FACTORS CONTRIBUTING TO CLIENTS DEFAULTING ANTI-RETROVIRAL TREATMENT AT MATOKS CAPRICON DISTRICT, LIMPOPO PROVINCE.

By

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DECLARATION

I, **Ratshihume Phumudzo Terrence**, student no: 11594495, declare that "**Factors contributing to clients defaulting Anti-retroviral treatment at Matoks Capricon district, Limpopo Province"** is my own work and that all sources that I have used or quoted have been indicated and acknowledged by means of complete references, and that this work has not been submitted for another degree at this university or any other institution.

SIGN……

DATE……

DEDICATION

This study is dedicated to the Department of Health, Provincial and District Management for the effective intervention with regard to factors contributing to clients defaulting Anti-retroviral treatment at Matoks Capricon district, Limpopo Province

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Abstract

Background: The provision of antiretroviral treatment for people living with HIV/AIDS has encountered many challenges associated with poor adherence in South African and other countries in Africa as a whole including globally. Taking ARVs Properly has shown to reduce viral load to a level where the virus becomes undetectable and these results in an increase of CD4 count cells. These decreases chances of oppotunistic infections but it requires a proper adherence and compliance to treatment which seems to be difficult to most patients on ART.

Purpose: The study investigated factors contributing to clients defaulting antiretroviral treatment.

Methodology: A qualitative explorative cross-sectional study design was conducted at Matoks in Capricon District, in the months of May, June and July 2017. A purposive sampling method was used to select 19 respondents whom where willing to voluntrily participate in the study from a population of People Living With HIV/AIDS (PLWHV). An indepth face to face interview was used to collect data, guided by a central question and probing. It was then analyzed by the use of eight steps of Tesch.

Results: The findings revealed that women were more defaulters than men. Shortages of antiretroviral treatment and most clients were unable to collect ART on time due to lack of transport to the clinic and the long distance from their perspective homes to the clinic. Socio economic conditions and indegenious health beliefs were some of factors identified.

Recommendations: extensive health education and promotion should be intensified to reach all community members of Matoks and PLWHA in terms of HIV/AIDS care and consistent taking of treatment that clients who live far away from the clinic will be able to collect the ARV treatment nearer to their place of residents.

Key words: challenges, defaulters, antiretroviral, factors, HIV/AIDS

LIST OF ABBREVIATIONS

AIDS	Acquired Immune Deficiency Syndrome
ART	Antiretroviral Treatment/Therapy
ARV	Anti-retroviral
CD4	Cluster Differentiantion 4
DoH	Department of Health
DOT	Directly observed therapy
HIV	Human Immunodeficiency Virus
HAART	Highly Active Anti-retroviral Therapy
NIMART	Nurse-Initiating Management of Antiretroviral Treatment
PLWHA	People living with HIV/AIDS
PHC	Primary Health Care
UNAIDS	United Nations Programme on HIV/AIDS
WHO	World Health Organisation

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CHAPTER 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

HIV (Human Immunodeficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) is a global problem and is one of the most destructive epidemics that the world has ever witnessed (Ayalu et al, 2011:1). HIV is incurable but anti-retroviral drugs (ARVs) delay progression of HIV to AIDS thereby improving the quality of life of those infected by HIV. Once a patient has been commenced on treatment the individual receives the treatment for life in order to benefit from the therapy. Due to several factors that affect adherence to any treatment for every human being including HIV/AIDS clients, interruption in ARV drug adherence results in treatment failure and drug resistance. In the absence of the cure of this pandemic disease, antiretroviral therapy (ART) is the only treatment for HIV and hence it prolongs the lifespan of HIV/AIDS clients on ART (UNAIDS, 2013).

Antiretroviral treatment is complex in the sense that it requires strict adherence to scheduled time and stick to dietary requirements. At the ART clinic, once a client has been considered eligible for HIV treatment, the client is offered counselling on the treatment regimens and adherence, then commenced on ART. Clients are required to take the treatment as prescribed, attend monthly review where progress is monitored and is also provided with monthly supply of antiretroviral drugs. The client is expected to adhere all the treatment instructions but sometimes it may not be possible therefore viral suppression may not be maintained (Crowley et al, 2015).

Global HIV statistics

HIV continues to be a major global public health issue. In 2016, an estimated 36.7 million people were living with HIV (including 1.8 million children) with a global HIV prevalence of 0.8% among adults. Around 30% of these same people do not know that they have HIV/AIDS disease. Since the start of the epidemic, an estimated 78 million have become

infected with HIV and 35 million have died of AIDS related diseases. In 2016, 01 million people died of AIDS related disease. In the USA 46% of all people living with HIV were (506 000) in 2013 and in Western and Central Europe, in 2014, 37% of all new HIV infections occurred among migrants from outside this region. Some acquired HIV in their home country, while others acquired HIV on their arrival, indicating the need for targeted interventions for this group. In 2014 at UK, 55% of men and 62% of women living with HIV/AIDS were from Sub-Saharan Africa (Mbirimtengerenji et al, 2013).

The vast majority of people living with the HIV are located in low and middle income countries with an estimated 25.5 million living in sub Saharan Africa. Among this group, 19.4 million are living in the East and Southern Africa which saw 44% of new HIV infections globally in 2016, (Avert, 2017).

HIV has strongly impacted the health status of various nations globally since its surfacing; with sub-Saharan countries being the most affected (UNAIDS, 2008). Of all people living with HIV globally, 9% of them live in Nigeria. Although HIV prevalence among adults is remarkably small (3.2%) compared to other sub-Saharan African countries such as South Africa (19.1%) and Zambia (12.5%), the size of Nigeria's population means that there were 3.2 million people living with HIV in 2013. Nigeria, together with South Africa Uganda, account for almost half of all annual new HIV infections in sub-Saharan Africa. This is despite achieving a 35% reduction in new infections between 2005 and 2013. Approximately 210,000 people died from AIDS-related illnesses in Nigeria in 2013, which is 14% of the global total. Since 2005, there has been no reduction in the number of annual deaths, indicative of the fact that only 20% of people living with HIV in Nigeria are accessing antiretroviral treatment (ART) (Marukutira, 2012).

Lesotho is one the worlds countries hardest hit by HIV, with the highest HIV prevalance after Swaziland. HIV prevalance was 22% in 2013, which has risen slightly from 22% in 2005. An estimated 360 000 people are living with HIV in Lesotho and 16 000 died from AIDS related diseases in 2013. HIV incidence has declined marginally from 30 000 new infections in 2005 to 26 000 new infections in 2013 (UNAIDS, 2012).

South Africa is reported to have the largest population of people living with the disease in the world, with 5.26 million people estimated to be infected in 2013 (Statistics South Africa

(Stats SA), 2013), followed by Nigeria in 2nd place and India being the 3rd largest population with HIV infected with more than 2 million people reported due to its large overall population, but with a prevalence rate of 0.30 in comparison to the prevalence rate of 0.60 in the US and 18.10 in South Africa (Central Intelligence Agency, 2011). Furthermore, the number of people living with HIV (PLWH) in South Africa is on a steep increase, with approximately 100,000 additional PLWH each year (UNAIDS, 2012).
South Africa has the biggest and most high profile HIV epidemic in the world, with an estimated 6.3 million people living with HIV in 2013. In the same year, there were 330,000 new infections while 200,000 South Africans died from AIDS-related illnesses. South Africa has the largest antiretroviral treatment program globally and these efforts have been largely financed from its own domestic resources. The country now invests more than $1 billion annually to run its HIV and AIDS programs. However, HIV prevalence remains high (19.1%) among the general population, although it varies markedly between regions. For example, HIV prevalence is almost 40% Kwazulu Natal compared with 18% in Northern Cape and Western Cape (Kang'ethe et al, 2015).

South Africa has a chronic shortage of trained health care workers, which is exacerbated by disparities between provinces and between the rural and urban sectors. The restructuring of health services in South Africa post 1994 and the adoption of a primary healthcare (PHC) approach have placed nurses at the frontline of improving access to PHC services, especially in resource-constrained settings. This has led the registered nurses in PHC to prescribe medication to patients under the Act (No 50 of 1978) which was subsequently amended through the promulgation of Section 38A of the Nursing Amendment Act (No 71 of 1981). Registered nurses in the service of the national Department of Health, the provincial administration, a local authority or an organization delivering a health service designated by the Director-General of Health were authorized to conduct a physical examination; diagnose a physical defect; and keep, supply, administer or prescribe medicine according to the set conditions. The role of nurses was further expanded in 2010 when the Department of Health allowed (under Section 56(6) of the new Nursing Act 33 of 2005) nurses trained in nurse-initiated and managed antiretroviral treatment (NIMART) to prescribe ART. (Crowley, et al, 2015).

South Africa currently has the largest antiretroviral program globally, the need to decentralize traditionally hospital-based HIV treatment and care services to PHC clinics where care is primarily nurse-led, has become apparent with an increasing patient volume, (Crowley et al, 2015). The decentralization was done in order to reduce the workload at referral hospitals and promote a good adherence to ART for the clients to collect HIV treatment at their perspective community clinics. Therefore, this study investigated the factors contributing clients to defaulting treatment at Matoks, Capricon District in Limpopo Province.

1.2 BACKGROUND OF THE STUDY

The Human Immunodeficiency Virus (HIV) infection remains a major public health crisis in South Africa and has continued to spread at an alarming rate among children, adults and old age. In response to this pandemic, many countries including South Africa have developed care and treatment programs. The ultimate goal of antiretroviral therapy is to achieve maximal and durable suppresion of virus replication. This will in turn to reduce the destruction of CD4 cells, reduce immune suppression and slow disease progression. These benefits however can only be achieved through consistent adherence to antiretroviral drugs in order to maintain adequate drug levels in the body. ART has greatly improved the overall health of individuals living with HIV/AIDS and several studies have reported increased virologic and immunologic effectiveness of ART and the consequent reduction of mortality and morbidity associated with HIV/AIDS (Balueth, 2013).

Poor adherence leads to rise in viral load and reduction in CD4 count leading to increase in morbidity and mortality among patient on ART with ultimate poor clinical outcomes and failure in the entire national ART programme. In addition, poor adherence to ART results in low survival, clinical, immunological and virological response for patients. Adherence to ART is one of the very important factors which determine treatment success and occurrence of viral resistance. The need for near perfect adherence to lifelong antiretroviral therapy [ART] during treatment is a major challenge in the administration of highly active anti-retroviral therepy [HAART] to HIV infected patients. Appropriate use of antiretroviral therapy [ART] has improved the health of many human immunodeficiency

virus [HIV] positive individuals who otherwise may have died. notably, the efficiency of any treatment depends on sustained high level of adherence to ART (Kheswa, 2013).South Africa has the largest antiretroviral treatment (ART) rollout program in the world, achieving a 75% increase in HIV treatment access between 2009 and 2011. In three provinces, the life expectancy of people receiving ART is now about 80% of normal life expectancy provided they do not start treatment late.

By October 2012, over two million people were receiving ART, surpassing the country's universal access target (80%) in accordance with the 2010 World Health Organization treatment guidelines (offering treatment to people with a CD4 count under 350). However, the new 2013 WHO treatment guidelines (treatment for those with CD4 counts under 500) have since made many more people eligible for ART and coverage has fallen to 42% (UNAIDS 2012).

In order to achieve higher levels of ART coverage, the South African government employed task shifting. Task shifting refers to the reallocation of tasks among available staff. In this case, nurses (rather than doctors) initiate ART; lay counsellors (rather than nurses) carry out HIV tests; and pharmacy assistants (rather than pharmacists) prescribe ARVs. This increases the number access points to treatment and care by reducing the ‘bottlenecks’ in the healthcare system created by a shortage of staff able to provide vital HIV services. Though treatment program have expanded rapidly, many South Africans still begin treatment with a very low CD4 count. In 2009, it was reported that the average CD4 count at which patients started treatment in South Africa was just 87. One study based in two Durban clinics found that 60% of patients were tested when their CD4 counts were below 200. Of these patients, just 42% had begun treatment within 12 months. Of those who were eligible for treatment, more than a fifth died, mostly before beginning treatment.

There are several factors that impact on adherence such as migration, which can be voluntary or forced and can impact on the efficacy of the treatment (Kheswa 2013).

Mbirimtengerenji et al, (2013) reported that other people default treatment not on purpose but are forced by circumstances, the authors reported that h prevalence among migrants has much to do with restrictive health policies, preventing access to treatment. However, 16 Europian countries including Spain and Sweeden do not provide treatment to undocumented migrants living with HIV. By contrast, Portugal and UK provide ART regardless of a persons immigration status. Treatment has a public health benefit by reducing viral load and preventing further transmission of HIV reducing long term health costs and African Americans are one of the groups affected.

In the study by Balueth (2013) it is reported that patients with financial dificulties are likely to default on follow up appointments at St Helens hospital in Johannesburg, South African. In addition to that, the unreported death and migration of patients adds to the problem. Another study conducted at Jimma hospital in Ethopia found that poverty and lack of money for transport was a major cause ‘of default to ART. Other factors like lack of food, mental illness, and having a partner with HIV negetive status or unknown status were also associated with default (Deribe et al. 2008). It has been argued that because of gender dimension on poverty, poor women are generally likely to be less compliant to treatment plans than their male counterparts (Kang’ethe et al, 2015).

In other cases, individuals simply refuse treatment despite being eligible. A study in Soweto found that of 743 newly diagnosed HIV-positive adults eligible to begin treatment immediately, 20% refused. More than a third gave "feeling healthy" as the reason for refusing treatment despite having a low CD4 count, with many also co-infected with tuberculosis (Kang’ethe et al, 2015).

Adherence to ART is a powerful predictor of survival for people living with HIV/AIDS (PLWHA). ART has improved the health of many HIV positive individuals who otherwise would have died. However, treatment efficacy relies on strict adherence which constitues a serious challenge to those clients receiving therapy. ART has improved the health of many clients due to proper adherence to treatment and this involves a clients ability to

follow treatment plan, that is to take medications at the prescribed time, frequencies, following restrictions regarding food, fluid and other medications (WHO, ART guideline, 2010). A critical aspect of ART adherence is the clients involvement and readiness to take ARV drugs.

The management of HIV/AIDS pandemic is one of the major problems towards patients on active antiretroviral therapy (HAART). In Limpopo, despite enrolling ARV'S to PLWHA there are still challenges that have been highlighted in the South African Strategic plan on HIV, STIs and TB prevention and care 2012 to 2016. Limpopo Province is one of the most rural province in South Africa, and it faces with tremendous challenges of poverty and access to ARVs due to transport issues, lack of availabilities of stock in most instances and the discrimatory practises associated with HIV and their beliefs in the use of traditional indegenious medicines and spirituality adherence is a problem. For the ARVs to be effective, several aspects must be considered by the health care provider and especially by the patient in order to obtain full therapeutic benefits. The aim of this study is to investigate factors contributing to clients defaulting ARV treatment at Matoks clinic in Capricon District, Limpopo Province.

1.3 RESEARCH PROBLEM

In the case of ART, adherence implies taking the drugs at their right quantities, at the right time and life-long. several studies have allued that adherence to chronic treatment is a problem, including ART. The researcher is a NIMART trained nurse working at the primary health care service and has observed a trend in PLWHA not adhering to the treatment follow-up and care. The table below indicate an escalating increase in defaulter rate in the past four years. There is a high rate of ART defaulters which seem to increase constantly and these leads to treatment failure which eventually cause drug resistance in the human body during reinitiation of ART. Consequences of which are high mortality, children left being orphans resulting in burden of the government social relief.

Table 1: defaulter rate 2013 to 2016 at Matoks clinic

Year	ART Initiation	Grand total of ART clients	Defaulter Initiation	Grand total of ART defaulters	Percentage of defaulter initiation	Grand total of defaulter
2013	162	811	40	196	25%	24%
2014	194	1005	62	258	32%	26%
2015	229	1220	73	331	32%	27%
2016	238	1458	72	403	30%	27%

Matoks clinic yearly statistic, TIER.NET

ART is a complex treatment which requires timely and daily administration of the drug and that can only happen if the clients are committed individually to take treatment as prescribed and life-long. Due to the increase of number of clients on ART and the rapidly spread of the HIV/AIDS pandemic, there is a need to investigate and explore deeply about factors contributing client's to defaulting ART.

1.4 AIM OF THE STUDY

The study aims to explore factors contributing to clients defaulting treatment at Matoks, Capricon District in Limpopo Province.

1.5 STUDY OBJECTIVES

- To explore factors contributing to clients defaulting ARV treatment at Matoks clinic
- To describe factors contributing to clients defaulting ARV treatment at Matoks clinic

1.6 RESEARCH QUESTION

The following research question will guide the study

What are the factors contributing to clients defaulting ARV treatment?

The research question led to the formulation of the research sub questions that will further guide the study as follows:

1. What are the factors that made you stop treatment?
2. How can your personal factors be solved regarding defaulting treatment?
3. What should be done to overcome these factors/ in your opinion, how can these factors be resolved?

1.7 SIGNIFICANCE OF THE STUDY

The study described and explored the factors contributing to clients defaulting ARV treatment and the findings of this study may provide information about ARV treatment challenges at PHC and district levels. Health management might improve the strategies for reducing defaulter rates through a coordinated NIMART and adherence programs. The study may add to the existing body of knowledge on ARV adherence, and on how to better support PLWHA to adhere to treatment regimens. The study may also contribute to the reduction of mortality and morbidity associated with HIV/AIDS, as well as the reduction of expenditure in the treatment of HIV/AIDS. Further more, if adherence is being strictly emphasized, clients will remain on the first line treatment regimen which is less cheaper and the burden of switching clients to the second line and third line treatment regimen therapy which is more expensive will be reduced as well as drug resistance will be reduced too.

1.8 DEFINITION OF KEY CONCEPTS

1.8.1 ***Adherence****- means to follow a particular set of beliefs or a fixed way of doing something (Oxford dictionary 9th ed).*

In this study, ***adherence*** is defined as the extent to which patients take medications as prescribed by their health care providers (Balueth, 2013).

1.8.2 ***Client****- is a person who uses the services or advice of a professional person or an organisation (Oxford dictionary 9th ed).*

In this study, a ***client*** refers to a patient who has HIV/AIDS has been registered and receives regular ART at Matoks clinic, the patient may collect treatment in other health facilities if he/she is away as long as a Green card is provided as evidence that the patient is registered.

1.8.3 ***Contributing-*** *to be one of the causes of something (Oxford dictionary 9th ed).*

In this study, ***contributing*** refers to any factor or aspect that can make the client not to take treatment or to default treatment (ARV).

1.8.4 ***Defaulter****- failure to do something that must be done by law (Oxford dictionary 9th ed).*

In this study, a ***defaulter*** is a client who misses two consecutive visits for collection of treatment and has not obtained any service from any other facility that offers HAART assuming that the patient does not take any ART medication during that period or later.

1.8.5 First line therapy

First line therapy in this study is defined as most common antiretroviral drug combination given to those beginning treatment consisting of two Nucleoside Reverse Transcriptase Inhibitors combined with a Non-nucleoside reverse transcriptase Inhibitors or a boosted protease inhibitor (Avert, 2012).

1.8.6 Second line therapy

Second line therapy in this study is referred to as drugs given to a person if HIV becomes resistant to the first line combination or if side-effects are particularly bad and include a minimum of three new drugs, with at least one from a new class (Avert, 2012).

1.8.7 Phamokate

Is a traditional/cultural name which best defines HIV/AIDS, it's often used by elderly people.

1.9 Paradigm Perspective

1.9.1 Meta-theoretical

The basic assumption of the study is that people living with HIV/AIDS (PLWHA) who has the knowledge regarding HIV/AIDS are more likely to use preventive practises and adhere to treatment than those without knowledge. When people have self-care capabilities, they are able to take care of themselves in all possible ways that can assist them to pro-long their life.

1.9.2 Theoretical framework

Orems self care theory

Orems general theory of nursing has been selected as a theoretical framework within the parameters of which to explore and describe factors leading clients to default ARV treatment at Matoks, Capricon district, Limpopo Province.

According to Orem (George, 2002), nursing is corncerned with individuals needs for self care action and the provision and management of it on a continuos basis in order to sustain health and life, recover from a disease or injury and cope with effects. She further defines it as an art and prudence, a service, role theory related to technologies and a comprehensive determination on why people can be helped. Orem's general theory of nursing consists of self care, self care deficit and nursing systems.

Self care it is the practise of activities that people living with HIV/AIDS (PLWHA) initiate and perform on their own behalf in maintaining their health, well being and life. It contributes to human structural integrity, human functioning and human development.

Self care agency, The human ability is engaging in self care. In this study, people living with HIV/AIDS (PLWHA) are encouraged to visit the clinic for ART refill on their appointment dates regularly.

Therapeutic self care demand, The totality of self care actions to be performed for some duration in order to meet self care requisites, people living with HIV/AIDS (PLWHA) taking ART regularly and consistenty, with regular visits being able to consent to adhere to treatment.

Self care requisites, They are actions directed towards the provision of self care, people living with HIV/AIDS (PLWHA) need to be given the necessary knowledge and support by the health care providers, proper adherence counselling and managing of side effects and other factors that can lead the client to default treatment in order for the people living with HIV/AIDS (PLWHA) to take care of themselves.

1.10 SUMMARY

In this chapter the background information, the research problem, aim and objectives, definition of terms and significance of study was discussed.

CHAPTER 2
LITRATURE REVIEW

2.1 INTRODUCTION

Literature review is conducted by researchers to determine how best to make a contribution to existing evidence and it also guides the researcher at the end of the study to assess if the findings are similar with other researchers' findings. It is necessary for topic selection, intergrating existing knowledge on a particular topic to what is being studied, to ensure that the proposed topic has not been tackled before and lastly to define an area of study as being original, Most research generally build on existing knowledge which guides the present research within the appropriate framework. (Polit & Beck 2012:95). There have been several studies aiming to identify and improve factors that can facilitate ART adherence after realization of the central role played by adherence in success of ART (Wekesa 2007:1). From the literature review there has been an overwhelming amount of evidence from clinical trials published which validated the use of ART as the only treatment known so far that suppresses HIV pandemic.

This chapter will discuss the following aspects: HIV pathology and mode of transmission, HIV treatment, definitions of adherence, non adherence and compliance, assessment and monitoring of adherence, factors affecting adherence antiretroviral treatment, health system factors, theoretical framework and summary.

2.2 HIV PATHOLOGY AND MODE OF TRANSMISSION

HIV was unknown until early 1980s and since then millions of people have been affected (Klaat 2013:6). The most affected age group are young persons aged between 15-24 years and this has affected the natural economies of the countries because of the loss of young to middle aged who are economically productive (Klaat 2013:6). When the HIV enters the bloodstream it attacks the white blood cell called T-Helper lymphocytes which are essential to the functioning of the immune system (Shaw 2013). Damage to the

immune system, which is marked by depletion of the CD4 T-lymphocytes, exposes the infected person to opportunistic infections and malignancies (Shaw 2013).

HIV is transmitted from one person to another through the contact of body fluids (Klaat 2013:26) and mothers who are infected with the HIV can pass the virus to their babies during pregnancy, at time of delivery through the birth canal or through breast milk. A person may take approximately 6 to 8 weeks to seroconvert to HIV positive status after contracting the infection and it is also estimated that one can live up to 8 to 10 years on average without treatment, before developing the clinical signs and symptoms of AIDS (Klaat 2013:26). There may be a risk of these HIV infected persons spreading the infection unknowingly as most of them are asymptomatic and do not seek medical treatment.

2.3 HIV TREATMENT

There is no cure for HIV and AIDS. Although a variety of therapies such as bone marrow transplantation, lymphocyte transfusions, thermic transplantation and therapeutic aphaeresis were tried to remove the virus they were not successful and are no longer employed (Klaat 2013:47). In the absence of cure, antiretroviral treatment is the only option that offers a dramatic reduction of the virus in an infected individual (Wekesa 2007:1). The aim of antiretroviral treatment is to reduce the amount of HIV in the body to a point where it is no longer possible to detect in the blood as it diminishes viral replication thereby reducing destruction of the immune system (Klaat 2013:48; WHO 2006:24). CD4 cell count is frequently checked for all patients on ART to assess the viral load as this is the most important indicator of response to ART (HSS Panel on Antiretroviral Guidelines for Adults & Adolescents 2013:26).

There are many kinds of antiretroviral drugs that attack the virus in different ways and for this reason the treatment entails use of combination of antiretroviral drugs and taking a combination of two or more antiHIV drugs is referred to as Highly Active Antiretroviral Therapy (Avert 2012:1). However, these antiretroviral drugs can only reduce the viral load as they stop virus multiplication therefore do not completely eliminate the HIV virus from the infected person (Klaat 2013:48). The most commonly used drug combination given to those beginning treatment consists of two Nucleoside/Nucleotide Reverse Transcriptase

Inhibitors (NRTI) with either a Non-Nucleoside Reverse Transcriptase Inhibitors (NNRTIs) and a boosted protease inhibitor (Avert 2012:1). HIV copies its own genetic code into the cell DNA when it enters the body. NNRTIs contain several medicines that aim to control the amount of virus in the body by preventing replication of the virus by primarily blocking HIV-1 replication (Sluis-Cremer & Tachedjian 2008:1). A combination of drugs that a person is given at the beginning is called first line therapy, then if HIV becomes resistant to this combination then a change to second line therapy is recommended (Avert 2012:1). A combination of first line drugs may include Tenofovir, Disoproxil Fumarate and Lamuvidine or Emitricitabine (WHO 2013:30).

Some of the common side effects that may occur from these ARVs include severe skin reactions, convulsions, liver damage, and central nervous system toxicity such as abnormal dreams, depression or mental confusion (WHO 2013:139). Antiretroviral drugs have different side-effects and these may have an impact on how the patients take the drugs (WHO 2006:24). In some countries several ARVs are combined in a single dose tablet, fixed dose combination (FDC) which ensures that a patient takes multiple doses together which is more convenient for the patient.

2.4 DEFINITIONS OF ADHERENCE, NON ADHERENCE AND COMPLIANCE

2.4.1 Adherence

Adherence to medication is defined as "*The extent to which a persons behaviour is consistent with health care recommendations".* Adherence can also mean an extent to which a patient takes medication as prescribed by the health care provider and it implies active collaboration in the treatment process and agreement to recommendations for the treatment (Balueth, 2013). In essence, the emphasis in adherence is on the interaction between the client and health care provider. The client is included in the decision making process and he/she takes owership of the priscribed treatment plan. Therefore WHO suggested client active participation with health proffesionals in their own care and that good communication should be established for effective clinical practise.

2.4.2 Poor adherence or non-adherence

The medicine deviations often lead to " non-adherence" or "poor adherence". According to WHO (2003), non adherence refers to failure to take medication as prescribed or by discontinuing treatment before completion of the course, taking more or less medication than prescribed and wrong frequency of dosing. Poor adherence on the other hand, refers to patient not able or willing to comply with the prescribed treatment, poor adherence and non-adherence are similar and are often used interchangeably. Medication deviation occurs when the patient takes the wrong antiretroviral medications different from the prescribed. Dosing deviation entails taking a smaller or larger amount of medication than prescribed and patients failure to take medication according to the required conditions such as taking medications on an empty stomach or with food and fluids as recommended by the health worker. Finaly, schedule deviation occurs when patients fails to take the prescribed dose of medication at all or not taking it on time.

2.4.3 Compliance

Compliance is defined as " the extent to which the patient follows medical intructions" (WHO, 2003) WHO futher argued that the term "intructions" implies that the patient is a passive, acquiescent recipient of expert advice as opposed to active collaborator in the treatment process. Compliance, therefore, undermines the active involvement of patients in the treatment planning and descision making process. The term adherence and compliance are often used interchangeably to describe commitment and faithfullness to treatment.

2.5 ASSESSMENT AND MONITORING OF ADHERENCE

Studies have established that self reporting, medication events monitoring system (MEMS), pill counting, pharmacy refill tracking, clinically monitoring of clinical parameters are common methods for assesing and monitoring adherence, (Balueth 2013).

2.5.1 Self report

Clents are asked to report their own adherence at each visit, the health care provider will alwaays ask the client about his/her adherence to ART progress. Clients provide a self

report on how many doses they have taken or fogotten to take during that specific period. This method is cost effective and flexible in design, and the collected data can be used to determine the reasons for non adherence. However, the challenge with self report could correlate strongly with actual medication intake by the patients. Another challenge of self report is that they reflect only short term or average adherence and may lead to over-estimation of adherence of patients over a long period. Although other clients can lie trying to impress the health care provider in fear of being critisized, judged or being offered poor service because the client will not be adhering to treatment accordingly and these leads to wrong information interms of monitoring adherence.

2.5.2 Electronic devices

Medical Event Monitoring Systems (MEMS) is an electronic device embeded in the lid of the medication bottle, MEMS is a special bottle caps containing computer chip that records the date and time of opening and closing of medication bottle. The data is interpreted with the assumption that a single dose is taken each time a bottle is oppened and closed. It is a good electronic device but not every country can afford to use it while they are paying enough millions to provide free ART to HIV/AIDS clients. Studies have found adherence measuring using MEMS caps to correlate fairly well with medication intake.

2.5.3 Pill counting

Health care providers especially doctors and pharmacists conduct pill counts durring scheduled clinic visits to ascertain clients adherence. with this method, it is possible for patients to manipulate pill counts by dumping pills prior to scheduled visits and this could lead to overestimation of clients adherence. It is one of the good technique to monitor adherence since the remaining pills during the due date to collect ARV treatment, the number of the remaining pills should correlate with the dates but the strategy is also easy to manipulate and leads to false adherence assessment. The challenge is that pill counting may destroy the trusting relationship between the health care provider and the clients because the clients may assumed that they are not being trusted by the health care providers. Although the method of pill counting has been widely used in measuring

adherence to ART, the method is not useful in assesing patients adherence particularly where the patient combines different pills

2.5.4 Pharmacy refil trucking

Pharmacy staff play a major role in supporting adherence to medication. Pharmacy refil data has been used as additional indicator of adherence. Patients collecting their medication regularly on their due dates are assumed to be adherent to their treatment and failure to honour their due dates for refill are indication for poor adherence. The disadvantages associated with pharmacy refil tracking are that, it is not a measure of intake medication and it requires the patients to use the same pharmacy for all refils.

2.5.5. Directly observed therapy (DOT)

Directly observed therapy has been extensively and successfully used in the TB management world wide. This is the only accurate method to monitor 100% adherence to ART but it is expensive and labor intensive and may not be an ideal for the ART patient because it will demand a large number of DOT supporters and due to the frequency of dosing of ART medication and the life long period of treatment, this ART DOTS may not be practicable unlike TB DOTs with shorter treatment duration of 6-9 months and of more simplified regimen

2.6 FACTORS AFFECTING ADHERENCE TO ANTI-RETROVIRAL TREATMENT

2.6.1 Patient factors

Patient factors are those that are related to an individual on ART, which may affect their adherence perfomance. These factors include psychosocial factors, patient lifestyle, Patients knowledge and beliefs abou HIV management, Daily schedule and forgetfulness, Medication factors, social support and transport cost were identified as barriers to ART adherence.

2.6.1.1 Psychosocial factors

A number of psychosocial factors such as depression and other psychiatric illness have been reported to hinder adherence to Antiretroviral Treatment. Recent studies has shown that male sex, white ethnicity, older age, higher level of education and literacy correlate with better adherence. However, depression also plays a major role to poor adherence to ARV's drugs. HIV/AIDS clients who experience anxiety and forgetfulness tend to overlook their psychological wellbeing and eventually become depressed, they may be overwhelmed by helplessness and hopelessness, become withdrawn, be emotionally detached and be preoccupied with suicidal ideation. A patient may be unmotivated or reluctant to honor or attend clinic appointments, especially when struck by poverty and lack social support, (Kagee, 2007).

2.6.1.2 Patient lifestyle

There has been some inconsistent evidence about whether alcohol is associated with adherence. Active use of alcohol and drug abuse have an influence on clients to adhere to treatment regimen by forgeting to take treatment correctly or skipping the whole regimen. Alcohol abuse contributes to non-adherence to ARV treatment by PLWHA. Drawing from Alcohol myopia theory which states that large amounts of alcohol consumption lead to the impairment of the brain until the drinker loses consciousness, PLWHA may default and in that process the viral load increases, the CD4 count drops and the treatment eventually resisting the system (Kheswa, 2013).

2.6.1.3 Patients knowledge and beliefs abou HIV management

Patients knowledge and beliefs about disease and medicine can influence adherence The understanding of a relationship between adherence and viral load and disease progression and the consequences of poor adherence and the impact it will have on the client and the whole family is of vital importance and is integral to good adherence behaviour. Clients knowledge about ART regimen and understanding of the relationship between poor adherence and build up of resistance predicts better adherence to ART.

Clients knowledge and beliefs about disease can influence adherence in many ways. A client who is more knowledgeable about HIV/AIDS, the importance of maintaining the recommended adherence level would tend to follow all the instruction regarding medication intake as compared to the client with no such information. In addition, negetive beliefs regarding efficacy of HAART may also influence ART adherence behaviour resulting to non-adherence (Nziva, 2013).

2.6.1.4 Daily schedule and forgetfulness

Reports have shown that patients with consistents and predictable daily routine find it easier to integrate daily pill taking into their daily lives and promotes adherence forgetfulness is a major obstacle in achieving optimal adherence to ART regimen. Some studies indicated that patient on ART often desire to take a treatment holiday due to reasons amongst others such as side effects in addition, due to the fact that ART is a life long treatment, patient become tired and weary of taking medication at the same time everyday. In a study done by Balueth (2013), it showed that if a patient on HAART is strongly motivated to adhere to the treatment such a patient will be adherent but on the other hand if the patient believes that discontinuing the medication is the right thing to do and if the social network is weak then the patient will eventually default.

2.6.1.5 Medication factors

HAART consist of complex regimen that can include up to 20 different pills/tablets/capsules of ARV, with multiple dosing throughout the day and specific foods and fluids related instructions and these are often difficult to follow for the majority of clients. The higher the frequency of taking treatment, the lower the chances of proper adherence for the client to follow Side effects has been consistently associated with the contribution to clients not adhere to treatment. Clients who experience more adverse reactions are less likely to continue with ART. HAART can also lead to serious adverse effects including nightmares, hallucination, neuropathy and diahorrea. Medication frequency and food restrictions appeared to have more influence on adherence to treatment. (Nziva, 2013) reported that clients who takes treatment once a day are more likely to adhere to treatment than those who takes treatment twice or three times a day.

This litrature review clearly shows that optimal adherence occurs with medications that cause less side effects and with low frequency of taking the medication e.g taking treatment once a day.

2.6.1.6 Social support

proposed that social support is an important factor in adherence in HIV medication, patients living alone without support had associated with an increase in non adherence and they agreed that having a partner, social or family support, poor interaction and better physical interaction and relationships where characteristics that promoted ART adherence. Discomfort with disclosure of HIV status is one of the reasons for defaulting the prescribed regimen. Fear of rejection or discrimination may prevent a clientfrom disclosing their HIV status to family members, friends by losing out of social support. (Pretorious et al, 2015)

2.6.1.7 Transport cost

In South Africa, ART services are accessed freely but most patients have to pay for their transportation cost to the ART clinic to access their medication and it results in poor adherence to HIV/AIDS treatment. This concurs with the study done by Chindedza et al, (2013) Findings of the research affirm that being from a low socio economic status can act as a barrier in the access to ART. Similar results were established in research done in Botswana, Tanzania and Uganda, were patients of a low socio economic status failed to get money to cover additional cost of accessing ART such as transport costs, in spite of ART being given for free. It was further revealed that in a similar study done in India where financial struggles with ART related costs like transport and food were seen to hinder adherence to ART.

2.6.2 Health system factors

Function and client friendly health system were crucial for a successful ART program. However, the functionality of many health systems has been affected due to the huge burden of HIV/AIDS on the system (Avert, 2012). The dwindling economy of many African

Countries contributed to lower infrastructural development and shortage of man power to tackle the disease.

Health system factors such as ART setting, client to health care provider relationship, long distance to health care facilities and lackof transport and socio cultural factor have been identified as barriers to adherence of ART.

2.6.2.1 ART setting

Health facilities characteristics such as the proximity to the patients home or place of work, the cost of getting there, the clinic openning and closing time, lack of services such as child care have negetive impacts on ART adherence On the other hand, the availability of privacy for consulting (where individuals are able to address their concerns in a safe and private environment) was a factor that promoted ART adherence. Although existing data is limited, aspects of clinical setting may be assisted with improved adherence. A friendly support and non-judgemental attitude of the health care providers ,convenient appointment scheduling and confidentiality contribute to better adherence (Nziva, 2013).

Structural factors not directly related to clients or medications also play a role influencing ART and health care facilities, health care beliefs, waiting time, opening time, availability of counselling services, social, economic, psychosocial support for PLWHA plays a major role in influencing the degree of adhering to the prescribed ART regimen (Nziva, 2013).

2.6.2.2 Client to health provider relationship

A meaningful and supportive relationship between a client and a health care provider helps a client to overcome significant barriers to ARV adherence. This relationship plays an important role in improving adherence to prescribed ARV drugs. It is believed to be a motivating factor for adherence to HAART. Trust and confidence in health care provider has been shown to increase levels of ART adherence. client overall satisfaction and trust with the health care provider and the clients opinion on the providers competency, providers willingness to include the client in decision making process. Two studies done on client-provider relationship to show the effect of trust on the client on the health care provider and the impact on clients ART adherence showed that good relationship

improved, the adherence ten-fold when compared to those clients who had no trust on the health care provider

Other factors that have been identified to strengthen the relationship include the perception of the health care provider competence, quality and clarity of communication, compassion shown by the provider and involvement of the client in the treatment decisions have identified as motivators of ART adherence. However, other factors such as inconvinience of the regimen where a client becomes frustrated by the health care provider especially in where misunderstandings occurs, treatment becomes complex and side effects becomes unmanageable has shown results to non-adherence (Balueth, 2013).

2.6.2.3 long distance to health care facilities and lack of transport

The distance to the health care facilities to collect ART plays a major role in contributing to clients to default ART, lack of transport to the health facilities in association with lack of employment also have a huge impact on poor adherence since the longer the distance to the health facility will also require transport which needs to be paid for each visit even though te ART its for free. Despite the fact that adherence is said to be 90% amongst people taking ART in Sub-Saharan and Africa, transportation over long distances from/ to health facilities remains an important barrier to sustain adherence to medications (Balueth, 2013).

2.6.2.4 Socio-cultural factors

Family and community support, disclosure of one's HIV positive status and cultural issues plays a vital role in adherence to ART, support from the community proved to enhance adherence to ART. Factors such as unemployment and poverty have been found to have an influence on ART adherence. A study, conducted at the Temba Lethu Clinic at Helen Joseph Hospital in Johannesburg, as well as a cross-sectional study conducted in Botswana of the social, cultural and structural determinants of treatment adherence, shows that financial problems are the leading cause of failure to follow-ups since these represents 34% and 44% of all the problems, (Balueth, 2013). HIV stigma and discrimination is still present in communities and families despite the positive advantages

of antiretroviral treatment therefore recommended need to encourage one to be open about the HIV positive status.

SUMMARY

In summary, although many strategies have been discussed, most studies agreed that the strategy of self reports were the most common, economical and reliable. This strategy was the most widely used in the clinical settings of assessing clients adherence to ART The use of more than one strategy such as self reports and pills count would enhance the accuracy of measuring ART adherence.

CHAPTER 3
RESEARCH DESIGN AND METHODS

3.1 INTRODUCTION

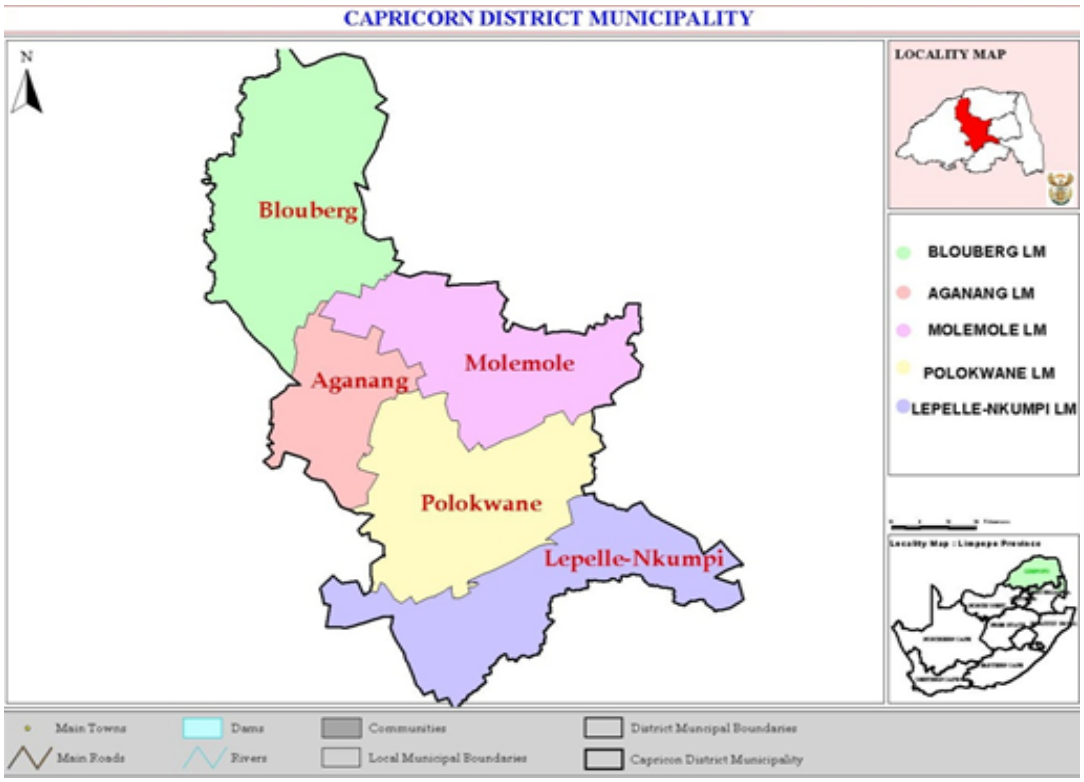
Polit and Beck (2012:733) defined methodology as the steps, procedures and strategies for gathering and analyzing data in a study. The fore, this chapter will present the research methods used for the study. The research design, sampling procedures, data collection process and research analysis approaches applied to address the research questions will be discussed. The first sections addressed issues to do with the study area and setting of the study, sampling procedure followed by data collection and analysis methods. The last section deals with issues related to ethical clearance.

3.2 STUDY SETTING

The study was be carried out at Matoks community which is one of the rural village in Molemole municipality, Capricon district, Limpopo province. The source of income to these community mostly is small markets, others use donkeys and kart to carry materials and deliver in the households of those who required them and social grant is also regarded as a source of income since theres a high birth rate and PLWHA who qualifies for social grant. The estimated population of these community consist of 7500 people. Matoks clinic is situated 12 Km just after passing Capricon tolgate on the N1 road to Polokwane and the clinic provides free antiretroviral therapy services and also serves as an initiation and maintanence site for patients who are on antiretroviral therapy.

The community has a variety of cultural and traditional beliefs, these includes their own ways of handling different diseases and some community members have challenges in accessing health services. It is characterized by poor infrastructure which is being reconstructed, with some areas being not accessible during rainy season which contribute to compromised health service delivery. The community has 01 police station, 01 district hospital, 06 primary health care clinics Major, 01 shopping complex, 27 primary schools including 01 special school and 16 secondary schools. Home languages are Sepedi which is a dominant language of them all, Venda, Tsonga and other African cultures from Zimbabwe, Mozambique, and also Somalia's.

IMAGE OF CAPRICON DISTRICT MAP



www.googlemaps.com

Molemole municipality is situated on the top right of the map and is marked by a pink colour.

3.3 RESEARCH DESIGN

A qualitative, explorative, descriptive study was conducted as it was the most suitable design to use when a problem or issue needs to be explored (Creswell 2007:39). The aim of this study was to deeply investigate factors contributing to clients defaulting ART treatment in Matoks. The descriptive approach allowed the clients to describe their experiences of things as they experienced them and these included hearing, seeing, believing, feeling, remembering, deciding, evaluating and acting (Polit & Beck 2012:495). By using the qualitative design the researcher was able to explore and understand the

meaning of individuals ascribed to their social or human problem (Creswell 2009:4). In addition, through face to face interviews, the researcher was able to gather multiple realities based on the actual words of the clients as they narrated their dynamic experiences of them being HIV positive and experiences of taking ARVs (Creswell 2007:18).

3.4 STUDY POPULATION

A population is any group that is a subject of research interest (Goddard & Meivile, 2014). The population was all HIV/AIDS clients but the study population was HIV positive adult clients who have not been collecting treatment for more than 2 months at Matoks clinic.

3.5 SAMPLING

Sample is defined as the selected group of people or elements (Grove et al, 2015). The participants were identified through purposeful homogenous sampling. Haber & LoBiondo-Wood (2014), defined sample as the group of people that the researcher will interview or observe in the process of collecting data to answer the research question. In this study, the aim was not to generalize findings to a target population but aimed to discover meanings, explore and explain events as close as possible to the people who had experienced the phenomena or culture that is under study (Polit & Beck 2012:515).

3.5.1 Sampling procedure

Purposive sampling approach was used. Polit and Beck (2012:517) described purposeful sampling as a strategy that allows researchers to select participants that most benefitted the study because they had rich data as they experienced the phenomena under study. Clients whom were selected for the study was HIV positive clients and had defaulted treatment for 03 months or more. With the assistance of Matoks clinic staff members including Lay counsellor, Pharmacist assistant, Social Workers, DOT supporters and FPD administrator at PHC, clients were identified and contacted and recruited to participate in the study through a consent form, meanwhile the clients are getting help to be re-initiated on treatment.

3.5.2 Inclusion criteria

The inclusion criteria was based on recruiting HIV positive clients who are collecting treatment at Matoks clinic, with the following characteristics:

- Has not been collecting ARV treatment for more than 2 months
- 18 years of age and above
- Able to provide informed consent

3.6 DATA COLLECTION

3.6.1 Data collection approach and method

Data collection can be defined as the process of gathering and measuring information on targeted variables in an established systematic fashion, which then enables one to answer relevant questions and evaluate outcomes (Lescroel et al, 2014). Data was collected from May to July 2017, the researcher conducted face-to-face interviews with the clients using a semi-structured interview guide and at the same time took detailed notes of the conversations (Annex 01). The researcher used an audio tape the conversations as well to ensure that interview data were the client's actual verbatim responses (Polit & Beck 2012:534).

3.6.2 Characteristics of data collection instrument

The data collection tool used was a semi-structured interview guide. The tool was also translated from English to vernacular language (Sepedi) to allow the researcher to express clearly the questions to the participants in the language they mostly understood and notes were taken and a quality audio tape was used to record the conversations.

3.6.3 Data collection process

Data collection was conducted at Matoks clinic and some at the client's homes and every effort was made to ensure that each client felt comfortable. Clients were recruited through the help of Matoks staff members, especially the Dot supporters who assisted by taking the researcher at some of the clients homes since they couldn't afford to come to meet the researcher at the clinic due to lack of money and transport.

Polit and Beck (2012:533) posed the need for qualitative researchers to gain and maintain a high level of trust with the participants and "be like them" as this will allow them to get rich data. During the data collection period the researcher spent more time with the

participants to ensure that he gains their trust and to make them feel comfortable to such an extent that the clients will be able to give more information during data collection. In turn, the researcher introduced himself to each client during the interview and explained the purpose of study.

Face to face in-depth interviews was conducted with the participants who volunteered to participate. The researcher ensured that the interview process was done according to the study protocol which included introductions, explaining purpose of study, what it entailed to participate and obtaining written consent before the interviews. The interviews captured information on socio-demographic characteristics, knowledge of HIV and ART, duration on ART, perceived benefits of ART, adherence facilitators, accessibility of ART, side-effects, disclosure, social and family support, and quality of health delivery. Face to face interviews allowed the researcher to adapt the questions as necessary and ensured that the questions were properly understood by repeating or rephrasing the question. Furthermore, the researcher was able to observe the client facial expression or body language which in turn gave the researcher a clearer indication of the clients' true honest feelings or emotions. However, face to face interviews may sometimes be biased as other clients tend to give social desirable answers and some may feel uneasy about answering personal questions (Joubert & Ehrlich 2007:108).

Data was collected until saturation occurred. Data saturation occurred at point where no information was obtained and redundancy was achieved (Creswell 2007:64; Polit & Beck 2012:521). In this study, although an estimated sample size of 15 to 20 clients was given, 19 clients were interviewed as the researcher had to collect data until saturation occurred. Open-ended questions were used as they allowed the clients to express freely their experiences of taking ART and at the same time the researcher was able to probe clients' answers.

Interviews were carried out in a relaxed atmosphere where 19 clients were able to narrate their stories in their own words. Sometimes in-depth interviews may not necessarily follow the sequence of asking questions as they appear in the interview guide as each point can be the beginning of a particular discussion (Joubert & Ehrlich 2007:320). Data was

captured by taking detailed notes of the conversations and audio recording to those who consented to audio tape. Clients who had issues or problems and needed help were referred back to counsellors.

3.7 DATA ANALYSIS

The purpose of data analysis is to organize, provide structure and elicit meaning from the data (Polit & Beck 2012:556). The tapes were played several times, then verbatim transcribed to text and the information was stored electronically in Microsoft word. Information from field notes were cross checked with verbatim responses of the participants and also stored electronically. Patton (2014), described data analysis as a way of transforming and modelling data that are collected with the goal of highlighting the essential information, coming up with conclusion and supporting decision making. The researcher read through the transcripts several times so as to get an understanding of the responses from the client and to search for common themes.

Thematic analysis method described in Polit and Beck (2012:562) was used to analyze data. The method was the most suitable as it relies on the similarity principle which entailed looking for units of information with similar content, symbols or meaning and the contrast principle which involved finding out how content or symbols differ from other content or symbol then identified what was distinctive about emerging themes or categories (Polit & Beck 2012:562).

3.8 TRUSTWORTHINESS OF THE STUDY

Creswell (2007:207) states that a qualitative researcher should personally be involved in every step of the research process, researcher need to go out and find the “truth” and ensure prolonged engagement in the field in order to understand the social reality of the clients. The researcher personally went out in the field, adhered to techniques for collecting data, was well versed about the character of the data, data analysis and reported true findings.

3.8.1 Credibility of the study

The researcher created a good rapport with the clients, interacted with the clients and had enough time to collect thorough, rich data. Data collection instrument was translated to vernacular language (Sepedi) and this ensured that questions were asked in a language that the participants understood. There was no language barrier as the researcher was well conversant with the clients' language. Multiple field visits were conducted and data was collected until saturation occurred. An accurate analysis and truthful reporting of findings was maintained by the researcher.

3.8.2 Dependability

Polit and Beck (2012:585) defined dependability as the stability or reliability of data over time and conditions. In this study the researcher took detailed field notes and audio taped the conversations, then transcribed audio tapes and cross checked with the information captured on the field notes. However, interpretation and approach to the study may be influenced by the researcher's past experiences, biases and prejudices (Creswell 2007:208). In this study the researcher set aside stories and past experiences.

3.8.3 Member checking

The researcher played back the audio tape at the end of each interview to confirm if the conversations were captured and also to confirm that the information was what the clients wanted to report.

3.8.4 Transferability

Transferability refers to the extent to which findings can be transferred in other settings or groups (Polit & Beck 2012:585). The data collected comprised of rich and detailed descriptions obtained from the clients and also the findings, interpretations and conclusions were supported by data. The detailed descriptions will enable the readers to assess whether the findings can be transferred or not and they will also consider the characteristics shared by the clients and the study site as well since this was a deep rural setting.

3.9 ETHICAL CONSIDERATIONS

With studies involving human beings as study participants, the researcher must exercise care and ensure that their rights are protected (Polit & Beck 2012:150). The researcher respected all the ethical issues pertaining to the study and these is shown by the following aspects.

3.9.1 Study permissions

Permission to conduct the study was initially sought and granted from the University of Venda Higher Degree Committee under ethic number SHS/17/PDC/10/2604. Permission was granted by the Limpopo Department of Health at Capricorn District about the study (Annex 04). Furthermore, permission to conduct study at Matoks was and then granted by the operational manager of Matoks clinic after seeing the two permission letters from the University of Venda and from the Limpopo Department of health and allowed the researcher to facilitate the study with the help of Matoks staff members. The operational manager further informed the area manager of Molemole PHC about the study being conducted and the Machaka traditional council was informed by the operational manager about the study.

3.9.2 Informed consent, confidentiality, anonymity and privacy

Informed consent entails that the participants are given adequate information about the research, understand it, and can consent or decline participation (Polit & Beck 2012:157). The researcher was given the opportunity to explain to the entire group the purpose of the study, what it entails to participate and emphasized that participation was voluntary. The researcher gave details on a one to one basis and explained what it entails to participate and the contents of the consent form to those who were willing to participate. A clear explanation was given to clients about the purpose of the study.

Anonymity issues were also explained that no names would appear on data collected but only codes will be used. Confidentiality issues were also mentioned that no one would have access to the information and that the information would not be shared with anyone except the supervisors. Clients who consented to participate were asked to sign consent

forms before the interviews. Also consent was sought from clients to audio tape the conversations and they were asked to sign consent forms for audio taping. Consent forms were translated to vernacular language (Sepedi) to ensure that the clients fully understood the contents of the consent form and they were given copies of the consent forms. Contact details of the researcher and the supervisor were disclosed to clients. All the clients interviewed were literate (able to read and write) therefore it was easier for them to read, understand the contents of the consent forms and to put their signatures (Annex 02). Clients did not use any financial expenses as the researcher followed them to their perspective homes, only those who stays near the clinic were interviewed at Matoks clinic.

3.9.3 Right to withdraw

Clients were also told about their right to withdraw at any time and that it would not jeopardize their treatment and no harm would be done to them, hence the voluntary participation was emphasized. However, audio-taping was not done to those who were not comfortable with audio tapes.

3.9.4 Risks and discomfort

Clients did not encounter any risk. However due to the nature of in-depth interviews the researcher had already made arrangements with the Lay counsellor to refer those who may have emotional disturbances but fortunately none of them experienced any discomfort.

3.10 SUMMARY

Research design, sampling procedures, data collection process and research analysis approaches utilized in this study were described. Ethical issues were also discussed.

CHAPTER 4
RESEARCH RESULTS AND DISCUSSIONS

4.1 INTRODUCTION

This chapter entails the research findings of the study based on the client's responses from the in-depth interviews conducted by the researcher during the data collection period. The clients interviewed were Sepedi language speaking although some mixed English with Sepedi during the interview, the clients interviewed were age of 22 years to 58 years.

The researcher interviewed 19 clients were 07 clients were males and 12 were females and data saturation was shown during the 16th clients and these was shown by the repetition of information during the interviews. Each interview lasted from the minimum of 20 minutes to 35 minutes. The interviews were focused on answering the following research question:

What are the factors contributing to clients defaulting ARV treatment?

4.1.1 Socio demographic characteristics of the participants

The researcher interviewed 19 clients were 07 clients were males and 12 were females, the clients interviewed were between the age of 22 and 58 years. 12 client's primary education and 06 had secondary education and mostly were employed as laborers/unprofessionally only 06 clients were professionally employed.

4.2 RESEARCH RESULTS

The study focused mainly on investigating factors contributing to clients defaulting ARV treatment and also identified factors within the client's treatment, socio-cultural and service delivery context. Based on the issues that arose from the client's responses the researcher identified five themes that contributed to the clients to default the ARV treatment. The table below indicates the themes and sub-themes that will be discussed in the study.

THEMES	SUB-THEMES
1. Knowledge deficiency	1.1 Lack of knowledge about HIV/AIDS. 1.2 lack of knowledge about ART 1.3 lack of knowledge about ARV side effects
2. Lack of social support	2.1 lack of family and relative support. 2.2 Failure to/fear of disclosure and fear of discrimination 2.3 Stigma and self-stigma 2.4 Government social grant/ Social grant dependency Syndrome. 2.5 Employment and unemployment issues.
3. Provision of service delivery	3.1 Client to health care provider relationship. 3.2 Long period of waiting and access of ART at clinic 3.3 Lack of transport to and from the clinic
4. Medication factors	4.1 access of ART and shortage of ARV at clinic 4.2 Pill burden
5. Cultural and religious beliefs	5.1 Cultural beliefs 5.2 Religious beliefs

4.2.1 THEME 1: KNOWLEDGE DEFICIENCY

The first theme that emerged was the knowledge of clients on HIV/AIDS, ART and side effects.

4.2.1.1 Lack of Knowledge about HIV/AIDS

Most clients knew about the disease of HIV/AIDS but not in full details. From the responses below it showed that most of the clients interviewed knew a little about HIV and AIDS and ART except for the consequences:

"I was told that there is no cure for HIV/AIDS and the only way to survive is to take the ARV treatment regularly but I did not understand how I got infected because my husband died 15 years ago and I have never been married or be involved with another man after my late husband, I kept myself busy by raising my grandchildren at home, some. I felt like am bewitched because I was not sleeping around after my late husband died, sometimes when am alone I think of going to see a traditional healer hoping to get a better explanation than the one I got at the hospital". Client (no: 01) Female-58-years-old. (In Sepedi).

"I never understand how I got these HIV/AIDS disease because it's been so long since I had sex when I was married many years ago, all I was doing was taking care of my grandchild since my daughter has passed on due to (Phamokate), even today I don't understand how I got infected because all I was doing was caring for my grandchild. Client (no: 02) Female-56-years-old (In Sepedi).

Information about HIV/AIDS pandemic seemed to be very little. For the patient to adhere to treatment, he/she must be knowing about the disease in full details and due to lack of information, it is the duty of the health care provider to explain in full details about the disease that the health care provider is introducing to the client. The causes of the disease including all modes of transmission and the behavior of the virus inside the body and then Introduce the ARV treatment in details and the importance of adherence to treatment and its full benefits in details. Explain the advantages and disadvantages of taking ARV's in

full details, hence client's knowledge and information about the disease will contribute to adherence. The study findings concur with Amico et al (2011:2) which revealed that a good understanding of HIV and AIDS was associated with good adherence.

4.2.1.2 Lack of Knowledge about ART

In-depth knowledge on ARVs assisted clients to make a decision of optimal adherence. With respect to information on ARVs, most clients were not quite knowledgeable on the names of the ARVs they were taking and some had confusions about them since they kept changing names and some were changing regimens with new ARV drugs. Below are some of the client responses:

I started taking ARV's of 3 pills, then they changed them I had to take 2 pills and then again they changed and I had to take 1 pill per day and only at night, so the one pills was not like the first 3 pills I had before because they use to make me sick, so I decided to take a break from the pills since am feeling okay, Client (no: 02) Female-56-years-old. (In sepedi).

Sometimes when I think of drinking these pills I get lazy since they are always changing and for what good reason I really don't know and each time they change the pills, I used to get sicker more and more, that's why I ended up stopping the HIV treatment. Client (no: 03) Female-37-years-old.

The pills are too many, find a cure because taking ARVs for life is not easy, can't there be a monthly injection to replace every day pills?" Client (no: 16) Male, 28-years-old.

Findings of these study shows that health care providers are not re-educating their clients about the changes of ARV drugs when they change and these is leading to confusion towards the clients and they end up defaulting treatment. Furthermore, health care providers should emphasize on how the mechanism of each ARV drug acts inside the clients body in order for the clients to be aware of certain changes in the body after taking

the treatment. Findings from this study concur with Maokisa (2011:35) that continuous education is one of the factors that promote adherence.

4.2.1.3 Lack of Knowledge about ARV side effects

Giving information to clients about the possible side-effects of ART may increase adherence levels as the clients will be prepared and know what to do if they experience side-effects. If side-effects are not managed well they may interfere with adherence to ART. Possible side-effects that may occur when one is taking ARVs were discussed with clients during counselling sessions and they were also informed that they should come back to see the nurse at the clinic and should not discontinue treatment on their own if they encounter side-effects. Among the common side-effects experienced by study clients were vomiting, rash, abscesses, numbness in lower legs. Most clients ended up quitting treatment due to side effects since they were unable to go back to the clinic. Below are some of the client response:

''The nurse who gave me the ARV for the first time just told me how to drink them and I should drink them at night since one of the side effects of these ARVs is drowsiness, although I experienced drowsiness it was not a problem but the severe side effects that occurred on the first week made me so sick to such an extent that I ended up stopping taking them'', Client (no: 03) Female-37-years-old.

''My pastor stopped me from taking ARVs when I disclose my status to him, he prayed for me and I believed in my pastor and the almighty God that these virus will not do anything to me in my body, so I stopped the ARV after the prayer and felt so relived since the ARVs were making me more sick after taking them'', Client (no: 19) female-36-years old.

Sometimes patients may not have a clear understanding of side-effects and tend to associate any illness that occurs to them whilst on treatment as side-effects of ARVs. Do (2011:139) also reported side-effects from antiretroviral medication as one of the most common factors that contributed to non-adherence to ART.

4.2.2 THEME 2: LACK OF SOCIAL SUPPORT

Social support was the second theme. Four categories were grouped as social support, psychological/emotional and spiritual support and economic support. Some of the other facilitators identified were discrimination, stigma, and disclosure.

4.2.2.1 Family and relative support

Support from family members, relatives and friends plays an important role in supporting PLWHA to maintain ART adherence. It was observed that most clients came to clinic to start ART alone and not accompanied by their relatives when they came for their monthly reviews. From clients responses it was noted that good support system from relatives, neighbors, family and friends was not facilitated on their adherence to ART as indicated in the responses below:

''When I disclosed my status to my family at home, everyone started to back away from me and I felt so lonely and neglected by my own family. They stopped to eat the food I cooked, my sister stopped sharing a room with me and I regretted why I disclosed my status to them because it seems like it was better when they did not know my status, I stopped taking those ARV treatment hoping to die fast and leave my family in peace since I was already feeling lonely in my family'', Client (no: 04) Female-23-years-old.

"I was working as a maid in the kitchen of my cousin in Seshego location, I sometimes had to be absent from work once a month in order for me to go and collect my ARV treatment and my boss was starting to be suspicious that mostly during every mid-month I skip work and give excuses, she started to ask lots of questions about my absence and I had to disclose my status to my boss hoping that maybe she will freely allow me to go to collect the ARV treatment once a month. Two months after I lost my job for no reasons, she just told me that I had to stop working for her until further notice but what surprised me was that after I left another maid was hired by her. I always blame myself for losing my job because I disclosed my status to her, maybe she did not her children to be taken care of by an HIV positive maid. Somehow I blame these disease for losing my job and disclosing my status to her" Client (no: 05) female-42-years-old.

A strong support from family, relatives, employers, employees and friends is regarded as essential which helps the clients to adhere to treatment. Furthermore, if these essential support is not given to the clients, they end up defaulting since most of them will think that it's better to die than to live alone with no one near you. This is also supported by Pretorius et al (2017) that availability of a strong supportive family and support group meetings for people living with HIV and AIDS increased adherence to ART.

Family support is vital to the patient in a sense that if the family provide warmth, unconditional regard and non-judgmental attitude the patient may find it easy to cope with whatever challenges he/ she might come across. Family support boosts the patients' self-esteem and it becomes easy for the patient to adhere to treatment and believing that he/ she will have a long and healthy life. In contrast, if a patient does not have the support it becomes difficult for him/her because what will follow is ill-treatment from family and the person will lose hope and that will lead the person to default on treatment (Kheswa, 2013).

4.2.2.2 Failure to/fear of Disclosure and fear of discrimination

Disclosure of one's HIV positive status is a significant factor towards ART adherence as it can have either a negative or positive impact towards ART adherence. Clients who disclosed their HIV positive status were able to get the necessary support required to enable them to adhere to ARV treatment. However, for some the decision to disclose was not an easy task as they thought they may end up being stigmatized and discriminated. Also the idea of decentralizing ART clinics and transferring patients to local clinics was not welcomed by some clients as they would meet neighbors in the same queue. However, most clients complained about the green cards that they were given to use when they arrive at the clinic to collect ARV for monthly re-fill since most people in the community knows that everyone who carries a green card to collect treatment at the clinic is HIV positive. Below are some of the client responses:

''I meet my neighbors at the local clinic where I am taking my ARVs, so they will all know that I am HIV positive and spread the rumors to such an extent that everyone in the community will know about my status and lose my marriage since am traditionally

married, although my husband and his family did not know my status because we were not tested since am married to an older man who understood his culture and tradition, I decided to stop the ARV treatment to save my marriage. I did not want my in laws or my husband to see my pills because they were going to ask many questions and eventually find out about my disease'', Client (no: 06) Female-26-years-old.

''When I disclosed my status to my family at home, everyone started to back away from me and I felt so lonely and neglected by my own family. They stopped to eat the food I cooked, my sister stopped sharing a room with me and I regretted why I disclosed my status to them because it seems like it was better when they did not know my status'', Client (no: 04) Female-23-years-old

Adherence can be optimized in the contexts where there was openness and acceptance of one's HIV positive status. Some women failed to disclose their HIV positive status and that they were taking ARVs as they feared being victimized by their husbands. Findings also concur with Marukutira (2012:66) that most participants who did not disclose their HIV positive status due to fear of being stigmatized failed to adhere to treatment. However, the issues of self-stigma still remains a problem in some patients as they are still not comfortable in revealing their HIV positive status to their neighbors and employers. Internationally, the literature review shows that HIV stigma tendency differ in urban and rural settings due to difference in social structure and the experiences of individuals living in those settings. In the African setting, HIV stigma acts as a power barrier to access health care as it inhibits HIV testing and disclosure of HIV status. In addition, stigma posed a serious problem to PLWHA and people associated with them as judgment from family members can be one of the worst personal struggles that PLWHA have to deal with, these often leads the infected individuals with existential questions about the meaning of their infection, their behavior as well as their HIV status as it relates to their family relationships (Pretorius et al, 2015).

4.2.2.3 Stigma and self-stigma

Because of AIDS stigma people who are aware of their status do not like to disclose it while at the same time still engage themselves in risky behaviors often with uninfected partners. Below are some of the client responses;

"I thought of telling my family about my status but I had a fear that I will be neglected and they will no longer continue to pay my fees at varsity and also take back the car they bought me on my 21st birthday party, hence they will assume that I got sick because of the car since having one at varsity is an advantage to women in campus, so I decided to stop treatment during school holidays when am at home and continue again when am back in campus. Am trying by all means to quit smoking and drinking alcohol because of my disease but it's not that simple because am already used to it'' Client (no; 07) Male-25-years-old.

I stopped taking the ARVs to save my marriage, my husband and his family was taking care of me while giving me anything that I need to make my life simple, so there was no way that they will love me if they knew that am HIV positive and am taking the ARV treatment. Client (no: 06) Female-26-years-old

Earnshaw et al (2013) self-stigma and HIV disparity model explicated three types of stigma including internalized stigma or self-stigma defined as the devaluing and discrediting of a person or a group because of stigma. Disease stigma consequently is the social link between a disease and negative behaviors toward a person or group with that particular disease within the social sphere (Deacon et al, 2005). AIDS stigma results in silence and denial, self-blame, rejection, violence, self-isolation, failure to disclose one's HIV status, secondary stigma of HIV services providers and so forth. HIV/AIDS stigma is related to negative emotions including shame, guilt, fear, and anxiety and self-blame. Not disclosing sero-status disrupts relationships, get in the way of social support provision, and reinforces negative feeling of shame and guilt. Disclosure of infection status on the other hand leads to adverse effects including family disintegration, isolation of HIV infected and affected people, divorce and discrimination by the family and the

community. Perceived stigma refers to the appraisal of experiences of prejudice, stereotypes, and discrimination from others in the past and anticipated stigma is the expectation of such bias to occur in the future. Hence, there are perpetuators and targets (passive victim) of stigma, with stigma existing at individual, family, health care setting and community levels (Earnshaw et al, 2013).

4.2.2.4 Government social grant /Social dependency syndrome

Poverty can affect ones adherence to ARV treatment. ARV needs to be taken with food to ensure that the mechanisms of action on each drug is able to function properly. South African government together with the department of SASSA took an initiative of providing a social grant for only 12 months for clients with CD4 count of less than 150 and are clinically sick and also unemployed to enable the clients to buy nutritional food for their body. Hence, clients of Matoks village since there is high unemployment rate, they tend to take these social grant money as their source of income. One of the client responded the following:

''Immediately after I was initiated on ARV's, the social worker from Matoks clinic decided to assist me with a social grant from SASSA to enable me to buy myself nutritional food. Since am an HIV positive single mother with 04 children and am not employed, the grant I get for my kids is not enough. So the grant for my HIV/AIDS condition was assisting to provide for my family. After 12 months they collected blood for my CD4 count at the hospital and it was 650, so on the 13 months I went to collect my monthly social grant at the ATM, only to find out that my social grant was cancelled. When I enquire at SASSA they said it was only for 12 months and they can't renew it since am physically well and coping well with treatment. So I decided to stop taking the ARV's so that my CD4 count will drop and get sick in order to qualify for SASSA grant and provide for my family'', Client (no: 08) Female-40-years-old. (In sepedi).

"Although I did not disclose my status to my employer because I was scared that I might not get the job if he knew about my status, I feel so lucky to be one of the clients who

qualified for SASSA grant since the money assists me and my family with some of our needs. Client (no: 10) Female-34-years-old.

The social grant from SASSA to HIV/AIDS clients is made to assist the clients for a short period of time but most unemployed clients are using it as a source of income to their families. Furthermore, clients have developed strategies to make sure that they keep on qualifying for social grant, thus resulting as a burden to the government in terms of increasing the budget for social grant and for buying expensive ARV drugs for second and third line regimen since defaulting treatment frequently results in clients developing drug resistance.

4.2.2.5 Employment and unemployment issues

The study revealed that clients who are self-employed had no problems in keeping appointments than those who are formally employed. Those who were formally employed faced challenges in meeting the review dates as they wanted to minimize the frequency of absenteeism at work, hence were suggesting a supply of up to 3 months but since there are challenges of the supply of ARV's from the depot to the clinics, sometimes there are shortages of ARV's to such an extent that one client could not get treatment for 3 months to avoid absenteeism at their perspective work place, these results in clients being compelled to go to the clinic to collect ARV's on a monthly basis. It was also noted that clients who did not disclose their HIV status to their employer found it very difficult to ask for time off from work to go for their monthly reviews. Below were some of the participants' responses:

''I am a truck driver who drives nationally and intentionally, sometimes on the due date for the collection of treatment, you may find that am out of the country. Furthermore, I was told to drink the ARV's at night because they are sedative, so I decided to stop taking the ARV's since I sometimes drive day and night and I cannot skip work and go to the clinic while am working for my family'', Client (no: 09) Male-43-years-old.

''It is difficult for me to ask for permission from my employer every month to come for the reviews, since I did not disclose to my employer he would become suspicious now because I excuse myself from work every month and almost on the same dates, so I only go to the clinic when I get a chance and this mean that sometimes I can spend 02 weeks without taking ARV treatment'', Client (no: 10) Female-34-years-old.

This study clearly shows that clients who were self-employed or had their own businesses adhered better than those who are formally employed as they had no hustles in trying to obtain permission from their employers. Only if the ARVs where affordable, clients would buy themselves at pharmacies during their lunch time or spare time at work since there are no long queues at private sectors. Maokisa (2011:32) that making cost of ARVs affordable and provision of other ART treatment related costs contributed to adherence.

According to the South African employment equity act No; 55 of 1998 in terms of prohibition of unfair discrimination "no person may unfairly discriminate, directly or indirectly against an employee in any employment policy or practice on ore more grounds including race, gender, sex, pregnancy, marital status, family responsibility, ethnic or social origin, color, sexual orientation, age, disability, religion, HIV status, conscience, belief, political opinion, culture, language and birth''. The purpose of this Act is to promote equal opportunity and fair treatment in employment through the elimination of unfair discrimination.
The employee have the right to go and consult when he/she is sick while at work or go and collect treatment to promote good adherence to treatment.

4.2.3 THEME 3: PROVISION OF SERVICE DELIVERY

The third theme that emerged was service delivery offered by the health workers at the local clinics. Theme 3 was further categorized into two categories and these entailed a poor interpersonal relationship between health care providers and the clients. Poor relationship with health care providers, long waiting period of time, and accessibility of ART were some of the facilitators to ART non-adherence.

4.2.3.1 Client to health care provider relationship

A good interpersonal relationship between clients and health care providers was found to be a strong facilitator to ART adherence but most of the clients showed that to be helped by a health care provider who knows you, it makes them to feel uncomfortable and makes them lazy to come and collect treatment. Below were some of the participants' responses:

''Nurses attitude when they see a green card with a client it's very painful, just because I get a little time to go to the clinic at 1pm while it's the nurse's lunch, they will talk to me in a harsh manner telling me why I did not come in the morning and not realizing that am in a uniform to show that am still at work. The receptionist shouted at me with other clients while I was at the waiting area saying that "all clients with green cards, the ARV's are not yet available and they should go and collect them at the hospital'', Client (no: 11) female-37-years-old.

"Although I stay very far away from the clinic and in my village there is no transport, it is very painful to walk a long distance to the clinic and when you arrive at the clinic, the nurses gives you a bad attitude and close themselves inside their consulting rooms and say they are on lunch. Am going to wait until they open again and get the ARV treatment and walk for another 03 hours to home. So it became too much for me to such an extent that I felt it was better to stop taking the ARV treatment. "Client (no: 13). Male-40-years-old."

According to a study done by Ganiyu (2014), the need for attitudinal change among some of the health care workers providing health care services to patients particularly the nurses, receptionist and admin clerks should be implemented to maintain a good working relationship between the clients and other patients and the health care providers. Similar findings were found in a study by Chizanga (2010:164), Do et al (2013:5), Ross et al (2011:4) that friendly and trusting relationship between clients and health care providers enabled clients to cope with their illnesses and also it encouraged clients to adhere to ARV treatment. Friendly and trusting relationship between clients and health care providers enabled clients to cope with their illnesses and also it encouraged clients to

adhere to ARV treatment. Furthermore, health care providers who have personal vendetta against clients because they are from the same community contributes to clients defaulting treatment.

4.2.3.2 Long period of waiting

Findings from this study indicated that service delivery was very bad as clients were served after a long period of waiting time. If clients are attended early they can always keep their appointments as long waiting hours are reduced because it frustrates the clients thereby forcing them to miss their appointments. Below are client responses:

''I came to the clinic at 5am and the clinic opens at 7am and I get to be assisted at 10am, this consumes most of my time when am waiting for assistance and it's not good for me and my family since am self-employed and time is money. So I decided to stop the treatment since am not feeling sick and I want to work for my family'', Client (no: 12) Male-37-years-old.

Am working at an Indian supermarket, I work every day to be able to get my salary with over time money in order to be able to provide for my family. I only get time to rest during my 01 hour lunch in which once per month I used to go to the clinic to collect my ARV treatment hoping to be assisted within that 01 hour so that I can rush back to work but it was not happening like that because the long period of waiting was too much and I couldn't risk losing my job because of over waiting and exceeding the time I was given by my boss while waiting to collect the ARV treatment. Client (no: 11) female-37-years-old.

Clients are more likely to miss their appointments if they are not attended within a reasonable time, they get impatient of long waiting period. South Africa currently has the largest antiretroviral programs globally and the need to decentralize traditionally hospital-based HIV treatment and care services to PHC, where care is primarily nurse-led has become apparent with an increasing patient volume. (Crowley et al, 2015). The purpose of decentralization is reduce the long period of waiting at Botlokwa hospital in Matoks since the dispensary pharmacy has a large number of patients to give different

medications to each and every patient entering the hospital. Long period of waiting to collect ARVs due to long queues at the clinic and shortage of nurses and high numbers of clients on HAART, combined PHC services with ART services delays the queue for the clients whom are at the clinic to collect ARVs and it results in clients missing their perspective dates of collection of ARV treatment and some results in defaulting the treatment. According to a study done by Ganiyu (2014), the establishment of more outlets where clients can easily pick up their drugs as a strategy of improving proximity to the care and reducing client waiting time.

4.2.3.3 Lack of transport to the clinic

Matoks is a deep rural area where transportation plays a major role in delaying progress of service delivery to the community members due to roads and infrastructures. Most clients who lives far away from the clinic are unable to get the benefits of ART properly because most of them are unable to come to collect ARV treatment due to lack of transport.

"Although I was told at the clinic that the ARV treatment should not be discontinued, sometimes I was unable to go to the clinic to collect the ART because I stay very far away from the clinic and there's a lack of transport in my village. The day that I get a chance for transportation I make sure that I go to the clinic to collect the ARV treatment "Client (no: 13). Male-40-years-old.

"I stay at Ga-Phasha village which is the first village of Matoks and it's extremely separated from other villages of Matoks by Dwaars River, there few transports in my village but since am unemployed and I can't afford to pay for transport to the clinic to collect ARV each time every month. I used to walk there with other village members to the clinic because to walk there alone is dangerous and scary since it's a long walk in the middle of the bushes. So I was not able to collect the ARVs in time and sometimes I had to default treatment because I couldn't go to the clinic and get them" Client (no:14) female-38-years-old.

It has been shown that people living with the Human Immunodeficiency Virus (HIV) and the Acquired Immunodeficiency Syndrome (AIDS) can a live normal and healthy life on condition that they receive their antiretroviral medication (ARVs) on a continuously without their treatment schedule being interrupted (Mkhoseng et al, 2016). Findings from this study revealed that most individuals discontinued ARV treatment when they were supposed to go and collect their monthly treatment and they couldn't go because of transport and walking to the clinic was not an option since the clinic is very far from villages like Sekakene and Ga-Phasha in Matoks.

4.2.4 THEME 4: MEDICATION FACTORS

The fourth theme that was identified entails factors that are related to medication. Shortage of drug supply of ARVs and pill administration were the two categories identified in these theme 4.

4.2.4.1 Access of ART at clinic and shortage of ARV supply

Matoks clinics had problems of experiencing delivery of ARV drugs, hence the clients where being referred to the community hospital to go and collect them. Furthermore, clients had to use their own transport or pay for a taxi since they could not walk to the community hospital since its far. These resulted in clients missing doses while waiting for the ARV supply. Below is some of the participant responds:

"Sometimes when I think of going to the clinic I think a lot because I borrowed money twice and went to the clinic to collect ARVs and I found that there are other ARV tablets which are not available and I have to come back again and check for them, I have to make another plan for transport to come back to the clinic'', Client (no: 15) Male-45-years old.

"Although I was told at the clinic that the ARV treatment should not be discontinued, sometimes I was unable to go to the clinic to collect the ART because I stay very far away from the clinic and there's a lack of transport in my village. The day that I get a chance

for transportation I make sure that I go to the clinic to collect the ARV treatment "Client (no: 13). Male-40-years-old.

Easy access to ART centers and affordable transport costs promotes adherence. Findings from this study indicates that clients who stays far away from the clinic were having problems of accessing ART due to the distance of going to the clinic and also due to lack of money for transport which is also scarce due to high unemployment rates. Availability of distance to the clinic and transport costs were found to be an issue as the ART clinic was not easily accessible. Patients who had easy access to ART clinics were more adherent than those who spent long hours travelling to collect treatment but those who stayed near the clinic at some time, they also failed to adhere to treatment due to shortage of ARV. According to Mokhoseng et al (2016) that people living with the Human Immunodeficiency Virus (HIV) and the Acquired Immunodeficiency Syndrome (AIDS) can a live normal and healthy life on condition that they receive their antiretroviral medication (ARVs) on a continuous, uninterrupted basis. However, with uninterrupted Antiretroviral Treatment (ART) the level of HIV in an infected person's body is kept at minimum levels and further weakening of the immune system is stopped since the virus can become dormant and the lives of HIV and AIDS infected persons prolonged.

4.2.4.2 *Pill burden*

ARVs are taken on a daily basis and are a lifelong treatment that needs commitment from the individual. Taking too many pills on a daily basis was identified as a factor that may contribute to non-adherence as reported by participants:

"The pills are too many, find a cure because taking ARVs for life is not easy, can't there be a monthly injection to replace every day pills?" Client (no: 16) Male, 28-years-old.

"I was taking ARV of one pill but I was not drinking them well and sometimes had to default because I travelled a lot doing my piece jobs to survive, I was re-initiated several times on ARV but the last time I quitted drinking ARV was when the nurse told me something about drug resistance when I was waiting to be re-initiated again. I was given 03 bottles

of different ARVs in which the nurse explained to me that it's a second line ARV treatment for HIV. I asked her why does she not continue with the one pill ARV she was giving before, she said I defaulted that ARV treatment several times to such an extent that I have developed resistance to that ARV and it can no longer function in my body. I drank the 03 types of ARV pills for few weeks and quit since they were so many and I couldn't take it anymore" Client (no: 17) male-45-years-old.

"I started taking ARV's of 3 pills, then they changed them I had to take 2 pills and then again they changed and I had to take 1 pill per day and only at night, so the one pills was not like the first 3 pills I had before because they use to make me sick, so I decided to take a break from the pills since am feeling okay". Client (no: 02) Female-56-years-old. (In sepedi).

Pill burden was mentioned as one of the factors that may contribute to low adherence levels hence clients preferred a monthly injection or a fixed dose tablet. Furthermore, clients whom did not qualify to get a fix dose combination are more likely to default due to the use of many ARV drugs to use. Pill burden was mentioned as one of the factors that may contribute to low adherence levels hence clients preferred a monthly injection or a fixed dose tablet. The findings of this study are concurs with those of Marukutira (2012:63) that pill burden and dosing times affected adherence levels.

4.2.5 THEME 5: CULTURAL AND RELIGIOUS BELIEFS

The fifth theme in these study was able to distinguish between cultural beliefs of the clients with their religion. These two categories played a role in contributing the clients to default treatment, furthermore, they are discussed below according to the perspectives of the participants.

4.2.5.1 Cultural beliefs

Culture plays an important role in determining the level of health of the individual, the family and the community. This is particularly relevant in the context of South Africa where values of extended family and community significantly influence the behavior of the

individual. The behavior of the individual in relation to family and community is one of major cultural aspect that has implications for ARV treatment and HIV/AIDS disease. Matoks village is a deep rural community where cultural factors plays an important role in the way that the community members treat different diseases. Furthermore, these cultural beliefs to some clients cannot be avoidable since they say they have lived by them and they have kept them alive thus far.

"Once I was diagnosed HIV positive, the nurse assisting me collected blood and explained everything to me and I was initiated on ARV a week after. I started drinking the ARV treatment and get sicker and sicker, so I decided to stop the ARV treatment and *went to see my family traditional healer to assist me with my sickness'', Client (no: 18) female-52 years-old. (In sepedi).*

"I felt like am bewitched because I was not sleeping around after my late husband died, sometimes when am alone I think of going to see a traditional healer hoping to get a better explanation than the one I got at the hospital". Client (no: 01) Female-58-years-old. (In Sepedi).

Cultural beliefs of the participants played a role of contributing the clients to default ARV treatment. These means that the health care providers are not providing adequate information to the community including traditional healers. Point of departure in understanding how people make sense of their illness, the client's cultural beliefs and practices must be explored. This concurs with a study done by Kheswa (2013), that many South Africans who are reluctant to know their health-status, hold on to the myth that HIV/AIDS was developed by White people to control their black counterparts, and that also contributes to non-adherence. Since in South Africa, 60 to 80% of people especially in rural areas (e.g. Limpopo, KwaZulu- Natal and Eastern Cape) rely on traditional healing for mental and physical treatment found that an alarming proportion of HIV- positive people have the tendency to stop taking their ARVs once they had sought help from traditional healers.

4.2.5.2 Religious beliefs

Every human has his/her own religious beliefs that they have been following from childhood and in adulthood, most participants believed that these religious beliefs has helped them to survive thus far. Hence, HIV/AIDS disease is regarded as a punishment from God and these results in different religions treating the same disease differently. Below were some of the participants' responses:

''My pastor stopped me from taking ARVs when I disclose my status to him, he prayed for me and I believed in my pastor and the almighty God that these virus will not do anything to me in my body, so I stopped the ARV after the prayer and felt so relived since the ARVs were making me more sick after taking them'', Client (no: 19) female-36-years old.

"I did visit a pastor after being diagnosed with HIV positive and I was on treatment of ARV, I visited the pastor because I did not understand how I got infected because my husband died a long time ago and all I was doing was caring for my grandchild because his mother who is my daughter passed on by (phamokate). The pastor prayed for me and told me to stop using the pills (ARVs) from the clinic and follow his rituals so that I can be cured, I got tempted to quit drinking the ARVs and follow the pastors rituals but before I quit the treatment, I spoke to my 1st born about it and he did not agree with it and I did not quit since I was already physically sick, I continued with the ARV treatment". Client (no: 02) Female-56-years-old (In Sepedi).

Pastors/Prophets and Sangomas should be well educated about HIV/AIDS so that they can understand the disease in full details so they could understand it from the virus itself and how it behaves inside the host, all modes of transmission and lastly about the ARVs in full details and the importance of the clients to adhere to treatment. Furthermore, they should continue with their practices but should avoid making the clients to stop the ARV treatment. A study by Mbirimtengerenji et al (2013:20-21) also revealed that most Christians adhered to ART than other religions whilst non-adherence was also noted in

some strong religious believers who believed that God had supernatural powers and heals HIV and AIDS and discontinued treatment.

HIV stigma is shame related, as it is believed that HIV is a punishment from God or people living with HIV/AIDS have not followed the word of God. PLWHA who disclose to their pastors, a prayer is conducted to cure HIV and because of the patient's faith and fear of doubting God's abilities, they stop the ARV treatment. In both developed and developing countries, patients tend to respect their religious beliefs alike, (Kheswa, 2013).

4.3 SUMMARY

Findings from the study were discussed in this chapter. Five main themes emerged from the responses from participants and these were mainly related to patients' knowledge levels of HIV/AIDS, social support, service delivery, medication factors, cultural beliefs and religion. Discussions compared findings from this study with previous studies shows that there is still a lot of work that the department of health and health care providers should do to re-enforce adhere in the clients and community members.

CHAPTER 5
SUMMARY OF RESEARCH FINDINGS, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION

5.1 INTRODUCTION

This chapter presents a summary and interpretation of the research findings, recommendations, limitations of the study and conclusion. The study investigated factors contributing clients to defaulting ARV treatment at Matoks. Findings from the study will be used to improve the ART program thereby ensuring that patients on ART will fully enjoy the benefits of ART if they maintain high levels of adherence.

5.2 PURPOSE OF THE STUDY

To investigate factors contributing to clients defaulting treatment at Matoks

Conclusion in relation to the objectives of the study

- To explore factors contributing to clients defaulting anti-retroviral treatment at Matoks
- To describe factors contributing to clients defaulting anti-retroviral treatment at Matoks

The central question “What” used during the interview and probing questions yielded the following sub-themes

5.3 SUMMARY AND INTERPRETATION OF THE RESEARCH FINDINGS

Five themes emerged and these were mainly related to patient’s knowledge on HIV and AIDS and ART, social support, service delivery, factors related to medication, cultural beliefs and religion impact of the indigenous value system.

5.3.1 EDUCATION ON HIV/AIDS, ART AND SIDE EFFECTS

Participants had a slight idea about HIV/AIDS disease but they did not know about the disease process and how it functions inside their body when they are infected. They just knew that HIV/AIDS is a disease that is shameful and it should be a secret and should

not be disclosed to people. Although they were educated about ART during counselling, participants showed that only few side effects were mentioned and they were told that if they come across them they should visit the clinic but they were not told on how to care for themselves during the period of side effects since most participants who experienced the side effects stayed far away from the clinic and some had transport issues.

5.3.2 SOCIAL SUPPORT

Social support was the second theme identified that was unable to facilitate adherence to ART. Clients whom were not fully supported physically, psychologically, socially, emotionally and spiritually were the ones who defaulted ART. Patients whom were self-employed adhered better than those who were formally employed as they did not have to obtain any permission from their employers to go and collect treatment. However, the study revealed that participants, who were depressed, stressed and had not disclosed their HIV positive status failed to adhere to their treatment as they were not getting the necessary support to adhere to ARV treatment.

5.3.3 SERVICE DELIVERY

The study shows that the clients were not happy or satisfied about the service delivery at Matoks because of long waiting time frame on the queue, the distance to go to the clinic, lack of transport from their places and the bad attitudes of health care providers if they arrive late at the clinic or during lunch time.

5.3.4 MEDICATION FACTORS

Clients complained about shortage of ARV treatment which contributes to them not to come and collect treatment during their perspective appointments, hence they get some ARV treatment and short of other ARV drug/s and which they have to come again after few days to check on them even though they live far from the clinic. Furthermore, other clients complained about many ARVs that they have to take every morning and evening every day of their lives. They further said that those patients whom are taking one tablet per day are better than them, they wish there was an injection for ARV that perhaps they can get every month because they are tired of drinking many pills per day.

5.3.5 CULTURAL AND RELIGIOUS BELIEFS

The last theme of the study is the cultural beliefs and religious belief. The study showed that these two aspects has mislead most clients due to lack of knowledge about the disease process and the ARV treatment, how it functions in their body and the importance of drinking them as prescribed and adhering to them. Furthermore, the trust they had in cultural and religious beliefs contributed a lot in leading the clients not to adhere to ARV treatment. Prophets and Sangomas had a slight understanding of HIV/AIDS that's why they contributed in misleading clients in defaulting ARV treatment.

5.4 INTEGRATION OF FINDINGS RELATED TO THEORETICAL FRAMEWORK

Orem's general theory of nursing has been selected as a theoretical framework within the parameters of which to contextualize and explain the factors contributing to clients defaulting Anti-retroviral treatment at Matoks, Capricon District, Limpopo Province.

According to Orem (George, 2002) nursing is concerned with individual's needs for self-care action and the provision and management of it on a continuous basis in order to sustain life and health, recover from disease or injury and cope with the effects. She further defines it as an art and prudence, a service, role theory related to technologies and a comprehensive determination on why people can be helped. Orem's general theory of nursing consists of self-care, self-care deficit and nursing systems.

Theory of self-care

The theory of self-care includes self-care, self-care agency and therapeutic self-care demand and self-care requisites.

Self-care- Is the practice of activities that individuals initiate and perform on their own behalf in maintaining life, health and well-being, which contributes to human structural integrity, human functioning and human development (George, 2002). Clients on ART are believed to be able to take care of themselves since health education was given was given to them during counselling before the initiate them on ART. Findings from the study

has showed that most clients were not able to take care of themselves by defaulting ARV treatment and continuing with unprotected sex.

Self-care agency –Is the human ability in engaging in self-care, based on their developmental state, socio-cultural orientation, health and available resources (George, 2002). Clients did not show their abilities to care about themselves by not going to clinic during their appointments for ART refill.

Therapeutic self-care demand –This refers to the totality of self-care actions to be performed for some duration in order to meet self-care requisite (George, 2002). Clients were not taking ARV treatment prescribed and not living a healthy lifestyle. According to Mkhoseng et al, (2016) people living with the Human Immunodeficiency Virus (HIV) and the Acquired Immunodeficiency Syndrome can a live normal and healthy life on condition that they receive their antiretroviral medication continuously without interruptions.

Self-care requisite –They are actions directed toward the provision of self-care and are common to all human beings during all stages of the life cycle (George, 2002). Clients require specialized self-care to prolong their lifespan but the findings from the study showed that clients are careless and do not put much effort to adhere to treatment, hence they end up defaulting ARV treatment.

Theory of self-care deficit

The theory of self-care deficit is the core of Orem's general theory of nursing because it delineates when nursing is needed. Nursing is required when a client is incapable or limited in the provision of self-care

All clients before being initiated on ART they went through counselling sessions as a way to emphasize adherence to ART they will be using lifelong. Although health education was given especially about side effects when the clients start with the ART, how to deal with the side effects and when to come back for checkup was offered to the clients but most of them defaulted the ART due to lack of transport to the clinic and the distance

between their perspective homes and the clinic. Some clients defaulted due to their cultural and traditional believes and these resulted as a way of not caring for themselves.

Certain factors played a role in contributing to the clients to default Anti-retroviral treatment which resulted in poor self-care for each client.

Theory of nursing systems

The nursing system is designed by the nurse based on self-care needs and abilities. The nurse utilizes the supportive-educative system since the adolescent is doing all herself care, but required to make decisions, control behavior and acquire knowledge and skills on contraceptives. With supportive –educative system the adolescents are assisted to perform the required measures through: Guidance, supporting them physically and psychologically, providing an environment that promotes personal development to meet the present demand of care and teaching (George 2002).

Clients need to care for themselves as a way of adhering to treatment, many clients do not manage to achieve optimal levels of adherence and failure to suppress viral replication completely inevitably leads to the selection of drug-resistant strains, limiting the effectiveness of therapy. Sub-optimal adherence to ART is the strongest predictor of failure to achieve viral suppression below the level of detection and most often underlies treatment failure. Although there are several factors that seems unavoidable that makes the client not to adhere to treatment, clients should live a healthy lifestyle as a way of caring for themselves continuously.

5.5 RECOMMENDATIONS

Recommendations were based on the challenges expressed by clients in making them adhere to the long life antiretroviral therapy. The following are the recommendations that has emanate from the study.

5.5.1 Availability of food

Most clients indicated that securing enough food was a challenge to them since most of them are not working, therefore they needed to be assisted with food. To curb this problem there is need to look for more donors that can assist with food to clients on ART whom are unable to get food for themselves irrespective of their nutritional status. It is also recommended that assistance with income for self-projects will help PLHWA to generate income that would enable them to cater for costs such as transport and other health costs.

5.5.2 Self -stigma

Self-stigma is still a challenge with some clients on ART. Adherence and counselling is needed for clients with self-stigma, hence it will help them to accept their disease condition and live a less stressful life with no isolation from other people and this will help them to collect treatment freely.

5.5.3 Service delivery

Most clients were not happy about the service delivery that they were not getting from Matoks clinic because of long waiting periods on the queue, the distance to the clinic, and shortage of ARV treatment during the appointment date. To curb this problem, the department of health should hire more health care workers and extend the program of home based care to assist in delivering ARV treatment to those clients who lives far away from the clinic and has transport issues.

5.5.4 Pill burden

Clients' responses indicated that it was not easy for them to remember to swallow many pills on a daily basis and to follow the prescribed schedules, therefore recommended to program planners to come up with a monthly injection, all ARV including second line and third line regimen should also be a fixed dose combination pill or find a cure for HIV.

5.5.5 Verbal abuse/domestic violence

Some clients indicated that verbal abuse and domestic violence impacted negatively on their adherence. Therefore there is need to enforce the law that can protect them from the verbal abuse from their relatives and spouses.

5.5.6 Target traditional healers and pastors on adherence

From clients responses, traditional healers and pastors including prophets should be taught about HIV/AIDS and the ARV treatment. Teach them in workshops about the disease process and the mechanisms of action on ARVs so that they could emphasize adherence during each consultation from their clients. The fore, there is a need to intensify health education on HIV and AIDS and stress on importance of ART adherence to pastors, prophets and traditional healers, these is evidenced by some clients who temporarily discontinued treatment after being ill advised by religious people.

5.5.7 Stigma and discrimination at work

Despite HIV work related policies that were introduced at perspective workplaces, it came out that clients on ART were still experiencing work related stigma and this affected their adherence to ARV treatment. Therefore there is need to ensure that the HIV policy is enforced and respected at every work institution including to house maids, transport employers. Every HIV positive client must be able to go collect ARV treatment irrespective of their job description.

5.5.8 South African Social Security Agency

The role of the social grant to HIV positive people is to maintain their nutritional status by giving them money to buy themselves food but most clients in the study were using it as a source of income. Furthermore, the clients have developed a strategy to maintain the social grant by defaulting treatment so that when they go to the clinic to be collected blood for viral load and CD4 count during their yearly routine, the CD4 count will remain low and they continue with the social grant. Therefore, there is a need to revise these grant policy for PLWHA because it's one of the major sources contributing to clients defaulting ARV treatment in Matoks.

5.6 LIMITATIONS OF THE STUDY

Selection bias may have occurred due to the nature of non-probability studies which uses the purposive sampling method to select study clients. The sample size limits the findings to be transferable to the larger population or District as a whole.

Recommendations

- Counsellors provide adherence counselling properly in order to enhance adherence to antiretroviral treatment
- Empowerment to PLWHA to accept the diagnosis to be self-reliant, avoid dependency
- Discrimination and stigma should be eliminated through changing mindsets and attitudes of individuals and communities.
- Indigenous beliefs should be dispelled through education and collaboration with religious and traditional stakeholders

5.7 FUTURE RESEARCH

The study was conducted to clients whom had been on ART for the minimum of 06 months and more, and has not been collecting treatment for at least 2 consecutive months and has volunteered to participate in the study through a consent form. So there's a need to conduct a research study on adherence indicators or monitoring mechanism of adherence.

5.8 CONCLUSION OF THE STUDY

Poor adherence to ART constitutes a major problem due to development of resistance to drugs, curtailing new strands of the virus. The study highlighted lack of education/ poor knowledge, social support, service delivery factors, medication factors and the impact of indigenous value system. In order to increase adherence to the appropriate level there is a need to be concerted effort of health workers, communities and non-governmental institution to ensure drug supply, patient education and social support.

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ANNEXTURE 01

INTERVIEW GUIDE FOR ART DEFAULTERS

Procedure:

Patients will be recruited via the ART computer program (TIER.NET) with the assistance of data captures whom will be able to see all patients on ART whom have not come to the clinic to collect their ARV treatment for the period of 03 months and above. The participants who meet the selection criteria (18 years and above and has not been collecting ART for more than 03 months) will be informed verbally about the study by the lay counsellor telephonically and as for those whom cannot be reached telephonically, the DOT supporters will inform them and a choice will be given to the participants to meet with the researcher or to decline. The researcher will explain to the participants' details of the study, then will hand over letters explaining the study and patient consent forms requesting permission to conduct the interviews with them as well as permission to audiotape the interviews. Once the letters of consent are returned, appropriate arrangements will be made for interviews to be conducted.

1. **What are the factors contributing to clients to default treatment?**

   Probing:

   - What made you to stop taking ARV treatment? / What are the factors that made you to stop ARV treatment?
   - In your opinion, what should be done to overcome the factors that made you to stop taking ARV treatment?

ANNEXTURE 02: Informed consent

PARTICIPANT CONSENT FORM

I…… Of…….hereby consent to participate in the study entitled Factors contributing to clients defaulting ARV treatment at Matoks, Capricorn District. It has been explained to me by Ratshihume Phumudzo Terrence and I confirm that I understand the nature of the study as it has been fully explained to me in details.

I have also been assured that I have the right to decline participation or withdraw from study at any point during the study without reprisal and or discrimination from the researcher or staff members of Matoks clinic.

I have been guaranteed the utmost confidentiality in the handling of the information and data about me. Any concerns about the study on my part have been adequately addressed. The researcher has also appealed to avail himself if and when any other concerns may arise from my part.
Signed……..Date…….

I confirm that I have fully explained to the participant the nature and scope of the study and the contents of this consent form in details. I confirm that no coercion or remuneration, monetary or otherwise has been offered to the participant to participate in the study.

Researchers signature…….. Date ……

ANNEXTURE 03

Transcript of a Client Interview

Interviewer: Good morning and how are you.

Participant: Morning to you too, am fine thanks for asking.

Interviewer: Thank you so much for allowing me to see u and also for being able to freely participate in my study.

Participant: My pleasure

Interviewer: Tell me about your life before you become HIV positive and how it is different from now while you are HIV positive.

Participant: Eish, that's a tough one and I really don't know where to begin

Interviewer: You can start anywhere its fine, as long as you feel comfortable about it
.

Participant: My life was quite okay when I was still having a boyfriend with no kids at secondary but the situation at home in terms poverty was different, when I was doing grade 11 I became pregnant with my first child and the father of my baby was supportive although he was doing piece jobs to support me and the baby.

***Interviewer*:** When you say the father was doing piece jobs to support you and the baby, where you not getting a grant from SASSA?

Participant: I got the money but it took some few months to get it after registering for it at SASSA.

***Interviewer*:** Okay

Participant: I then decided to quit school since I was not passing well at school also and I wanted to be a full time mother to my baby. But then again I got pregnant again and again and again and during my third pregnancy I was told that am HIV positive and the father of my kids was now working in Gauteng doing his piece jobs that side and I was depending on him for child support as well as the SASSA grant for my kids. He then left me for another wife in Gauteng and he stopped to support me and his kids.

***Interviewer*:** Am sorry about that

Participant: It's okay, I tried to report him to social workers for him to support me but they failed because he had no stable job since he was doing his piece jobs. Because I am not educated and I don't even have matric, I decided to stop dating and focus on helping my kids grow and I got a job at an Indian supermarket here at Matoks complex, although the salary was little but it was much better than not working at all.

***Interviewer*:** So how is the work going so far?

Participant: Not that bad because I can combine my 04 kids SASSA grant money with my salary and try to survive by it.

***Interviewer*:** So what made you to stop taking monthly ARVs at the clinic?

Participant: I used to take them well without disruptions but other workers from the supermarket were stopped from work but luckily I was not stopped, so our lunch time here at work is very few minutes. I once defaulted for 7 months and become very sick to such an extent that I almost got admitted in the hospital. When I was in the process of being reinitiated again on ARV, a social worker came to with a nurse and my file.

***Interviewer*:** What did the social worker need from you with a nurse?

Participant: The social worker said to me, because am clinically sick and my CD4 count it's very low I qualify to get a SASSA grant for being HIV positive. I couldn't believe what she was telling me because I didn't know that people whom are HIV positive get a grant from SASSA for being HIV positive. At first I thought she was joking but the following month I believed her when I went to collect the money during pay day of SASSA and I was so shocked and happy at the same time.

***Interviewer*:** Okay

Participant: I then combined my salary from the supermarket together with my new income from SASSA and with my 04 kids social grant from SASSA and things where much beta at home. Because of the grant money I was getting I was doing everything possible to ensure that I don't miss my appointment for collecting ARVs in fear of my grant money that could be cut if I don't comply maybe.

***Interviewer*:** So you saying that the grant money made you to comply with HIV treatment?

Participant: (laughing) yah you can say so because my salary was not enough for my kids and other siblings since am a single mother.
***Interviewer*:** so what then?

Participant: Eish, things started to be hard on the 13th month of going to collect the social grant money.

***Interviewer*:** What happened?

Participant: I did not get paid and I was told to go and enquire at SASSA to know the reasons why my social grant was stopped. I was told that the grant was only valid for 12 months and it was only assisting me to gain weight by buying nutritional food but to me I was using it as another source of income to my family. Then I get to realize that all those efforts I have put to ensure that I drink treatment and to never miss any appointment for

collecting ARVs, I blame those efforts for discontinuing my SASSA grant because when they review my viral load after 12 months of taking ARV, they said that my viral load is very low and I no longer qualify for that grant.

***Interviewer*:** And then?

Participant: I defaulted ARV treatment for another 07 months so I can be sick again and qualify for that kind of grant since it was very much helpful in my family

.

Interviewer: so what happened after 07 months of not collecting ARV treatment?

Participant: I became very sicker than the last time I defaulted treatment

Interviewer: And then?

Participant: I was put back on ARV treatment again and that time the pills I was using them at first where not working properly and the new ARV drugs were given to me and I start to become physically fit and strong and my viral load was decreasing, said the clinic nurse.

Interviewer: Were you given the SASSA grant again?

Participant: Yes I was.

Interviewer: Since you got sicker than the last time you defaulted ARV treatment and took a long time to recover while the new AARV drugs were introduced to you so that you can be okay and pick up, will you ever default ARV treatment again in order to qualify for the SASSA grant?

Participant: No offence but yes I can default ARV treatment.

Interviewer: (laughing) why would you do that, you can die and leave you kids suffering without you by your side?

Participant: Only if you were a single mother working at an Indian market with 04 kids and other siblings, you would do whatever it takes to support your family by doing anything possible to put the food on the table for them.

Interviewer: How old are you if I may ask?
Participant: 40 years old

Interviewer: Are you a Christian or you follow traditional ways?
Participant: (laughing) both

Interviewer: According to your situation, what do u think could be done to avoid/stop the clients from defaulting ARV treatment? Remember that when you default ARV frequently, you develop something called drug resistance which makes it impossible for a client to use the same ARV drugs he/she was using before defaulting treatment because they won't function inside the body and that is why you were also given new drugs when they reinitiate you again on ARV drugs. Those drugs are called second line regimen, if you default again they reinitiate you with third line regimen if your body has developed drug resistance for regimen two, hence the second and third line regimens are very expensive that is why it is advisable to ensure that all clients remains in regimen one and that is being ensured by making sure that all clients are not defaulting ARV treatment of regimen one which is less expensive.

Participant: (shocked) Eish, I did not know much about that information but I think people like me whom are HIV positive and not working well like I do should be given the SASSA grant until they die to avoid them from defaulting ARV treatment and make the government spend more money for buying the expensive ARVs for defaulters.

Interviewer: Don't you think that will make everyone to want quit their jobs and sit down and wait for the grant money every month?

Participant: (laughing) I was talking on my side hey

Interviewer: (laughing) Thank you so much for your time and honesty, your information will be very much useful to a lot of people and it will be published the way I explained it to you before u signed the consent form.

Participant: Am also thankful for being interviewed, maybe a lot of single HIV positive mothers like me will be helped too.

Interviewer: Thanks once more and enjoy the rest of your day
Participant: Good bye

ANNEXTURE 04

RESEARCH AND INNOVATION
OFFICE OF THE DIRECTOR

NAME OF RESEARCHER/INVESTIGATOR:
Mr PT Ratshihume

Student No:
11594495

PROJECT TITLE: **Investigating factors contributing to clients defaulting anti-retroviral treatment at Matoks, Capricorn district, Limpopo Province.**

PROJECT NO: **SHS/17/PDC/10/2604**

SUPERVISORS/ CO-RESEARCHERS/ CO-INVESTIGATORS

NAME	INSTITUTION & DEPARTMENT	ROLE
Prof DU Ramathuba	University of Venda	Supervisor
Prof AK Tugli	University of Venda	Co- Supervisor
Mr PT Ratshihume	University of Venda	Investigator – Student

ISSUED BY:
UNIVERSITY OF VENDA, RESEARCH ETHICS COMMITTEE

Date Considered: May 2017
Decision by Ethical Clearance Committee Granted
Signature of Chairperson of the Committee: .....
Name of the Chairperson of the Committee: Prof. G.E. Ekosse

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ANNEXTURE 05

LIMPOPO
PROVINCIAL GOVERNMENT
REPUBLIC OF SOUTH AFRICA

DEPARTMENT OF HEALTH

Enquiries: Stols M.L (015 293 6169) Ref:4/2/2

Ratshihume PT
P.O. Box 473
Shayandima
0945

Greetings,

RE: Investigating factors contributing to clients defaulting ARV treatments in Matoks, Capricorn District, Limpopo Province, South Africa

The above matter refers.

1. Permission to conduct the above mentioned study is hereby granted.
2. Kindly be informed that:-
   - Research must be loaded on the NHRD site (http://nhrd.hst.org.za) by the researcher.
   - Further arrangement should be made with the targeted institutions, after consultation with the District Executive Manager.
   - In the course of your study there should be no action that disrupts the services.
   - After completion of the study, it is mandatory that the findings should be submitted to the Department to serve as a resource.
   - The researcher should be prepared to assist in the interpretation and implementation of the study recommendation where possible.
   - The above approval is valid for a 3 year period.
   - If the proposal has been amended, a new approval should be sought from the Department of Health.
   - Kindly note, that the Department can withdraw the approval at any time.

Your cooperation will be highly appreciated.

Head of Department

13/07/2017
Date

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