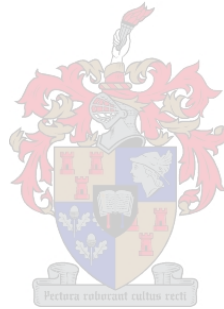


**Barriers to Antiretroviral adherence of HIV/AIDS patients under the
Wellness Programme in Mogwase Health Centre**

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Assignment presented in partial fulfillment of the requirements for the degree of
Master of Philosophy (HIV/AIDS Management) at Stellenbosch University.



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March 2012

Declaration

By submitting this assignment electronically, I declare that the entirety of the work contained therein is my own, original work, that I am the sole author thereof (save to the extent explicitly otherwise stated), that reproduction and publication thereof by Stellenbosch University will not infringe any third party rights and that I have not previously in its entirety or in part submitted it for obtaining any qualification.

Georgina Shadi Moremi

January 2012

Summary

This study determines barriers affecting Antiretroviral Adherence to patients on the wellness programme .It was undertaken at Moses Kotane Health Sub-District in Mogwase Health Centre.

A qualitative study was done using a structured questionnaire which included open and closed –ended questions. A total of 20 people (6 male and 14 female) who are HIV positive and on ART participated in the study. Participants were aged 21 years and above. Data was analyzed using qualitative methods. Frequencies were used for analysis of closed ended questions. Themes were identified in open-ended questions.

The responses given by the patients gave an insight on barriers affecting ART of HIV/AIDS adherence under the wellness programme in Mogwase Health Centre although the study population was too small to make conclusions of a generalized nature to all those on ART. In this study, it was revealed that the following barriers may play a role in poor adherence: Transport issues, financial burden, food insecurity, forgetfulness and lack of social support. The main finding in this research was that many barriers thought to be contributing to poor adherence do not seem to have influence on ART adherence in this setting although general ART adherence of patients at Mogwase Health Centre is low.

To enhance good adherence, it is of paramount importance that ART be rolled out to the lowest level health centres, and mobile point should reach patients in order to avoid transport cost, more nurses should be trained on prescribing and dispensing of ART, and patients should be given at least 3 months supply of ART. Lastly.it would be of importance to conduct a similar type of study in the future on a larger scale to verify the results of this study.

Opsommning

Die studie, wat onderneem is in Moses Kotane Sub-District in Mogwase Gesondheid Sentrum, toon dat Antiretrovale vasklewing tot pasiënte 'n hindernis veroorsaak in die welstandsprogramme. 'n Kwalitatiewe studie is gedoen deur die gebruik van gesruktureerde vraelyste met oop en geslote vrae waarvan 'n total van 20 mense (6 manlik en 14 vroulik), wie HIV positief en op ART is, deelgeneem het aan die studie.

Deelnemers was 21 jaar en ouer. Herhalings was gebruik vir die analisering van geslote vrae en temas was geidentifiseer in oop vrae. Die vrae wat deur pasiënte beantwoord is gee 'n insig oor die hindernisse wat ART of HIV/Vigs onder die welstandsprogram in Mogwase Gesondheid Sentrum veroorsaak, alhoewel die populasie deur wie die studie gedoen is te klein was om 'n definitiewe uitsluitel te gee.

Hierdie studie het getoon dat die volgende hindernisse 'n rol speel in die swak bywoning: vervoer probleme, finansiële druk, gebrek aan voedsel, vergeetagtigheid en sosiale ondersteuning.

Die hoof bevinding van die studie was dat die hoeveelheid hindernisse nie bydra tot swak bywoning tot ART van pasiënte by Mogwase Gesondheid Sentrum baie laag is.

Om die bywoning te verhoog is dit uiters noodsaaklik dat ART beskikbaar gestel word tot die laagste vlak van gesondheidsentrums, mobiele punte moet pasiënte bereik om sodoende vervoerkostes uit te skakel, meer verpleegkundiges moet opgelei word om ART voor te skryf en uit te gee. Pasiënte moet ten minste van 3 maande se voorraad voorsien word.

Laastens is dit noodsaaklik om 'n soortgelyke tipe studie in die toekoms op groter skaal te doen om die resulte van hierdie studie te bevestig.

Acknowledgements

The Researcher would like to acknowledge the contribution made by participants by completing questionnaires and those who agreed to be interviewed. I am especially indebted to Dr Greg Munro, my supervisor for guidance while I worked on this dissertation.

I would also like to thank Moses Kotane Health Sub-District and Mogwase Health Centre for giving me permission to conduct the research. My appreciation also goes to my family and friends for the everlasting moral, social and spiritual support and understanding.

Lastly I would like to express my sincere gratitude to God Almighty who led and guided me through this programme even at difficult times.

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Chapter 1: Introduction

This chapter presents background of the study, research problem, significance of the study, aim and objectives and the preliminary literature review. Furthermore research design and methods, ethical consideration and outline of chapters are presented.

1.1. Background

HIV is a pandemic which affects every part of the globe. It has a broader meaning than compliance which encompasses the extent to which a patient follows instructions implying understanding, consent and partnership. Adherence to treatment encompasses more than adherence to medication like ARV. Furthermore, it is the intention of this study to review the adherence to ARV treatments among the eligible HIV/AIDS patients. In an ideal situation, a 100% level of adherence is required for ARV treatment success. However, adherence is a problem in poor countries due to multifaceted factors. Studies show that there is no significant difference in adherence between resource limited and resource rich countries, thus patients have trouble in taking 100% of their pills. It is therefore recommended worldwide that for any ARV programme there should be a concurrent plan for adherence assessment and support. A near perfect adherence should be where there is 95% and above adherence (IAVI 2002).

According to Kagee, 2004, non-compliance with medication for HIV/AIDS has been cited as one of the major problems in South Africa. It is resulting in high rates of relapse, re-hospitalization, morbidity and mortality.

Researchers indicate that non adherence with antiretroviral therapy is strongly associated with HIV disease progression and mortality. It is further indicated that HIV/AIDS is the fourth most common cause of death in the world and is estimated to have killed 3.1 million individuals and infected 4.9 million persons in 2005 (Women's HIV/AIDS Care Guide, 2005).

It is reported that Highly Active Antiretroviral Treatment (HAART) has dramatically reduced mortality and morbidity due to HIV. It is effective because it reduces HIV

replication and allows the regeneration of CD4 counts. Antiretroviral therapy can increase the length and quality of life and productivity of patients. Antiretroviral regimens have improved survival and decreased the incidence of opportunistic infections in people with HIV to a certain extent. Strict adherence to HAART regimens is crucial in order to maintain a low viral load and prevent the development of a drug resistant virus. Patients do not return to follow up on schedule and are likely to be non-adherent to prescribed HAART regimens. It is found that there is growing concern about loss to follow-up and non-adherent to antiretroviral therapy as significant barriers to care in Uganda (Cummins et al .,2002,15).

According to Cummins et al., researchers state that the development of resistance to one ARV drug can lead to cross resistance with other ARV medications. For those with HIV non-adherence may result in deterioration in health and lead to an increase in opportunistic diseases resulting in hospitalization.

1.2 Research problem

Patients attending Mogwase Health Centre who are on ART have a history of not adhering to treatment. As such this has to be investigated to identify why they do not adhere to the treatment. Adherence issue need to be addressed because clients will develop resistance, drug sensitivity tests have to be performed and these are very expensive. The drugs are very expensive and their side effects are often intolerable which can result in the clients' not taking treatment as prescribed. Antiretroviral can increase the length and quality of life and productivity of patients. Antiretroviral regimens have improved survival and decreased the incidence of opportunistic infections in people with HIV to a certain extent. Strict adherence to HAART regimens is crucial in order to maintain a low viral load and prevent the development of drug resistance virus. Patients do not return to follow up on schedule and are likely to be non-adherent to prescribed HAART regimens.

Good adherence to antiretroviral therapy is necessary to achieve the best virological response, lower the risk that drug resistance will develop and reduce morbidity and mortality. Little is known about the rate of adherence as an area of study. It is

therefore justifiable to conduct this study on the factors which contribute to adherence and develop proper structures for support and improving.

1.3 Significance of the study

It is expected that the study will succeed in contributing to the creation of knowledge based on a South African context. The findings will also provide HIV/AIDS patients and significant others with information. Furthermore, the findings will provide a knowledge base for the barriers affecting ART adherence to the infected patients in wellness programmes. Taking HAART regimens is not an easy task since it is a lifetime treatment. It will contribute to the Sociological/Anthropological understanding of non-adherence and be useful in developing interventions that will take into consideration the problems faced by people taking ARV treatment at Mogwase Health Centre as a whole. It is expected that the qualitative data collected in this study will be made available to health planners such as Department of Health and it is hoped that this will lead to better designed, better directed and more culturally sensitive intervention programmes to deal with socio-cultural problems associated with non-adherence.

1.4 Research question

Based on the problem that has been identified, the researcher formulated the following research question:

- Which barriers affect ART adherence to patients on the wellness programme?

1.5 Aim and objectives

1.5.1 Aim

To determine barriers affecting Antiretroviral adherence to patients on the wellness programme in order to improve ARV adherence which can be useful for planning and intervention.

1.5.2 Objectives

In order to achieve the aim of this study, the following objectives will be formulated:

- To identify problems that HIV patients are experiencing in ART adherence.

- To gather information from ARV users and support groups on improving ARV adherence.
- To provide guidelines for more needs driven support services in Mogwase Health Centre to improve ART adherence.

1.6 Operational definitions

Adherence: Adherence to ART is taking all ARV pills in the correctly prescribed doses at the right time and in the right way observing any dietary restriction.

AIDS: this refers to a progressive immune deficiency caused by infection of CD4+ T cells with the human immunodeficiency virus (HIV).

Viral load: levels of virus found in the blood per 10 millilitres (ml).

Virology: The study of viruses and viral diseases.

Immunology: The branch of biomedicine concerned with the structure and function of the immune system, innate and acquired immunity, the bodily.

Mortality: The number of deaths during a particular period of time among a particular type or group of people.

Morbidity: Departure from a state of physical or psychological well-being, resulting from disease, illness, injury, or sickness, specially where the affected individual is aware of his or her condition.

Barrier: A barrier is something which prevents people from doing something or limits what they can do.

CD4 counts: A measure of the number of helper T cells per cubic millimeter of blood, used to analyze the prognosis of patients infected with HIV.

Mogwase: The name of the Health Centre where the research was conducted.

Moses Kotane: The name of the Health Sub-district.

1.7 Demarcation of the study

Chapter 1: Introduction

Chapter 2: Literature review

Chapter 3: Research Methodology

Chapter 4: Results and Findings

Chapter 5: Conclusion and Recommendation

Chapter 2: Literature review

2.1. Introduction

Adherence has been shown to have a direct impact on virological suppression and on treatment success. Researchers report that this is reflected in the positive patient outcomes seen in ART programme (Journal of HIV Medicine, 2010).

Antiretroviral therapy has greatly improved the overall health of individuals living with HIV/AIDS. Studies conducted reported increased virologic and immunologic effectiveness of ART and the consequent reduction of mortality and morbidity associated with HIV/AIDS (Lima et al., 2009).

It is reported that adherence to Antiretroviral Therapy (ART) is a powerful predictor of survival for individuals living with Human Immunodeficiency Virus (HIV) and AIDS. Concerns about incomplete adherence among patients living in poverty have been an important consideration expanding the access to antiretroviral therapy in Sub-Saharan Africa (Mils et al., 2006). Perfect adherence to HIV medications is critical for successful treatment, particularly for prevention of viral replication (Safren, et al., 2001). Along the same lines, it is indicated by researcher that the length and the quality of life among persons living with HIV have dramatically changed with the advent of ART (Russel et al., 2004).

This chapter presents a literature review of epidemiology of HIV/AIDS, adherence to ART, consequences of poor adherence and importance of adherence. Further discussion will include measurement of adherence, barriers to ART adherence, and strategies for improving adherence and also Disability grant, HIV/AIDS and Antiretroviral adherence and the strategic measures for improving adherence are also discussed.

2. 2. Epidemiology of HIV/AIDS

The HIV/AIDS epidemic is affecting an increasing number of women and girls. Almost half of the people living with HIV/AIDS in Sub-Saharan Africa are females between 15-24 years of age. In the other regions, women and girls also now

represent an increasing proportion of people living with HIV/AIDS, compared with figures from five years ago (WHO,2006). AIDS is one of the most destructive epidemics the world has ever witnessed, claimed 3.1 million lives in 2005 of which more than half a million (570 000) were children. Currently an estimated 40, 3 million people are living with HIV worldwide of which 2.3 million (2.1-2.8 million) are children under 15 years.

HIV management has drastically changed in the current era of effective powerful Antiretroviral Therapy. Therapeutic strategies have expanded greatly from historical treatments with a single antiretroviral drug to combination therapy that includes at least three different drugs from up to three different classes, (Highly Active Antiretroviral Treatment - HAART). However, many factors can affect the ability of HAART to suppress viral replication, including low potency of one of the drugs in the combination due to viral resistance to therapy. The major factor determining the success of HAART is sustained and optimum adherence to therapy as poor adherence increases the risk of virologic failure and viral resistance (Glass, 2006).

According to the WHO, in 2006 around 39.4 million people were living with HIV/AIDS. Approximately 3.1 million people have died of AIDS. The number of people living with HIV/AIDS has increased over the past two years. The estimated number of people living with HIV/AIDS in Eastern Asia grew by almost 50% between 2002 and 2004, an increase largely due to the growing HIV/AIDS epidemic in China. In Eastern Europe and Central Asia, there were 40% more people living with HIV in 2004 than in 2002. The main causes of this increase were Ukraine's resurgent epidemic and the ever-growing number of people living with HIV/AIDS in the Russian Federation. However, the HIV/AIDS epidemic continues to expand globally. Access to treatment and care, and support for people living with HIV/AIDS remains grossly inadequate. At the end of 2001, fewer than 4% of people in need of antiretroviral treatment in low and middle income countries were receiving it and fewer than 10% of people living with HIV/AIDS had access to palliative care or treatment for opportunistic infections. Antiretroviral Therapy has also made a significant impact in preventing new infections in children as more HIV-positive mothers gain access to treatment preventing them from transmitting the virus to their children. Around 200 000 new infections among children have been prevented since 2001(WHO, 2006).

According to Nsimba, (2010), the HIV epidemic had large macroeconomic effects due to the loss of lives of individuals during their productive years. Households have been facing large financial burdens due to loss of income, support from the family members who die of the disease as well as the increasing costs of treatment of HIV/AIDS infections and associated opportunistic infections. Lack of strict adherence to highly active antiretroviral therapy is considered to be one of the key challenges to AIDS care worldwide. Estimates of average rates of non adherence with ARV therapy range from 50% to 70% in many different social and cultural settings and the risks associated with non adherence are extensive at both individual and societal levels. Treatment adherence has been closely correlated with viral suppression, while non adherence has contributed to progression to AIDS the development of multidrug resistance and death. Even short term non adherence may result in rapid recovery of plasma viraemia, leading to treatment failure. Adherence is perceived as a significant barrier to the delivery of ARV therapy in Sub-Saharan Africa. Little is known about the rates of adherence or predictors of adherence in Africa. The study shows that in poor countries, adherence can be a problem for a number of fully defined reasons such as lack of transportation or lack of food. Furthermore, adherence is best thought of as a variable behaviour rather than as a constant characteristic of an individual.

In Botswana, where treatment coverage is 80%, AIDS-related deaths have fallen by over 50% over the past five years and the number of children newly orphaned is also decreasing as parents are living longer. Data from the AIDS Epidemic Update also show that at 33.4 million, (31.1 million–35.8 million) there are more people living with HIV than ever before as people are living longer due to the beneficial effects of antiretroviral therapy and population growth. However the number of AIDS-related deaths has declined by over 10% over the past five years as more people gained to access to the life saving treatment. UNAIDS and WHO estimate that since the availability of effective treatment in 1996, 2.9 million people's lives have been saved (WHO, 2009).

According to Weiser, et al., (2003) HIV/AIDS is the leading cause of death in Sub-Saharan Africa. According to 2001 estimates, there are 28, 5 million people living with AIDS in Africa. Botswana currently has the highest estimated prevalence of HIV

infection in the world. The 2002 UNAIDS update suggested that more than 330 000 people of a population of 1.5 million in Botswana have been infected with HIV and there were 26 000 estimated deaths due to AIDS in 2001 alone.

According to new data in the 2009 AIDS epidemic update, new HIV infections have been reduced by 17% over the past eight years. Since 2001, when the United Nations Declaration of Commitment on HIV/AIDS was signed, the number of new infections in Sub-Saharan Africa is approximately 15% lower, which are about 400,000 fewer infections in 2008. However, in some countries there are signs that new HIV infections are rising again.

The continuing rise in the population of people living with HIV reflects the combined effects of continued high rates of new HIV infections and the beneficial impact of antiretroviral therapy. HIV/AIDS continues to be a major global health priority. Although important progress has been achieved in preventing new HIV infections and in lowering the annual number of AIDS related deaths, the number of people living with HIV continues to increase continue to be a significant global cause of premature mortality in the coming decades (World Health Organization, 2008). Although AIDS is no longer a new syndrome, global solidarity in the AIDS response will remain a necessity. Epidemic patterns can change over time. As the regional profiles in this report highlight, national epidemics throughout the world are experiencing important transitions. It is also contributing to increases in HIV prevalence impact of increased access to treatment on epidemiological trends Furthermore, the rapid expansion of access to antiretroviral therapy is helping to lower AIDS-related death rates in multiple countries and regions (UNAIDS,2009).

2.3. Adherence to ART

According to Wekesa, (2007), patient adherence to Antiretroviral Treatment (ART) is an issue that is growing in prominence and generating a growing interest with ART roll-out. In the absence of a cure, ART is the only available option that offers the possibility of dramatically reducing HIV/AIDS-related morbidity and mortality, thus improving the status of people living with AIDS. However, successful administration of this treatment depends on sustained and strict adherence to the prescribed regimens (WHO,2009). To achieve the beneficial outcome of suppression of viral

replication, decrease in viral load, increases in CD-4cell count, and improvement of the quality of life, ART requires perfect adherence rates (as high as 95%). Failure to observe this adherence threshold leads to treatment failure, disease progression and emergence of drug resistant HIV/AIDS strains. As reported by Castro, (2005), patients need to achieve 100% adherence to ART in order to keep correct amount of drugs in their bodies to fight the virus.

It is reported that, the survival of people diagnosed with HIV/AIDS dramatically improve with access to HAART. Such therapy employs a combination of antiretroviral agents, protease inhibitors (PIs), nucleoside reverse transcriptase inhibitors, non-nucleoside reverse transcriptase inhibitors, nucleotide reverse transcriptase inhibitors, and fusion inhibitors—to suppress viral replication and reduce the likelihood of developing HIV mutations that could lead to the development of drug-resistant viral strains. Highly Active Antiretroviral Treatment (HAART) also prevents further viral destruction of the cellular immune system, thereby, allowing for increases in the level of CD4+ cells, which improves the immunologic response to opportunistic infections (Castro, 2005).

Adherence to medicines for chronic health conditions in general is not well documented in developing countries, and what is known is far from encouraging. Results of research on adherence to long-term medicines in Malaysia revealed that only 44% of patients were adherent and the issues of overdosing, under dosing, and wastage were very prevalent. Studies revealed that in China, 47% of patients were adhering to treatment. However, adherence rates to ARV medicines for patients with AIDS may appear to be a different story. Particularly in Africa, some studies have reported very high levels of adherence, from 85–99% (WHO, 2006).

Adherence to ARVs is contained within a continuum of total doses, frequency, and timing. Good adherence is described as taking one's medicine as prescribed and agreed between the patient and health provider. Poor adherence includes missing doses completely, as well as taking drugs inappropriately (taking doses at the wrong times or not adhering to dietary requirements associated with a drug). Studies have recognized a clear association between viral suppression and the percentage of antiretroviral doses taken as prescribed. Specifically, greater adherence is

associated with better viral suppression. Reviews of numerous studies revealed that 95% or greater adherence is necessary in order to achieve and maintain undetectable viral loads among most patients treated with Highly Active Antiretroviral Therapy (HAART). Among patients who achieve this level of adherence, the virus is suppressed in 78%–100% of cases after six to ten months of therapy. The likelihood of virologic failure increases for patients with adherence rates lower than 90%. However, some patients reach undetectable viral loads with much lower adherence rates (USAID, 2008).

Few studies have reported on adherence within “normal” clinical settings. As ARVs become available to more patients, the importance of understanding differences in levels of adherence within the context of the normal clinical setting becomes more apparent. Additionally, most studies of adherence to ARVs in Africa that relied on self-reporting have restricted the definition of adherence to the number of pills taken versus the number prescribed (“pills-taken adherence”). The researcher uses the term “correct use adherence” to refer to adherence where pills are taken appropriately (WHO, 2004).

Studies of patients receiving antiretroviral treatment in Africa have evaluated the difference in adherence between patients on Triomune compared to those on more complex triple antiretroviral regimes. Similarly, little is known in Africa about socio-demographic and psychosocial differences between patients who are adherent compared to those who are not (USAID, 2008).

2.4. Consequences of poor adherence

According to Shah (2007), non adherence can lead to inadequate suppression of viral replication, continued destruction of CD4 cells, progressive decline in immune function and disease progression drug resistance, increased viral load, increased sickness and increased possibility of death. Furthermore it also leads to limited future treatment options and higher costs to the individual and ARV program.

It is reported that non adherence increases the risk of viral mutations, which can result in cross resistance to other medications or transmission of multi resistant virus strains, and thus the risk for initial therapy failure in subsequently infected

individuals. It is further stated that even high and sometimes complete adherence does not prevent accumulation of HIV drug resistance mutations. Sub-optimal adherence remains a critical issue in the development of resistance. Adherence is very important to guarantee the effectiveness of ART (Glass et al., 2006).

2.5. Importance of adherence

Researchers indicate that adherence is vitally important in the treatment of HIV. The Studies have found that optimal suppression of the virus requires around 95% of adherence. Adherence directly impacts on how well ARV medication stops HIV from reproducing. When a patient misses a dose of medication, the virus has the opportunity to reproduce itself. When this happens, viral load (the amount of HIV in a blood sample) increases. Often when viral load goes up, CD4 count, which is a measure of how healthy your immune system is, goes down. A weak immune system puts a patient at risk of developing AIDS-related conditions. When the virus multiplies itself, some of the copies are not in their original form. These are known as mutations and some of them may be resistant to one or more of the medications a patient is taking and render them useless. Adherence to treatment regimens is essential to the success of HAART in patients infected with HIV. Multiple research studies have clearly demonstrated the close association between proper adherence to HAART and decreases in both plasma HIV RNA levels and HIV-associated mortality rates. In an effort to maintain virologic suppression, adherence levels of 95% are required for patients treated with HAART. However, community reports suggest that actual adherence levels are often far lower than those required for successful HAART. Studies revealed that 40% to 60% of patients are less than 90% adherent. Multiple reasons for non adherence to HAART regimens have been reported by patients infected with HIV (Battaqlioli-DeNew, 2007).

2.6. Measurement of adherence

According to HIV Clinical Resource (2006), measurement of adherence is challenging in both clinical and research settings and usually relies on any one or a combination of the following methods: Self-reporting, Pill counts, Pharmacy records, Electronic pill bottle monitors, Therapeutic drug monitoring, and Computer-assisted self-interview (CASI) assessment. Adherence measurement provides an opportunity to reinforce the adherent patient and to flag patients that require support to improve

adherence. Without formal assessment of adherence the opportunities for interventions are lost. The measurement of adherence including the history of dosing is therefore the first step towards the design and implementation of interventions to improve adherence

There are many methods to measure adherence including electronic devices, pill counts, and drug assays. However, in clinical practice, the most efficient method to measure adherence is simply to ask the patient. It is critical to ask over time as patients' adherence will vary, for example, in response to re-initiation of substance abuse. When asked in a nonjudgmental way, most patients (80% in several studies) are truthful about their medication taking. To get the most reliable information, patients should be given permission to have missed doses, asked in a nonjudgmental way, and given a specific time frame (USAID, 2007).

According to American Public Health Association, 2004 some of the well documented methods include clinical assessments, prescription refills, biological assays, medication event monitoring, and directly observed therapy. Each method is associated with advantages and disadvantages (Oyegoke, 2010).

Basic techniques have been developed for quantifying adherence and they have limitations. These measurements will be discussed as follows:

2.6.1. Assays: These have been used in clinical trials to measure the last dose taken, however, these assays are often impractical because of their expense and lack of general availability. Assays typically measure only recent doses and thus provide limited data. Adherence may be overestimated if patients are more conscientious about taking their medication before a clinic visit.

2.6.2. Electronic Monitoring Systems: Examples such as the Medication Event Monitoring System (MEMS) are inserted into medication bottle caps; and contain a computer chip that records the date and time of opening and closing of the bottle. Interpretation of these data assumes that a single dose is taken each time the bottle is opened and may lead to inaccuracies if multiple doses are removed at once. Adherence data are providing valuable insight into the association between drug taking and viral load as well as approaches that may be useful for improving adherence (Chesney, 2000).

2.6.3. Pharmacy records: This can also give important information regarding adherence when available to the clinical staff. Serum drug level tests are now commercially available. These are most useful when patients professing adherence or not responding well to therapy (Laura & Cheever, 2005).

2.6.4. Pill count: It is easy to perform subject to patient “pill dumping “can be used to measure under adherence and over adherence .This does not reveal consistent medication usage or consistent intervals for dosing. Pill counts have been widely used. The return of excess pills provides tangible evidence of non adherence. However pill counts require patients to return the medication packaging to the clinician. Even in the clinical trial situations, patients tend to forget the packages or inadvertently discard them. There have also been reports that patients other than those with HIV, are aware that pill counts are being conducted and engage in pill dumping to appear adherent. As a result, pill counts typically overestimate adherence.

2.6.5. Patients report: This has the advantage of low cost and flexibility design (questions suit individual language abilities). The data is easily collected and can help to determine the reasons why patients are non adherent. Researchers assume that patients can accurately recall their behaviour and provide honest answers Simple and direct reporting can lead to overestimation of adherence and may therefore only reflect short-term adherence. It is effective as a direct correlation to HIV disease progression and medication adherence. Self reports can be helpful for understanding the dynamics surrounding missed medication (Anthony et al., 2003).

2.7. Barriers to ART adherence

There is little evidence of the causes of non-adherence to ART in resource poor-settings. Studies conducted seem to suggest factors being the barriers to ART adherence and these are discussed hereunder:

2.7.1. Stigma

Stigma is the mark of blame, rejection, disapproval and shame that society places on conduct and conditions. This statement is supported by Wekesa (2007), who states that HIV/AIDS elicits stigma from society more than any other disease. Stigma,

which exists at both household and community levels, is a key barrier to HIV/ AIDS care, treatment, and prevention programmes in all research sites, and its impact on social support systems and the psychological well-being of people living with HIV is pervasive. People living with HIV reported that they experience difficulties in disclosing their status due to the fear of stigma and discrimination. Disclosure of status was often linked to advanced stages of AIDS with some people disclosing their status just before death (Summary Report, 2006).

2.7.2. Depression

According to Meta analysis published in the online edition of the Journal of Acquired Immune Deficiency, depression has a significant important on adherence to antiretroviral therapy. It is a strong predictor of non adherence among persons treated for HIV. It is also common in the society and is frequently experienced by HIV individuals and their significant others. People with HIV/AIDS often experience depression because they feel that they have lost so much in life and that they themselves are to blame for it (Van Dyk, 2008). Diagnosis of HIV is often associated with an increase in depressive symptoms.

2.7.3. Provider- patient relationship

Researchers report that barriers related to the health care provider patient relationship included in patient satisfaction with their provider as well as quality of communication with the provider. Communication barriers were thought to contribute to poor adherence. Providers felt that this primarily affected patients who spoke languages different from those of their providers. It is further reported that lack of communication about ART between health care professionals and patients, time constraints during consultations, lack of counseling skills and patients follow up may contribute to non-adherence. Counselors stressed the importance of the physician communication to the importance of ART adherence. In the initial phase, before the start of treatment, there might be problems in communication between patients and providers. One problem in patient –provider relationships in treating HIV-infected children was the rotation of residents in the hospital setting (Biadgiligh et al., (2009).

2.7.4. Health Care system

Researchers report that long waiting times for clinic services were reported as an important barrier and ability to return to the clinic for service and to pick up medication. This might be stigmatizing in a working population as spending additional time in the clinic and may require additional time off work. This contributed to their dissatisfaction with clinic services and made them more likely to stop coming to the clinic to pick up their medications. Furthermore, human resources shortages e.g. nurse, doctors, community health workers, counselors and home-based caregivers, are experienced at the health facility level. Infrastructural constraints included old, dilapidated or insufficient equipment and a shortage of space. These issues tended to feature more prominently, although not exclusively, among health facility staff rather than by users of the clinics (Summary Report, 2006).

2.7.5. Language and cultural barriers

It is found that language barriers can lead to errors and a possible violation of confidentiality. Older patients who are accustomed to an age-based power structure may feel helpless or upset when English-proficient children assume this position of power over them. Poor adherence to pharmaceutical treatment has been found to be significantly more prevalent among non English speaking patients compared with their English speaking counterparts. Factors such as the clinician's language, eye contact, ability to listen, communication skills, and consultation style can foster or hinder collaboration with the patient. Factors that facilitate the relationship include the provision of understandable information, openness to questions, sensitivity and respect for the patient, interest and trust in the patient, and ongoing availability (Avery, 2007).

2.7.6. Traditional and cultural beliefs

Traditional and cultural beliefs play a major role in people's explanations of the aetiology of HIV. How individuals perceive the nature and cause of their illness may act as a barrier to compliance. In seeking the cause of their illness some patients especially black South Africans, have turned to traditional medicine for answer and for a cure (Van Dyk, 2008).

It is further reported that non prescribed medicine such as traditional medicine use appeared to affect adherence negatively. It is further reported that clarification to health care providers of how to counsel patients on the use of traditional medicines while on ART is very important (Van Dyk,2004). It is reported that patient increase power of perceptions of traditional healers. Most people in Zimbabwe have been affected by AIDS and have some knowledge about the disease. This has meant that fewer of them are resorting to traditional cures and explanations such as witchcraft, which were common at the earlier stages of the epidemic and with the introduction of ART, they are appreciating the potential of biomedical technologies.

2.7.7. Beliefs and knowledge

A patient's beliefs about their illness and the effectiveness of medication are predictive of adherence. There are beliefs about the meaning of medications in people's daily lives, which could undermine adherence. A number of people believe that medications are supposed to be taken only when one is ill, and/or to cure an illness for a short duration, not for life (Wekesa, 2007). As reported by Wenger et al., (1999), a patient's level of knowledge about HIV disease, a belief that HAART is effective and prolongs life and recognition that poor adherence may result in viral resistance and treatment failure all impact favorably upon a patient's ability to adhere. Among the patients, lack of interest in becoming knowledgeable about HIV and a belief that HAART may cause harm will affecting adherence. Research suggests that a good level of understanding about HIV/AIDS and awareness of the consequences of non-adherence are associated with good adherence (Fisher as cited by Sharon 2006). For example, understanding of the issues around HIV/AIDS such as what the CD-4 cells mean can enhance adherence. It is, therefore, expected that misinformation and misconceptions about the treatment would compromise an individual's ability to adhere. Indeed cases of lacking correct information is abound (Wekesa, 2007).

2.7.8. Religion

Researchers indicate that religious convictions have been indicated and believed to play a crucial role in ART adherence. Research conducted on attitudes and beliefs

surrounding HIV disease and adherence to ART, reveals that multiple factors influence adherence to medical treatment. It showed that certain religious practices are positively associated with adherence and on the other hand certain beliefs are negatively related to ART adherence. It is therefore very important that religious beliefs and practices are addressed during counseling as part of medical care (Sharon et al., 2006).

2.7.9. Substance abuse

It is reported that non adherence was associated with the use of cocaine, marijuana or sedatives (including alcohol). Alcohol plays an important part in non adherence to ART. It is also reported that drug users are often unable to comply with long and complex regimens and it is found that alcohol use problems are associated with patients missing their doses. Alcohol consumption has been found to be one of the determinants of poor adherence. Excessive alcohol users are known to access medical help at a later phase of the disease and receive less preventative treatment (Koopman et al., 2003). Substance abuse is a further threat to adherence. Research shows that HIV positive patients receiving ART, difficulties in obtaining medication was associated with non-adherence among heavy drinkers while a poor fit of the regimen with the patient's lifestyle was associated with non-adherence among drug users who drank heavily. Among sample of HIV positive persons whose ART use was monitored, those with poor adherence had higher rates of substance abuse than those who adhered adequately. Alcohol use has been linked to non-adherence, especially in resource-rich settings. As a result of the problems associated with alcohol and smoking in as far as taking medication is concerned, some PLWAS report to have either quit or cut down on their consumption Wekesa, (2007).

2.7.10. Health literacy

Health literacy is a barrier to adherence among patients living with HIV/AIDS. It involves an awareness of the importance of adherence despite the absence of actual symptoms. The longer-term health consequences of non-adherence may be severe as symptoms will develop and the disease will progress unchecked. As health literacy is often related to educational level, among poor communities in South Africa

characterized by limited educational opportunities, health literacy is likely to be low (Kagee,2007). Researchers found that 49% of HIV patients stated that they believed ART could cure HIV. The belief that ART could cure HIV was associated with a low level of education. Closely tied to health literacy regarding ART is HIV related knowledge, which has often been shown to be associated with ART adherence recommended that health providers include questions focused on knowledge of HIV in their assessment of medication readiness and the need for adherence support. The relationship between literacy and health is complex. Literacy impacts health knowledge, health status, and access to health services. Health status is influenced by several related socioeconomic factors. Literacy impacts income level, occupation, education, housing, and access to medical care. Furthermore, the poor and illiterate are more likely to work under hazardous conditions or be exposed to environmental toxins (Glass, 2010).

2.7.11. Financial burden

Having a low income may inhibit clinic attendance because of patients' inability to pay for transport or child care. As financial resources may need to be directed elsewhere, funds for travel to the clinic may not be available and child care may not be readily accessible for parents who attend clinic visits (Kagee, 2007).

These costs may seem minimal to health professionals and decision makers, but bearing these costs often translates into difficult household decisions about who eats, who works, or who goes to school. In resource poor countries people live below the poverty line and there is often no medical insurance or disability pension for people living with HIV. Lack of finance emerged as the greatest barrier to taking HAART. It is further reported that financial constraints reported were food while waiting to see health care provider and the cost of nutritious foods that HAART patients are recommended to eat while taking the medication (Katabari, 2002). Medications and clinic visits cost money and may stress an already stretched budget (Grierson,et al., 2000). Respondents also cited illiteracy as a problem in their communities and social security grants in particular the disability grant, was often reported as the only source of income in a household. Households in receipt of

social grants can make strategic choices about accessing health services as managing transport and other costs becomes easier.

2.7.12 Transport factors

As indicated by (Kagee,(2007), transport related barriers to accessing health services were mentioned at both the clinic and hospital level with the latter posing significantly more problems because they are fewer in number and generally situated in towns or cities. There was a general perception that the health care centres that provided ARVs were situated too far away and were thus inaccessible. People used a variety of means to travel to the clinic and ARV health facilities ranging from walking, taking taxis, hiring private cars and in some extreme cases, using wheelbarrows. The poor condition of roads exacerbated difficulties travelling to health centres especially in rainy weather. This transportation issue also reveals the geographical distribution constraints that patients face, highlighting the need to decentralize treatment centres. The transport costs involved in attending ART literacy programmes together with a patient supporter was also cited as being a deterrent to the uptake of ARVs. Being in receipt of a disability grant appeared to render transport costs less burdensome. Patients who cannot afford adequate levels of food often also struggle to meet the transport costs associated with going to the health clinic to attend monthly medical reviews and to pick up their monthly supplies of drugs. This was particularly the case with patients who lived further away and who had no other choice but to walk and was often unable to find the time and energy to make the journey. Costly transportation fees for monthly check ups were cited as the most prevalent barrier to enrolling in adhering to HAART (Katabari, 2002).Distance may discourage patients to attend clinics. In conditions of poverty, some patients had to travel from place to place to search for support from various family members, which meant that it was often difficult for them to attend their monthly reviews and drugs collections. Antiretroviral Therapy (ART) is available mostly in cities, towns and major villages. For people in rural areas to access ART, they have to travel long distances and this becomes a problem with those of low socioeconomic status. This is supported by Hardon, et al., 2006 who state that although ART is free, transport costs are an important reason why ARV users fail to visit the health facility for follow up and refill.

2.7.13 Food Insecurity

It is reported that a key component of counseling and support that health providers provide ARV users involves their advice on the importance of patients eating nutritional foods as part of their treatment regimen. ARVs work best if complimented by a nutrition rich diet. If patients struggle finding food and witness little progress, coupled with the discomfort that comes with taking powerful drugs on an empty stomach, meant that some patients discontinued their treatment. Studies show that there is an increased demand for food, especially at the initial stages of the treatment as the body regains strength. The important demand for food may not be met by a section of those living with HIV in resource poor settings (Wekesa, (2007).

According to Zuurmond, (2008), in a study on adherence to ART challenges and successes, the respondents stated that they were not taking treatment because they were hungry. In order to support better adherence, medications must be taken on a full stomach and proper nutrition can help lessen some of the side effects as well as strengthening general resilience. Once a person is commenced on treatment and the condition improves, the appetite also improves. Additionally, if the medication is taken on an empty stomach, then it cannot be tolerated. Most people reported having experienced food insecurity on a regular basis and basic services (such as water) were often unaffordable or non-existent. Poor patients may not have enough money to buy food, causing hunger to negatively affect their propensity to adhere to ART. Lack of food is therefore a challenge for ARV users (Summary Report, 2006).

2.7.14 Homelessness

Among homeless individuals, adherence may be compromised when they experience increased housing instability or stay in settings not conducive to adherence, such as moving from a residential hotel to a shelter, not having a secure place to keep medications, or not having a refrigerator for certain medications (HIV Clinical Resource, 2006). It is often assumed that homeless patients face insurmountable barriers to adherence with medications. Certainly, homelessness itself creates many challenges to adherence. Additionally, many homeless patients have mental illness or substance abuse that may further contribute to non adherence. However, homeless patients can be successful in taking HAART. The

study found that homeless and marginally housed patients from San Francisco, 38% of the 32 homeless patients taking protease inhibitors had high levels of adherence. However, the group appears to be highly selected since only 34 of 153 patients in this marginally housed cohort were prescribed HAART (Laura & Cheever, 2005).

2.7.15 Economic dependence

It is reported that women's economic dependence on men can serve as a barrier to women's adherence. Husbands unwillingness to accept their HIV status and to support their treatment can sometimes result in women being threatened with divorce if they insist that they are HIV positive in the face of a husband's disbelief. This was found to limit some women's control over treatment seeking decisions and ability to begin and adhere to HAART. Economic dependence on spouses was a particular barrier among those women who had not disclosed their HIV positive status to their partners. It is reported that economic dependence is another barrier to antiretroviral adherence because patients were economically dependent on their husbands who either provided or controlled the households finances (Skovdal, 2003).

2.7.16. Social support

Social support is defined as the attachment among individuals or between individuals and groups which improves adaptive competence in dealing with short-term crises and life transitions as well as long term challenges, provisions and stresses. Researchers report that living alone and lack of support have been associated with an increase in non adherence. Social isolation is predictive of non adherence. It is further reported that having a partner, social or family support, peer interaction and better physical interactions are characteristics of adherent patients. Furthermore, degree of adherence is not solely the result of psychological processes, but is also the product of interactions with family, friends and healthcare providers (Williams et al., 2005). There is some emerging evidence to show that social support is vital in fostering adherence for PLWHAS on treatment. Social support is obtained from different sources such as partners, children and kin. These could help adherence behaviour by taking a leading role in reminding the PLWHAS to take the pills. Kith and kin could also provide support by purchasing the necessary dietary requirements

recommended for ART intake programme. There is an indication that PLWHAS gain social support when they disclose their HIV status (Wekesa, (2007)).

2.7.17. Side effects

Researchers indicate that side effects associated with each individual antiretroviral drug are well described. Anticipation and fear of side effects also impacts upon adherence. Poor adherence has been associated with patients desire to avoid embarrassing side effects in certain situations e.g. attending a job interview. Side effects may cause someone to stop taking medication. Patient's treatment may deviate from the prescribed medication and regimen. This is often termed non-compliance or non-adherence. Patients may be confused about their medication and need clarification, while other who is well-informed may actively resist complying with their prescribed treatment. A patient may discontinue using prescribed medication, taking an incomplete dose, change dosage amount, frequency or time of day medicine is taken and initiate taking someone else's medications for a perceived common symptom and forgetting to take a medication (Avery, 2007). ART treatment is known to cause some side effects to some patients. Some of the documented side effects include vomiting, nausea, anaemia, hepatitis, skin rashes, dizziness and hallucination (Wekesa, 2007).

2.7.18. Adverse Regimen Characteristics

According to Biadgiligh et al., (2009), most of the caregivers and health care workers reported that patients dislike high dosages (heavy pill burden) and patient dislike of taking the medication, and the children spitting out the medication are causes of poor adherence to the medication regimens. It is further reported that caregivers report the time of administration of the prescribed drugs may conflict with normal working hours. Negative characteristics of particular medication regimens are common barriers to adherence. Youth who feel healthy before starting ARVs will be very unlikely to accept having significant side effects, especially if they last more than a week or two. Side effects such as diarrhoea, rashes, or jaundice may be particularly troublesome because youth frequently worry that friends and contacts may assume they have HIV. Suggesting and rehearsing responses that patients can give to their friends if they experience side effects may help (e.g. "I got this rash from a medication my doctor gave me for an infection.").

2.7.19. Patient characteristics

According to Jean as cited by Mills (2006), patient characteristics are the most common and complex factors affecting adherence. Recent unpublished research on adolescent adherence to ART indicates that greater self-efficacy and, to a lesser extent, better outcome expectancy were associated with improved adherence. Though yet to be evaluated in research, adolescent developmental factors are believed to affect adherence. Younger and more impulsive patients are more likely to forget or not prioritize taking their medications. Adolescent patients may be more easily distracted by issues of daily life. Some adolescents are extremely concerned that taking medications might inadvertently reveal their HIV status, and this can have profound impact on their adherence. Adolescents have limited social support. In some cases, cultural or other factors may hinder youth from disclosing to their families, and some youth may be estranged from their families as a result of a variety of issues. Low level of education may impact negatively on some patient's ability to adhere, while high level of education has a positive impact belief about medication; centres around eight reported barriers pertaining to beliefs/perceptions about medications: some common barriers in this category included: side effects (either real or anticipated), complicated regimens, and the taste, size, dosing frequency, and /or pill count. Other barriers include doubting the efficacy of HAART, having a decreased quality of life, uncertainty of long term effects and unwanted changes in body image (Mills et al., 2006).

2.8. HIV/AIDS and Disability Grant

Disability grants were also a major concern for people living with HIV. Large numbers of those ineligible for grants had no other source of income. Using CD4 counts as eligibility criteria for accessing grants precludes many from receiving desperately needed funds and may have several negative effects on treatment and prevention efforts. These include poor nutrition and resultant poor health outcomes for people living with HIV and lack of access to services, which potentially increases dropout rates and the number of adherence defaulters. Conversely, some people may use services opportunistically to access grants (Summary Report, 2006).

According to the Social Assistance Act 2004, a person is eligible for disability grant if he/she has a physical or mental disability, and is unfit to obtain by virtue of any service, employment or profession the means needed to enable him /her to provide for his/her maintenance. The disability grant accounts for the third largest social assistance grant provided by the South African government after the Child Support grant and old age grant.

Researchers indicate that a number of people living with HIV/AIDS have accessed disability grants once they have fulfilled the set down criteria. Recent increase in demand for disability grants has been attributed in part to increase in number of people becoming disabled after contracting HIV with reduced immune status leading to a level where they are sick enough to be classified “unfit to obtain by virtue of any service, employment or profession needed to enable him or her provide for his /her maintenance. The disability grant is supposed to ensure that AIDS –sick patients can afford proper nutrition and transport to clinic. This invariably serves as an indirect way of promoting adherence among individuals taking HAART. It has been indicated that individuals who are receiving HAART generally tend to have their health restored within a space of time but such timing varies from individual to individual. Consequently, it is expected that these individuals should lose their disability grant since they are no longer too sick to work. They stand the risk of finding their health threatened again in the presence of unemployment and inadequate supports most obviously by poor nutrition which undermines the person’s immune system and reduces the effectiveness of HAART. People on HAART need regular, nutritious meals to enjoy optimal benefits since nutrition is essential for medication adherence. According to studies conducted disability grant aided the adherence to ARV medications in most patients and care-givers express concern that patients may not comply with their medications if the grant is withdrawn. HAART patients experience problems or difficulties on purchasing the food once their grant is cancelled. The role of disability grants in influencing people living with HIV/AIDS to adhere to antiretroviral medications is important as it was found that patients believed that the grant is a motivating factor to treatment adherence (Olugbenke, 2010).

2.9. Strategies for improving ART adherence

Strict adherence to antiretroviral therapy is extremely important to achieve viral suppression and avoid the risk of mutation, the development of resistance strains and drug failure (Van Dyk 2008:105). Strategies for improving ART adherences are discussed as follows:

- According to (Van Dyk (2008:107) health workers should establish whether patients are ready to take medication regularly and it is a good idea for health workers to see if the patient can commit to take every single dosage of Bactrim before starting him/her on antiretroviral medication. There must be patient-provider communication whereby health workers should establish respect and unconditional acceptance.
- The HIV health care team can provide support through office visits, home visits, and telephone calls, especially in the first instance to treat substance abuse and depression before initiating antiviral therapy days and weeks of antiretroviral therapy (Laura & Cheever:2005).
- Several patients believed that improving their communication with their providers was a feasible and important goal in improving adherence. Health care professionals pointed out strategies to be recommended for improving adherence to antiretroviral therapy, including educating the community about adherence as well, and disclosure of HIV status to children as early as possible based on the developmental stage of the child. The importance of providing income-generating schemes and harmonisation of the work rendered by non-governmental organisations should be encouraged. Moreover, patient-provider interaction should be encouraged before commencement of the medication, in order to improve adherence. Enhancing the psychological make-up of the caregivers is of importance as continued education for illiterate attendants and counselling might help improve adherence. The health worker should stress ART drug adherence, health education should be tailored in mass media to the community and provision of nutritional support to the caregiver should be stressed as well. Because of high levels of illiteracy and misconceptions, messages contained in posters and pamphlets must be augmented by in-depth discussions about HIV and AIDS at the community level. The use of respected community stakeholders

to deliver messages about HIV and AIDS in a wide range of contexts should be explored (Summary Report, 2006).

- Educational activities need to be scaled up in order to address traditional beliefs that prevent people from seeking appropriate medical interventions for urgent health problems and from using remedies that are harmful.
- Collaboration between traditional healers and Western medical practitioners is increasing and should be further promoted. Traditional healers must receive training and information on HIV and its management, and ways to encourage partnerships between the two health systems need to be explored.
- NGOs and CBOs have a crucial role to play in providing information and training on ARVs. Target audiences include the broader community, traditional healers, health facility workers, religious and traditional leaders, and local organizations such as women or youth groups. Training should include information on treatment centres, eligibility criteria, adherence, side effects, and healthy living.
- The public health sector transport programme must be revitalised. Additionally, innovative ways must be found to provide affordable and reliable transport to people wishing to access health care services especially from clinic to hospital level. One possible alternative would be to explore the potential to form a public-private partnership with existing taxis in the area given that many people living with HIV live in relative poverty, strategies to improve their nutritional status are needed. More needs to be done in terms of establishing the efficacy of immune boosters. A cost-benefit analysis of the usefulness of various commercially available products may assist people living with HIV in deciding how best to use limited resources. Strategies to reduce the cost of commercially available supplements may be needed if they are proven efficacious in improving the immune status of people.
- Given the South African Government's endorsement of the use of traditional medications, more effort needs to be invested in establishing the benefits and risks of their use. The government may need to regulate the Sale and use of supplements. An unintended consequence of the current information strategies on adherence, such as those emphasizing 100 percent adherence, may be to discourage people from taking ARVs. A balance needs to be found

between promoting ARVs and informing people of the potential dangers and side effects of treatment. Strategies to increase treatment promotion and support may address this issue.

- Clinicians should encourage patients to state in their own words what they understand about treatment instructions and to ask questions when additional information is needed. They should also encourage patients to be honest by responding in a nonjudgmental, supportive manner when patients report non-adherence. When a patient reports non-adherence, the clinician should respond in a way that enhances an open and honest partnership. Clinicians can be supportive by acknowledging that treatment for multiple disorders is challenging because of the increased pill burden and added responsibility and stress of adhering to more than one regimen. Being actively supportive by welcoming the patient's honesty will mitigate any shame that the patient may feel about his/her poor adherence (HIV Clinical Resource, 2006).
- Patients should enlist the aid of family and friends to promote their adherence. The HIV health care team can provide support through office visits, home visits, and telephone calls, especially in the first treat substance abuse and depression before initiating antiviral therapy days and weeks of antiretroviral therapy (Laura & Cheever, 2005).
- Treat substance abuse and depression before initiating antiviral therapy. If there is no antiretroviral emergency, patients with active substance abuse and depression should have these co-morbidities addressed before initiation of antiretroviral therapy. Individualize therapy based on patient preferences regarding fear of specific side effects or specific medication and negotiate the regimen with the patient.

2.10. Conclusion

Preventing non adherence is a better treatment approach than strategies in which the primary focus is on identifying and rectifying non-adherence once it has been established. HIV care and treatment facilities include such preparative approaches for promoting adherence into their treatment programmes.

Chapter 3: Research Methodology

3.1 Introduction

This chapter explains the methodology that was used in the entire study. The chapter detailed study area, study design, target and study populations, sampling techniques, research instruments, ethical considerations, data collection, data quality control, data management and analysis.

3.2 Target population and sampling

Bless and Higson-Smith (as cited by De Vos et al., 2002:91) defines population as the set of elements that the research focuses on and to which obtained results should be generalized. The population of the study was the group from which the researcher chose to draw their conclusions. The researcher based the study on HIV/AIDS patients at Mogwase Health Centre (situated in town of Rustenburg, north of Pilanesburg). The total population of infected patients in the wellness programme is 300. The population consisted of both male and female HIV/AIDS patients that are under the wellness programme.

A sample is a sub-section of the total target population selected to participate in the research (David & Sutton, 2006:369). The researcher used purposive sampling which is a non-probability sampling. Purposive sampling is defined as selecting a sample of observations that the researcher believe will yield the most comprehensive understanding of the subjects of the study. This research study focuses on 20 participants including both male and female (as the sample size). The inclusion criteria comprised of HIV/AIDS patients who had started ART and were willing to participate in the study.

3.3 Types of research

According to Longman dictionary (2005) qualitative research is research undertaken to gain insights concerning attitudes, beliefs, motivations and behaviors of individuals to explore a social or human problem and include methods such as focus groups, in depth interviews, observation research and case studies. The reason for using qualitative research is to explore substantiate areas about which little is known or about which more is known to gain novel understanding.

In particular qualitative research seeks to understand a given research problem or topic from the perspectives of the local population it involves (Mack et al, 2005). Furthermore, researcher aims to gather an in-depth understanding of human behavior.

3.4 Research design

David and Sutton (2006:647) define research design as the framework for the research process involving the collection and analysis of data. In this study, the researcher used an exploratory design. The exploratory design was chosen because the researcher wanted to gather detailed information about the subject. The researcher therefore used a qualitative method in the study hence it is based on a world view that is holistic and thus explores the depth, richness and complexity inherent in phenomenon.

3.5 Approaches to qualitative research designs

The approach of qualitative research design that researcher used is phenomenology. According to (Christensen,2011) phenomenology involves the description of an individuals or group of individuals conscious experience of a phenomenon such as the death of a loved one, a counseling session, an illness or experiencing a specific emotion such as guilt, anger or jealousy. The researcher attempts to gain access to each participant's life world, which is the research participant's inner world of subjective experience.

Data collection method is the period in the researcher's project that involves engaging with a target sample or population from whom data is collected (David & Sutton (2006:361).The bulk of data for this study was based on qualitative methodologies. This is because the key problem for this studies, namely; non-adherence to ARVs can best be captured using a qualitative methodologies. In this study, data was collected using questionnaires method. Questionnaire was designed by the researcher and consisted of closed and open ended questions. It was distributed to the patients and researcher assisted with explaining some of the questions in the questionnaire if someone did not understand

3.6. Data analysis

According to Polit and Hunger (1999), the purpose of data analysis is to impose some order on a large body of information so that data can be interpreted. The nature of this research study was qualitative. Analysis assisted the researcher to make suggestion from the data or sample to the general population. Therefore, the information collected from the respondents was analyzed and the results presented in the forms of tables and charts.

3.7 Ethical consideration

Research ethics is defined as a set of principles that assist the community of researchers in deciding how to conduct ethical research (Christensen et al., 2011:96). Ethical issues need to be considered when conducting research, while human beings are the objects of study. In addition, it is important to understand ethical and legal responsibilities of conducting research. The researcher identified the following ethical issues in the study:

- The respondents identities would not be revealed and thus anonymity will be assured
- Informed consent would be obtained.
- The respondents would be advised that they are free to decline or withdraw from the study at any time should they wish. This ensured personal freedom.
- Confidentiality and privacy would be assured by conducting interviews in a private room.
- Cultural customs of patients would be respected.

Chapter 4: Results and Findings

4.1. Introduction

The primary aim of this chapter is to present, analyze and interpret the data collected from the twenty patients sampled at the Mogwase Health Centre. The data was collected through a questionnaire analyzed and is presented in the form of tables, pie charts and bar graphs.

4.2 Data Analysis instrument

The researcher used questionnaire as a method to collect data. According to Polit and Hunger(1999),the purpose of data analysis regardless of the type is to impose some order on a large body of information so that data can be synthesized, interpreted and communicated in a research report. In this study, tables and charts were used to analyses responses to questions.

4.2.1.1 Data collection and analysis

The data was collected through questionnaire analysed and presented in the form of tables, pie charts and bar graphs.

4.2.1 Demographic data

Demographic data was collected to provide detailed information on the respondents focusing on five variables; age, marital status, gender, educational and employment status.

4.2.2. Age of respondents

Information on the respondent's age was vital to indicate the age group of the respondents who participated in this study.

Table 1: Age of respondents

Response	No. of respondents	Percentage
21-30	09	45
31-40	7	35
41-50	2	10

51-60	1	5
61 and above	1	5
Total	20	100

Table 1 shows that the majority of the respondents, (45%) were in the age group of 21-30 years. The distribution of the age categories thus indicates that the majority of the respondents were young people.

4.2.3. Marital status of respondents

The information on marital status of the respondents was important to establish if there was a link between respondents' marital status and their challenges to ART adherence.

Table 2: Marital status of respondents

Response	No. of respondents	Percentage
Never married	10	50
Married	4	20
Divorced	0	0
Widowed	6	30
Total	20	100

Table 2 indicates that the majority of the respondents (50%) were never married, possibly due to the fact that the majority of the sample was a young age.

4.2.4. Sex of the respondents

Information on sex was necessary to identify the respondents on the basis of their sex.

Figure 1: Sex of the respondents

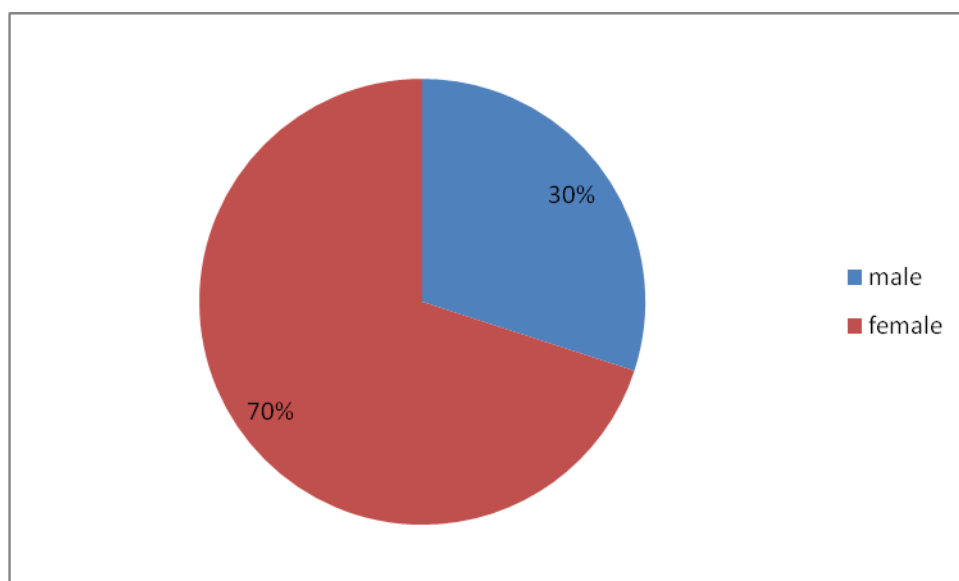


Figure 1 indicates that seventy percent (70%) of the sample comprised women while men made up 30%.

4.2.5. Educational level of the respondents

Information on educational level of the respondents was necessary to determine if there was any relationship between educational level and the barriers to ART adherence the respondents were experience experiencing.

Figure 2: Educational level of the respondents

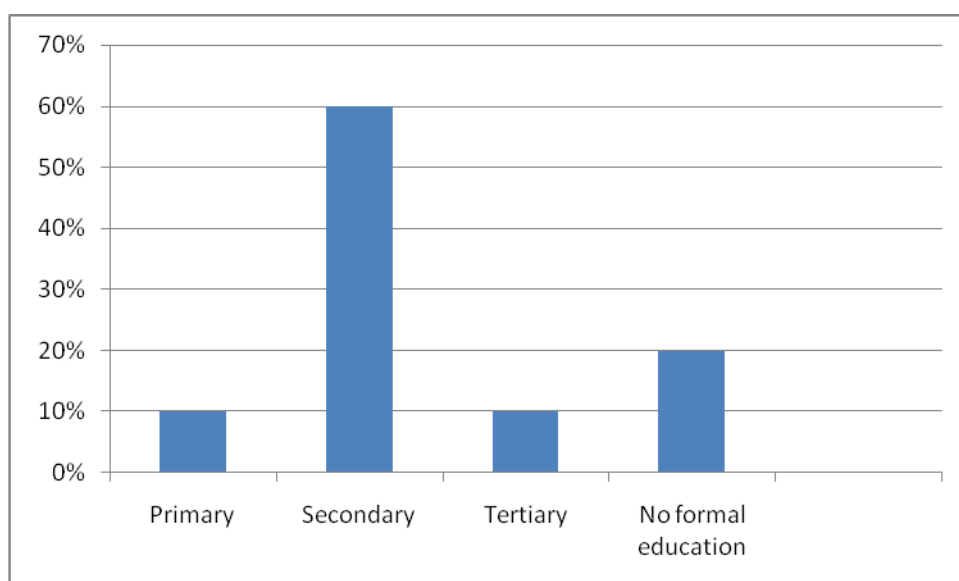


Figure 2 indicates that 60% of the respondents have secondary education while 20% have no formal education.

4.2.6. Occupation of the respondents

Information on occupation of the respondents was necessary to determine their financial stability.

Figure 3: Occupation of the respondents

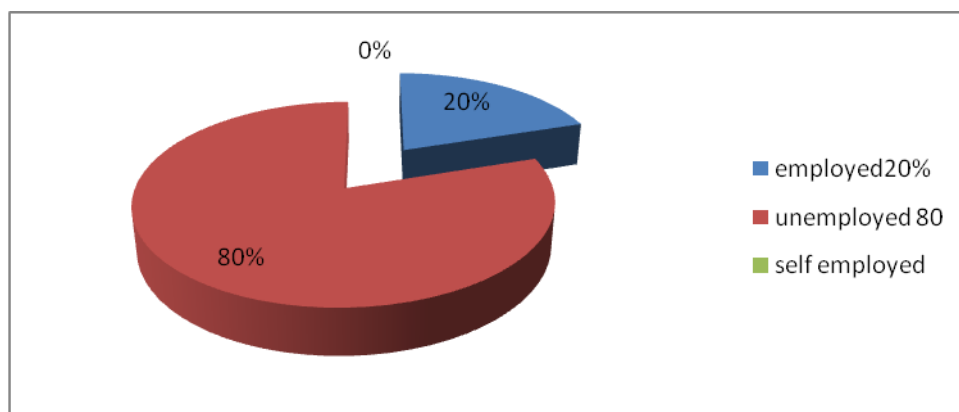


Figure 3 reveals that 80% of the respondents were unemployed and 20% were employed. This could be attributed to the fact that majority of the respondents had no post school education (see Figure 2). There is a correlation between level of education, occupation and health literacy.

4.3. Barriers to ART adherence

Information on barriers to ART adherence was sought in order to establish respondents' views about their experiences in ART adherence.

4.3.1. Stigma

The information was necessary to determine if respondents experienced stigma during disclosure of their status.

4.3.1.1: Respondents experienced stigma since they started Highly Active Antiretroviral Therapy (HAART)

Table 3: Responses on whether respondents experienced stigma since they started Highly Active Antiretroviral Therapy (HAART)

Responses	No. of respondents	Percentage
Yes	15	75
No	5	25
Total	20	100

Table 3 shows that majority of respondents (75%) experienced stigma since they started Highly Active Antiretroviral Therapy (HAART), while 25% indicated that they did not experienced stigma. These data supports findings of Wekesa, (2007), who states that HIV/AIDS causes more stigma in society than any other disease.

4.3.1.2 Respondents who did not disclose their HIV status to family, relatives and friends due to stigma.

Table 4: Responses of respondents who did not disclosed their HIV status to family, relatives and friends due to stigma.

Responses	No. of respondents	Percentage
Yes	12	60
No	8	40
Total	20	100

Table 4 reveals that the majority of respondents (60%) did not disclose their HIV status to family, relatives and friends due to stigma. The data concurs with the Summary Report, (2006), who states that people living with HIV reported difficulty disclosing their status due to the fear of stigma and discrimination. Forty percent (40%) of the respondents did disclose their HIV status to the family, relatives and friends.

4.4. Depression

This information was sought in order to obtain the general views of respondents who experienced depression

4.4.1: Respondents suffered from depression after being diagnosed HIV positive.

Table 5: Responses on whether respondents suffered from depression after being diagnosed HIV positive.

Responses	No. of respondents	Percentage
Yes	4	20
No	16	80
Total	20	100

Table 5 shows that 80% of the respondents did not suffer from depression after being diagnosed HIV positive. This data is in contrast to other studies e.g. Van Dyk, (2008), who state that people with HIV/AIDS often experience depression because they feel that they have lost so much in life and that they themselves are to blame for this.

4.5. Patient-provider relationship

This helped in exploring possible relationships between the respondents and the health provider.

4.5.1 Respondents received counseling from the health provider during their ART initiation.

Table6: Responses whether respondents received counseling from the health provider during their ART initiation.

Responses	No. of respondents	Percentage
Yes	12	60
No	8	40
Total	20	100

Table 7 indicates that 60% of the respondents received counseling from the health provider during their ART initiation and 40% of the respondents did not receive counseling, which is cause for concern.

4.5.2: Relationship between the respondents and health providers.

Figure 4: Relationship between the respondents and health providers.

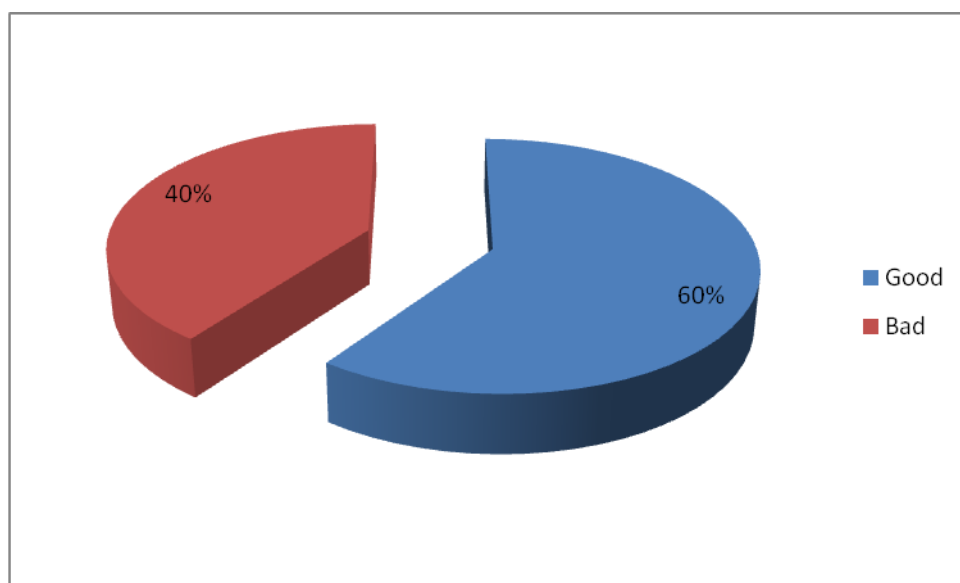


Figure 4 indicates that majority of respondents (60%) had good relationship with the health providers and 40% of respondents indicate that they have bad relationship. The data is supported by Wekesa, (2007), who states that there is a growing recognition that a great deal of adherence hinges on the positive interaction between the patients and the health care provider.

4.5.3 Respondents who experience bad relationship towards the Health workers.

All respondents indicated that health providers communicate negative towards them and there is no positive interaction between the respondent and the health provider.

4.6. Health care system

The information was necessary for finding out the level of service satisfaction at the clinic.

4.6.1. Responses on whether respondents receive excellent service.

Figure 5: Responses on whether respondents receive excellent service.

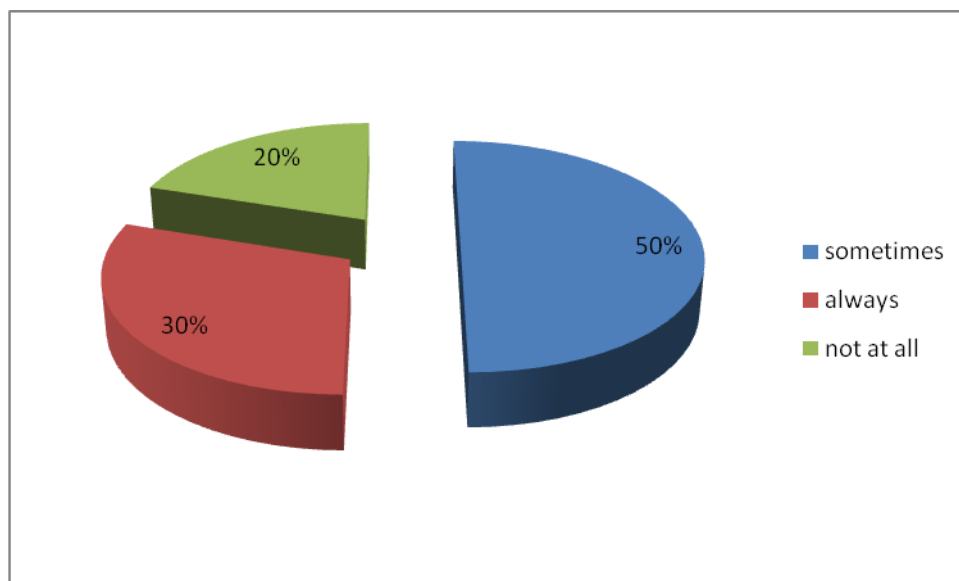


Figure 5 reveals that 50% of the respondents stated that they sometimes receiving excellent service while 30% of respondents reported that they always receive excellent service. As indicated by the Summary Report, (2006) human resources shortages were experienced at the health facility and these shortages referred to nurses, doctors, community health workers, counselors and home based caregivers, which could impact on levels of service provided.

4.6.2. Responses on privacy maintained during consultation.

Table 7: Responses on privacy maintained during consultation.

Responses	No. of respondents	Percentage
Yes	0	0
No	20	100
Total	20	100

Table 7 reveals that all respondents (100%) report that privacy was maintained during their consultation.

4.6.3. Responses on time spend when respondents came for review.

Figure 6: Responses on time spends when respondents came for review.

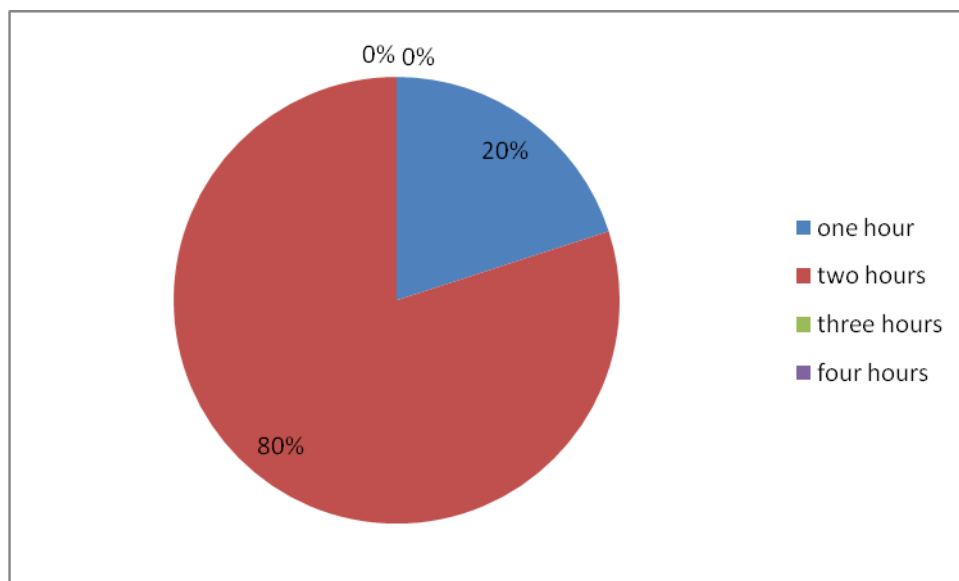


Figure 6 indicates that 80% of respondents spend two hours when they came for review. The data concur with Summary Report, (2006) which state that those long waiting times for clinic services were reported as an important barrier ability to return to the clinic for service and pick up medication. Only 20% of respondents spent one hour or less on their review.

4.7. Language and cultural barriers

The information was collected in order to find out if language and cultural barriers lead to poor adherence of ART.

4.7.1. Respondents who felt helpless because of language and understanding.

Table 8: Responses on whether respondents feel helpless because of language and understanding

Responses	No. of respondents	Percentage
Yes	11	55
No	9	45
Total	20	100

Table 8 indicates that the majority of respondents (55%) feel helpless because of language and understanding. The data may support Avery, (2007), who states that older patients who are accustomed to an age-based power structure may feel helpless or upset when English proficient children assume this position of power over them.

4.8. Traditional and cultural barriers

This section was meant to find out if traditional cultural beliefs play a major role in ART adherence.

4.8.1 .Responses on traditional medicines beliefs.

Table 9: Responses of traditional medicines beliefs.

Responses	No. of respondents	Percentage
Yes	9	45
No	11	55
Total	20	100

Table 9 shows that 55% of the respondents do not have significant belief in traditional medicines, while 45% of respondents indicated that they believe in traditional medicines. The data is supported by Van Dyk (2008) who states that in seeking the cause of their illness some patients especially black South Africans, have turned to traditional medicine for answer and for a cure.

4.9. Belief and knowledge

Information was needed to find out if respondents have little knowledge about the ARV drugs.

4.9.1. Responses on ART belief as therapy

Table 10: Responses on ART belief as therapy

Responses	No. of respondents	Percentage
Yes	9	45

No	11	55
Total	20	100

Table 10 shows that the majority of respondents (55%) do not believe in ART, while 45% of respondents do. The data is in line with findings by Wekesa (2007), who states that a number of people believe that medications are for a short duration, not for life.

4.9.2 .Responses on views for ARV drugs usage

Figure 7: Responses on views for ARV drugs usage

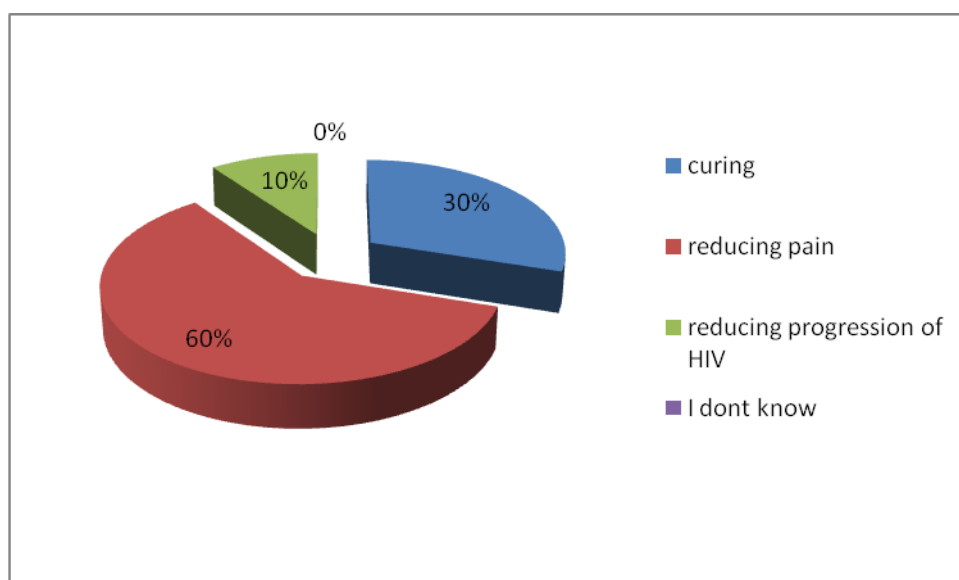


Figure 7 indicates that 60% of respondents view ARV drug use as to reduce pain, while 30% view it as curative. Furthermore 10% of respondents correctly view drug use as reducing progression of HIV. The data is in line with Wenger et al, (1999) who states that lack of interest in becoming knowledgeable about HIV and a belief that HAART may cause harm in affecting adherence.

4.10. Religion

Information is needed to determine if religion plays a role in ART adherence

4.10.1. Responses on the religious convictions that have been indicated and believed to play a crucial role in ART adherence.

Table 11: Responses on the religious convictions that have been indicated and believed to play a crucial role in ART adherence.

Responses	No. of respondents	Percentage
True	12	60
False	8	40
Total	20	100

Table 11 shows that 60% of respondents agree that religious convictions have been indicated and believed to play a crucial role in ART adherence, while 40% of respondents did not agree with the statement. The data is supported by Sharon et al., (2006), who states religious practices are positively associated with adherence and on the other hand certain beliefs are negatively related to ART adherence.

4.11. Substance abuse

The aim of asking this question was to find out if substance abuse is a threat to adherence.

4.11.1 Respondents who are consuming alcohol while on ART.

Table 12: Responses of respondents who are consuming alcohol while on ART.

Responses	No. of respondents	Percentage
Yes	11	55
No	09	45
Total	20	100

Table 12 indicates that 55% of respondents are drinking alcohol while are on ART, while 45% of respondents responded that they do not drink alcohol. The data agrees with Kopman et al (2003) who state that drug users are often unable to comply with long and complex regimens and it is found that alcohol use problems are associated with patients missing their doses.

4.11.2 Frequency of alcohol consumption

The respondents who cited that they drink alcohol indicated that they drink at least once a week.

4.11.3 respondents who use alcohol because they relieve stress of being diagnosed HIV positive.

Figure 8: Responses of respondents who use alcohol because they relieve stress of being diagnosed HIV positive.

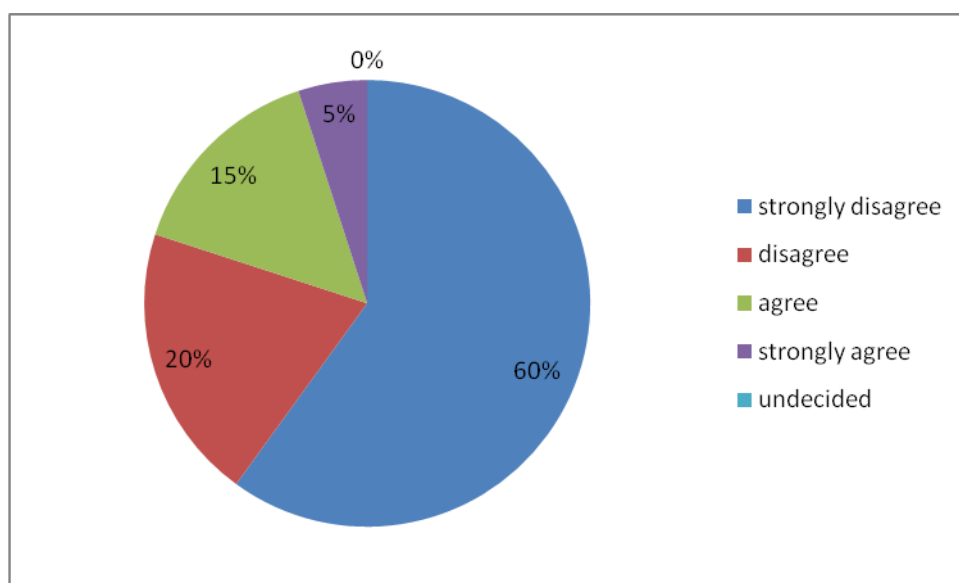


Figure 8 indicates that 60 % of respondents strongly disagree with the statement, while 20% of respondents also disagree. Furthermore only 15% of respondents state that they use alcohol because they relieve stress of being diagnosed HIV positive.

4.12. Health literacy

The information was necessary for finding out the level of health literacy among the respondents.

4.12.1 Poor literacy that is associated with low levels of understanding of medical instructions and adherence to ART.

Table13: Responses on poor literacy that is associated with low levels of understanding of medical instructions and adherence to ART.

Responses	No. of respondents	Percentage
True	18	90
False	2	10
Total	20	100

Table 13 shows that 90% of respondents agree that their literacy levels affects understanding of medical instructions. The data concurs with Kagee, (2007), who states that as health literacy is often related to educational level, among poor communities in South Africa characterized by limited educational opportunities, health literacy is likely to be low.

4.13. Financial burden

The aim was to find out if financial stability of the respondents impacts on ART adherence.

4.13.1 .Respondents who experience lack of income.

Table 14: Responses of respondents who experience lack of income.

Responses	No. of respondents	Percentage
Yes	20	100
No	0	0
Total	20	100

Table 14 shows that 100% of respondents experience lack of income when coming to clinic a visit. The data is in line with Kagee, (2007), who states that having a low income may inhibit clinic attendance because of patients' inability to pay for transport or child care.

4.14. Transport cost

The aim was to find out if transport factors are a barrier to accessing health services.

4.14.1: Respondents who experience transport problem.

Table 15: Responses of respondents who experience transport problem.

Responses	No. of respondents	Percentage
Yes	20	100
No	0	0
Total	20	100

Table 15 shows that 100% of respondents experience transport problems when trying to access drugs at the clinic. The data is supported by Katabari (2002) who state that costly transportation fees for monthly check ups was cited as the most prevalent barrier to enrolling in adhering to HAART.

4.15. Food insecurity

The information was needed to understand if lack of food enables respondents to discontinue ART.

4.15.1. Responses on experience to expenses of nutritious foods.

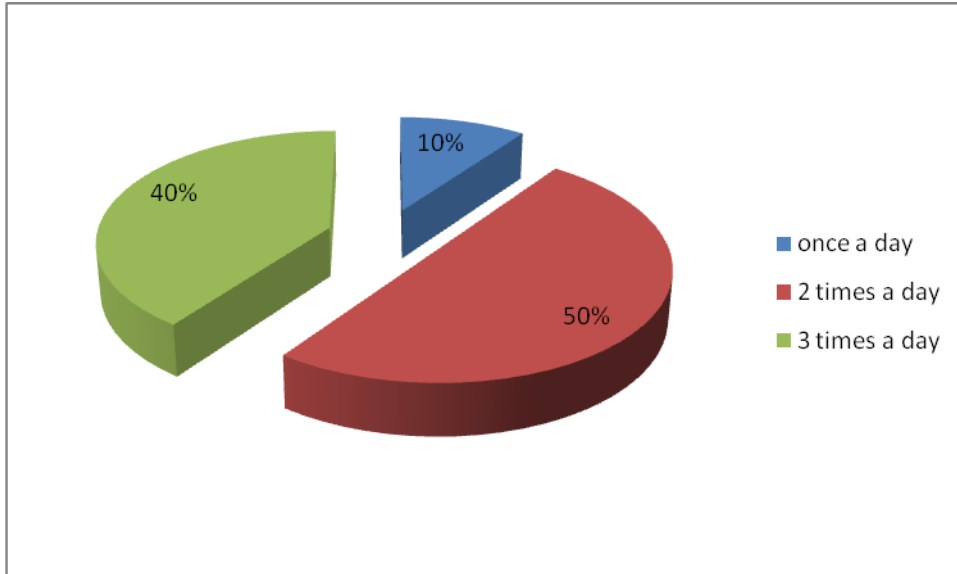
Table 16: Responses on experience to expenses of nutritious foods.

Responses	No. of respondents	Percentage
Yes	20	100
No	0	0
Total	20	100

Table 16 shows that 100% of respondents experience extensive expenses in accessing nutritious foods. The data concur with Wekesa, (2007), who state that if patients struggle finding food and witness little progress coupled with the discomfort that comes with taking powerful drugs on an empty stomach, meant that some patients discontinue their treatment.

4.15.2. Respondents who take the meals on daily basis.

Figure 9: Responses of respondents who take the meals on daily basis.



4.16. Homelessness

This was important to find out if homelessness plays a major role in ART adherence.

4.16.1. Responses on whether respondents have secure place to store medication.

Figure 10: Responses on whether respondents have secure place to store medication.

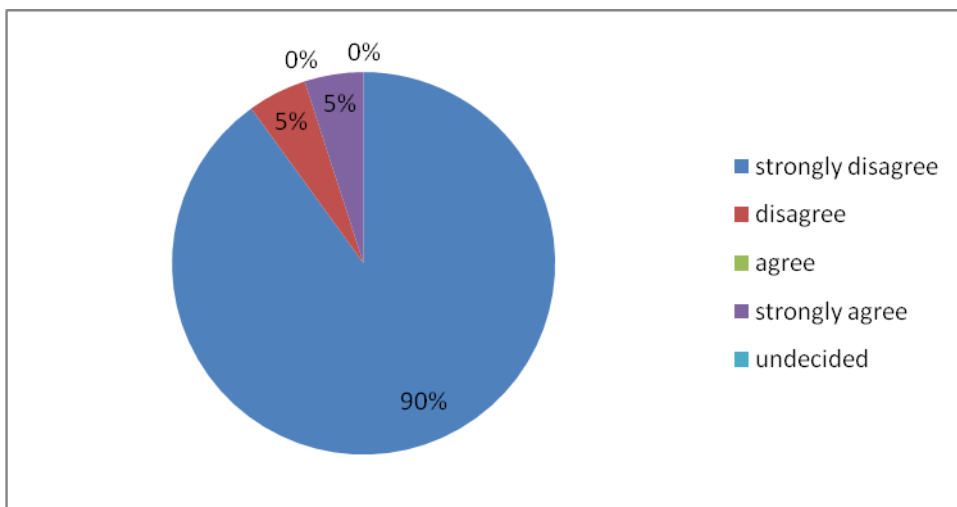


Figure 10 indicates that 90% of respondents did not agree with the statement, while 5% of respondents responded that they disagree. Furthermore 5% of respondents agree with the statement that they do not have a secure place to keep medications because they are experiencing housing stability.

4.17. Economic dependence

The information was needed to find out if economic dependence can serve as a barrier to ART adherence.

4.17.1. Responses of respondents that economic dependence on spouses is a barrier to women/men who did not disclose their HIV positive status

Figure 11: Responses of respondents that economic dependence on spouses is a barrier to women/men who did not disclose their HIV positive status.

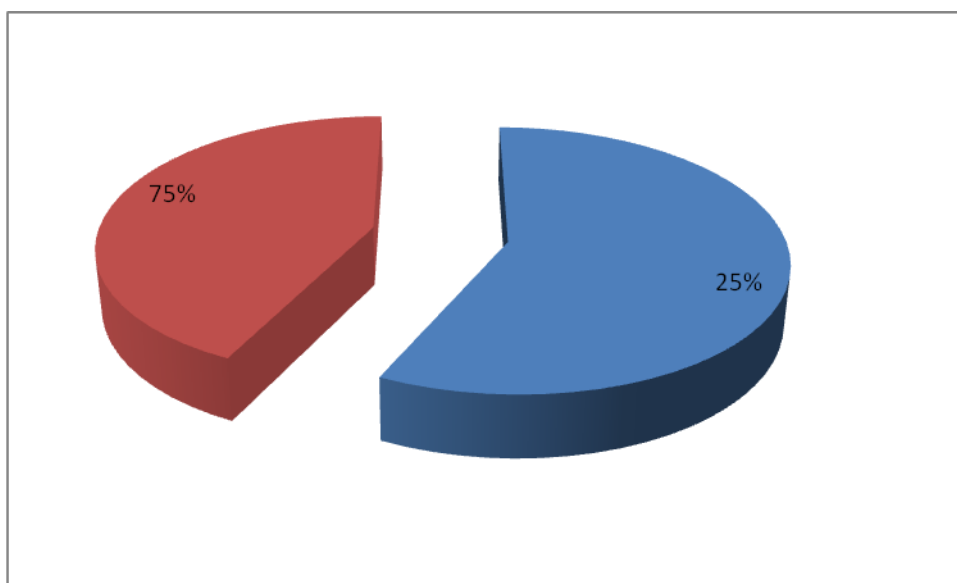


Figure 11 indicates that the majority of the respondents (75%) agree with the statement, that disclosure of status is affected by economic dependence, while 25% of respondents did not agree. The data concurs with Skoval (2003) who states that husband's unwillingness to accept their HIV status and to support their treatment can sometimes result in women being threatened with divorce if they insist that they are HIV positive in the face of a husband's disbelief.

4.18. Social support

The aim was to find out if respondents receive social support from the significant others.

4.18.1. Respondents who have any family, friends or community member support for taking their ARV medication.

Table 17: Responses of respondents who have any family, friends or community member support for taking their ARV medication.

Responses	No. of respondents	Percentage
Yes	8	40
No	12	60
Total	20	100

Table 17 indicates that 60% of respondents do not have family, friends or community members supported for taking ARV medications, while 40% of respondents receive social support. The findings agree with Williams et al.,(2005) who state that having a partner, social of family support, peer interaction and better physical interactions are characteristics of adherent patients.

4.19. Side effects

The aim of this question was to find out if side effects have an impact in ART adherence.

4.19.1 Respondents who experience side effects with ARV medication

Table 18: Responses of respondents who experienced side effects with ARV medication.

Responses	No. of respondents	Percentage
Yes	20	100
No	0	0
Total	20	100

Table 18 indicates that 100% of respondents experience side effects. The data is supported by Hardon et al., (2006), who states that side effects of ART can also cause patients to miss or totally stop taking them even if they were given the relevant information because of the discomfort.

4.19.2. Responses on the kinds of side effects experienced by respondents.

A total of 100% of respondents cited that they experience side effects and they experience pimples, skin rashes and sometimes nausea and vomiting.

4.20. Adverse regimen characteristics

The information was needed to understand if respondents were able to follow an ARV treatment regimen.

4.20.1 Responses of respondents who take number of pills in a day.

Figure 12: Responses of respondents regarding number of pills in a day.

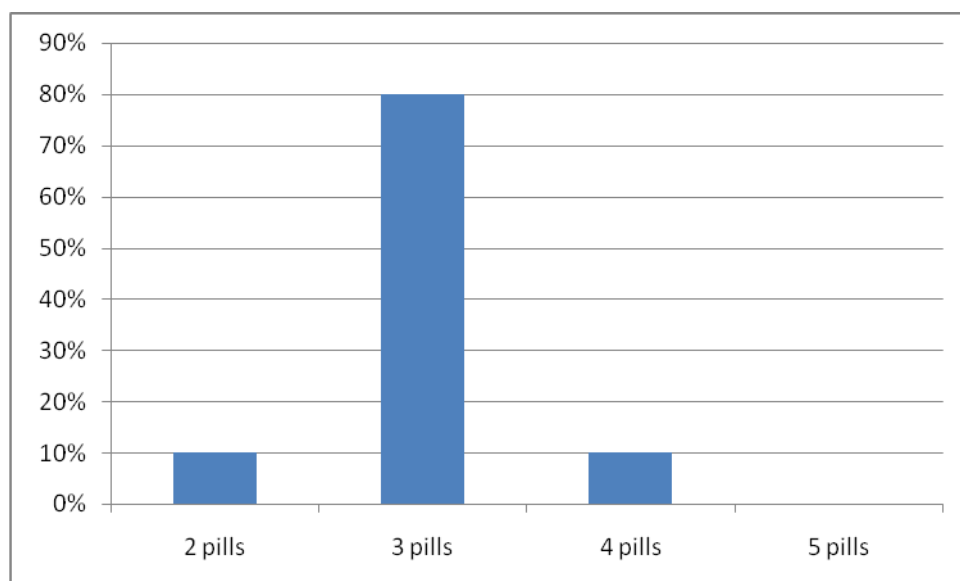


Figure 12 shows that the majority of respondents (80%) take 3 pills a day, while 10% of respondents take 2 pills a day. Furthermore another 10% of respondents take 4 pills a day

4.20.2. Responses on the place to collect ARV drugs

Figure 13: Responses on the place to collect ARV drugs

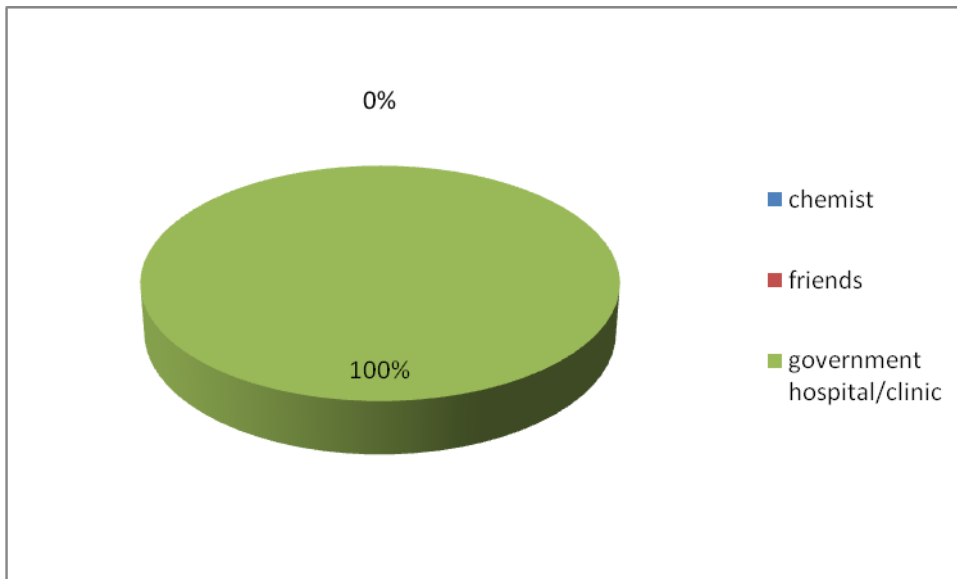


Figure 13 show that all respondents receive their medication at a government hospital or clinic.

4.20.3. Responses on the commonly used tool to remember treatment plan

Figure 14: Responses on the commonly used tool to remember treatment plan

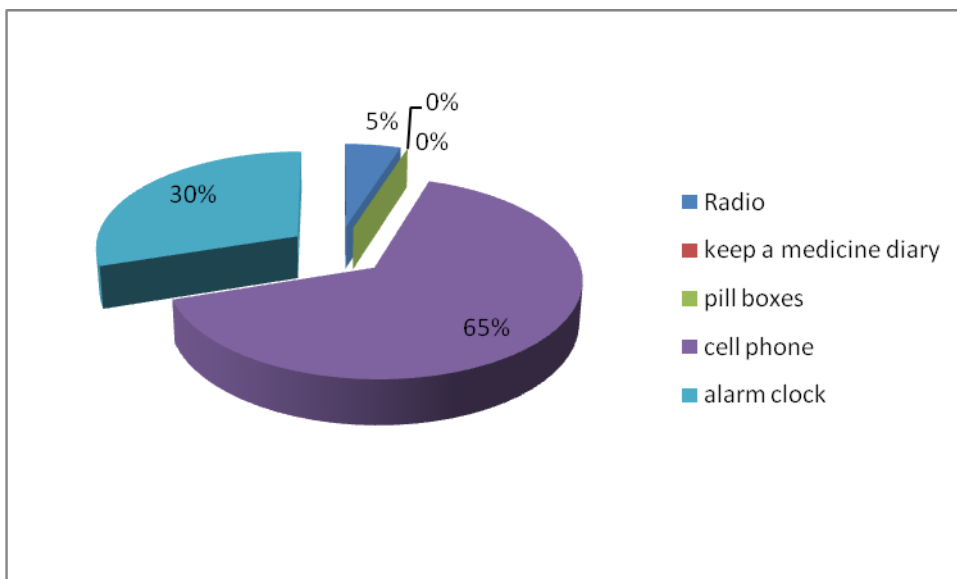


Figure 14 indicates that 65% of respondents use a cell phone as a reminder tool, while 30% of respondents use an alarm clock.

4.20.4. Responses of respondents who missed some dose.

Table 19: Responses of respondents who missed some doses.

Responses	No. of respondents	Percentage
Yes	18	90
No	2	10
Total	20	100

Table 19 shows that 90% of respondents admit to missing some doses, while 10% reported not missing any doses. The data agrees with Mill, (2006) who indicates that younger and more impulsive patients are likely to forget or not prioritize taking their medications (the majority of respondents in this study are of a young age group).

4.20.5. Response on why doses were missed

All respondents indicated that they missed doses due to not setting the alarm to remind them or due to the fact that they were distracted by issues of daily life.

4.21. Patient characteristics

The information was collected to understand patient characteristics in relation to ART adherence.

4.21.1. Response on motivation to take antiretroviral medication

Fifty percent (50%) of respondents cited that ART improves their health, while another 50% indicated that ART prolonged their lives. In addition this seems to be an indication that ART is making a difference in their quality of life.

4.22. HIV/AIDS, Disability grant and ART adherence

The information was collected to find out if the disability grant has an impact in ART adherence.

4.22.1. Responses of not complying with ARV treatment if the grant is withdrawn

Figure 15: Responses of not complying with ARV treatment if the grant is withdrawn

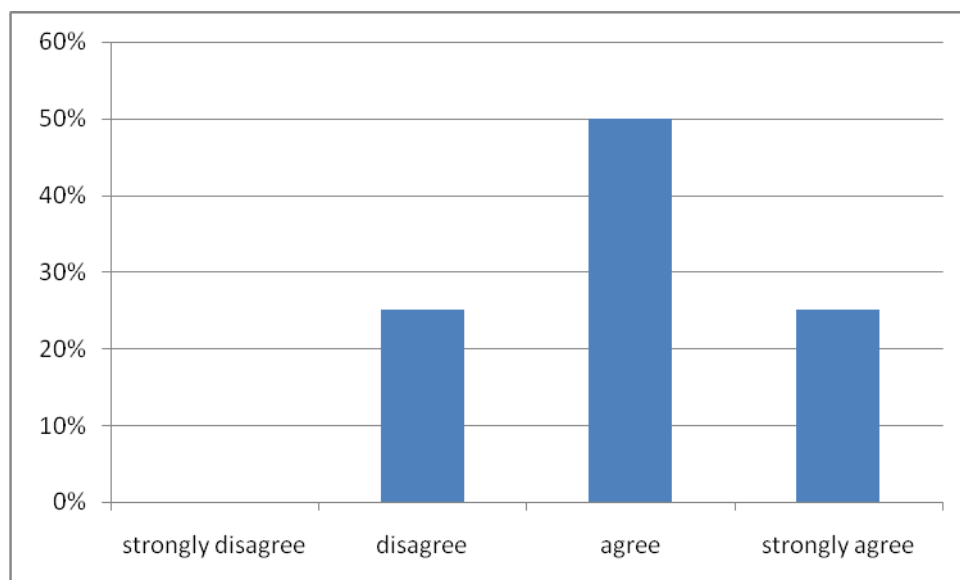


Figure 15 indicates that 50% of respondents agree that they will not comply with ARV treatment if the grant is withdrawn. The data is in line with Summary Report (2006) which indicates that using CD4 counts as eligibility criteria for accessing grants precludes many from receiving desperately needed funds and may have several negative effects on treatment and prevention efforts.

4.23. Strategies for improving ART adherence

This was important to find out if respondents are able to provide views of improving the ART adherence.

4.23.1. Responses on strategies to improve ART adherence

Respondents cited the following strategies:

- Continued education from health providers
- Provision of transport
- Patients to be issued 3 months supply in order to reduce transport cost.
- Waiting time should be reduced
- Train more health providers for ease of ART rollout
- For habitual defaulters, treatment should be stopped.

Chapter 5: Conclusion and Recommendations

5.1. Introduction

This chapter sums up the findings of the research; outlines the implications of the study findings; the conclusions based on the research findings; recommendations and suggestions for further research.

The study was conducted in order to identify barriers to antiretroviral adherence of HIV/AIDS patients. It should be noted that the sample was small (20) to derive generalizable conclusions from but some light could be shed on why patients do not adhere to ART.

5.2 Overall findings

The findings of the study are discussed hereunder':

5.2 .1 Demographic characteristics

The study sample was made of 70% female and 30% males. The majority of the respondents were between the ages of 21 and 30. Out of 20 respondents, 50% were never married, 20% were married and 30% were widowed. It also appeared that most of the participants terminated education at secondary level.

5.2.1 Stigma

All participants were able to participate in the study. The majority of the participants were not able to disclose their HIV status to the family, relatives and friends due to stigma. These findings indicate that stigma may be an obstacle to poor ART adherence.

5.2.2 Patient-Provider relationship

The findings have revealed that participants complain about the communication break down with the health provider hence there is no good communication and the relationship amongst them is mostly negative. In this study, it seems that patient-provider relationship might be a contributing factor to poor ART adherence.

5.2.3 Health Care System

The findings have revealed that long waiting times can have an impact on adherence as people who get delayed might not want to come back. This is in line with the Summary Report, (2006), which indicated that long waiting times for clinic services were reported as an important barrier and ability to return the clinic for service and to collect medication.

5.2.4 Language and cultural barriers.

It was ascertained that respondents who answered that they feel helpless because of language competency may have had experience of language difficulties with health providers and also to the older patients who are accustomed to an age-based power structure and may feel helpless. This reflects that language and cultural barrier may have an impact on poor adherence.

5.2.5 Traditional and cultural barrier

Fewer respondents did not believe in traditional medicines for cure of HIV. These findings indicate that traditional cultural barriers may not be a hindrance to poor ART adherence.

5.2.6 Belief and knowledge

From the results in this study, it seems that respondents are less knowledgeable about the meaning of ART medication in their daily lives. This might be an indication that beliefs and knowledge factor could hinder adherence.

5.2.7 Religion

It was ascertained that respondents who agree with the statement that 'religious convictions have been indicated and believed to play a crucial role in ART adherence' may have experienced influence of religion in a positive way. In this study, it seems that religion may not be a contributing factor to poor adherence.

5.2.8 Substance abuse

Some of the respondents reported that they drink alcohol while on ART. Those who indicated that they drink did so to relieve the stress of being diagnosed HIV positive.

This reflects that substance abuse factor may be a contributing factor to poor adherence.

5.2.9 Health Literacy

The majority of respondents indicated that their health literacy is low due to the fact that they left their education at a secondary level. This findings indicate that health literacy may be a factor that contributing to poor adherence.

5.2.10. Financial burden

All respondents cited that they experience lack of income as a barrier to attending a clinic visit. This is supported by Kagee, (2007), who stated that lack of money for travel constrains the ability of patients to visit treatment centres, which may lead to missing their follow up sessions and adhering to treatment.

5.2.11 Transport cost

All respondents cited transport as one of the issues that might be a contributing factor to poor ART adherence. Most of the respondents stay far from the ART site and as such have to spend a lot of money on their monthly visits to the ART site. To compare how much they spend on average per visit to the ART site and the average monthly income, a big portion is spent on transport alone. In this study, transport cost reflects as a contributing factor to poor adherence.

5.2.12 Food insecurity

All respondents indicated that they experience considerable expenses for nutritious foods that HAART patients are recommended to eat while taking ART medication. This is supported by Wekesa, (2007), who state that patients struggle finding food and witness little progress, coupled with the discomfort that comes with taking powerful drugs on an empty stomach, meant that some patients discontinued their treatment. It seems that food insecurity may be a contributing factor to poor adherence.

5.2.13. Economic dependence

The majority of respondents responded positively to the question and it seems are the ones who have experienced economic dependence and disclosure issues. In this

study, it seems that economic dependence might be a contributing factor to poor ART adherence.

5.2.14. Social support

The findings indicate that many respondents lack social support from family, friends and community members. This might be an indication that lack of social support might be a hindrance to poor ART adherence.

5.2.15. Side effects

All respondents cited that they experience side effects which may make them not adhere to medication. (This is supported by Hardon et al., 2006), who stated that side effects of ART can also cause patients to miss or totally stop taking them even if they were given the relevant information. This factor seems to be an additional hindrance to poor ART adherence.

5.2.16. Adverse regimen characteristics

Despite knowing the benefits of ART, some of respondents still reported missing some doses of ART. Many reasons were given for missing doses. Many cited forgetfulness as one of the reasons, in spite of also indicating that they had something they could use to remind them to take medications.

5.2.17. HIV/AIDS, disability grant and ART adherence

The majority of respondents indicated that they are not going to comply with ARV treatment if the grant is withdrawn. In this study, this reflects as a factor that is contributing to poor ART adherence.

5.2.18 Summary

From this study, it has been revealed that the following factors may play a role in poor ART adherence: transport issues, financial burden, food insecurity, forgetfulness and social support.

The main finding of this research was that many additional factors thought to be contributing factors to poor adherence, do not seem to have an influence on ART adherence at the Mogwase Health Centre. The factors identified by the researcher

that do not seem to contribute to poor adherence include, religion and homelessness. As a result, of the above five factors, the general adherence of patients at Mogwase Health Centre is low.

5.3. Recommendations

Recommendations based on this study include the following:

5.3.1 Transport cost

This study indicated that transport might be one factors contributing to poor ART adherence. To curb this problem, ART distribution should be rolled out to even the farthest areas. If possible, patients on ART should be provided with or receive some form of subsidized transport.

More nurses should be trained on prescription and dispensing of ART so that roll-out of ART can be made easier as they work in areas that are out of reach presently. Patients should be provided with at least three months supply of ART depending on the availability of ARV medication. As such, this will reduce number of visits to the health centre and transport expenses will be reduced.

5.3.2. Financial burden

Patients should receive a disability grant for first six months in order to be financially stable so that they can afford buying nutritious food recommended for ART patients.

5.3.3. Food insecurity

While the patients were waiting for consultations, they should be provided with supplements. The Social workers at the health centre should make recommendations for them to receive social relief that is available at the South African of Social Security Agent (SASSA).

5.3.4. Social support

This factor is regarded as a barrier to ART adherence. Having a partner, family support and peer interaction increase patient adherence. Therefore patients should interact with the family, friends and health providers in relation to their treatment.

They must also avoid social isolation and have a good working relationship with health providers.

5.3. 5 Department of Health and other stakeholders

Transport problems are commonly identified in findings of studies of this nature. It is therefore recommended that there be provision of income generation activities geared towards people living with HIV/AIDS (PLWHA) to ensure financial security as this will enable them to pay for transport costs.

Antiretroviral therapy should be rolled out to the lowest level health centres or there must be down referral site e.g. feeder clinics and mobile point where patients can collect their medication. Thus congestion at Mogwase Health Centre and waiting period will be reduced. Furthermore, this will make it easy for patients to obtain ARV drugs since no travelling expenses will be involved.

5.3. 6 Suggestions for further research

As mentioned, main findings of this research was that many factors thought to be contributing to poor adherence, do not seem to have an influence on ART adherence at Mogwase Health Centre. Therefore, suggestions for future research include conducting a similar type of study on a larger scale to verify the results of this study. This could include focus group discussions as part of the research design. This will enable respondents to give a firsthand and personal account of what the contributing factors to their poor adherence are. Lastly, there is a need for a study on co-treatment of AIDS and other infections to determine the effect of combination therapy on ARV adherence.

5.4 Conclusions

- Level of adherence (74%) was sub-optimal but comparable to other developing countries.
- The five major factors affecting ARV adherence in this study population are transport issues, financial burden, food insecurity, forgetfulness and social support.

- Taking ARV drugs without eating adequate food consumption made patients suffer from side effects thus making them avoid taking their medication.
- Stigma, discrimination, lack of family and community support are major obstacles to ART adherence.
- Co-treatment of HIV and other infections remains a major challenge. Type of ARV drug and dosage levels can also influence ART adherence.

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Appendix A



AFRICA CENTRE FOR HIV/AIDS MANAGEMENT

23 August 2011

Moses Kotane Sub-District
Mogwase Health Centre
0314

Dear Sir/Madam

Re: Intended study pertaining the barriers to Antiretroviral Adherence of HIV/AIDS patients under Wellness programme in Mogwase Health Centre

Ms Georgina Shadi Moremi MPhil student (16345010) at School of Economic and Management Sciences, The Africa Centre of HIV/AIDS Management at Stellenbosch University, South Africa intends to conduct research to barriers to ART adherence of HIV/AIDS patients under Wellness programme in Mogwase Health Centre.

The target group will be both male and female patients aged 21-65 and above. The sample size is 20 HIV/AIDS patients. The participants will be provided with questionnaire for those who will experience difficulties in completing the questionnaire on their own and preferred to be interviewed, the questionnaire will be used as interview guide. The participants will be given 20 minutes to complete the questionnaire. The questionnaire will then be collected and kept in a private place for confidential purposes.

The research is primarily academic but the results of this study will be made available to the Mogwase Health Centre at Moses Kotane Sub-District if requested. We therefore kindly requested permission for Ms G.S Moremi to carry out this study at the mentioned facility. The study should run from September 2011.

Kind Regards

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MOSES KOTANE HEALTH SUB - DISTRICT

LETTER OF PERMISSION

TO WHOM IT MAY CONCERN

This communiqué serves to grant permission to Ms G.S Moremi to conduct her study at Mogwase Health Centre as requested.

Hope the above shall be found in good order.

Mr OE Serape
Facility Manager

2011/08/25
Date

Appendix B

Questionnaire

Title: Barriers to Antiretroviral Adherence of HIV/AIDS patients under Wellness programme in Mogwase Health Centre.

Instructions

- I) Indicate your answer by placing X in the box beside the appropriate response.
- II) Check instructions carefully to answer questions that are applicable to you.
- III) Give as much information as you have in the spaces provided for questions that need your explanation or any additional information
- IV) There is no right or wrong answer.
- V) You won't be victimised in anyway for participating, so answer the questions as honestly as possible.

Your co-operation will be highly appreciated.

SECTION A: DEMOGRAPHIC DATA

1. Age

a.21-30	
b.31-40	
c.41-50	
d.51-60	
e.61 years and above	

2. Marital status

a. Never married	
b. Married	
c. Divorced	
d. Widowed	

3. Gender

a. Male	
b. Female	

4. Educational level

a. Primary	
b. Secondary	
c. Tertiary	
d. No formal education	

5. Occupation

a. Employed	
b. Unemployed	
c. Self employed	

SECTION B: BARRIERS TO ANTIRETROVIRAL ADHERENCE

a) STIGMA

6. Did you experience stigma since you started Highly Active Antiretroviral Therapy (HAART)?

a. Yes	
b. No	

7. As a result of stigma, I did not disclose my HIV status to the family, relatives and friends

a. Yes	
b. No	

b) DEPRESSION

8. Did you suffered from depression after being diagnosed HIV positive?

a. Yes	
b. No	

c) PATIENT-PROVIDER RELATIONSHIP

9. Were you told by the health provider the importance of completing the full course of ARV treatment?

a. Yes	
b. No	

10. Have you received counselling from the health providers during your initiation of ART?

a. Yes	
b. No	

11. How is the relationship with the health providers?

a. Good	
b. Bad	

If bad, explain further

d) HEALTH CARE SYSTEM

12. Health workers at the clinic provide excellent service to ART patients.

a. Sometimes	
b. Always	
d. Not at all	

13. Was privacy maintained during consultation?

a. Yes	
b. No	

14. How much time did you spend time when you came for review?

a. One hour	
b. Two hours	
d. Three hours	
e. Four hours	

15. Did you wait for long before being attended?

a. Yes	
b. No	

e) LANGUAGE AND CULTURAL BARRIERS

16. Did you feel helpless because of language speaking?

a. Yes	
b. No	

f) TRADITIONAL CULTURAL BARRIERS

17. Do you believe in traditional medicines?

a. Yes	
b. No	

g) BELIEF AND KNOWLEDGE

18. Do you believe in ART?

a. Yes	
b. No	

19. In your own view, what is ARV drugs used for?

a. Curing	
b. Reducing pain	
c. Reducing progression of HIV	
d. I don't know	

h) RELIGION

20. Religious convictions have been indicated and believed to play a crucial role in ART adherence.

a. True	
b. False	

i) SUBSTANCE ABUSE

21. Do you drink alcohol while you are in ART?

a. Yes	
b. No	

If yes, how often-----

22. I use alcohol because I relieve stress of being diagnosed HIV positive.

a. Strongly disagree	
b. Disagree	
c. Agree	
d. Strongly Agree	
e. Undecided	

j) HEALTH LITERACY

23. Poor literacy is associated with low levels of understanding of medical instructions and adherence to ART.

a. True	
b. False	

k) FINANCIAL BURDEN

24. Did you experience lack of income when coming to clinic visit?

a. Yes	
b. No	

I) TRANSPORT COST

25. Do you experience transport problem when trying to access drugs at the clinic?

a. Yes	
b. No	

m) FOOD INSECURITY

26. Do you experience lot of expenses of nutritious foods that HAART patients are recommended to eat while taking ART medication.

a. Yes	
b. No	

27. How often do you take you meal on daily basis?

a. once a day	
b. 2 times a day	
c. 3 times a day	

If other, specify-----

n) HOMELESSNESS

28. I do not have a secure place to keep my medications because I'm experiencing housing instability.

a. Strongly disagree	
b. Disagree	
c. Agree	
d. Strongly Agree	
e. Undecided	

o) ECONOMIC DEPENDENCE

29. Economic dependence on spouses is a barrier to women/men who did not disclose their HIV positive status.

a. True	
b. False	

30. Spouses unwillingness to accept their HIV status and to support their treatment can sometimes result in spouses being threatened with divorce.

a. True	
b. False	

p) SOCIAL SUPPORT

31. I am able to get all necessary support from the family members.

a. Strongly disagree	
b. Disagree	
c. Agree	
d. Strongly Agree	
e. Undecided	

32. In the last one month, did you have any family, friends or community member who supported you to take your ARV medications?

a. Yes	
b. No	

q) SIDE EFFECTS

33. Did you experience side effects since you take ARV medication?

a. Yes	
b. No	

If yes, what kind of side effects did you experienced?

r) ADVERSE REGIMEN CHARACTERISTICS

34. Are you able to follow ARV therapy regimen?

a. Yes	
b. No	

35. How many pills do you take in a day?

a. 2 pills	
b. 3 pills	
c. 4 pills	
d. 5 pills	

36. Do you experience challenges with ART medication?

a. Yes	
b. No	

37. Where do you collect your ARV drugs?

a. Chemist	
b. Friends	
c. Government Hospital and clinic	

If other, specify-----

38. What other drugs (besides ARV) are you currently in?

a. Pain killers	
b. appetitive stimulants	
c. sleeping pills	
d. TB treatment	

If other, specify-----

39. What do you use to remember your treatment plan?

a. Radio	
b. Keep a medicine diary	

c. Pill boxes	
d. Cell phone	
e. Alarm clock	
F.Any other(state)	

40. Is there a time that you have missed some dose?

a. Yes	
b. No	

If yes, why?

s) PATIENT CHARACTERISTICS

41. What motivates you to take Antiretroviral Therapy?

SECTION C: HIV/AIDS, DISABILITY GRANT AND ART ADHERENCE

42. I, m not going to comply with ARV treatment if the grant is withdrawn

a. Strongly disagree	
b. Disagree	
c. Agree	
d. Strongly Agree	
e. Undecided	

SECTION D: STRATEGIES FOR IMPROVING ADHERENCE

43. What do you think should be done to improve ART adherence?

Thanks for your co-operation!