be used to employ more doctors, nurses and other health workers and the remaining 40% would go towards other government health expenditure. In order to account for this budget constraint, it was further assumed that the government would finance 50% of the extra health expenditure by reducing spending in other departments or within the health department (Ellis et al., 2003:16-17).

In another study, it was reported that cost models that suggest excellent adherence could be cost-effective in the United States, but little data is available from resource-limited settings. It was, however found that in South Africa higher adherence to combination ART was associated with lower total monthly healthcare costs in a dose–response pattern, primarily due to significantly lower hospitalisation costs for patients with higher ART adherence (Nachega, Mills and Schechter, 2010:4). As a first line treatment, combination ART can be delivered relatively cheap as generic formulations are now available in South Africa. However, if drug resistance develops and these
medicines are no longer effective, second line ARVs may be required. These second line ARVs are much more expensive than first line medicines. Thus if ART costs continue to decline (for example, by increasing availability of generic drugs), then the relative contribution of ART costs to total costs will decline, further accentuating cost savings in patients with higher adherence (Nachega et al., 2010:4).

It can therefore be stated that there is a critical need for research, including an assessment of cost-effectiveness of ART adherence in resource limited settings as well as the impact of improving ART adherence on costs and clinical outcomes.

The same online search yielded some studies that were conducted in other developed and developing countries and reported as follows:

In a retrospective cohort study in the United States of America, of the 325 previously antiretroviral medication-naïve HIV-infected individuals initiating first ART from 1997 through 2003, the results indicated that better adherence to ART was associated with decreased health care utilisation and associated costs (Gardner, Maravi, Rietmeijer, Davidson and Burman, 2008:1).

In another study carried out in the USA, non-adherence was associated with an additional statistically significant risk of hospitalisation ranging from 43 – 54% and partial adherence was associated with a 38% increase in health care costs (Cohen, Davis and Meyers, 2012:1).

In a study conducted in China, it was reported that consistent adherence to ART led to a reduced utilisation of medical resources, such as decreased number of non trauma hospitalisation’s, shorter hospital stays and reduced hospitalisation expenses. The effective use of ART therefore slows down the progression of HIV/AIDS which in turn reduces the high medical cost of inpatient HIV/AIDS care (Wang, Zhou, He, Luo, Li, Yang, Fennie and Williams, 2009:1).

In a study conducted in New Zealand in 2012, it was reported that non-adherence increased hospitalisation costs by $0.06 million and reduced treatment costs by $2.1 million due to non-adherence reducing the number of drugs taken, and therefore the costs of drug medications across HIV and AIDS patients (Schilling et al., 2012:21).

In HIV and AIDS, expensive treatment regimens have to be used to achieve the same level of treatment success as the adherent population. As a result, the overall cost implications of ART could be far more in circumstances characterised by low adherence rates. Given that the financial resources used for ART programmes are constrained in many countries like South Africa, the government’s ability to achieve nationwide access would be undermined by non-adherence. It is then important to quantify the costs associated with low adherence to ART (Chawana, 2010:32).

Objective 4: To investigate the Current Adherence Management Strategies and to Recommend a Range of Effective and Efficient Adherence Management Strategies

The Current Adherence Management Strategies that are being employed for Patients Receiving Antiretroviral Treatment at Murchison Hospital

In consultation with the operational manager of the ARV clinic at Murchison Hospital, it was determined that the current adherence management strategies for patients receiving ART at Murchison Hospital were aligned with the two policy documents published by the Department of Health of South Africa listed below:

1. The National consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults (2014)

The 2014 Guidelines include a detailed list of strategies to be used for adherence management which begins at the time of diagnosis of disease. These strategies are employed by the Hospital’s ARV clinic in ensuring adherence is enforced and subsequently maintained. These steps are as follows (Department of Health, 2014:36-37):

- Adherence counselling should begin at the time of diagnosis, where patient education on HIV should be explained in detail. Furthermore, the treatment plan should be explained and expected clinic visits discussed.
- To encourage disclosure to family or friends who can support the treatment plan.
- To monitor and offer ongoing adherence support by being supportive and non-judgmental to encourage open and honest patient communication.
- To ensure that the adherence goal is >95% of doses taken and to note that patients with adherence <80% require more adherence support.
- Routine adherence discussion/education with adherence counsellors is valuable. This should be an open-ended discussion, with time for questions and key points about adherence reinforced.
- Patients should be reassured on the transient nature of side-effects such as nausea and vomiting at treatment initiation.
- Encourage caregiver participation in a support group.
- There should be monthly counselling visits for the first three months and quarterly thereafter, and feedback given to the rest of team to develop a better profile of the patient’s environment.
- Identify food insecurity and actively address this through government support programmes.
- Ensure communication between clinic visits and between referral points.

Apart from these strategies, it was also reported that the ARV clinic utilises an instrument which is termed a ‘Patient Adherence Record’ to measure a patient’s overall adherence. This instrument was obtained from the 2010 guidelines and an example of it is provided in the appendices (Department of Health, 2010:38). This instrument utilises four measures of non-adherence in order to calculate a patient’s overall adherence namely: self reports, visual analogue scale, pill identification test and pill counts. These measures are an effective way of assessing adherence especially in resource limited settings like South Africa.

**Recommending a Range of Effective and Efficient Adherence Management Strategies**

In order to achieve an efficient adherence management programme, it needs to be understood that adherence includes: taking treatment as prescribed, keeping to appointments for test results, referrals and any other further investigation. The patient’s motivation to continue engaging with care regardless of eligibility for ART is influenced by their experience with the healthcare system and the attitude of healthcare providers. (Department of Health, 2014:36).

ART adherence support services that involve all health care team members, including physicians, nurses, midwives, pharmacists, medication managers and social workers in meeting the individual patient needs is of utmost importance for the efficient management of adherence. There are many adherence interventions that can be used to improve adherence and each of the options can be customised to suit various needs and settings. Simple, effective and feasible interventions are required in order to sustain virologic suppression and avert the development of ART drug resistance (KZN Health Research and Knowledge Management, 2015:6).
The following adherence management strategies have been seen to enhance adherence at all levels as determined by a systematic review of studies that have been done in this regard. It is important to note that some strategies here are already being utilised but their use must be further strengthened (KZN Health Research and Knowledge Management, 2015:6; Department of Health, 2014:36-37; Department of Health, 2010:18):

- Patient counselling at points during treatment: The whole clinic team needs to support adherence at all points of intervention, spend time with the patient and explain the disease, the goals of therapy and why the need for adherence that ensures virological suppression as often as it is needed.
- Negotiate a treatment plan that the patient can understand and to which he/she commits.
- Health education to ensure treatment literacy: Improve understanding as patients often have limited knowledge and understanding about why they have to take ART, how it works and how it benefits them.
- Health education leaflets and group health education classes from tabletop flip charts.
- Reinforcing factors about the disease and the need for treatment.
- Reinforce the use of adherence tools for example, pillboxes and/or daily dosing diary.
- Mobile phone calls or short message service (SMS) as reminders for patient appointments.
- Involvement of family, friends or even adherence counsellors in-patients’ treatment program (Consider using a ‘treatment buddy’ or even directly observed therapy for an agreed period).
- Late attendance tracing of patients by councillors
- Training of adherence support workers regarding the adherence support strategies
- Systematic monitoring of adherence at the clinic during visits for refills
- Arrange home visit if available to be undertaken by the nominated community care giver, or trained home-based carer.
- Access to drug and alcohol counselling.
- Emergency relief for nutritional support.
- Support with disclosure to family or/and friends.
- Self reporting on adherence should be encouraged
- Explain to patients how to avoid adverse drug-drug interactions.
- Focus on patient-provider shared decision-making.
- Empower patients to manage their condition themselves.
- Ensure patients understand the risks of not taking their medications.
- Address fears and concerns.

It was reported by Ross, Aung, Campbell and Ogunbanjo (2011:1-5) in their study on the factors that positively influence adherence to antiretroviral therapy by HIV and/or AIDS patients and their caregivers that the factors which most influenced adherence were; the acceptance of HIV status, a belief in ART, a supportive relationship with the health care providers, the importance of disclosure to significant others and lastly the importance of adherence classes.

Disclosure to significant others appeared to be a key factor in promoting adherence and was identified by patients as critical, as it allowed families to be involved in the care and support of the patient. The disclosure to family members promoted adherence in practical ways such as reminders to take pills, and material support such as the provision of financial support and food. The importance of disclosure has also been recognised in other studies and is thus a pre-requisite for patients accessing ARTs at South African government roll-out sites. A study conducted in Tanzania found that tangible and emotional support from family members facilitated adherence.
and a study from Cote d’Ivoire identified absence of social and family support as a factor leading to poor adherence (Ross et al., 2011:1-5).

Another key factor identified was that of adherence classes. It was reported that they are essential as they provide information about the disease, its progression, the correct doses of medication, and possible side effects: all of which are important for patients and help to ensure adherence to medication (Ross et al., 2011:1-5).

In another study conducted by the AIDS research institute of the University of California San Francisco (UCFS), surveys of persons being treated for HIV were found to emphasise difficulties of integrating medications into their daily lives as the major challenge to adherence. It was thus concluded that non-adherence to HIV drug regimens should be viewed as a multifaceted problem most effectively addressed with multi-component programs (Bamberger, Bangsberg, Chambers, Ciccarone, Colfax, Deeks, Ekstrand, Grant, Hecht, Kahn, Swanson, Taylor and Thomas, 2000:3).

Based on this, the Partnership in AIDS Clinical Trials (PACT) program was implemented as a demonstration project to study and model treatment adherence supports. It provided patients enrolled in clinical trials with trained facilitators who met individually with patients in person or on the phone. The sessions focused on 1) clarifying the patients drug regimen, 2) developing an individualised plan for integrating the regimen into daily life, 3) self-monitoring of adherence, 4) enhancing communication with treatment staff, and 5) problem-solving around episodes of non-adherence. This support program was shown to improve adherence (Bamberger et al., 2000:3).

Assessing the patient’s readiness to begin ART is another important strategy that may be used to improve adherence. This assessment should include the patient’s knowledge of the HIV disease, treatment and prevention as well as provide ART information, viral load and CD4 count as well as the expected treatment outcomes based on the above. Adherence-related information regarding strict adherence measures, the consequences of poor adherence, the following of treatment plans, identification and support for facilitating factors as well as addressing potential barriers are also important during this stage (KZN Health Research and Knowledge Management, 2015:7) (OARAC, 2015:190-193).

The individualisation of the treatment with patient involvement in the decision making process is another strategy that has proven effective. The treatment plan must be understood by the patient so that the patient can commit to it and it must involve the patient’s daily schedule, tolerance of pill size, number and frequency and food requirements. The involvement of the patient in the treatment plan will contribute in the establishment of patient-provider relationship over time which might improve adherence and produce effective treatment outcomes (KZN Health Research and Knowledge Management, 2015:2-7) (OARAC, 2015:190-193).

In a study that assessed the impact of a community-based adherence support service on the outcomes of patients on ART conducted in selected government HIV treatment sites in South Africa which is the technique of taking medication under the supervision of adherence counsellors trusted family members or community lay workers, it was noted that a significantly higher proportion of patients with a community-based adherence councillors remained in care, regularly picked up their treatment from ART clinics and were virologically suppressed as compared to those that did not have these councillors. Therefore, this study concluded that integrated community-based adherence support is crucial (Igumbor, Scheepers, Ebrahim, Jason and Grimwood, 2011:2).

Other adherence management strategies may include the use of technology to improve adherence. Emerging technologies-based intervention strategies recently evaluated for their ability to improve
adherence include pill organisers, electronic reminders, education devices and cell phones (Nachega, Mills and Schechter, 2010:4).

Though the use of pill-box organisers and reminder key-rings are an attractive method for resource-limited settings, they are yet to be evaluated. Cellular telephone technology, however, may be of great assistance to provide reminders for adhering to medication schedules and keeping clinic visits as a large percentage of patients have cellular phones even in resource limited settings. This approach has shown to be culturally relevant for cell phone owners, largely confidential, is not affected by distance, and can be uniquely modified to meet patients’ individual education or lifestyle needs. As an example, one company in South Africa texts soccer results and jokes to tuberculosis patients and, more recently, to HIV patients, rather than sending just clinical reminders (Nachega et al., 2010:4).

In a study conducted in South Africa by Adefolalu, and Nkosi (2013:9-11) titled ‘The Complex Nature of Adherence in the Management of HIV/AIDS as a Chronic Medical Condition’, several methods were identified as strategies to improve adherence to ART. These are as follows:

- **Antiretroviral Therapy Strategies**

  This included simplifying regimen characteristics, simplification of dosing schedules, reduction of pill burden, and adjusting dietary restrictions to match patients' daily activities. The caregiver system has been widely used where relatives or friends agree to assist the patient in adhering to the medication. They remind patients to take their medication, encourage them and assist in keeping hospital appointments. This approach has led to improved ART adherence among some HIV-infected persons. Social support not only assists the patient in adhering to ART but can also provide psychological support.

- **Adherence Tools for Patients**

  Pill boxes are containers used for storing the ARV tablets for regular use as prescribed and they enable the patient to take the medication correctly. Pill charts involve visual display of the pills in terms of their colour, shape, name and dosage of the medication during counselling which is very useful especially among the uneducated patients.

  Electronic devices such as beepers, alarms and watches that remind patients to take their medication according to the prescribed schedule are also used to enhance adherence. In addition, telephone calls and mobile-phone text messages have been shown to improve medication adherence in HIV infected individuals. Medication diaries are very useful in understanding the patterns of drug use by the patient and the reasons for not taking the medication regularly. Diaries are used by the patients to document the time and date of taking the medications and missed doses and the reasons for it. This tool may also be used to identify side-effects or other problems that the patient may encounter in the course of taking ART.

- **Health System and Service Delivery Interventions**

  Family nutritional support for HIV positive patients on ART improves adherence leading to good clinical outcomes, and this could be integrated into ART adherence interventions as an effective and comprehensive community-based primary care.

  Providing of transportation to the health facilities among HIV patients and integration of home-based care into ART services has led to improved attendance in clinic appointments.
ART regimens need to be chosen by taking into consideration the patient’s working and family life, especially the cost implication of the drugs to ensure continuous supply so that adherence can be optimised.

In a study conducted in Nepal, several recommendations were made for the improvement of adherence to ART, of these; four important strategies are provided below (Shigdel, 2012:50):

- Health care providers should offer clear instructions and proper counselling to patients focusing on managing side effects.
- To improve adherence it is important to empower patients by providing skills to take medicines in public places, where they might have to hide to take medicine due to other socio-cultural obligations. In addition, governments should encourage a supportive environment where patients do not have to worry about stigma and discrimination.
- To encourage patients to adhere to their medication, community support such as Community Care Centers (CCCs), Comprehensive Care Center and home-based care need to expand in areas which have high levels HIV patients.
- Addressing mental health issues and illness was also identified as a factor in non adherence. A published trial (i.e., five-session Balance Project) showed that focusing on the management of side-effects was beneficial on ART adherence. It also showed that efforts to improve patients’ skills in managing side effects had a potential to reverse the negative impact that perceived side effects have on ART adherence (KZN Health Research and Knowledge Management, 2015:9-10).

The growing availability of HIV treatment in developing countries like South Africa means that an expanded and more effective adherence assistance service is critically important. Health authorities should therefore adapt clinical treatment guidelines, disseminate information on antiretroviral therapies to the public, health professionals, and policy makers, and train medical personnel in the correct use of HIV medications and in culturally appropriate strategies for enhancing adherence (Bamberger et al., 2000:3). Furthermore, ART adherence needs to be tackled using a multidisciplinary approach due to the difficulty in predicting which patients will adhere to treatment and those who will not; as a person’s past adherence is the only predictor of future adherence (Adefolalu, and Nkosi, 2013:11).

RESEARCH METHODOLOGY

Introduction
Research can be defined as something that is undertaken in order to find out things in a systematic way, thereby increasing knowledge (Saunders et al, 2009:5). Furthermore, research methodology can be defined as the approach taken to acquire information required (McNabb, 2010:13). This chapter provides an overview of the research design and methodology that guided this study. The research philosophy and strategy is introduced and subsequently the target population, sample, research instrument, pilot study, administration and collection of the questionnaire, data analysis, validity and reliability, limitations, bias and ethical considerations are described and discussed.

Target Population
The target population is defined as the entire group of people that are of interest to the researcher and thus were considered to be those patients that attended Murchison District Hospital ARV clinic on a monthly basis to collect their ARV medication.

A sample size is defined as a subgroup of the population. The sample size should only be large enough to allow for the creation of statistically sufficient numbers (Saunders et al, 2009:210-211), thus a sample size of 150 patients who were on treatment for a minimum of six months, were over
the age of 21 and who had previously defaulted their ART treatment (at least once in the last six months) according to pharmacy prescription records were chosen for this research study.

Limitations of the Research
There are various delimitations to this research. One of the methodological shortcomings of this research is that non-probability purposive sampling was used in order to collect the data. Since the probability that a person would be chosen is unknown, it cannot be claimed that the sample is representative of the larger population. Therefore the non-representative nature of the sample means that the results could not be generalised to the general population of HIV positive people currently on antiretroviral treatment. The questionnaires were only available in English and Zulu, thus a requirement of the study was that participants be English or Zulu first or second language speakers. Furthermore, respondents must have been over the age of 21, had to have been on ART for a minimum of 6 months and defaulted at least once in the previous 6 months according to pharmacy prescription records. There were two limitations to this study. The first limitation was the time constraints placed on the questionnaire administration phase. This was due to the research study approval by the Department of Health taking much longer than initially anticipated. The second limitation was that in the literature review phase of the dissertation, a systematic search of literature relating to the adherence management strategies that are currently being employed by institutions either in South Africa or in any other countries yielded no results. All the sourced articles did not look at what strategies were currently in use but focused on new strategies that could be implemented. In South Africa, however, the currently used adherence management strategies are in line with Department of Health policy and thus this information was used in documenting the strategies that are currently in place.

RESULTS, DISCUSSION AND INTERPRETATION OF FINDINGS
Question 1

The majority of participants were female with 55.83%, while males made up 44.17% of the participants. This can be calculated as 67 females and 53 males out of a mean of a 120 participants, which is similar to the proportion of patients collecting ART at Murchison Hospital. These findings are consistent with other studies as set out in chapter 2, with the first being in South Africa, were women were said to experience higher levels of poverty and encounter greater barriers to accessing care than men because of multiple work and child-care burdens, restricted mobility, and economic dependence upon men (Kagee et al, 2011:5), and the second in Nepal were it was reported that due to socio-cultural and economic restrictions put upon women, they found it
far more difficult to adhere to their ART medication than their male counterparts did (Wasti et al, 2012:7). However, these findings are in contrast to a study conducted in Botswana, were researchers noticed that being male and having a history of failure to refill ART at a pharmacy were significant risk factors for suboptimal adherence among HIV/AIDS-infected patients (Ndiaye et al, 2013:1).

**Question 2**

**Figure 4.2 Participant Demographics: Age**

![Age Distribution](image)

The majority of the participants fell into the 31-40 age groups with the minimum age range being 21-25. It can thus be seen that the majority of participants were over the age of 30 (70 participants) as compared to the 50 participants being between 21 and 30 years of age. These findings are consistent with a study conducted in Nepal which reported that ART adherence decreased significantly with increasing age (Shigdel et al, 2014:113). It is also consistent with a study done in Maputo where older patients were seen to be those who more interrupted their treatment in comparison to younger patients. This was thought to occur as the older patients might be in treatment longer so they might have been exposed for larger periods of time to the adversities and difficulties of treatment adherence (Moreno, De Matos and Cabral, 2014:645). This is however in contrast to other studies that have been done where adherence was shown to increase with age. In these studies non-adherence showed a positive correlation with younger age (Nakiyemba, 2004:11).

**Question 3**

**Figure 4.3 Participant Demographics: Ethnicity**

![Ethnicity Distribution](image)
The majority of the participants were Black (91.67%), with no White participants and a minority of Coloured participants (5.83%) and Indian participants (2.50%). In this study, we did not find an association between non-adherence to ART and ethnicity and a possible explanation for this finding is because the study was conducted in a hospital situated in a rural area were the majority of individuals that reside here are African and is thus a homogeneous population with little variation in this regard.

**Question 4**

**Figure 4.4 Participant Demographics: Home Language**

The majority of the participants’ home language was Zulu, with English second and Afrikaans being the least. The questionnaire was available in English and Zulu, thus enabling all the participants to understand the questions and answer appropriately in line with questionnaire selected. A very small percentage of participants (3.33%) spoke languages besides those available in the questionnaire. This can thus be seen as a limitation as other languages besides English and Zulu were not utilised in the questionnaire construction phase. In this study, no association between non-adherence to ART and language was found and a possible explanation for this finding is because the study was conducted in a hospital situated in a rural area were the majority of individuals that reside here are African and is thus a homogeneous population with little variation in this regard.

**Question 5**

**Figure 4.5 Participant Demographics: Highest Qualification**
The majority of participants (48.33%) had a matric qualification, with (43.33%) of respondents not completing matric. A small percentage of (7.50%) had stated that they possess a diploma and (0.83%) stated that they were in possession of a degree. This is consistent with two other studies as discussed below: In the first study it was reported that a lower level of general education and poorer literacy impacted negatively on some patient's ability to adhere whilst a higher level of education had a positive impact (Nakiyemba, 2004:11). In the second study non-adherence was relatively higher among less educated respondents (those with a matric pass or less) as compared to better educated (tertiary qualification). It was found that better educated people generally have greater access to information and are more likely to make better-informed decisions (Nwauche Nwauche, Erhabor, Ejele and Akani, 2006:16).

**Question 6**  
**Figure 4.6 Participant Demographics: Employment Status**

The majority of participants were unemployed (54.17%), whilst 34.17% had stated that they were employed and 9.17% had stated that they were self-employed. This is consistent with a study conducted by Nachega Nachega, Uthman, Peltzer, Richardson, Mills, Amekudzif and Ouédraogof, (2015:34), were it was reported that patients with HIV infections who were employed were 27% more likely to adhere to ART than those who were unemployed. In this study it was found that one of the barriers to ART adherence in both developed and developing countries, was a financial constraint, which may be considered a proxy for unemployment. Furthermore, it was reported that employment facilitates adherence to HIV treatment because it is associated with, for example, an increased social support. This is in contrast with another study, were it was reported that employment status did not have an effect on adherence to treatment (Bam et al, 2011:10).

**Descriptive Statistics**  
**Section B**  
4.1.1.1. **Question 7-16**

**Table 4.1: Patient-Related Factors**

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Have Told my Friends and Family About my HIV Status</td>
<td>2.5%</td>
<td>8.3%</td>
<td>3.3%</td>
<td>30.8%</td>
<td>55%</td>
</tr>
<tr>
<td>I Receive Enough Support From my Immediate Family</td>
<td>1.7%</td>
<td>6.7%</td>
<td>5.8%</td>
<td>35%</td>
<td>50.8%</td>
</tr>
<tr>
<td>I Receive Enough Support From my Friends</td>
<td>3.3%</td>
<td>12.5%</td>
<td>10.8%</td>
<td>26.7%</td>
<td>46.7%</td>
</tr>
<tr>
<td>I Fully Understand my Condition and Need for Treatment</td>
<td>0.8%</td>
<td>1.7%</td>
<td>3.3%</td>
<td>35.8%</td>
<td>58.3%</td>
</tr>
<tr>
<td>I Believe That my Medication Will Help me Feel Better</td>
<td>0%</td>
<td>2.5%</td>
<td>1.7%</td>
<td>34.2%</td>
<td>61.7%</td>
</tr>
</tbody>
</table>
Question 1 aimed to determine how many of the participants had disclosed their status to family and friends. Non-disclosure of HIV status was seen to be a barrier to adherence, therefore making it difficult for patients to maintain their ART without support (Barnet et al, 2013:172-173). 86% percent of the participants reported that they had disclosed either to their friends or family. This can be seen as a demonstration that the patient has accepted their status and it also minimises the likelihood that non-adherence will occur as the family members they have disclosed to can assist in reminding and motivating patients to adhere to their treatment. Question 2-3 aimed to determine the perceived family support of participants. The lack of family support acted as a barrier to adherence as an unhelpful family member or friend can negatively affect adherence whereas family support enhances adherence (Wasti et al., 2012:1-9). Here it was found that a collective 86% and 73% received adequate support from their family and friends respectively.

Question 4-5 and 9-10 aimed to determine the participants knowledge of ART, belief in and perception of ART. In terms of the knowledge of ART, due to the low health literacy in many resource-constrained countries, many patients consider medication only as a tertiary measure following the onset of symptoms, rather than as a prophylactic intervention (Kagee et al., 2011:5). A collective 94% had stated that they understood their condition and need for treatment, which indicates good health literacy whereas a collective 80% had stated that they continue to take their medication even if they felt better and 17% had stated that they stop therapy. This can be considered an area that requires intervention by improving patient counselling regarding ART and its effects.

Perception is concerned with people’s beliefs that they can exert control over their own motivation, thought processes, emotional states and patterns of behaviour. Negative perceptions as to the efficacy of ART and its effects could act as barriers and thus prevent adherence (Wasti et al., 2012:1-9). Question 5 and 10 aimed to determine this belief in and perception of ART. A collective 96% had stated that they believe that ART will make them feel better and not worse therefore indicating a firm belief in ART. A collective 61% had stated that the daily administration of ART does not interfere with their lives and 33% stated that it did interfere. This may be considered an area that requires intervention by proper planning for patients in terms of their daily medication schedules.

Question 6-8 aimed to determine the psychosocial factors of participants such as depression, anxiety and stress amongst others. Given the multiple stressors that poor communities face and the poor access to professional psychiatric treatment, the prevalence of untreated depression among South African communities is likely to be high (Masokoane, 2009:48). In a study in Brazil, it was concluded that psychosocial factors like anxiety and depression can contribute to non-adherence to antiretroviral therapy (Calvetti et al, 2014:8-15). In a South African study, it was found that the onset of depression in HIV-positive patients is negatively associated with ART adherence (Moosa and Jeenah 2012:148). A collective 93% stated that they are able to concentrate as well as feel capable of making decisions, whereas a collective 89% stated that they felt reasonably happy. This indicates an overall positive response.
Question 17-19

Table 4.2: Medication-Related Factors

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Know Whether to Take my Tablets With or Without Food</td>
<td>0.8%</td>
<td>10%</td>
<td>6.7%</td>
<td>30.8%</td>
<td>51.7%</td>
</tr>
<tr>
<td>I Remember to Take my Treatment on Time</td>
<td>0.8%</td>
<td>9.2%</td>
<td>4.2%</td>
<td>32.5%</td>
<td>53.3%</td>
</tr>
<tr>
<td>My Treatment Program is Easy to Follow</td>
<td>0.8%</td>
<td>4.2%</td>
<td>5.8%</td>
<td>30.8%</td>
<td>58.3%</td>
</tr>
</tbody>
</table>

Treatment programmes that involve close monitoring and severe lifestyle alteration in terms of meals and reminders may lead not only to frustration and treatment fatigue, but also ultimately to non-adherence (Ayenigbara, 2012:3). Question 17-19 aimed to determine whether medication-related factors were associated with non-adherence to ART. In terms of the participants understanding the need to take their treatment with or without food, a collective 83% stated that they do know and 11% stated that they did not. In terms of remembering to take their treatment on time, 86% stated that they do remember and 10% stated that they do not. A collective 90% of participants stated that their treatment program was easy to follow whereas only 5% stated that it was not. Due to an overall positive response to these questions, it can thus be reported that these medication-related factors do not have an effect on patient non-adherence to ART.

Question 20-23

Many facilities in Southern African countries have long patient waiting times, inadequate infrastructure and facilities, and insufficient staff (Kagee et al., 2011:5). The limited availability and accessibility of ARV’s, health care providers, counsellors and facilities leads to longer waiting times, restricted opening hours and inconvenient appointment schedules (KZN Health Research and Knowledge Management, 2015:3). Question 20-23 aimed to determine whether health care delivery system-related factors were associated with the non-adherence to ART.

Table 4.3: Health care delivery system-related factors

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Receive Enough Support From my Health Care Provider</td>
<td>0%</td>
<td>5%</td>
<td>6.7%</td>
<td>31.7%</td>
<td>56.7%</td>
</tr>
<tr>
<td>I Have had Health Education and Information Given to me</td>
<td>0%</td>
<td>2.5%</td>
<td>3.3%</td>
<td>36.7%</td>
<td>57.5%</td>
</tr>
<tr>
<td>I Wait a Long Time to Collect my Medication When I Come</td>
<td>18.3%</td>
<td>28.3%</td>
<td>3.3%</td>
<td>16.7%</td>
<td>33.3%</td>
</tr>
<tr>
<td>My Appointment Dates are Made for my Convenience</td>
<td>1.7%</td>
<td>5%</td>
<td>1.7%</td>
<td>40.8%</td>
<td>50.8%</td>
</tr>
</tbody>
</table>
In terms of support from health care providers, health education and information classes and convenient appointment dates, a collective 88%, 94% and 92% stated that they agree that these measures have been implemented and an overall positive result is seen here. In terms of waiting time at clinic for medication pickup, 50% of participants had agreed that they wait a long time whereas 47% disagreed to this. This can be considered as an area requiring intervention by using the various adherence management strategies to assist in implementing measures to decrease patient waiting times.

**Question 24-27**

**Table 4.4: Social and environmental-related factors**

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Have Enough Money to Come to the Hospital Monthly to Collect my Medication</td>
<td>4.2%</td>
<td>17.5%</td>
<td>18.3%</td>
<td>24.2%</td>
<td>35.8%</td>
</tr>
<tr>
<td>I Have a Continuous Access to Basic Services (Lights, Water, and Sanitation) at my Home</td>
<td>1.7%</td>
<td>4.2%</td>
<td>4.2%</td>
<td>33.3%</td>
<td>56.7%</td>
</tr>
<tr>
<td>I Have to Hide From Others When Taking my Medication</td>
<td>26.7%</td>
<td>28.3%</td>
<td>10.8%</td>
<td>15.8%</td>
<td>18.3%</td>
</tr>
<tr>
<td>My Employer Gives me off to go Collect my Medication</td>
<td>17.5%</td>
<td>20.8%</td>
<td>20%</td>
<td>19.2%</td>
<td>22.5%</td>
</tr>
</tbody>
</table>

Question 24-27 aimed to determine whether social and environmental-related factors were associated with the non-adherence to ART. Money has emerged as a common barrier to adherence in many studies, as respondents report economic worries related to the cost of (a) transport, (b) prescription, (c) diagnosis, and (d) food (Wasti et al, 2012:6). A collective 60% stated that they have enough money to attend hospital visits whereas 22% stated that they did not. Certain measures can thus be put into place to ensure that this 22% are referred out to institutions closer to their homes. A collective 90% stated that they had access to basic services at their homes. In another study reviewed, it was found that due to stigma and discrimination, patients often missed their doses as a result of fear of being identified as HIV positive (Kheswa, 2014:452). A collective 34% agreed that they had to hide from others when taking their medication whereas 55% state that they did not have to hide away. This is an area of great concern and thus requires appropriate measures to be implemented as part of the management strategies, due to the fear of being victimised and/or rejected by their family or community, a fear of exposure is generated, which in itself affected adherence (Wasti et al., 2012:6).

The high rate of unemployment in many low income countries like South Africa means that many patients do not have regular employment and thus make themselves available as day workers to employers. Often, this need for a day’s wages eclipses the potential benefit of a clinic visit, thus leading to non-adherence (Kagee et al., 2011:3). A collective 42% agreed that their employers give them time off to collect their treatment on a monthly basis whereas 38% stated that they were not allowed this opportunity. This can also be seen as an area requiring intervention by, for example, awareness campaigns to make employers more aware of the severity of non-adherence.
Question 28

Table 4.5: Co-medication and pill fatigue

<table>
<thead>
<tr>
<th>Item</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Blood Pressure Medication</td>
<td>38.3%</td>
<td>61.7%</td>
</tr>
<tr>
<td>Diabetes Medication</td>
<td>25.8%</td>
<td>74.2%</td>
</tr>
<tr>
<td>Heart Condition Medication</td>
<td>7.5%</td>
<td>92.5%</td>
</tr>
<tr>
<td>Depression Medication</td>
<td>10%</td>
<td>90%</td>
</tr>
</tbody>
</table>

Question 28 aimed to assess the effect of co-medication on non-adherence to ART. As can be seen above, there are considerable numbers of participants taking medication for high blood pressure and diabetes. This could lead to pill fatigue and thus tend to cause non-adherence to treatment. In a reviewed study, it was reported that participants who were satisfied with their treatment and were not taking any medication for other illnesses were found to be more adherent to ART treatment than to the corresponding comparison groups (Demessie et al, 2014:1-10).

Question 29

Table 4.6: Alcohol consumption

<table>
<thead>
<tr>
<th>Item</th>
<th>0</th>
<th>1 to 2</th>
<th>3 to 4</th>
<th>4 to 5</th>
<th>Greater Than 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Monday to Thursday</td>
<td>79.2%</td>
<td>13.3%</td>
<td>3.3%</td>
<td>3.3%</td>
<td>0.8%</td>
</tr>
<tr>
<td>Friday to Sunday</td>
<td>69.2%</td>
<td>9.2%</td>
<td>10.8%</td>
<td>8.3%</td>
<td>2.5%</td>
</tr>
</tbody>
</table>

Question 29 aimed to determine if alcohol intake had an effect on non-adherence to ART. The majority of participants reported that they did not consume alcohol, be it during the week or over the weekend (79% and 69% respectively). A considerable percentage of participants (13%) however stated that they did consume alcohol during the week (1 to 2 glasses). Over the weekend, it was stated that 31% of participants consume alcohol, with 9% consuming 1 to 2 glasses, 11% consuming 3 to 4 glasses and 8% consuming 4 to 5 glasses. The intake of alcohol has been shown to cause treatment non-adherence.

As most of the participants who drink usually do it over the weekend it is safe to assume that the adherence rates go down over weekends. Alcohol is an enzyme inducer, which means that it is an agent that increases the activity of enzymes in the body resulting in an increase in metabolism and therefore decreasing the serum concentration of the drug rendering the drug ineffective. Excessive alcohol intake may also cause nausea, vomiting and this may make tolerating ART more difficult. In a study conducted in Cape Town, Khayelista, alcohol use emerged as the most cited reason for failure. It affected adherence in two ways: Firstly, patients often forget to take their medication when drinking. Secondly, as with the timing of medication, patients understood that they could not drink and take their ARVs literally and stopped treatment altogether (Barnett et al, 2013:172-173).
Question 30
Figure 4.7: Number of tablets taken daily

![Bar chart showing the number of tablets taken daily.](chart1.png)

Question 31
Figure 4.8: Time at which tablets are taken

![Bar chart showing the time at which tablets are taken.](chart2.png)

Question 30-31 aimed to determine if the number of pills taken as part of regimen as well as the frequency of daily doses contribute towards the non-adherence to ART. Patients who take once-daily regimens have shown higher rates of adherence than those patients that take more than once-daily regimens (KZN Health Research and Knowledge Management, 2015:3). The majority of patients are on a single tablet regimen and are taking their treatment at night (70% and 68% respectively). A small percentage of participants are taking two and three tablet regimens (10% and 11% respectively) and 19% of participants are taking their medication twice daily (morning and night). Overall, it can be stated that the once-daily regimen is a good predictor of adherence to ART and thus the different regimens should be adjusted in order to allow for patients to take their treatment once daily thereby increasing adherence.
Question 32

Figure 4.9: Mode of Transport to Hospital

Question 32 aimed to determine if the mode of transport to the hospital by participants on a monthly basis had an effect on non-adherence to ART. As most patients who attend public health facilities do not have private transport they rely chiefly on public means and due to their limited incomes characteristics, this may in some cases preclude even using public transport. Thus, if the hospital is located far from the residential township, patients often have to walk, which may require considerable effort and thus may cause non-adherence to treatment (Kagee et al., 2011:3-5). The majority of participants had stated that they use public transport (58%), whereas 26% stated that they came to the hospital by foot and 14% used their own transport. This can thus be seen as an area requiring intervention which may include implementing systems to enable patients to collect their medication closer to their homes.

Question 33

Table 4.7: Side-effects of ART experienced

<table>
<thead>
<tr>
<th>Item</th>
<th>None</th>
<th>Minor</th>
<th>Major</th>
</tr>
</thead>
<tbody>
<tr>
<td>Constipation</td>
<td>61.7%</td>
<td>35.8%</td>
<td>2.5%</td>
</tr>
<tr>
<td>Diarrhoea</td>
<td>62.5%</td>
<td>30.8%</td>
<td>6.7%</td>
</tr>
<tr>
<td>Bloating / Gas</td>
<td>47.5%</td>
<td>45%</td>
<td>7.5%</td>
</tr>
<tr>
<td>Abdominal Cramps</td>
<td>55.8%</td>
<td>40%</td>
<td>4.2%</td>
</tr>
<tr>
<td>Dizziness</td>
<td>69.2%</td>
<td>30.8%</td>
<td>0%</td>
</tr>
<tr>
<td>Fatigue</td>
<td>37.5%</td>
<td>56.7%</td>
<td>5.8%</td>
</tr>
<tr>
<td>Headache</td>
<td>56.7%</td>
<td>40%</td>
<td>3.3%</td>
</tr>
<tr>
<td>Fever</td>
<td>45.8%</td>
<td>50%</td>
<td>4.2%</td>
</tr>
<tr>
<td>Can't Sleep</td>
<td>69.2%</td>
<td>24.2%</td>
<td>6.7%</td>
</tr>
<tr>
<td>Can't Eat</td>
<td>75.8%</td>
<td>21.7%</td>
<td>2.5%</td>
</tr>
<tr>
<td>Loss of Weight</td>
<td>46.7%</td>
<td>47.5%</td>
<td>5.8%</td>
</tr>
<tr>
<td>Fat Accumulation</td>
<td>61.7%</td>
<td>30%</td>
<td>8.3%</td>
</tr>
<tr>
<td>Nausea</td>
<td>53.3%</td>
<td>37.5%</td>
<td>9.2%</td>
</tr>
</tbody>
</table>
Question 33 aimed to determine the various side effects experienced by participants and their effect on non-adherence to ART. According to Barnett et al. (2013:172), in a study conducted in Cape Town, one-third of patients identified side-effects as a reason for treatment failure, citing nausea, vomiting, stomach pains and cramping as the most common. Side effects have also contributed in no small measure to the decreased adherence in patients in a study undertaken in Nigeria with temporary side effects including transient reactions such as diarrhoea and nausea and longer lasting effects such as lipodystrophy and neuropathy. Lipodystrophy, according to the author affects between 30% and 60% of persons on treatment (Ayenigbara, 2012:3). Factors such as drug toxicity or intolerance, discomfort associated with side effects, and dissatisfaction at having to make changes in terms of diet, exercise activities and work habits play an important role in the patient’s quality of life (Masokoane, 2009:54). Various side effects were identified as being present by the participants and these included all the listed items in minor occurrence ranging from 20% - 57%. Proper counselling regarding the warning signs and symptoms of side effects as well as management strategies may assist in the prevention of non-adherence and early drug self-discontinuation by patients (Masokoane, 2009:54).

**Research Question 3: What are the effects of non-adherence to ART on the organisation?**

**Section C**

**Question 34-38**

Table 4.8: The effects of non-adherence to ART on the organisation

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Have Been Admitted Into Hospital due to me Defaulting</td>
<td>38.3%</td>
<td>40%</td>
<td>0%</td>
<td>13.3%</td>
<td>8.3%</td>
</tr>
<tr>
<td>I Have Been Admitted due to Side Effects of my Medication</td>
<td>38.3%</td>
<td>39.2%</td>
<td>3.3%</td>
<td>12.5%</td>
<td>6.7%</td>
</tr>
<tr>
<td>My Treatment has Been Changed Because of me Defaulting</td>
<td>37.5%</td>
<td>38.3%</td>
<td>2.5%</td>
<td>12.5%</td>
<td>9.2%</td>
</tr>
<tr>
<td>I Feel That the Health Care Professionals are Experienced Enough to Treat me</td>
<td>1.7%</td>
<td>0.8%</td>
<td>0.8%</td>
<td>25.8%</td>
<td>70.8%</td>
</tr>
<tr>
<td>I can Speak to a Councillor When I need to Without Feeling Judged</td>
<td>3.3%</td>
<td>0.8%</td>
<td>1.7%</td>
<td>25%</td>
<td>69.2%</td>
</tr>
</tbody>
</table>
Question 34-38 aimed to determine the effects, if any, that non-adherence to ART had on the organisation and its management thereof. Medication non-adherence is a very important issue in medical care as it imposes a considerable financial burden upon health care systems (Vermeire et al, 2001:1). A total of 5 questions were asked with the first 2 questions aimed at determining if non-adherence and or the occurrence of side effects to ART increases the likelihood of being admitted into the hospital thereby increasing the cost of care in terms of hospitalisation costs. A collective 78% of participants stated that they disagreed with these statements, however 22% and 19% had agreed with question 34 and 35 respectively signifying that a considerable number of patients from the sample (26 and 23 respectively) had been admitted into hospital due to these reasons and thus have contributed to the increasing cost of care for non-adherent HIV/AIDS patients. This is consistent with findings from other studies. In a study conducted by Ellis et al, (2003:16-17), it was reported that the financial strain on the public health sector was severe, not only as a result of the sheer number of people seeking health care, but also because health care for AIDS patients in terms of hospitalisation and treatment is more expensive than for most other conditions. In another study carried out in the USA, non-adherence was associated with an additional statistically significant risk of hospitalisation ranging from 43 – 54% and partial adherence was associated with a 38% increase in health care costs (Cohen et al, 2012:1). Question 36 aimed to determine if non-adherence to ART was associated with any changes to regimens due to effectiveness of the drugs which also led to an increase in the cost of care in terms of treatment costs. A collective 76% stated that they disagreed with this statement; however, 22% stated that this was the case. Given that the financial resources used for ART programmes are constrained in many countries like South Africa, the government’s ability to achieve nationwide access would be undermined by non-adherence. It is then important to quantify the costs associated with low adherence to ART (Chawana, 2010:32). Question 37-38 aimed to determine whether the various costs associated with the attracting, recruiting and retaining of health care personnel where being utilised to its completeness in terms of professionalism, knowledge and the rendering of quality service to patients. A collective 97% and 94% agreed to question 37 and 38 respectively, thus concluding that these costs to the organisation are being utilised effectively.

Research Question 4: What adherence management strategies are currently in place for patients collecting Antiretroviral Treatment at Murchison Hospital?

Section D

Question 39-43

Table 4.9: The current adherence management strategies of patients receiving ART at Murchison Hospital

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Received Counselling When I was Started on Treatment</td>
<td>0.8%</td>
<td>0.8%</td>
<td>0%</td>
<td>25%</td>
<td>73.3%</td>
</tr>
<tr>
<td>I am Counselling Regularly and Even After Defaulting my Treatment</td>
<td>0.8%</td>
<td>10%</td>
<td>4.2%</td>
<td>27.5%</td>
<td>57.5%</td>
</tr>
<tr>
<td>The Health Care Workers Show Empathy When Counselling</td>
<td>0%</td>
<td>0%</td>
<td>4.2%</td>
<td>40.8%</td>
<td>55%</td>
</tr>
<tr>
<td>I am Constantly Told by the Health Care Worker why it is Important to not Miss a Pick up</td>
<td>0%</td>
<td>1.7%</td>
<td>5%</td>
<td>37.5%</td>
<td>55.8%</td>
</tr>
<tr>
<td>I Find the Process of Medication Collection an Easy Process From File Pick up to Dispensing</td>
<td>0.8%</td>
<td>2.5%</td>
<td>3.3%</td>
<td>35.8%</td>
<td>57.5%</td>
</tr>
</tbody>
</table>
Question 39-43 aimed to determine if the current adherence management strategies in use at Murchison Hospital were effective in terms of reducing the non-adherence of patients to ART. In order to achieve an efficient adherence management programme, it needs to be understood that adherence includes: taking treatment as prescribed, keeping to appointments for test results, referrals and any other further investigation. The patient’s motivation to continue engaging with care regardless of eligibility for ART is influenced by their experience with the healthcare system and the attitude of healthcare providers. (Department of Health, 2014:36). A collective 98% of participants stated that they had received counselling when initiating treatment. A collective 85% stated that they were counselled regularly. A collective 96% stated that the health care workers show empathy when counselling. A collective 93% stated that they are constantly told by the health care workers about the importance of adherence and the same percentage stated that they find the process of medication collection easy. This shows an overall positive result in terms of the current adherence management strategies being employed.

Research Question 4: What recommendations can be made to Murchison Hospital to ensure that adherence to Antiretroviral Treatment can be better managed and minimised?

Section E

Question 44-50 aimed to determine if the recommendations of various additional adherence management strategies will be received by patients willingly as well as to see if the foundation for the implementation of some of the recommendations were inherent in the population.

Question 44-45

<table>
<thead>
<tr>
<th>Item</th>
<th>Strongly Disagree</th>
<th>Disagree</th>
<th>Neutral</th>
<th>Agree</th>
<th>Strongly Agree</th>
</tr>
</thead>
<tbody>
<tr>
<td>I Have Friends and Family who are Willing to Help me not Forget to Take my Medication Daily</td>
<td>1.7%</td>
<td>7.5%</td>
<td>9.2%</td>
<td>30.8%</td>
<td>50.8%</td>
</tr>
<tr>
<td>I Have Attended Hospital or Community Based Workshops Directed at HIV Adherence and Disease Awareness</td>
<td>10%</td>
<td>25.8%</td>
<td>12.5%</td>
<td>30%</td>
<td>21.7%</td>
</tr>
</tbody>
</table>

A collective 52% of participants had stated that they have attended either hospital-based or community-based workshops aimed at adherence and disease awareness, while a collective 36% stated that they had not. This is an area requiring intervention as health education is essential to ensure treatment literacy by improving understanding as patients often have limited knowledge and understanding about why they have to take ART, how it works and how it benefits them. The implementation of health education workshops, group health education classes from tabletop flip charts and the handing out of health education leaflets will assist in patient awareness of the disease and treatment thereof. In a study conducted, another key factor identified was that of adherence classes and it was reported that they are essential as they provide information about the disease, its progression, the correct doses of medication, and possible side effects: all of which are important for patients and help to ensure adherence to medication (Ross et al., 2011:1-5).
A collective 82% of participants stated that they had either friends or family that were willing to assist with medication reminders. It can be seen in question 46 and 47 as well that participants have family who assist them with medication reminders as well as prepare their meals showing that a support system is available to the majority of patients. The involvement of family, friends or even adherence councillors in-patients’ treatment program (consider using a ‘treatment buddy’ or even directly observed therapy for an agreed period) can be implemented as this support system allows for it.

In a study that assessed the impact of a community-based adherence support service on the outcomes of patients on antiretroviral therapy (ART) conducted in selected government HIV treatment sites in South Africa, it was concluded that an integrated community-based adherence support is crucial (Igumbor et al, 2011:2).
Question 48

Figure 4.12: Cell phone ownership

Question 48 aimed to determine if patients were in possession of a cell phone that could be used as a medication reminder tool. A collective 93% stated yes to this question thus providing a basis for the implementation of a medication reminder system as used below in a study that was conducted. In this study, it was reported that cellular telephone technology may be of great assistance to provide reminders for adhering to medication schedules and keeping clinic visits as a large percentage of patients have cellular phones even in resource limited settings. This approach has shown to be culturally relevant for cell phone owners, largely confidential, is not affected by distance, and can be uniquely modified to meet patients’ individual education or lifestyle needs. As an example, one company in South Africa texts soccer results and jokes to tuberculosis patients and, more recently, to HIV patients, rather than sending just clinical reminders. Mobile phone calls or short message service (SMS) can thus be utilised as reminders for patient appointments (Nachega et al., 2010:4).

Question 49

Figure 4.13: Proximity of hospital from participant’s home
Inferential Statistics

Factor Importance – Repeated Measures ANOVA

Initially, Section B items 7 to 16 were combined for a global measure of a patient-based global factor, items 17 to 19 were added for a measure of a medication-based global factor, items 20 to 23 were summated to obtain an assessment of a healthcare delivery system-based global factor, and items 24 to 27 were added to obtain a measure of a social and environmental-based global factor. The variables were standardised prior to proceeding, with the standardisation based on the variables with the highest number of initial items included on the variable (10 items in this instance).

The descriptive statistics for each of the variables are displayed in Table 4.11. Mauchly’s Test of Sphericity was violated, $\chi^2 = 26.047$, $p < .001$, indicating the necessity to adjust for the sphericity assumption violation. In particular, since the Epsilon value was above .750, the Greenhouse-Geisser adjustment was used. The result indicated a statistically significant difference between one and more of the measures, $F(2.616, 311.322) = 54.538$, $p < .001$. In particular, significant differences were evidenced between the patient-based global factor, the medication-based global factor ($p < .001$) and the social and environmental-based global factor ($p < .001$). Specifically, patient-based global factor had a higher mean score than the medication-based global factor and a lower mean score compared to the social and environmental-based global factor. The medication-based global factor was significantly different from the healthcare-based global factor ($p = .001$) and the social and environmental-based global factor ($p < .001$). That is, the medication-based global Factor had a lower mean score as compared to the other factors that were significantly different. The healthcare-based global factor was significantly different from social/environmental-based global Factor ($p < .001$). The social and environmental-based factor had a higher mean score.
The patient-based global factor was not significantly different from the healthcare-based global factor ($p = .152$).

Overall, the results suggest that the most important factor is the social and environmental-based factor, which, compared to the other factors, may have the most important influence in relation to non-adherence to ART. The factors identified under social and environmental factors in the questionnaire were those of financial resources, employment and its effects on medication collection, stigma and discrimination and access to basic amenities such as lights and water. It can thus be stated that these factors had the most influential effect on the participant’s non-adherence to ART.

Table 4.12: Descriptive Statistics of each variable

<table>
<thead>
<tr>
<th>Variable</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>Skewness</th>
<th>Kurtosis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient-based Factor</td>
<td>120</td>
<td>20.50</td>
<td>5.12</td>
<td>.231</td>
<td>.107</td>
</tr>
<tr>
<td>Medication-based Factor</td>
<td>120</td>
<td>16.92</td>
<td>7.72</td>
<td>.799</td>
<td>-.296</td>
</tr>
<tr>
<td>Healthcare-based Factor</td>
<td>120</td>
<td>18.96</td>
<td>6.96</td>
<td>.231</td>
<td>-.590</td>
</tr>
<tr>
<td>Social and Environmental-based Factor</td>
<td>120</td>
<td>25.29</td>
<td>7.17</td>
<td>-.217</td>
<td>.295</td>
</tr>
</tbody>
</table>

Demographic Differences

Considering the social and environmental-based global factor evidenced the highest mean score and, perhaps, has the most significant influence on ARV treatment adherence, a range of analyses were conducted to determine whether there were significant differences between the social and environmental-based global factor in relation to the various demographic factors that were examined.

Gender

An independent samples $t$-test was calculated with Gender as the grouping variable and the social and environmental-based global factor as the dependent variable. The result indicated a non-statistically significant difference between females ($N = 63$, $M = 25.34$, $SD = 6.54$) and males ($N = 53$, $M = 25.24$, $SD = 7.96$), $t (118) = .076$, $p = .940$. This indicates that males and females reported similarly across the social and environmental-based global factor. No correlation can thus be made between gender and social and environmental factors of non-adherence.

Age

A one-way ANOVA was calculated with age as the grouping variable and the social and environmental-based global factor as the dependent variable. The result indicated a non-statistically significant difference between the 21 to 25 Years ($N = 20$, $M = 27.75$, $SD = 4.44$), 26 to 30 Years ($N = 30$, $M = 26.00$, $SD = 7.24$), and 31 to 40 Years ($N = 40$, $M = 23.00$, $SD = 8.03$), and Greater than 40 Years ($N = 30$, $M = 26.00$, $SD = 6.81$) groups, $F (3,116) = 2.426$, $p = .069$. Although there appear to be differences between the mean social and environmental-based global factor scores across the groups, the differences appear to occur by chance and are not reflective of the target population. Thus, the results suggest that the social and environmental-based global factor does not differ based on the age of the patients. No correlation can thus be made between age of participants and social and environmental factors of non-adherence.
Ethnicity was not tested as there were too few individuals in the Coloured and Indian groups. Highest qualification was also not tested as there were too few individuals that selected the diploma and degree categories.

**Employment Status**

A one-way ANOVA was calculated with employment status (“Other” was omitted due to a low group number) as the grouping variable and the social and environmental-based global factor as the dependent variable. The result indicated a statistically significant difference between one and more of the following groups: Employed (N = 41, M = 21.65, SD = 7.64), Unemployed (N = 65, M = 27.69, SD = 5.88), and Self-Employed (N = 11, M = 22.50, SD = 5.81), $F(2,114) = 11.667, p< .001$. In particular, there was a significant difference between Employed and Unemployed ($p< .001$), with a higher mean score reported amid the Unemployed group. Unemployed and Self-Employed were significantly different ($p = .043$), with a higher mean score reported for Unemployed. Therefore, it appears as though the social and environmental-based global factor has a more substantial influence amongst those who are unemployed as opposed to those who are employed or self-employed. This could be due to a number of reasons namely:

- The high rate of unemployment in many low income countries like South Africa, thus patient’s that do not have regular employment make themselves available as day workers to employers and often, the need for a day’s wages eclipses the potential benefit of a clinic visit (Kagee et al., 2011:3).

- Poverty is likely to affect adherence to care, as financial resources may need to be directed elsewhere, funds for travel to a medical facility that provides ART may not be available due to unemployment, and child-care may not be readily accessible for parents who attend appointments. The combined stresses associated with poverty, such as inadequate housing, community violence and unemployment thus tend to increase non-adherence (Kagee et al., 2011:3-5).

- Money has previously emerged as the most commonly mentioned barrier to adherence in many studies. This, therefore, may remain a major reason as to why some individuals may not be able to come to the health facility to collect their treatment regularly (Wasti et al., 2012:6).

**Side Effect Differences – Repeated Measures ANOVA**

Each of the ARV side effects that were examined (item 33) were compared to determine whether particular side effects appeared to disturb the patients included in the sample more than others. Nineteen of the side effects were compared, with “Other” being omitted due to a lack of specificity associated with the option. Mauchly’s Test of Sphericity was violated, $\chi^2 = 531.799, p< .001$, indicating the necessity to adjust for the sphericity assumption violation. In particular, since the Epsilon value was below .750, the Greenhouse-Geisser adjustment was used. The result indicated a statistically significant difference between one and more of the measures, $F(11.445, 1361.945) = 8.631, p< .001$. In particular, there were significant differences between constipation and seizures ($p = .003$), diarrhoea and seizures ($p = .001$), bloating/gas and seizures ($p< .001$), abdominal cramps and seizures ($p < .001$), fatigue and seizures ($p< .001$), headache and seizures ($p< .001$), fever, and seizures ($p< .001$), can’t sleep and seizures ($p = .001$), loss of weight and seizures ($p< .001$), fat accumulation and seizures ($p < .001$), nausea and seizures ($p< .001$), muscle pain and seizures ($p< .001$), numbness and seizures ($p< .001$), rash and seizures ($p = .001$), and depression and seizures ($p = .033$), with a lower mean score evidenced for seizures in all cases. Bloating/gas was significantly different from dizziness ($p = .003$) and depression ($p = .022$), with a higher mean score reported amid bloating/gas. Dizziness was significantly different from fatigue ($p< .001$), headache ($p = .001$), loss of weight ($p = .001$), and nausea ($p = .021$), with a lower mean score found for dizziness in each instance.
Fatigue was significantly different from can’t sleep ($p<.001$), can’t eat ($p<.001$), muscle pain ($p = .013$), vomiting ($p = .016$), numbness ($p = .001$), rash ($p = .001$), and depression ($p<.001$), with a higher mean score reported for fatigue as compared to these side effects. Fever was significantly different from can’t eat ($p<.001$); with a higher mean score reported for fever. Can’t eat was significantly different from loss of weight ($p<.001$) and nausea ($p = .005$), with a lower mean score reported for can’t eat. Loss of weight was significantly different from rash ($p = .029$), with a higher mean score reported for loss of weight.

Generally, the results suggest that seizures are the least experienced side effect, whereas fatigue appears to be the most substantial side effect experienced. From the results it can be concluded that fatigue followed by fever, loss of weight, bloating, muscle pain, headache and abdominal cramps were stated to be the more common side effects experienced by participants with fatigue being 57% and abdominal cramps 40%. Fatigue may include pill fatigue, which may be caused by co-medication or just general fatigue or tiredness as an adverse effect of ART.

Reliability

Section B
Cronbach’s alpha, a measure of internal consistency, was computed for the Section B items 7 to 27. The finding indicated acceptable internal consistency and reliability for the 24 items included in this portion of the questionnaire, $\alpha = .783$. Hence, the section possessed appropriate reliability for the use of each of the items included in the questionnaire.

Section C
Cronbach’s alpha was computed for the Section C items 34 to 38. The finding indicated moderate, but acceptable internal consistency and reliability for the 5 items included in this portion of the questionnaire, $\alpha = .668$.

Section D
Cronbach’s alpha was computed for the Section C items 39 to 43. The finding indicated appropriate internal consistency and reliability for the 5 items included in this portion of the questionnaire, $\alpha = .721$.

Research Question 2: Applicability of the Theoretical Models of Adherence to the reasons for non-adherence that were identified
With regard to the Informational-Motivational-Behavioural Theory, the results from the questionnaire suggest that the participants had received the appropriate information (with 94% of participants agreeing to question 23). Furthermore the results also suggest that they had personal motivation (with 94% and 96% agreeing to questions 10 and 11) (with 81% and 61% disagreeing with questions 15 and 16) and social motivation (with 86% and 73% agreeing to questions 8 and 9).

This model therefore states that if these two factors are achieved, the behavioural skills necessary to adhere to ART will be present and therefore lead to the fundamental determinant of behaviour, which in this case is adherence. Despite this the participants in this study still did not adhere to their treatment as they were initially selected according to these criteria. Therefore this model is not an accurate predictor of a patient’s adherence to ART as other factors other than information and motivation need to be considered such as: access to transport, stigma, and unemployment, patient waiting time at hospital, negative emotions and attitudes amongst others.
With regard to the Theory of Planned Behaviour, the results from the questionnaire suggest that the participants had both positive and negative attitudes towards the behaviour, which in this case was adherence. The positive attitudes (with 94% and 96% agreeing to questions 10 and 11 and 81% and 61% disagreeing with questions 15 and 16) along with the negative attitudes (with 50% agreeing to question 24 and 34% agreeing to question 26) as well as the subjective norms (with 86% and 73% agreeing to question 8 and 9) and perceived behavioural control which involves internal and external control factors such as abilities, skills, opportunities and barriers (with 82% agreeing to question 17 and 18) will lead to adherence behaviour.

Although this theory possesses certain elements not contained in the above theory and suggests that the negative attitudes towards adherence behaviour have led to the non-adherence of these participants, it is still not helpful in understanding a health promoting behaviour such as adherence to ART as this theory is largely dependent on rational processes and does not allow explicitly for the impacts of emotions or religious beliefs on behaviour, which may be relevant to stigmatised diseases such as HIV/AIDS (Munro et al, 2007:8).

With regard to the Health Belief Model for persons receiving ART, their HIV positive status, CD4 count, and quality of life could constitute the health concern. The questionnaire suggests that the prospect of deterioration in health status, leading ultimately to death which was determined via health information and counselling being given (as seen in question 10 and 21 with 94% agreeing to these questions) is the perceived threat; and factors such as stigma and waiting times (with 50% agreeing to question 22 and 34% agreeing to question 26) may be the perceived barriers. The perceived benefit of ART prolonging life and making the patient feel better (with 96% agreeing to question 11) along with cues to action such as a strong patient-provider relationship (with 88% agreeing to question 20) could assist in overcoming the barriers identified and thus promoting healthy behaviour or adherence. In the case of this study, the participant barriers were most likely to have overcome the perceived benefit thus causing non-adherence, however this model still seems to be the most accurate describer of adherence behaviour from the three cognitive theories identified. The major limitations of the model is its failure to take into account the influence of social relationships and the inability to address behavioural coping skills (Unni, 2008:17).

CONCLUSIONS AND RECOMMENDATIONS
Findings from the study
The findings from the study are discussed under two headings namely; findings from the literature review and findings from the primary research.

Findings from the literature review
An extensive review of relevant literature was conducted to establish and present the information as per the objectives of the study. However, only a summarised report is presented under this heading.

To identify as well as examine the reasons as to why patients on ART are not adhering to their treatment
These reasons have generally been categorised into four broad categories namely: patient and family-related factors, medication-related factors, health care delivery systems-related factors and social and environmental-related factors (KZN Health Research and Knowledge Management, 2015:2).
Patient and family-related factors:
Gender differences was shown to be related to non-adherence to ART as some studies revealed that females tend to default treatment more than males due to higher levels of poverty and socio-cultural status (Kagee et al., 2011:5), while other studies found that males tend to default treatment more often (Ndiaye et al., 2013:1). Health literacy, in terms of the knowledge of HIV and ART was shown to cause non-adherence as many patients consider medication only as a tertiary measure following the onset of symptoms, rather than as a prophylactic intervention (Kagee et al., 2011:5). Alcohol use was also seen to cause non-adherence as patients often forget to take their medication when drinking (Barnett et al, 2013:172-173). Psychological factors, such as anxiety, depression and perceived stress, were shown to have an inverse correlation with health improvement of patients living with HIV/AIDS (Calvetti et al., 2014:8-15). Non-disclosure of HIV status was found to be a barrier to adherence, therefore making it difficult for patients to maintain ART without support at their home (Barnet et al., 2013:172-173).

Medication-related factors:
Patients who were taking once-daily regimens were shown to have higher rates of adherence than those patients that were taking more than once-daily regimens (KZN Health Research and Knowledge Management, 2015:3). In many studies, it was reported that patients identified side-effects as a reason for treatment failure and non-adherence, citing nausea, vomiting, stomach pains and cramping as the most common (Barnett et al, 2013:172). Patients who were not taking co-medications were found to be more adherent to ART treatment than to the corresponding comparison groups (Demessie et al, 2014:1-10)

Health system delivery-related factors:
The limited availability and accessibility of ARV’s, health care providers, counsellors and facilities leads to longer waiting times, restricted opening hours and inconvenient appointment schedules which tend to increase non-adherence. Additionally, the presence of judgemental health care workers and limited privacy could lead to non-adherence (KZN Health Research and Knowledge Management, 2015:3).

Social and environmental-related factors:
Poverty was reported to be a likely factor to affect adherence to treatment and the combined stresses associated with poverty, such as inadequate housing, community violence and unemployment were shown to increase non-adherence (Kagee et al., 2011:3-5). Stigma and discrimination was also reported as patients tend to often miss their doses as a result of a fear of being identified as HIV positive, or as seen at the clinics and being on ARV medication for the rest of their lives (Kheswa, 2014:452; Wasti et al., 2012:6). Money emerged as a common barrier to adherence due to high unemployment rates with most studies reporting economic worries related to the cost of transport and food (Kagee et al., 2011:3-5; Wasti et al., 2012:6).

To provide an overview of the theoretical models of adherence and their applicability to the reasons for non-adherence
The theoretical models of adherence that were identified included: Health Belief Model, Theory of Planned Behaviour and Informational–Motivational–Behavioural Model. These theories are of a social cognitive nature and have been shown to explain adherence behaviour.

- The Health Belief Model is a psychological model that attempts to explain and predict health behaviours such as adherence, by focusing on the attitudes and beliefs of individuals.

- The theory of planned behaviour regards the intention to be adherent with medications being influenced by constructs such as attitudes towards the behaviour, subjective norms, and perceived behavioural control (Unni, 2009:18)
The informational-motivational-behavioural model states that information, motivation, and behavioural skills are the fundamental determinants of behaviours such as the adherence to ART (Kagee, 2008:9-10).

**To assess the effects of non-adherence to ART on the organisation**

A key finding in the literature review showed that the associated cost of care was the most important effect that non-adherence had on the institution as an increase in non-adherence was seen to be proportional to the associated costs for the institution. The most important costs that were identified here were hospital and treatment costs (Schilling et al, 2012:6-7):

**Hospital Costs**: These are health care and medicine costs that occurred due to increased morbidity and hospital visits as a result of non-adherence to medical instructions and recommendations. In the case of HIV/AIDS, the costs for hospitalisation events are due to opportunistic diseases as a direct result of non-adherence.

**Treatment Costs**: These are changes in the costs of treating the disease due to non-adherence where patients have to be put on second line therapy which comes at a higher cost on average as compared to first line therapy.

**To investigate the current adherence management strategies of patients receiving ART at Murchison Hospital and to recommend a range of effective and efficient adherence management strategies**

In the literature review, it was noted that the current adherence management strategies that were being employed by Murchison Hospital ARV clinic were aligned with the two policy documents published by the Department of Health of South Africa namely; The National consolidated guidelines for the prevention of mother-to-child transmission of HIV (PMTCT) and the management of HIV in children, adolescents and adults (2014) and the Clinical guidelines for the Management of HIV and AIDS in Adults and Adolescents (2010).

These policy documents were seen to have a range of strategies that were effective and that allowed for patients to remain adherent.

Apart from the above strategies, a range of other effective and efficient strategies were listed to be recommended to management. From this list, a few strategies were seen to be utilised in other studies that were researched. These strategies are listed below (KZN Health Research and Knowledge Management, 2015:6; Department of Health, 2014:36-37; Department of Health, 2010:18):

- **Health education to ensure treatment literacy**: Improve understanding as patients often have limited knowledge and understanding about why they have to take ART, how it works and how it benefits them.
- **Health education leaflets and group health education classes from tabletop flip charts**.
- **Reinforce the use of adherence tools for example, pillboxes and/or daily dosing diary**.
- **Mobile phone calls or short message service (SMS) as reminders for patient appointments**.
- **Involvement of family, friends or even adherence councillors in-patients’ treatment program (Consider using a ‘treatment buddy’ or even directly observed therapy for an agreed period)**.

**Findings from the primary research**
Findings from the primary research are presented in accordance to the extent in which the research questions were answered.

**Research Question 1: What are the reasons for non-adherence to Antiretroviral Treatment at Murchison Hospital?**

- The majority of participants were female with 56%, while males made up 44% of the participants, which is consistent with other research findings and also is a good representation of the HIV positive patients collecting treatment at Murchison Hospital.
- The majority of the participants fell into the 31-40 age groups with the minimum age range being 21-25. It can thus be seen that the majority of participants were over the age of 30 (70 participants) as compared to the 50 participants being between 21 and 30 years of age, which is consistent with other research studies.
- The majority of participants (48.33%) had shown to have a matric qualification, with (43.33%) showing to have not completed matric. A small percentage of participants (7.50%) had stated that they possess a diploma and 0.83% stated that they were in possession of a degree, signalling that the association between education and disease understanding is an important factor.
- The majority of participants were unemployed (54.17%); whilst 34.17% had stated that they were employed and 9.17% had stated that they were self-employed, signalling that this may be a reason for non-adherence.
- 86% percent of the participants reported that they had disclosed either to their friends or family, while only 14% stated that they had not, signalling that disclosure of HIV status is being done and thus not a determinant of non-adherence.
- A collective 94% had stated that they understood their condition and need for treatment, which indicates good health literacy whereas a collective 80% had stated that they continue to take their medication even if they felt better and 17% had stated that they stop therapy.
- A collective 61% had stated that the daily administration of ART does not interfere with their lives and 33% stated that it did interfere, signalling a need for proper scheduling of patient treatment requirements as well as patient education as to treatment and how it works.
- A collective 93% stated that they are able to concentrate as well as feel capable of making decisions, whereas a collective 89% stated that they felt reasonably happy.
- Over the weekend, it was stated that 31% of participants consume alcohol, with 9% consuming 1 to 2 glasses, 11% consuming 3 to 4 glasses and 8% consuming 4 to 5 glasses. This is likely to be a barrier to adherence to treatment.
- 38% stated that they are taking medication for HIV as well as high blood pressure and 26% stated that they are taking medication for both HIV and diabetes, signalling a possibility of pill fatigue and thus non-adherence.
- Various side effects were identified as being present by the participants and these included all the listed items in minor occurrence ranging from 20% - 57%. This can be considered a reason for non-adherence and requires intervention.
- In terms of support from health care providers, health education and information classes and convenient appointment dates, a collective 88%, 94% and 92% stated that they agree that these measures have been implemented.
- In terms of waiting time at a clinic for medication pickup, 50% of participants had agreed that they wait a long time whereas 47% disagreed to this, signalling that intervention needs to be aimed at decreasing waiting times.
- A collective 60% stated that they have enough money to attend hospital visits whereas 22% stated that they did not signalling that poverty is considerable and patients can simply not afford to attend their visits monthly.
A collective 34% agreed that they had to hide from others when taking their medication whereas 55% state that they did not have to hide away signalling that stigma and discrimination is rife and needs to be addressed.

A collective 42% agreed that their employers give them time off to collect their treatment on a monthly basis whereas 38% stated that they were not allowed this opportunity, signalling that there is a great need for awareness of the condition and importance of adherence to the general community.

The majority of participants had stated that they use public transport (58%), whereas 26% stated that they came to the hospital by foot and 14% used their own transport signalling that affordability of taxi fare could possibly be a barrier to adherence.

**Research Question 2: What is the applicability of the theoretical models of adherence to the reasons for non-adherence that were identified?**

- The informational-motivational-behavioural theory was seen not to be an accurate predictor of a patient’s adherence to ART as other factors other than information and motivation are not considered, such as: access to transport, stigma and unemployment, patient waiting time at hospital, negative emotions and attitudes amongst others.

- The theory of planned behaviour was also seen not to be an accurate predictor of a patient’s adherence to ART as this theory is largely dependent on rational processes and does not allow explicitly for the impacts of emotions or religious beliefs on behaviour, which may be relevant to stigmatised diseases such as HIV/AIDS (Munro et al, 2007:8).

- The health belief model was shown to be the most accurate predictor of a patient’s adherence to ART as it takes into consideration other factors related to non-adherence that the other theories fail to identify. In the case of this study, however, the participant barriers were most likely to have overcome the perceived benefit thus causing non-adherence.

**Research Question 3: What are the effects of non-adherence to ART on the organisation?**

- A collective 78% of participants stated that they had never been admitted into hospital due to them defaulting treatment or due to them experiencing side effects, however 22% and 19% had agreed with these statements respectively, signifying that a considerable number of patients from the sample had been admitted into hospital due to these reasons and thus have contributed to the increasing cost of care for non-adherent HIV/AIDS patients.

- A collective 97% and 94% agreed to question 37 and 38 respectively, thus concluding that the recruitment and other human resource costs to the organisation are being utilised effectively.

**Research Question 4: What adherence management strategies are currently in place for patients collecting Antiretroviral Treatment at Murchison Hospital and what recommendations can be made to management in terms of more effective and efficient adherence management strategies?**

- 98% of participants stated that they had received counselling when initiating treatment.
- 85% of participants stated that they were counselled regularly.
- 96% of participants stated that the healthcare workers show empathy when counselling.
- 93% of participants stated that they are constantly told by the healthcare workers about the importance of adherence.
- 93% of participants stated that they find the process of medication collection easy.
- 52% of participants had stated that they have attended either hospital-based or community-based workshops aimed at adherence and disease awareness, while a collective 36% stated that they had not, thus signalling a need for these workshops to be set up and maintained.
82% of participants stated that they had either friends or family that were willing to assist with medication reminders thus signalling the use of support structures as reminder aids for patients as an adherence management strategy.

93% of participants stated that they did own a cell phone which thus allows for a range of technical adherence management strategies to be implemented.

65% of participants stated that they lived far from the hospital whereas 35% stated that they did not signalling that interventions should focus on referring patients out to clinics or other service providers closer to their homes.

54% of participants stated that they preferred to collect their treatment at their local clinic thus signalling that the community care givers and community centres have to be advertised better thus allowing patient’s to be able to utilise these facilities.

**Conclusion**

The aim and research objectives of this study have been addressed in terms of the research questions. The linkage between the findings of the literature review and the findings from the primary research has been addressed above and an overall conclusion to each research question is provided below:

Research question 1 aimed to determine the reasons for the non-adherence of patients to ART at Murchison Hospital. From the statistical analyses, it was concluded that the social and environmental-related factors were the most influential reasons associated with non-adherence in this study, although other reasons from patient and family-related factors, medication-related factors and health care delivery system-related factors have contributed to non-adherence as well. The social and environmental factors identified were that of financial difficulties, stigma and discrimination, employer’s not allowing patient’s time off from work and transport-related problems. Medication-related factors like side effects also contributed to non-adherence as well as other factors like gender, age, unemployment, alcohol use, perceptions of ART and patient waiting times.

Research question 2 aimed to determine whether the theoretical models of adherence behaviour could be used to describe non-adherence to ART. Here it was seen that although the theory of planned behaviour and the informational-motivational-behavioural theory could be used to describe adherence behaviour, they had many deficiencies in terms of certain elements that were not included in the theories such as emotions, attitudes and stigma amongst others. The Health belief model seemed to be the most accurate predictor of adherence behaviour as it catered for these elements.

Research question 3 aimed to determine the effects of non-adherence to ART on the organisation. The cost of non-adherence on the organisation was regarded as the most influential effect, which is seen as either hospital or treatment related costs. Although majority of the participants stated that they had never been admitted in hospital or changed treatment due to non-adherence, there was a considerable percentage that stated they had. This can thus be regarded as a concern as the costs associated with non-adherence is highly avoidable.

Research question 4 aimed to determine the current adherence management strategies being employed by the institution and it was seen here that the institution has implemented strategies that are in line with those set out by the department of health in terms of policy documents. From the participant’s responses in section D, it can be concluded that these strategies are effective and can therefore be maintained at the institution. Research question 4 further aimed to determine other adherence management strategies that could be recommended to the institution so as to reduce non-adherence to ART. As per the participant’s responses in section E, it seems that there are many adherence strategies that could be used effectively on top of those already employed. These will be discussed in the recommendations below.
**Recommendations**

Objective 4 of this research study aimed to recommend a range of effective and efficient adherence management strategies. Based on the recommended strategies listed in chapter 2 under objective 4 as well as the research findings in chapter 4 and 5, the following recommendations have been selected. These recommended strategies need to be employed by the management of Murchison Hospital in order for adherence management to be addressed successfully (KZN Health Research and Knowledge Management, 2015:6; Department of Health, 2014:36-37; Department of Health, 2010:18):

- Health education to ensure treatment literacy: Improve understanding as patients often have limited knowledge and understanding about why they have to take ART, how it works and how it benefits them. This assists in patients perceptions of ART and HIV.
- Health education leaflets and group health education classes from tabletop flip charts. This will assist communities to interact and help each other and result in a greater understanding of HIV.
- Reinforcing factors about the disease and the need for treatment.
- Negotiate a treatment plan that the patient can understand and to which he/she commits.
- Providing access to drug and alcohol counselling at no cost to the patient.
- Patients should be reassured on the transient nature of side-effects such as nausea and vomiting at treatment initiation as well as being educated on how to manage various other side effects and in addition to consult the health care worker as soon as side effects become serious.
- Implementation of strategies to reduce waiting times at medication collection points. This could be done via: waiting time surveys, looking for bottlenecks and subsequently removing them and employee management in terms of needs during busy times.
- Addressing stigma and discrimination by awareness campaigns at schools, churches, places of employment, community meetings amongst others.
- Employer awareness programmes to make employers more aware of the disease progression and need for treatment.
- To involve the department of transport to assist with busses to transport patients from their homes or nearby community centres to the institution regularly at minimal to no cost to patients.
- The reinforcement of the importance of disclosure of HIV status to family and/or friends.
- To engage the community to accept community care givers and community centres into their localities. This can be done by awareness campaigns aimed at educating patients on the benefits of these.
- To recruit more staff and personnel to assist in these community centres and to train them appropriately.
- Ensure availability of ART at all times and to manage patients immediately if stock shortages occur.
- Allowing patients that are adherent for over 12 months to collect 2-3 month’s supply of treatment at once thus reducing patient numbers at clinic so that staff may focus more attention on the non-adherent patients.
- To engage other government departments in focusing on employment opportunities within the area.
- Reinforce the use of adherence tools for example, pillboxes and/or daily dosing diary to be used as memory aids.
- Mobile phone calls or short message service (SMS) as reminders for patient appointments to be initiated at institutional level.
• Involvement of family, friends or even adherence councillors in-patients’ treatment program (Consider using a ‘treatment buddy’ or even directly observed therapy for an agreed period).
• Training of adherence support workers regarding the adherence support strategies.
• Systematic monitoring of adherence at the clinic during visits for refills.
• Arrange home visit if available to be undertaken by the nominated community care giver, or trained home-based carer.

Areas for future research

• There is not much research of this nature conducted in South Africa and in Kwa-Zulu Natal in particular, thus the need for more research of this nature is critical.
• Due to non-probability sampling being used in this study, the probability that a person would be chosen is unknown, therefore the non-representative nature of the sample means that the results could not be generalised to the general population of HIV positive people currently on antiretroviral treatment. Future research should thus utilise probability sampling and be able to generalise findings to the entire population.
• The questionnaires were only available in English and Zulu, thus a requirement of the study was that participants be English or Zulu first or second language speakers. Future research should include Xhosa and Afrikaans in the questionnaire construction phase.
• A study of this nature should be done at clinic level, thus accessing a larger population and sample as the Primary Health Care system is where the majority of patients collect their treatment.
• Studies of this nature in future should be able to quantify the cost associated with non-adherence to ART, thus more studies on economics of non-adherence needs to be carried out.
• The statistical analysis could be extended to consider some of the more complex relationships that may emerge.
• In this study, respondents must have been over the age of 21, had to have been on ART for a minimum of 6 months and defaulted at least once in the previous 6 months according to pharmacy prescription records. Future research should involve all patients on ART and be able to determine the adherence rate as well.
• Future studies should include open-ended questions to probe the reasons for participant’s selection of certain factors.

Conclusion
This study was undertaken to investigate the challenges surrounding the management of antiretroviral treatment programmes in Murchison District Hospital. The aim of the study was to assess the reasons for non-adherence of patients to Antiretroviral Treatment at Murchison District Hospital and its implications on the organisation.

Non-adherence is a crucial challenge in the management of ART programmes and this study has provided an in-depth analysis of this challenge. The various reasons for non-adherence were identified as their effect on the organisation was established. The theories of adherence behaviour were addressed, the various adherence management strategies were discussed, and a range of effective and efficient strategies were recommended as well. This study can thus allow the management of Murchison Hospital to utilise these findings to improve on the various policies and procedures of adherence management and to be able to produce quality care for its patients and maintain it.

This chapter concluded the study, recommended strategies that will improve the management of adherence and suggested areas for future research. The aim of this study has been fulfilled by achieving the stated objectives and answering all the research questions.
BIBLIOGRAPHY


