EXPLORING THE LACK OF ADHERENCE TO ANTIRETROVIRAL TREATMENT FOR PEOPLE LIVING WITH HIV/AIDS LINKED TO VICTORIA HOSPITAL, EASTERN CAPE

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DECLARATION

I, Yandisa Mboto do hereby declare that this work with the exception of quotations or references which have been attributed to their authors is entirely my own work and has never been submitted elsewhere.

Signed: **Date:**

Ms. Y.C Mboto

DEDICATION

This dissertation is dedicated to my parents, Zakuthini and Nobanzi Mboto Thank you, with deep gratitude, for being so generous with your love, wisdom, support and time. I treasure the wonderful, moments of my cherished childhood. I am eternally thankful for the values and work ethic you instilled in me, which kept me going on this arduous labyrinth journey.

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"It always seems impossible until it is done." Nelson Mandela

At first, it seemed like an impossible journey. This thesis was made possible with the contribution of some people/individuals. It is not possible to mention all those who contributed to the success of this study. However, I wish to express my sincere gratitude to the following people:

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- Lastly but not least, all the participants for their willingness to participate in the study.

ACRONYMS & ABBREVIATIONS

AIDS	**Acquired Immune Deficiency Syndrome**
ART	**Antiretroviral therapy**
ARV	**Antiretroviral drug**
CD4	**Cluster of differentiation**
DOT	**Directly Observed Treatment**
D4T	**Stavudine**
HAART	**Highly active antiretroviral therapy**
HIV	**Human Immunodeficiency Virus**
HCWs	**Health Care Workers**
OAA	**Optimum Adherence to ARVs**
NGO	**Non-governmental organisation**
WHO	**World Health Organization**
PLWHA	**People living with HIV/AIDS**
TB	**Tuberculosis**
VCT	**Voluntary Counselling and Testing**
QOL	**Quality of Life**
FGD	**Focus Group Discussion**
KIM	**Key Informant Method**
UNICEF	**United Nations Children's Fund**
UN	**United Nations**
UNAIDS	**United Nations Programme on HIV and AID**
UNDP	**United Nations Development Programme**

ABSTRACT

The research was based on exploring the lack of adherence to antiretroviral treatment for people living with HIV/AIDS in the case of Victoria Hospital, Eastern Cape. The main research objectives were to explore factors contributing to Lack of adherence on ARVs. To determine the role of the family in supporting PLWHA on adhere on ARVs. Investigate why women living with HIV/AIDS were more likely to adhere to treatment. The study was qualitative, exploratory and descriptive in nature, with 22 participants which compromised male and females. The research tool was in-depth interviews, utilised semi structured (open –ended) questions to gain insight into the experiences, feelings and opinions of the participants. Data analysis was conducted using coding and themes. The research findings revealed that PLWHA in Alice and the surrounding rural areas are faced with many challenges concerning adherence to ARVs, namely: poverty, experience disfiguring side effects, financial constraints, and transport related factors, experience of lack of support, stigmatisation and discrimination negative influence of alcohol consumption, forgetfulness, and lack of knowledge about ARVs and separation and divorce. Recommendations were made with regard to increasing the rate of adherence of PLWHA to antiretroviral treatment.

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CHAPTER ONE

1.1 Introduction and Background

Human Immune Deficiency Virus/Acquired Immune Deficiency Syndrome (HIV/AIDs) is no longer life threatening, as there are many treatments which are registered and brought forth in so many countries to lengthen the life span of people living with HIV/AIDS. The condition is now regarded as chronic but manageable (Sepetla &Tlali, 2011). However, increased deaths and weakening of those living with the virus continue to cause grave worry especially in countries hardest hit by the epidemic such as South Africa. It is estimated that 40 million people worldwide are living with HIV and this number includes adults and children (Heywood, 2009; Ramphele, 2008). There is fear that following the drug regimen or drug protocol is one of the challenges that need to be addressed if the ARVs are to effectively prolong the lives of those living with the virus (Heywood, 2009; Kang'ethe, 2010a). It is therefore important that researches are carried out in countries badly hit by the epidemic such as South Africa to discover why some people living with the virus usually fail to follow the drug protocol and therefore manage to live positively.

Perhaps the country of South Africa needs more research on the underpinnings of non- adherence. For example there are glaring subjective reports that some (People Living With HIV/AIDs) PLWHA linked to the Victoria Hospital the demarcated area of study are not adhering and therefore vulnerable to change from one line of anti-retroviral (ARVs) treatment to another within a small time frame, be increasingly weak and therefore fail to take advantage of the miraculous effect associated with ARVs (Kang'ethe, 2010a). This poses a national challenge in that ARVs are very expensive and therefore poses a public burden (Treatment Action Campaign (TAC), 2007). A national survey conducted in 2013 estimated that approximately 4.2 million South Africans are infected with HIV/AIDS. By 2008, half a million people were receiving antiretroviral treatment in South Africa and between 3000 and 4000 were dying daily (Heywood, 2009). This justifies an investigation to find out how the of lack adherence to ARV's by PLWHA affects their lives and the underpinnings thereof. The findings of the study will possibly affect the policy environment regarding to adherence and advocate for PLWHA to strengthen adherence to ARV's and therefore afford to liver positively.

1.2. Problem Statement

Statically, South Africa is one of the countries in Africa and the world with the highest rates of HIV/AIDS epidemic (Ramphele, 2008). About 10% of the South Africans are believed to be sero-positive. This poses a heavy public burden as these people have to be accessed with ARVs. However, the government and the general population are worried because of the increased report of PLWHAs failing to take ARVs according to the medical protocol. Local reports suggest that most people who are attended at the Victoria Hospital are also not adhering to the treatment and therefore are likely to face early deaths, become seriously sick, or face the challenge of the medical fraternity changing from one line of ARV regimen to another. This, of course has serious financial obligations, as well as poses social and political dimensions. It is therefore important that investigation as to why people are failing to adhere to treatment is done. The researcher, therefore, would like to engage in an empirical investigation to bring to the fore an array of reasons behind this phenomenon.

1.3 Aims of the study

1.3.1 Broad Objective

The main focus of this study is to explore the lack of adherence to antiretroviral treatment by people living with HIV/AIDS linked to the Victoria Hospital, Eastern Cape

1.3.2Specific objectives of the study

- To explore the factors contributing to non-adherence to ARVs by PLWHA linked to Victoria Hospital, Eastern Cape Province.
- To establish the effects of non-adherence to ARV's
- To explore support systems that can help PLWHA to enhance adherence.
- To investigate by gender people who are most likely to adhere on treatment.

1.3.3 Research Questions

- What factors contribute to non-adherence on ARVs by PLWHA linked to Victoria Hospital, Eastern Cape Province?
- What are the effects of failing to adhere to ARV's by the PLWHA?
- What supporting systems are available to enhance adherence to ARVS among the PLWHA?
- Who are likely to adhere between men and women living with HIV/AIDS?

1.4 Theoretical Framework

The cognitive-behavioural model is a problem-focused approach that helps and calls on people to identify and change dysfunctional beliefs (US Department of Justice, 2013). The underlying assumption of this model is that thoughts influence emotions, which in turn influence behaviour. For example some people taking ARVs possess the following myths: ARVs deforms people's bodies, ARVs heals and therefore no need to take the ARVs any longer, when one is taking ARVs, one cannot have children; and that one can use ARVs in tandem with the traditional healers medication etc. (Kang'ethe, 2012). Therefore, such faulty thinking needs to be subjected to cognitive behavioural model for such individuals to change. If this theories applied to PLWHA linked to Victoria Hospital and taking ARVs, this researcher believes that they will change and stick to the drug protocol.

1.5 Significance of the study

The study is important because its results are likely to inform the practice by various practitioners working in the HIV/AIDS domain and possible be able to convince the ARV defaulters to follow the medical protocol. The results of the study are likely to be used to reformulate and possible to restructure the policy on ARVs with the hope of adequately addressing the challenges associated with ARV defaulting and preventions issues generally. The results are likely to influence HIV/AIDS campaign and ARV education generally. The results of a study could also bring in invaluable literature that other researchers can utilize in researching in the domain.

1.6 Research Methodology

Methodology refers to methods and general approaches to empirical research. It is also the strategy researcher use to make investigations (Creswell 2009). Research methodology has three components, research design, methods of data collection and data analysis.

1.6.1 Research design

Research design is a strategy that acts as a blue print informing the study’s conceptualization to the end (Bless, Higson-Smith & Kagee, 2007:71).This research will be qualitative in design and specifically it will use a case study. Qualitative research focuses more on finding out the deeper meaning of particular human experience that are intended to generate theoretically richer observation that are not easily reduced to numbers (Babbie & Rubin 2001:44). According to De Vos, Strydom, Fouche, Delport (2011), qualitative research is concerned with describing and understanding rather than explaining or predicting human behaviour. In this research, qualitative method was be used to get answers of the to the research problem The design was used form of a case study meaning that only a few samples were investigated through subjecting them to an in-depth enquiry.

1.6.2 Population

The study population comprised of HIV positive adults aged 18 to 65 years, registered for ARV treatment at ARV site Victoria Hospital in Alice. This population was considered appropriate as they were people who have been taking treatment and have encountered challenges of associated with non-adherence in the contemporary and past epochs.

1.6.3 Sampling criteria

Thompson (2012) defines sampling as a process in which predetermined number of observation will be taken from larger population. According to Marlow (2011), non-probability sampling allows the researcher to intentionally select those elements that are information rich, which makes it the sampling method of choice in qualitative studies. The sampling technique to be used in this study will be purposive.

1.6.4 Sample size

The sample size was 18 support group members comprising of females and males, two nurses and 2 caregivers serving the Victoria Hospital. However, the number of participants that was interviewed was determined by data saturation principle.

1.6.4 Data Collection Method

Methods of data collection refer to the methods the researcher uses in the process of information or data collection (Welman et al., 2005:135). The following are the methods that this study will employ.

1.6.4.1 In-depth- interviews

In-depth interviews were utilized to collect in-depth data on the views, interview was conducted by IsiXhosa and in case there was any participant who does not understand IsiXhosa, English will be used.

1.6.4.2 Focus group discussions (FGD)

Focus group discussions were used because they allow participants to express their own feelings directly without being constrained by rigid predetermined questions.

The focus group discussions were fundamental in this study as the results corroborated and strengthened the results of the phenomenon under study.

1.6.5.3 Key Informant Method (KIM*)*

Key Informant Method was utilized to facilitate the exploration in-depth qualitative information as presented by those individuals that have expertise and knowledge of the phenomenon under study.

1.6.6 Research Instruments

In order to gather relevant data on challenges associated with lack of adherence, this study used an interview guide.

1.6.7 Data Collection Process

To accelerate the data collection process, the researcher gathered the data in isiXhosa language as the majority of the research participants were comfortable in expressing practice in South Africa.

1.7 Study Limitations

The study was based on a limited sample of twenty two (22) participants recruited only from Alice area. The study participants were also reluctant in giving information during data collection which made the research spend much time with one group. Logistical challenges also were felt where by the research and the participants did not have adequate transport facilities.

1.8. Ethical Consideration

According to De Vos et al., (2011), ethical principle should therefore be internalised in the personality of the researcher to such an extent that ethically guided decision making and humane and sensitive treatment of participants become part of the total lifestyle. In this research the ethics such as confidentiality, anonymity, deception and informed consent was applied.

It has therefore become normal practise for the ethical implications to be made explicit, together with procedures to be used to deal with them (Creswell, 2009).

Ethical clearance was also obtained from the University of Fort Hare's Research and Ethics Committee.

1.9. Definition of terms and concepts

The following concepts are defined for clarification purposes:

Adherence for the patient, adherence means taking all the pills and doses in accordance with the manner prescribed by the doctor (HIV and AIDS Clinical Management Programme, 2004).

Acquired immunodeficiency syndrome (AIDS)

AIDS is a disorder of cell-mediated immunity characterized by opportunistic infections, malignancies, neurologic dysfunction, and a variety of other syndromes. AIDS is the most severe manifestation of a spectrum of HIV-related conditions (Mark et al., 1999).

Antiretroviral (ARVs) drugs

ARVs are medications for the treatment of infection. They block the enzymes used by HIV to replicate itself and by so doing suppress the replication of the HI virus (Evian, 2003).

Cluster of Differentiation (CD4)

It is a molecule found on cytotoxic T lymphocytes and it is the major receptor for HIV and is the main target of HIV infection (Douglas et al., 2008)

Family Support

Family support is when parents, children, sometimes including grandchildren and other relations give strength, help, or encouragement to someone who is on antiretroviral therapy, for example, with regard to reminding family members on how to take medications (HIV and AIDS Clinical Management Programme, 2004).

Polypharmacy

The term polypharmacy generally refers to the use of multiple-medications by a patient. The term is used when too many forms of medication are used by a patient; more drugs are prescribed than clinically warranted, or even when all prescribed medications are clinically indicated but there are too many pills to take ("pill burden"). Furthermore, a portion of the treatments may not be evidence- based. The common result of polypharmacy is increased adverse drug reactions and higher costs Michelle D. et al (2009).

Highly Active Antiretroviral Therapy (HAART)

Patients with HIV/AIDS are treated with a combination of three (or more) different types of ARVs; usually two nucleosides reverse transcriptase inhibitors (NRTIs) with either non-nucleoside reverse transcriptase inhibitor or one or two protease inhibitors. This type of regimen, as opposed to mono- or dual-therapy, is referred to as HAART (Pratt, 2003).

Human Immunodeficiency virus (HIV)

HIV is a virus caused by one of two related retroviruses (HIV-1 and HIV-2) in a wide range of clinical manifestations varying from asymptomatic carrier states to severely debilitating and debilitating and fatal disorders related.

1.10 Chapter outline

The structure of the study followed this structure:

Chapter 1: Background and Introduction

This chapter gave a background and introduction to the study, the problem statement, aims and objectives and significance of the study.

Chapter 2: Literature review and theoretical approach to the study.

Chapter 3: Research methodology (This entails all the procedure of gathering data as well as the method of analysing and interpretation of the data collection.

Chapter 4: Data Analysis (Data collection will be analysed and interpreted using qualitative techniques

Chapter 5: Discussion of findings (conclusions and provide recommendation and suggest further/future areas of study).

1.11 CONCLUSION

Chapter one was a background chapter that sets the stage for all the following four chapters. Its meticulous crafting from the study's background, problem statement and the objectives and research questions largely determines the precision of the following four chapters. It also laid a ground for every promising work in the literature review, research methodology, data analysis and interpretation, and discussions conclusions and recommendations. More so, it permitted both the researcher and the readers to forecast how other chapters unfolded.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

HIV/AIDS is no longer life threatening, as there are many treatments which are registered and brought forth in so many countries (Sepetla and Tlali, 2011). In the same vein, the role of World Health Organization has been critical in encouraging fruitful campaign as pertains the consumption of ARVs in the developing world. This is through forging a strong collaboration with the local HIV/AIDS bodies. For example, the collaboration between the World Health Organisation and the Uppsala Monitoring Centre has created a global network to encourage countries to share data and information about the benefits and risks of treatments to the public (WHO, 2009). However, and despite these huge efforts in bolstering the state of treatment in an endeavour to tackle HIV/AIDDS head-on, it is ironical that many people living with HIV/AIDS (PLWHA) have had a challenge pertaining to adherence to ARV treatment especially in countries such as South Africa and Botswana hardest hit by the epidemic (Kang'ethe, 2010, 2012, 2014). Definitely, adherence to treatment implies compliance with the health practitioner's protocol to taking the drugs. Also following the uptake of the ARVs is also referred to as drug protocol (Kang'ethe, 2010, 2012, 2014)

Global Statistics

According to CMIS Bulletin (2008), Indian studies show that among its 179 ART centres, all the people living with HIV/AIDS from 15 centres showed an adherence rate of 95 %. While during the initiation of National ART programme in 2004, NACRO reported 7% loss to follow up cases and 3% PLWHA did not adhere to ARV treatment. They further argue that NACRO seeks to stop the progress and reverse the epidemic in India by integrating programmes for prevention, care, support and treatment. Mills, Nachega, Bangsberg, Singh, Rachlis and Wup (2006) state that the goal of NACRO programmes is to provide antiretroviral treatment for PLWHA. According to them, up to 30 000 adults and 40 000 children by March 2012had achieved a high level of adherence to ARV and reduced the number of PLWHA who did not adhere to ARVs.

Further, Remien, Hirky, Johnson, Weihart and Whiteeler (2009), indicated that United States and European Countries have shown that adherence worsens over time, HIV illness improves, symptoms weakens, and side effects increase. This implies that adherence is not static, but rather changes with time and long term programme efforts may not be necessary for long term effects.

South African Statistics

Southern Africa is the region of the world most affected by HIV/AIDS epidemic, In a South African national survey in 2007, an estimated 5, 4 million people were reported to be infected by HIV. The report estimated that by the year 2008, half a million people were receiving antiretroviral treatment in South Africa and between 3000 and 40000 were meeting their deaths everyday (Heywood, 2009).

Provincial level statistics

The South African cabinet has committed the government high level of poverty and unemployment in 2010, 67% of the adults over the age of 18.nsure effective provision of the ARVs, through all the public health sectors. This saw the Department of Health produce its operational plan to have 54,004 people on treatment by 2011. Nicoli (2012) indicates that the Western Cape has the widest coverage in terms of ARV access. Perhaps this may explain that it has the lowest HIV prevalence than all the provinces in South Africa. He also argues that the Western Cape is the first to launch the ARV programme as far back as May 2001. Nicoli (2012) also indicates the success story of the Western Cape in that the region experiences a median rate of 93, 5% adherence, while Gauteng province has 88% of adherence**.**

2.1. Factors contributing to non –adherence to ARVs

Successful management of HIV infection requires more than 95% adherence to ARV treatment to prevent the development of resistant strains of HIV and to reduce the viral load until it is undetectable (KZN Department of Health; 2004 and Bhangwanjee, Govender, Akintola, Peterson, George, Johnstone and Naidoo, 2011). Treatment adherence is therefore, crucial in order to improve the virologic and immunologic responses. As such, it is important to understand the risk factors to non-adherence. The risk factors leading to non-adherence to ARV treatment are discussed herein.

2.1.1 Poverty in rural areas

Visser and Moleko (2007) denote that poverty is not only the lack of money, but also manifests in hunger. The above researchers also mention the effects of poverty such as shelter, hunger, violence, and lack of social support , which all can contribute to non- adherence in ARV treatment.

According to Mills, Nachega, Bangsberg, Sigh, Rachlis (2006), lack of food is a serious barrier for PLWHA to adhere to antiretroviral treatment. This is because health practitioners always advise that ARVs need to be taken when one has eaten adequately, otherwise they may fail to be effective (Kang'ethe, 2010, 2012, 2014). The above researchers also argue that the shortage of food due to poverty in general poses serious setback to the success of ARVs. From personal experience, lack of food due to poverty can also lead to serious unethical practices. For instance, some PLWHA have been reported selling their ARVs in order to get food. It is therefore believed that if the clinics could collaborate with other food donating agencies to donate food to the very poor, perhaps this can reduce chances of drug defaulters. Otherwise, poverty has detrimental effects towards a successful ARV uptake. This may also explain why the death rates of the poor people who are on ARVs have been rising compared to those with resources to afford a good diet. Perhaps the complexities associated with the ARV defaulting and the ultimate deaths of PLWHA or being in a debilitating states of health no doubt has made the epidemic become a sophisticated. This has been exacerbated by the unrelenting HIV/AIDS cases in South Africa (Ramphele, 2008; Barnett and Whiteside, 2006). To this end, Dr. Des Martin of the South African HIV Clinicians' Society describes the epidemic as follows: “South Africa is host to a burgeoning HIV epidemic of catastrophic proportions” (UNAIDS, 2006:8). UNAIDS (2006) has noted that HIV/AIDS in South Africa is a complex social issue underpinned by issues of poverty, lack of empowerment of women, gender violence and the legacy of the apartheid era. Other factors that contribute to the epidemic are related to sexual behaviour and exposure to high risk groups such as truck drivers, prisoners and mining communities (National Department of Health of South Africa, 2008).

2.1.2 Culture and Belief Systems

According to Wasti, Randall, Simkhanda and Van Teijilingen (2011), cultural factors such as their beliefs, practices, and perceptions about life in general that shape people's societal identities largely influence their attitudes and behaviours towards ARV treatment adherence. It is therefore; important to understand the patient's cultural beliefs and practices in order to gain insight into the way people make sense of their illness.

To this end, Moratioa, (2006) states that religious practices and spiritual beliefs play a major role in a person's health, and this impacts hugely on PLWHA and their treatments. However, the study also report that some religious beliefs inculcate to their followers the notion that people who are living with HIV/AIDS are sinners and therefore need not be sympathised at. Some religious faiths also discourage the consumption of the ARVs and even stigmatize the PLWHA. This is common among the apostolic this has negatively affected individuals who are HIV positive, especially in relations to their treatment and adherence and has set in a wave of stigma and discrimination. This is serious in South African where the state of stigma is still high compared to its neighbouring countries such as Botswana (Kang'ethe, 2015; Heywood, 2009).

For an example, an individual may not feel comfortable taking treatment in front of his or her congregants because of the discrimination and rejection that he or she might have to face (Byamugisha, Steinitz, Williams, Zondi, 2002). According to Zou, Yamanaka, John, Ostermann and Thielman (2009), religiously 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 they sin against God (Byamugisha , Steinitz , Williams , Zondi, 2002). Among some apostolic churches in South Africa, cases of the PLWHA religious faithful have been reported to abandon ARV's taking the ARVs after they have been prayed for by their pastors. Some of those who abandon become very serious and some even succumb to death within a short span of time. Otherwise, some pastors have also been reported advising their PLWHA faithful to abandon taking their ARVs. However, this is a controversial issue because some strong prophets and pastors have prayed to the PLWHA and after they go for tests they have tested negative immediately. Perhaps that's why so many PLWHA these days are vising the Nigerian church of Prophet T.B Joshua because reliable reports confirm that his prayer is enough to change PLWHA sero-positivity. However, subjective information suggests that the healing process depends on people's level of faith. This undoubtedly mirrors what most religious sacred literatures such as the Holy Bible says (MacArthur, 1997). To corroborate the information above, Wet et al (2001) state that belief is viewed as having impact to deadly attitudes and passive resignation which hinder in treatment adherence.

Today, cases of ARVs and the use of holy water have become very common in a score of apostolic churches. This is negatively affecting the pace of adherence among the PLWHA. For instance, Bishop Nala of Durban church claims that a bottle of his “faith water” was adequate to turn those who are seropositivity to being sero-negative. This has made those who claim to heal HIV/AIDS to unethically call themselves doctors. For example pastor Nala has been using the title “Dr” on the label of the bottle water he uses. This is ironically despite having no any formal education. When prophets claim that they are healing or curing HIV, the poor

PLWHA stop adhering to their treatment and follow the prophets' myths with a hope of getting cured (Maslala & Dzanibe, 2013).

Perhaps a huge blow to the HIV/AIDS campaign and of course adherence is the belief that PLWHA have been bewitched. According to Nsimba, Irende and Comoro (2010) the belief in witchcraft which is associated with HIV/AIDS infection still prevails and dependence on traditional healing occurs. To this end, Kimoni, Menderson and Kahn (2010) study reveal that patients and their relatives succumb to the belief that the HIV/AIDS emanates from evil spirits sent by their enemies. This therefore defeats any attempt to convince such people of the need to follow the drug protocol associated with maintaining them healthy. Such people with such beliefs can even throw away the ARVs given in the clinics. In addition, other people especially in the rural areas may hold the belief or convinced by their relatives that the disease emanates from the ancestors who are angry and therefore needed to sacrifice animals in order to placate them. This has made the PLWHA poor as they follow the traditional healers' protocol and advice to make such sacrifices. This makes them to distant themselves from following the ARV drug regimen.

Wastiet, et al (2011) postulate the fact that even some traditional healers tends to overlook the issue of treatment and base their facts and healing on witchcraft. The belief in evil spirits and witchcraft can lead to non-adherence to the treatment by the PLWHA. According to Ashforth and Natrass (2006), some of PLWHA understood HIV infection as a form of pollution and often use the term 'dirty blood'. Therefore, they will use unorthodox methodologies such as inducing vomiting to cleanse the 'dirt' out of their blood. Sometimes they have their skin cut slightly in order to ooze blood that is believed is dirty. Consequently, they will not adhere to ARV treatment because its purpose will not be viewed as relevant to their cultural belief.

2.1.3. Alcohol abuse

According to Jaquet, Ekouevi, Bashi, Abaubarike, Messou, Traore, Zannou, Ba-comis, Minga, Allou, Eholie, Bissagnene, Jasco and Dabis (2010), alcohol is a huge factor to ARV non-adherence to treatment. Perhaps this is because people who drink are likely to forget to take their medication, or may miss to take the medication at the right time. Perhaps this is one of the reasons that the PLWHA who abuse alcohol are likely to succumb to death easily. Alcohol also makes the blood weaker and therefore weakens the potency of the ARVs. When South Africa has the highest number of people living with HIV/AIDS in the globe and also having the highest record of alcohol taking in the globe, it could be possible that an inextricable relationship between cases of HIV/AIDS and poor adherence and taking of alcohol exists (Coon & Mittere, 2010)

On the other hand, Braithwaite and Bryant (2010) state that alcohol consumption because liver failure and even the ARV treatment drugs can also have an effect on the liver. Therefore, if a patient is on ARV treatment and is consuming alcohol, he/she is at a high risk of suffering from liver failure. Under an environment of heavy alcohol intake, a PLWHA can easily omit a few doses of treatment. Since many people who abuse alcohol usually find it hard to stop drinking, this puts an inextricable relationship between the state of alcohol and poor or failed adherence (Kang'ethe 2007).

2.1.4. Denial

According to Xochihua–Diaz (2009), denial and fear of HIV infection amongst newly diagnosed patients, plays a major role towards the refusal to start the ARV treatment. The study further state that patients in denial and who are miss informed about HIV and treatment end up not adhering to treatment and some of the patients do not even want to start the ARV treatment.

It is pathetic that many people in South Africa with HIV and families are becoming reluctant or denying their status. This is perhaps of the limited level of knowledge they have pertaining to the HIV/AIDS disease itself, its aetiology, and many other facets surrounding the disease. In fact some people who have limited knowledge about the disease believe that contracting the disease is equal to facing a death sentence. They also cannot see any possible liveable life while one is seropositive. According to a research carried by Taylor (2004), some of the participants denied their HIV status completely. This is because of self-stigma as well as the societal stigma that PLWHA faced. Perhaps one of the mistake that HIV/AIDS campaigners do is to think that a successful HIV/AIDS campaign can be boosted and bolstered when PLWHA disclose their status and therefore come out openly to face the society. This is very risky. The campaigners should be concerned with how much knowledge about HIV/AIDS they have exposed the PLWHA with. This researcher believes that once the PLWHA have adequately understood many facets of the disease, they can easily come out to help others (Treatment Action Campaign, 2007).

2.1.5. Unavailability of ARV treatment in clinics and hospitals

With a breakthrough of the consumption of ARVs in South Africa especially after the court battle the Treatment Action Campaign led and declared that the government should access ARVS to all the needy PLWHA (TAC, 2007), most hospitals and public health facilities have faced an increasing number of patients. This has caused queues and possible shortage of the drugs. The fact that access is free has also seen many people who cannot afford private services from the private health facilities taking advantage (Campbell, 2005). Subjective information on the ground suggest that patients who only rely on these clinics and hospitals for their treatment are likely to fail to adhere in the event that the supply is not timeous or is absent altogether. In some cases, unethical practice of some people borrowing some to others has not been uncommon. There is also a danger that the borrower and the donor might not be taking the same medication. This can therefore be a recipe of confusion and the one who donates and the borrower might end up defaulting especially if the donor's supplies end before the actual scheduled time.

The distance to the centres of dispensing the medication can be far and with looming poverty in some rural areas, lack of transport to visit the clinics especially if there has not been regular supply can easily lead to defaulting. The situation can be complicated where the ARVs are only supplied once by a mobile clinic. This means that if something happens like losing the medication, or one forgetting where one has kept it can possibly lead to defaulting. Also in circumstances where people rely on the mobile clinics, a possible failure by the mobile clinic to make a visit especially during the rainy seasons or during winter season when it very cold this can lead to possible defaulting (Nsimba et al 2010). Also there are cases when the clinics do not get timeous supplies. This is likely to cause confusion in the treatment plan and is a recipe of non-dherence.

2.1.6 Gender violence and male dominance

According to Strebels, Simbayi, Van Wyk, Henda and Nqeketho (2010), the major challenge some women are facing in relation to adherence is fear that if their intimate partners might find out about their HIV status, they might even chase them out of their homes. This means that they are even not free to take medication especially at the appointed time if circumstances do not allow. This also means that they are not able to disclose or freely engage in any fruitful discussion with others on HIV/AIDS. They are under duress and this can pose a challenge for them to adhere to treatment. The study by Murray, Semrau, Mc Curley, Thea, Scott, Mwiya, Kanka, Bass and Bolton (2009) indicated that non-adherence to ARV treatment by women has to do with fear of being physically abused, fear for their relationship and marriage to collapse. In this study, it was reported that their husbands or partners could leave them if they were to reveal their status to them. Moreover they were afraid of being accused of infecting their partners.

Kagee (2011) points out that when a female partner discloses or takes ARV treatment; they do not only face the challenge of being subjected to physical abuse, but also emotional abuse from their partners. These women also fear that their partners might leave them and they will have no one to financially and emotionally support them.

2.1.7 Women and depression in HIV

According to WHO (2007), several studies have assessed the role of gender in psychiatric morbidity, particularly depression and anxiety. Majority of such studies in South Africa have reported higher rates of depression and anxiety among women compared to men. Women with HIV infection in India face higher caregiver burden, more stigma and poor healthcare, which probably contribute to the higher prevalence of depression. With this kind of situations, adherence to treatment may face an arduous and an uphill task.

2.1.9 Psychosis in HIV infection

The state of other bodily health deficits also contributes to people's capacities to respond to various kinds of treatments. This is because such states may affect one's socio-psychological state to an extent that one may not be in a position to think straight about a challenge like taking ARVs. For example the presence of psychotic symptoms in patients with HIV contributes to difficulties in medical care and residential placement and may have other serious consequences. New onset psychotic symptoms are not uncommon in HIV infection. One of the earliest studies reviewed cases of new onset psychosis in HIV infected patients and reported that patients with symptoms and abnormal computed tomography (CT) and electro encephalography (EEG) tended to have relatively rapid deterioration in cognitive and medical status. They also show a greater neuropsychological impairment. Psychotic symptoms can appear as a part of delirium, dementia or any other organic brain syndrome (Maguire, 2002). These may make a PLWHA to forget taking medication, make one have some temperaments that will stop one from normally engaging with others, as well as impeding one's natural way of doing things. People with various cognitive challenges, for example, find themselves in a position they cannot reason well and are therefore impeded from making proper decisions such as those of taking medications timeously (Maguire, 2002).

2.1.8 Cognitive dysfunction related to HIV infection

Cognitive disorders and subtle cognitive impairment are seen throughout the spectrum of HIV infection. Delirium occurs frequently among hospitalized HIV infected patients with reported prevalence ranging from 32 per cent (Lisa, 2004). The aetiology of delirium is often multi factorial in HIV infection and patients are susceptible to the development of delirium in the context of underlying HIV brain infection, common use of poly pharmacy and the frequency of multiple medical complications (Morthy, 2009). Evaluation and correction of the underlying medical cause of delirium is of primary importance. Prompt management of agitation due to delirium is extremely important because of the distress caused to the patient and family, potential for self-harm as well the potential for exposure of HIV to others (Lemens, 2012). Repeated mental status examinations, careful review of medications, thorough physical and neurological examinations, search for infections/metabolic abnormalities, neuroradiology examination, CSF examination and EEG are essential in evaluation of delirious patients (Thabane et al, 2010)

2.1.10 Fear of divorce or separation

According to Junga and Blystad (2010), women are the most vulnerable when it comes to HIV in marriages because in most cases, they are the ones who go for HIV testing and when they test positive, it becomes difficult to disclose to their husbands because they do not know the reaction after they disclose. The environment then becomes difficult to go to the clinic for medication, or even taking their medication freely. This can easily contribute to non-adherence.

Syles, Wong, Cunningham, (2006) state that women who are HIV positive and on treatment find themselves in a difficult position to take treatment because of reasons such as not disclosing to their husbands, because they are afraid that their marriages will come to an end if they disclose. The study reported that most women in the rural areas are fully depending on men for financial support and when the issue of HIV comes to the surface, men tend to respond in a negative manner. In the study reported above by Syles et al, one of the respondents stated that her husband told her that if upon going for a HIV/AIDS test she was to test positive, then she was going to be divorced as that would be an indicator that she was not faithful or trustworthy. Therefore, this means that in certain instances, some women tend not to adhere to treatment because they are afraid of their marriages coming to an end, and end up not having any financial security.

Moreover; Reimien and Mellins (2007) stated that marriages end up being broken because of HIV and women become victims of ill-treatment and discrimination and physical abuse. This is because women are in general more conscious about their health than men. Upon men knowing their wives or partners status, they use their patriarchal power to maintain that it is women who were unfaithful and yet they themselves usually refuse to go for test to ascertain their status. Therefore, many women tend to keep quiet and tread through a journey of excruciating pain while the men they fear to disclose to could be the culprits responsible for the advent of the virus in their marriages. This environment poses challenges of adherence if one is taking ARVs. It also poses challenges of living positively. This is because positive living may entail the closer partner giving her the much needed psychosocial support and love. Also women, more than men are ready to sacrifice their lives in order to see their marriages survive. They therefore persevere various gender based violence whether, emotional, physical, or psychological (Kang'ethe, 2014a, b). In many African countries, cases of women living with HIV/AIDS losing their homes, inheritance, possessions, livelihoods and even their children when their partners die have not been uncommon (Jackson, 2002).

2.1.11 Depression and Adherence to treatment

According to British HIV Society (2011), the scientific research findings postulate that the patients reported that the health professionals involved in the ARV treatment programme tend to overlook their psychological wellbeing. This is despite the treatment challenges they are facing such as depression, anxiety and forgetfulness.

Hao (2012) states that depression has potential of being a challenge to successful treatment programmes, as they often have negative thoughts because of the side effects the treatment has, can result in a patient’s non adherence to ARV treatment.

Kagee (2007) denotes the hopelessness that a person has, may be unmotivated or reluctant to honour or attend clinic appointments. They may be overwhelmed by this helplessness and hopelessness, a person becomes withdrawn and most of the time wants to be alone, therefore; then the patient will receive any type of support. Khanyemba (2006), confirm that HIV involvement of the central nervous system can affect memory.

In addition Wagner (2011), states that there are different types of depression, but the one that affects adherence mostly is the severe depression, because when a person has this type of depression can easily become a forgetful person, and the forgetfulness hinders the level of adherence to treatment.

2.1.12 Discrimination and religion

Moratioa (2006), states that religious practices and spiritual beliefs play a major role in a person’s health, and this benefits people who are HIV positive and on treatment in living a positive life. However the study also report that a strong believing congregation, concerning sin and moral principles attach stigma to HIV and discriminate those who are HIV positive. This affects individuals who are HIV positive negatively especially, in relations to treatment and adherence. For example and individual may not feel comfortable taking treatment in front of his or her congregants because of the discrimination and rejection that he or she might have to face.

2.1.13 Stigma, Prejudice and Discrimination

Globally, stigma and discrimination are major obstacles leading to treatment seeking behaviour and effective HIV/AIDS prevention and care, especially in Sub Saharan Africa (Monjok, Smesny, Okokon, Mgbere and Essien, 2010). In addition patients often missed their doses as a result of fear of being identified as HIV positive and being on ARV medication for the rest of their lives.

According to Sayles, Wong, Kinsler, Martins and Cunningham (2009), the process of stigma involves the identification and labelling of human differences, linking labelled person to negative stereotypes and discriminating in the process. Furthermore, the process of stigma is difficult and is rooted in deviance from the values and social norms of a community. Low levels of quality of life and high levels of stigma are known risk factors of lower levels of adherence to treatment especially ART(De-boer,Mirjam, Sprangers, Prins, Pythia and Nieuwkerk, 2011). Sahay, Ghate and Mehendale (2009) also indicate that stigma and patients own attitude towards pills and treatment also influence adherence.

In the Western Cape province, HIV is referred to as “ulwazi” which means that thing, that does not only implies that there is no cure but also suggest that is a stigmatised illness that cannot be referred to by name (Cloete, Strebel, Simbayi, Van Wyk, Henda and Nqeketho, 2010).

According to Kehler (2006), policies to address HIV-related stigma have been minimal. The reason for this slow response is that stigma could not be meaningfully addressed because it was believed to be cultural, context-specific, and a sensitive issue (Kehler, 2006). Stigma and the fear of discrimination restrict PLWHA in the choices they make. The impact of stigma on the health care system results in barriers that HIV positive individuals encounter in accessing health care. Health care providers' fear of contagion and death can have a negative impact on their attitudes toward and treatment of HIV positive patients. Providers of ancillary and support services to people living with HIV/AIDS fear stigmatisation themselves because of their work with HIV positive patients (HRSA Care Action, 2003).

2.1.14 Disclosure

A number of incidents of stigma and discrimination have been reported worldwide. In South Africa, Skinner and Mfecane (2004), cite the murder of Gugu Dlamini in Durban in December 1998 for openly stating that she was HIV positive. Mpho Mtloung and her mother were murdered by her husband in the year 2000 for the same reason. In 2004, Lorna Mlofane was raped and later murdered by three rapists after they learned that she was HIV positive. In many cases HIV positive children have been denied admission into schools, the best known of these was Nkosi Johnson in Johannesburg. The practices of exclusions extend to the workplace, within the military, in homes, communities and rejection from families (Skinner and Mfecane, 2004). In Kenya, a woman was deprived of her inheritance after her husband died of an AIDS-related illness and she was blamed by her in-laws for bringing HIV into the household (USAIDS, 2006). Health care workers in Ukraine coerced a pregnant woman into being sterilised after they discovered her HIV positive status during delivery (USAIDS, 2006). When monks started providing support to AIDS orphans in Cambodia, community members avoided the local temple. In Vietnam, HIV positive injection drug users were denied access to antiretroviral therapy. In Mexico, a man was fired after being diagnosed with tuberculosis because his fellow workers feared that he may be HIV positive (USAIDS, 2006). Society expects women to uphold its moral traditions. Women tend to be more stigmatised for having ‘failed’ as proper women or are blamed for ‘bringing’ HIV into the family or marriage (ICRW HIV/AIDS Stigma, 2006). HIV/AIDS stigma is thus a barrier to disclosure. Disclosure of HIV status is a complex issue but is viewed as an important step in breaking the silence of HIV/AIDS. HIV-positive people who disclose their positive status are in a strong position to increase awareness of the disease, extend their support to other HIV-positive people, and encourage others to take preventive measures so that they do not get infected. This could be possible if an enabling environment was created which encouraged HIV-positive people to disclose without increasing their vulnerability (Harrison, 2006). The problems that HIV-positive people encounter are the social realities and complex issues that restrict their ability to make decisions about disclosing their status (Harrison, 2006). According to Harrison (2006:3) “there is a conspiracy of silence in South Africa where ignorance and lack of understanding are the source of much prejudice and discrimination”.

PLWHA fear the negative consequences of disclosure and do not negotiate safe sex or access available prevention methods. They do not disclose their HIV-status, nor do they seek available treatment, support and care (Kehler, 2006). Disclosure of HIV status is an important aspect in creating awareness and openness about the disease and may lead to de-stigmatisation of HIV/AIDS (Ncama, 2007). Disclosure removes the mystery surrounding HIV. Disclosure of HIV-status to family or friends also increases the awareness of the disease and prepares individuals to take the necessary precautions to protect themselves from being infected (Harrison, 2006). PLWHA who disclose their status experience an improvement in their mental and physical health through increased acceptance of their condition, and a reduction in the stress of having to cope with their illness in secrecy (Harrison, 2006). An increase in the number of PLWHA disclosing their HIV status will reduce the stigma, discrimination and denial that surround HIV/AIDS (Linch, 2004). Furthermore Public health researchers have identified non-disclosure of HIV-positive status to sexual partners as a critical issue in AIDS prevention. HIV positive individuals who know their HIV status and continue to adopt risky sexual behaviour by having unprotected sex could infect a series of unsuspecting partners. Of particular significance to public health is the non-disclosure of HIV status in relation to the prevalence of the disease, risky sexual behaviour and the extent to which unprotected sex is practiced between sero-discordant partners. AIDS intervention programmes should be directed at promoting sexual responsibility and increasing the rates of consistent safer sex among HIV-positive persons (Ciccarone et al., 2003).

2.2 Effects of non-adherence to ARVs

Non- adherence to ARVs has many and serious dangers attributed to it. Many of the effects are severe and irreversible has in most cases have led to death. Among the many effects of non-adherence a few are discussed.

2.2.1Side-effects

Hardon,Akurut,Comoro,Ekezie,Irunde,Gerries,Kglatwane,Kinsman,Kwasa,Maridadi, Moroka,Moyo,Nakiyemba, Nsimba, Ogenyi, Oyabba,Temuand Laing(2007), said that sides effects mentioned by patients who are using ARV treatment are body rash, swollen legs, nausea, headache, increase heart rate, diarrhoea and vomiting.Kyaja,Mulika and Ayebare (2010) also indicate that antiretroviral side effects have negative impact on patients and their quality of life and adherence to treatment. They further argue that the side effects also have contributed immensely to adherence because, some PLWHA when they experience this sides effects they stop taking the treatment that leads to severe illness and death

2.2.2 Resistance to ARV treatment

Remien and Mellins (2007), elucidate that missed doses of ART are associated with the development of resistant virus that may lead to treatment failure, viral progression, and the possible transmission of ART-resistant strains of HIV. Furthermore; the National Minority AIDS Council (2012), reveals that although the treatment resistance may develop, there are HIV treatment options to manage drug resistant HIV.

2.2.3 Psychiatric disorders as a reaction to HIV infection

Phobias and fears related to HIV and AIDS have been reported early in the history of HIV infection1. There have been reports from the late eighties describing the problems of the “worried well”- i.e., people with an overwhelming fear of having contracted AIDS. The initial reports were predominantly from homosexual men and users of IVD who were particularly at risk for HIV infection. Subsequently, there have been reports of a spectrum of disorders such as anxiety disorders, panic, hypochondriacally beliefs and obsessive-compulsive disorders related to HIV infection. These could be primary disorders or manifested as psychopathology in depression and/or psychotic disorders.

2.2.4 Post -traumatic stress disorders

Post-traumatic stress disorders and multiple loss syndromes have been described in some persons who have experienced AIDS related multiple losses. Chandra et al (1995). States that HIV positive woman have a higher prevalence of posttraumatic stress disorder symptoms. Evaluation of anxiety in HIV infected individuals should take into account the variety of medical conditions, which can present with anxiety symptoms. Many of the medications used in treatment of HIV/AIDS have been reported to cause anxiety as a possible side effect. Psychoactive substances, both prescribed and recreational, should also be considered in evaluation of anxiety.

2.2.5 Kaposi’s Sarcoma

Hop and Israel (2007) define Kaposi’s sarcoma as a malignant tumour found under the skin and in the lining of the mouth and rectum, characterized by brown or purplish spots. It is rare in persons who are not HIV infected and may thought of as an opportunistic infection in persons with damaged immune systems and low CD4 count .Project Inform (2011) states that Kaposi Sarcoma is a cancer of blood vessels mainly affecting the skin, mouth and lymph glands, this disease can also affect the body internal. This HHV8 virus does not have severe symptoms but there acute infections such as fever, rash and swollen lymph glands however when the HHV8 develops into Kaposi sarcoma the most obvious signs are lesions found in the skin usually on the legs and feet and in the mouth.

2.2.6 Nausea and vomiting

Subjective information suggests that, almost all antiretroviral drugs, as well as many other medications, can cause nausea (feeling sick) and vomiting, especial during the first few weeks of treatment. Although this side effect can reduce appetite, it is important to keep when possible, and replace lost fluids and electrolytes (as with diarrhoea).

2.2.7 Diarrhoea

Diarrhoea is common side effects of many ART drug-especially protease inhibitors. Sometimes an antiretroviral drug causes diarrhoea for only few weeks, in other last for a long as the drug is taken; most of people are not taking their treatment due to the side effects because they make them sicker.

2.2.8 Alcohol Abuse

According to Mocaiber, David, de Oliveira, Perreira, Volchan, Fgueira, Vila and Mochado-Pinheiro (2011), alcohol myopia theory shows that the attention ability of an intoxicated person is reduced. They further advance the view that this reduction makes it difficult for a person to process environmental motivations in a reasonable manner. This statement attests to the fact that a patient who is on ARV treatment might be ill-informed and not adhere to treatment because, of the alcohol consumption and intoxication. For instance; if a patient has to take the medication a certain time and he/she is under the influence of liquor it can happen that the patient ignores the treatment because of the fact that the cognitive ability is limited.

In addition, Giancola, Josephs, Parrott, and Duke (2010) state that alcohol or intoxication impairs the capacity to good intentions. For example; a patient has to take medication and he/she knows that his or her survival depends on it, but because of alcohol influence, the patient tends not to adhere to treatment therefore; the good intensions of patient are tempered by the intoxication. Furthermore, Grant and McDonald (2005) also highlighted that alcohol intoxication limits or marginalizes the cognitive capacities of people. Therefore; some patients who consume alcohol can ignore important things to do in their daily routine and this leads to non-adherence.

According to Jaquet, Ekouevi, Bashi, Abaubarike, Messou, Traore, Zannou, Ba-comis, Minga, Allou, Eholie, Bissagnene, Jasco and Dabis (2010), alcohol contributes to non-adherence to ARV treatment by PLWHA. Considering that

PLWHA who are on treatment needs to be on their sober state of mind as treatment time needs to be consistent. Drawing from alcohol myopia theory which states that large amount of alcohol consumption lead to the impairment of the brain until the drinker loses consciousness (Coon & Mittere, 2010), PLWHA may default treatment due to that and in that process the viral load increases, the Cd4 count drops and treatment eventually resisting the system (Braithwaite & Bryant, 2010).Once under the influence of alcohol, PLWHA have tendencies to deny their health status and continue to practice unsafe sex (WHO, 2005).

2.3 Support mechanisms for PLWHA

2.3.1 Support group

Support groups are an informal resource that attempts to provide healing components to a variety of problems and challenges. An informal support outside of family, friends, or professionals often provides greater understanding, more similarity, an opportunity for empathy and altruism, and a sense of identity for participants (Encyclopedia of mental disorders 2011). Support groups for PLWHA are usually formed to provide care and support to people infected and affected by HIV and AIDS (Cohen in Mundell 2006). Support groups for PLWHA's help with support, care and treatment and in advocacy to tackle stigma (De Barros et al. 2004). In addition, support groups educate people and create awareness of HIV and AIDS, and work towards reducing new infections, stigma and discrimination for PLWHA. Visser et al. (2005) sums up the functions of support groups for PLWHA as providing PLWHA with a safe environment to talk about the virus, share their experiences, and learn from stories of other infected individuals. Learning new ways to handle challenges, cope with changes in their lives, and maintain new behaviours

(Encyclopedia of mental disorders 2011). There is evidence that participating in support groups for PLWHA benefits the individual, according to Simbayi (2008) several studies have shown that support groups are effective in reducing psychological distress both in PLWHA and in other chronic illnesses, Support groups have also been found to be effective in improving coping styles and psychosocial adjustment of PLWHA. Sikkema (2002) also maintain that support groups for PLWHA is able to assist its members in working through their difficulties associated with being HIV positive provided an opportunity for the participants to give and receive meaningful support.

2.3.2 Social support

Social support is defined as network of family, friends, neighbours and community members that is available in times of need to give psychological, physical and financial help and this also includes the health care providers (Tengpe, 2005). Furthermore, Support refers to assisting people in handling difficult life situations such as HIV infection. This implies the communication between an HIV positive person and a person who has the strengths and possibilities to productively manage the situation a person living with HIV is in. The assistance can consist of various types of support, such as physical, emotional, social, spiritual, material and practical support, depending on the needs of the supported person (Uys, 2003). Physical support for instance, such as relaxation training, meditation or massage, may improve the quality of life during difficult times (Department of Health, 2003). Others find spiritual guidance a meaningful and comforting way of support and many people living with HIV need this in addition to other types of support. The various types of support a person living with HIV may need, can be provided by a support system in which the different types of support and referrals to these types of support are present.

Russell and Schneider (2000) point out that people living with HIV who participate in a support system have expressed the importance and healing effect of being able to share and meet with others. An important part of such a support system is a support group which consist of HIV positive people who meet on a regular basis to talk about their difficulties or simply to relax and enjoy each other's company (Van Dyk, 2003). Next to that, they can support one another in emotional, spiritual, physical and psychological aspects of daily living and functioning (Department of Health, 2003). However, support groups should be seen as a substitute for other support interventions. Therefore, referrals to multidisciplinary team, which can provide physical, social, spiritual, material or practical support and referrals to the formal health sector are important to encounter the different needs of the people living with HIV are essential within a support system (Pienaar, 2004 Uys, 2003). In this study, support is initially interpreted in the wide context that is described above, since the more specific needs of support are explored and described in the course of the study.

2.3.3 Health care services and health care workers support

Primary care physicians can play an important role in helping patients adjust to the news of a positive test result (Remien & Rabkin, 2001). Health workers have been overwhelmed by the impact of HIV/AIDS on the public health services, with the majority of resources in many facilities going to treat people presenting with opportunistic infections or dying from AIDS-related illnesses. This has resulted in overcrowding of under resourced hospitals, with health care professionals working under difficult conditions in places where there is also shortage of staff. Staff morale is often very low as a result of these poor conditions and also because of the distress of being unable to treat people effectively. The working conditions are made worse still by inadequate training of staff (Aids Foundation South Africa, 2005).

In sub- Saharan Africa there is a lack of potential to provide basic health care services, let alone the burden of providing ART to the PLWHA. There is also a great shortage of medical doctors in this region. This means that the more the number of people who need ART, the more the number of doctors needed so that they are able to monitor the patients on treatment (Van Damme, Kober, & Laga, 2006).

As it has been pointed out earlier, the number of PLWHA is increasing daily but health care workers are not. Instead, the majority of health care providers choose to work in private practice which makes it difficult for the PLWHA who come from disadvantaged family backgrounds to access such services. Benatar (2004) reported that there is a shortage of medical officers in South Africa despite the government's effort of training new medical officers. Despite lack of medical assistance the majority of patients live far away from hospitals which make collection of medication difficult.

Some of these patients have to travel more than 30 km to their nearest hospitals. Some of them complain about the hours they have to spend on the queue to see a medical practitioner.

In KwaZulu Natal the Department of Health offered a mobile clinic services which made monthly visits to the area, but this proved to be insufficient as people complained that they needed frequent visits. Some patients cannot afford transport costs and if they do afford those costs, chronically ill patients are often treated and turned back home due to shortage of hospital beds (Campbell, Nair, Maimane, & Sibiya, 2008). As the rate of HIV persons increases and as they experience opportunistic infections, the demand of health care services also rises up (Ehlers, 2006). With the unavailability of resources, PLWHA are also faced with HIV-related illnesses. In South Africa, access too many medications to treat symptoms associated with HIV infection is limited to the hospital and inpatient setting (Shawn, Campbell, Mnguni, Defilippi, & Williams, 2005).

Pierret, (2007), states that it is now widely accepted that effective available medical technologies such as antiretroviral drugs have transformed HIV/ AIDS from a severe life threatening condition to an established chronic disorder within a list of other such conditions that can be effectively managed. According to Westburg and Guindon (2004), this has resulted in a shift in emphasis from preparing people to die, to prepare them to live positively with the virus, the drugs and the required life-style changes.

There have been accounts of PLWHA who have been brought back from near-death (Persson, 2004).There were large number of PLWHA who died before the existing of ARV treatment. According to Sharma, Singh, Laishram, Kumar, Nanco and Armed (2006), PLWHA benefit better when in a relationship with their relatives and friends and when they adhering on ARV treatment. Aleksandra (2006) believes that effects on ARV adherence can be in a form of personal and emotional resources, suggesting that patients who received both personal and emotional resources will benefit from HIV and live a better life for a number of years. He goes on to say that when the PLWHA adhere to the ARV treatment their CD4 counts increase and their viral load decrease, this contributes towards their emotional stability. The following strategies and mechanism a can be used to support PLWHA adhere better to the drug regimen.

2.3.4 Community intervention

Community development and participation is a key component for improving the health of disadvantaged groups and communities. There has been a paradigm shift from the biomedical and behaviourally-oriented interventions to a community development perspective in health promotion activities. The involvement of grassroots communities in planning and implementing health interventions impacts positively on communities (Campbell, 2003). People living with HIV/AIDS are afforded an opportunity for self-development by community-based organisations. For example, the Siyam'kela Project (2003) trains their members in leadership skills so that they can involve them in community development projects (USAIDS, 2006). The issues pertaining to community participation revolve around arguments raised regarding the recognition of local communities in the strategic and operational decisions about health service design and delivery. The factors that undermine the level of health service of marginalised communities are differential access, cultural differences, racism and communication difficulties (Campbell, 2003).

On the issue of health-enhancing behaviour, it can be argued that local community groups should participate in the design and implementation of campaigns to promote behavioural change. It is anticipated that people follow the example of their peers and are more likely to change their behaviour because they trust their peers (Campbell, 2003). Health promoters have recognized the need for involvement in ‘community-strengthening programmes’ and seek to create ‘health-enabling communities’. These relationships are based on trust, mutual support and involvement in local community projects. Multi-sectorial collaboration and partnerships are key components in strengthening communities and creating health-enhancing environments (Campbell, 2003).

In addition Paulo Freire (cited in Campbell et al., 2005:814) “an important step toward mobilizing people with AIDS would involve initiatives that work toward facilitating the participation of local community groups in critical thinking programmes”. These programmes aim to expose the practices that sustain the stigma and undermine individuals who challenge these programmes. Critical thinking programmes are directed at marginalized communities, young people and women, the denial of young people’s sexuality, and the denial of the sexual activities of women. These programmes explore ways in which social institutions such as the church, family and traditional leadership system do or do not contribute to the marginalization of those infected and affected by HIV and AIDS. Community participation, alongside education and legislation are powerful weapons against stigma. The key role of community-participation is to promote all forms of critical consciousness that threaten to expose the unequal social relations sustained by stigma (Campbell et al., 2005).

2.3.5 Family Support

Family support is when parents, children, sometimes including grandchildren and other relations give strength, help, or encouragement to someone who is on antiretroviral therapy, for example, with regard to reminding family members on how to take medications (HIV and AIDS Clinical Management Programme, 2004).The family is probably most significant social system within which all individuals function (Ambrosin,Emeritus, 2005).It is the closest , most intense, most durable, and influential part of mesosystem Bronfenbrenner(1990).According to Bronfenbrenner ecological theory ,the family can also act as a support mechanism. A family that function within an unsupportive environment is much more susceptible to family problems than one functions within a supportive environment (Ambrosino, Emeritus,

Emeritus and Ambrosino,2005).The extended families can provide emotional support to their beloved families even if they are not staying together

2.3.6 Government intervention

According to Regensburg (2013) there is an initiative of a fixed dose combination of two or more active drug in a single pill. Instead PLWHA taking two or three different pills, can take one pill a day which include several ARVs .Furthermore Liezen (2013) said fixed combination contain tenafivor, TDF, FTC, or 3TC and efavirenz first line regimen. This Atripla, tribuss fixed dose combination have been available in the public sector but this year is available to public sector, which are developed. In addition Marteen (2013), mention that there is a little doubt that they are effective and associated with a high degree of PLWHA improved treatment adherence. This atripla, tribuss fixed dose combination can contribute to PLWHA to adhere to ARV treatment.

Fixed-dose combination ARV

Fixed dose combination, or FDC as it will be referred to from this point, is a combination of two or more active drugs in a single pill. The FDC ARV that will be rolled out in South Africa is a single tablet which contains a combination of the tenafivor (TDF), emtricitabine (FTC) and efavirenz (EFV).

Difference between FDC and the current ART regimen

With the introduction of FDC, all new patients, pregnant women and breastfeeding mothers will be offered FDC. The main difference between FDC and the current ART regimen is that these patients will have to take one pill once a day instead of three or more pills multiple times a day.

The benefits of the changeover to FDC for patients

The changeover to FDC will have a major impact on the quality of lives of people living with HIV in South Africa. FDC is more convenient, easier to take and with fewer side effects. The patient will also have to undergo fewer laboratory tests once he/she is on treatment. As a result of all of these benefits, we hope that adherence to ARVs will improve.

2.3.7. Antiretroviral Treatment

According to Van dyk (2008), the first antiretroviral drug AZT (zidovudine) was approved for use in 1987, in 1994 ART was used for mother to child transmission prevention and the use of HAART (highly active antiretroviral therapy) was introduced in 1995. He further advances the point that there are four goals of ARV treatment; it is virological because it reduces as much viral load as much as possible, immunological as it restores the immunological function so as to improve immune functioning, therapeutic; to improve the quality of life of those infected and lastly epidemiological, to reduce HIV related sickness, death and impact of transmission. Furthermore; since the introduction of first regimen (AZT, 3TC, NVP and D4T) its purpose was to increase life expectancy, prevent infection and reduce viral load (Wagner, Kahn and Blower, 2011).

The ARV treatment is used by PLWA with the CD4 count below 200 in other circumstances by PLWA with severe opportunistic infections who are sick and pregnant women start the treatment even if the Cd4 count is above 200 (Treatment Action Campaign, 2007).

Simon (2006) posits that although these life-saving anti-retroviral drugs (ARVs) help people living with HIV to have longer and healthier lives, however; low or non-adherence seriously compromises the value of this treatment. On the other hand Shweni (2009) adds that ARV treatment sometimes bears a lot of risks such as effects, viral resistance and treatment failure when non-adherence is prevalent.

2.4. Adherence by gender

There is argument that women are likely to adhere to ARVs than the men do. Therefore to establish this, there is a call to look into the following aspect of HIV/AIDs in regard to gender issues (Treatment Action Campaign, 2007).

2.4.1 Gender and HIV/AIDS

Men living with HIV/AIDS have greater rates of suicidal ideation than women living with HIV/AIDS and this are likely to be associated with HIV-related physical symptoms (Kalichman, et al, 2000). Most men and women who have a pre-existing depression it starts to worsen after they are diagnosed with HIV. It also becomes chronic depression when they lose employment, they start to have financial problems, and they suffer isolation and poor health due to HIV/AIDS. However women tend to suffer more social isolation and stigmatization (Lichtenstein, Laska, & Clair, 2002).

This is likely to be because of various factors. Women are expected to engage in heterosexual relationships with one partner. If a woman is married extra-marital relationships are unacceptable. It comes as a surprise to the society when a woman present being HIV positive. The concluding comment is that she was cheating not giving her the benefit of the doubt that perhaps she might have contracted the virus from her partner. Women are vulnerable to a number of social challenges. There are activities that put women at risk of contracting HIV such as injecting drugs and high-risk sexual behaviours.

These behaviours themselves make women vulnerable to violence, family problems and inadequate social support (Hader, Smith, Moore, & Holmberg, 2001). Stigma is a major contribution to difficulties in psychological adjustment among HIV positive men and women. Stigma or discrimination directed towards PLWHA becomes more frequent as overt symptoms of the illness emerge (Vanable, Carey, Blair, & Littlewood, 2006).

Other women living with HIV indicated that they were isolated by significant others in their lives once they disclosed that they were HIV positive. These isolated women, reported that they valued social support. They said that support groups helped them in talking about their feelings with people who understood them and who did not judge them (Enriquez, Lackey, & Witt, 2008). This is also supported by Hudson, Lee, Miramontes and Portillo, (2001) who indicated that women feel stigmatized and devalued due to HIV and they have to wait for a certain period to seek medical care. A study conducted by Siegel and Schrimshaw (2005), indicated that women living with HIV in the HAART era believe that being on HAART were more likely to report health-related stressors such as stigmatization and disclosure issues. HIV positive gay men indicated that learning that one is HIV positive is the most difficult thing to accept.

Their reactions included depression, denial, and anger and self-blame. This led to difficulties in adhering to antiretroviral treatment. However, they indicated that social support plays an important role to medication adherence (Brion & Menke, 2008).

Emotional support was reported to be helpful by both HIV asymptomatic and symptomatic gay men living with HIV (Pakenham, 1998).

Men living with HIV are also admitted to care facilities with complaints such as weakness, (tiredness and fatigue), weight loss, disease progression, and pain and medication adherence (Fields & Selwyn, 2003). In South Africa, Simbayi, et al. (2007) indicated that men living with HIV experienced more internalized stigma than women living with HIV. A study conducted in the United States of America found that women living with HIV, especially those who are socially and economically marginalized, continue to experience significant distress, even when they receive ongoing medical care and have access to HAART (Remien, Exner, Kertzner, Ehrhardt, Rotheram-Borus, Johnson, Weinhardt, Kittel, Goldstein, Pinto, Morin, Chesney, Light food, Gore-Felton, Dodge, Kelly, & NIMH Healthy living project trial group, 2006). Having larger social networks is associated with better mental health and overall quality of life in women living with HIV/AIDS (Gielen, McDonnell, Wu, O'Campo, & Faden, 2001).

This can mean that having more people whom you can rely on is better than having few people. Having more people around is better because at least one of them might be available unlike when there are few people who might all not be available in times of need. Women living with HIV are more concerned about their health. This is evident by a study conducted by Enriquez, Lackey and Witt (2008) which indicated that women living with HIV desired a high frequency of health care interventions. Sanders (2008) also mentioned that more women experience stigma and feelings of ambivalence. The stigma is also added by nurses who have judgmental attitudes towards people with HIV/ AIDS, especially regarding the means by which the patient contracted the disease and the extent to which nurses believed this to be self-inflicted (Surlis & Hyde, 2001).

Men and women living with HIV/AIDS report high prevalence of fatigue. This high prevalence of fatigue is associated with physical and psychological symptoms such as fever and depression (Voss, et al. 2007). Women also experience high levels of fatigue and greater fatigue severity (Husain, Stewart, Arseneault, Moineddin, Cellarius, Librach, & Dudgeon, 2007). Solomon, Venkatesh, Brown, Verma, Cecelia, Daly, Mahendra, Cheng, Kumarasamy and Mayer (2008), examined gender-based differences in the quality of life in men and women living with HIV in South India and found that women reported more psychological challenges than men. Women living with HIV/AIDS reported poor health-related quality of life than men living with HIV (Mrus, Williams, Tsevat, Cohn, & Wu, 2005). Women with HIV/AIDS had worse conditions than men in most aspects of life. This is because of lack of positive perception of their role in the society and cultural beliefs in addition to the stigma attached to the disease (Nojomi, Anbary, & Ranjbar, 2008).

Prevalence of current and lifetime Axis I anxiety disorders did not differ between men with or without AIDS. Other studies found that men with more HIV symptoms, physical limitations, and greater fatigue reported higher levels of stress and anxiety (Sewell, Goggin, Rabkin, Ferrando, McElhiney, & Evans, 2000). Reports of the caregivers of children living with HIV/AIDS indicated that more girls exhibited withdrawn/depressed symptoms (internalizing) than boys (Burgos, Hernandez-Rief, Mendoza, Castillo, & Shor-Posner, 2007). A study conducted in South India found that women have lower scores on several areas of Quality of Life compared to men (Chandra, Satyanarayana, Satishchandra, Satish, & Kumar, 2009).

2.4.2 HIV/AIDS and Woman of different ages

Stigma associated with age and HIV stigma place many people at social and psychological disadvantage. This leads to combined stress which makes difficult for personal coping mechanisms. Older adults who disclosed their HIV status reported that they felt that social services and health professionals were blaming them and discriminating them for contracting HIV/AIDS (Vance, Moneyham, Fordham, & Struzick, 2008).

Adolescents who are orphaned by AIDS are more likely to experience AIDS-related stigma which leads to depression, post-traumatic stress, conduct problems and behavioural problems (Cluver, Gardner, & Operario, 2008). Lack of adequate emotional support and feelings of isolation affects the individual's coping mechanism and this contributes to depression and suicidal ideation in older people living with HIV/AIDS (Vance, et al. 2008).

The study that was conducted by Burgoyne and Renwick (2004) indicated that social support contributes significantly to adults living with HIV/AIDS. Older people living with HIV/AIDS who had thought about suicide indicated to have received less social support from their family and friends (Kalichman, et al. 2000). Decline in physical functioning and death can contribute to depression. Adults aging with HIV are likely to experience comorbidities besides HIV. HIV itself may result in fatigue and depression leading to suicidal ideation (Vance, et al. 2008). Louwagie, Bachman, Meyer, Booysen, Fairall and Heunis (2007) indicated that HAART is effective in improving health related quality of life among adults living with HIV. Children and adolescents are faced with the challenges of adhering to treatment (HAART) (Abadı´a -Barrero & Castro, 2006).

On the other hand, older people who are HIV positive are faced with multiple challenges. They are faced with difficulty of making medical decisions and they are more likely to have shorter survival times than young people who are HIV positive despite being on HAART (Levy, Ory, & Crystal, 2003).Older people living with HIV/AIDS showed shorter survival time than younger people living with HIV even when they show good response to HAART (Navarro, Nogueras, Segura, Casabona, Miro, Murillas, Tural, Ferrer, Jaen, Force, Vilaro, Garcia, Masabeu, Altes, Esteve, Sued, Riera, Clotet, Podzamczer, & Gatell, 2008).

Adults living with HIV found that identifying someone whom they can trust and share their burden of HIV status is an important part for adherence with medication. Social support was found to be an important aspect of bringing hope in these people’s lives (Nam, et al. 2008). Lowe, Gibson and Christie (2008) conducted a study in Jamaica amongst adolescents who were infected with HIV and found that adolescents living with HIV who had poor social support reported to have psychiatric symptoms than those who had good social support. Social support intervention might be particularly beneficial for older persons living with HIV infection (Chesney, Chambers, Taylor, & Johnson, 2003). In the US, Liu, Johnson, Ostrow, Silvestre, Visscher and Jacobson (2006) found that older age was significantly associated with worse physical functioning. Older people living with HIV/AIDS may find themselves alone at home as their adult children have left them.

This exposes them to loneliness and lack of social support. Hawkley and Cacioppo (2007) argue that loneliness comes with ageism. They further added that those aging with HIV may be particularly at risk for fragile social networks and social isolation. Older people may have a comorbid illness while living with HIV/AIDS (Piette, Wachtel, Mor, & Mayor, 1995). Moreover, women displayed poorer mental health than HIV-seropositive men (Cook, Cohen, Burke, Grey, Anastos, Kirstein, Palacio, Richardson, Wilson, & Young, 2002).

2.5 Theoretical framework

Theoretical framework is the structure that can hold or support a theory of a research; the framework introduces and describes the theory which explains the research problem under the study (William, 2006).

In this study, the researcher supports and explains it through the use of theories that regard to behaviour of the humans in relation to living and doing their daily activities. This study is grounded on cognitive behavioural theory.

2.5.1 The Cognitive behavioural theory

The cognitive-behavioural model is a problem-focused approach that helps and calls on people to identify and change dysfunctional beliefs (US Department of Justice, 2013). The underlying assumption of this model is that thoughts influence emotions, which in turn influence behaviour. For example some people taking ARVs possess the following myths: ARVs deforms people's bodies, ARVs heals and therefore no need to take the ARVs any longer, when one is taking ARVs, one cannot have children; and that one can use ARVs in tandem with the traditional healers' medication etc (Kang'ethe, 2012). Therefore, such faulty thinking needs to be subjected to cognitive behavioural model for such individuals to change. If this theory is applied to PLWHA linked to Victoria Hospital and taking ARVs, this researcher believes that they will change and stick to the drug protocol. Behaviour modifications approaches have not been solely concerned with overt behaviour .There are theoretical accounts of depression, such as that of Lewinsohn, which although based on a behavioural theory concerning origins, also examines the mood changes and self-image of the sufferer.

2.5.1.1 Behavioural change theories to improve lives of PLWHA

According to Wekesa (2012) the shared theory of HIV/AIDS related behavioural change interventions include; Health Belief Model, Theory of Planned Behaviour and Information-Motivation-Behaviour Skills Model. Taddeoet et al (2008) and Wekesa (2012) further explain that these theories, identified personal factors associated with adherence to ARV treatment, as being the patient's perception of vulnerability to drug-resistant HIV, severity of viral load, effectiveness of proposed treatment, perception of challenges to adherence, own attitudes and attitudes of family and friends towards treatment regimen. The core of these behavioural change models is the rational assessment of the cost (barrier) and benefit analysis in adopting behaviour, with patients who have incorrect information doing incorrect analysis (Munro, Lewin, Swart and Volmink ,2007).

In relation to these models an example would be that, PLWHA will weigh the cost of non-adherence to ARV treatment against the benefit of sustained marriage/ relationship, discriminate or consuming alcohol on weekends and be perceived as having a social life. If the patient does not know the dangers of non-adherence, he may want to protect their marriage, want to avoid being stigmatised and discriminated or may give -in to the instant gratification of alcohol consumption and would want to be seen as being cool, in the expense ARV treatment that will improve the quality of his life. People who are well informed about the development of drug-resistant ARV will rather adhere to ARV treatment and continue to pursue their dreams, than getting involved in risky behaviours.

According to Kohler, Behrnam and Watkins (2007), the cost perception is not only the function of an individual but as a result of social interactions. Hence, the importance of information, education and behavioural change intervention in ARV non-adherence programmes should not only be designed for individuals but for the broader context which shape the individual, as a person does not live in an island.

2.5.1.2 Reinforcement

Reinforcement is way of promoting or encouraging a certain behavioural aspects by delivering a stimulus immediately after the response or an act has been done. This is done to ensure future occurrence of the action. Therefore, this would be important in helping PLWHA in adhering to their treatment through rewarding and encouraging them. On the other hand, strict rules on those who fail to adhere would play a role though not fully advocated for in this research.

2.5.1.3 The different between positive/negative reinforcement

Positive reinforcement is the offering of desirable effects for behaviour with the intention of increasing the chance of that behaviour being repeated in the future. It allows involved parties to focus on the positive aspects of the situation. Most of positive reinforcements have to do with rewards. Negative reinforcement occurs when a certain stimulus is removed after a particular behaviour is exhibited, resulting in the behaviour happening less in the future (Coon 2009),

Behaviour therapies entail a variety of methods, including the following

- Positive reinforcement: presentation of a reinforce contingent on response to the increase the frequency of that

- Negative reinforcement: increasing the strength of a response by removal of an aversive stimulus.

- Fading: transfer of a conditioned response from one stimulus to another in Progressive step.

- Response prevention: physical prevention of a response which has been linked by an individual to reduction of a negative emotional state.

2.7 Conclusion

This chapter examined literature relating to lack of adherence to ARV treatment. The theoretical framework also discussed. The next chapter discusses the methodology procedures employed in this study.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

This chapter discusses the research methodology or design implemented for the study. Research Methodology is the manner in which the research is carried out. The methodology chapter therefore contains the description of the research, the methods used, the research design, the population that was studied and the research instruments. Attention was also given to the participants, the research context, data collection, data analysis and ethics.

3.1 Research design

This study makes used qualitative. Methodology is the processing of bits of absolute truth by the researcher which formed collected data. According to many researchers, there are two research methods, namely quantitative and qualitative (Mouton, 2009).

The purpose of this research is to explore the lack of adherence to people living with HIV/AIDS linked to Victoria hospital, Alice, Eastern Cape province. This chapter describes the research design and method of research used. The study adopted qualitative research approach because of the nature of the topic. Data were collected from patients and health care workers through semi-structured interview schedule for qualitative approach. According to Mouton (2009), research methodology is about the study of research methods or strategy for research. It can be combination of methods that best enables the achievement of the research objectives. In this study, the researcher has discussed several components of methodology, research designs, data collection methods, population, sampling, data analysis as well as ethical considerations, which were useful for the study.

3.1.1. Qualitative Research Design

A research design is a plan which includes every aspect of proposed research study from the conceptualization of the problem right through to the dissemination of the findings (Mouton, 2009). In this study, the researchers employed qualitative approach and a case study as a research design (De Vos, et al 2011). Babbie (2007) further explains that qualitative research allows subjects being studied to give the much richer answers to questions put them by the researcher. This gives valuable insights into what might have been missed by any other method.

Qualitative researchers attempt to study human actions from the perspective of the social actors themselves. The primary goal of employing this approach is to define, describe and understand rather than explain human behaviour. Succinctly, qualitative approach is explorative and descriptive in nature (Babbie, 2012). This study also used participatory methodologies such as in-depth one-to-one interviews and participant observation. This is understandable because the study wanted to explore the thinking, feeling, attitudes, behaviour, and perceptions of the support group members with regard to challenges of non-adherence to ARVs treatment.

3.1.2 Advantages of Qualitative Approach

According to Rubin and Babbie (2011), qualitative research focuses on gaining understanding rather than offering explanation, using naturalistic observation rather than controlled measurement, with subjective experiences and interpretations in an attempt to understand the reality of people’s plight from the perspective of an insider as opposed to that of an outsider. On the other hand, Hardwick and Wisely (2011) describe qualitative research as being more intuitive, subjective and deep.

3.1.3 Trustworthiness in qualitative Approach

Mouton (2009) attributes trustworthy as another quality that clarifies the notion of objectivity as manifested in qualitative research. A good qualitative research has to have its data results displayed in a form of trustworthy and credibility. This is important because the results from a qualitative study depends on what the participants deemed to be true, and not what may have been recorded in literature about a phenomenon being studied. Also, the results must embrace the quality of neutrality. Trustworthiness refers to the confidence that a qualitative researcher have in his/her data. In this study, this was assessed using the criteria of credibility, transferability, dependability and conformability (Polit & Beck 2006). Succinctly, the above qualities have been defined. One of the key criteria addressed by qualitative researchers that indicate credibility is internal validity. The quality of internal validity ensures that the research study measures or test what the study intends to achieve.

Transferability in qualitative research demonstrates that the results of the work at hand can be applied to a wider population. Dependability addresses the issue of reliability and is an indication to show that if the work were repeated, in more or less the same contexts and with the same methodology, and the same participants, it is likely to yield the same findings. Neutrality refers to the degree to which the findings are those that were solely given in the field by the participants or informants (Guba, 1981). During the process of conducting interviews, the researcher was aware of the interaction between herself and the data. Acknowledgement and analysis of this process is termed reflexivity (Lietz, Langer & Furman 2006). Lietz et al., (2006) describe audit trail as keeping track of the decisions which led to the choice of particular steps in the research procedure. Reasons for the choice of research design, sampling type and sample size and methods of data collection and analysis were described in this chapter.

3.1.4 Sampling methodologies and Techniques

Thompson (2012) defines sampling as a process which a predetermined number of observations are taken from a larger population. According to Marlow (2011), non-probability sampling allows the researcher to intentionally select those elements that are information rich, which makes it the sampling method of choice in qualitative studies. Therefore, non-probability sampling procedure was employed using purposive sampling technique. This is because the participants were chosen by the researcher and constituted those that best met the purpose of the study or fitted the purpose of the research.

3.1.5 Sample Size or Unit of Analysis

The sampling size comprised of 22 support group members (men and women,) between the ages of 18 and 60 years, who were Xhosa speaking and were linked with Victoria Hospital ARV clinic. 2 nurses, 2 care-givers as well as 18 people who were taking ARV treatments were interviewed. All these people interviewed were subjected to the FGDs.

3.1.6. Sample selection criteria and Recruitment

The samples selected samples met the following qualities which include: They were PLWHA taking ARVs and served by the Victoria Hospital, Eastern Cape Province. The sampling also considered gender thereby including women and men over the age of 18 who knew their status as at the time of the study. Also the samples revealed those people who had been taken ARVs for a period between six and 24 months at the time of the study and residing in Alice as well as surrounding villages and receiving care and treatment at the Victoria Hospital, Eastern Cape Province. Another factor which contributed to the choice of the sample was recruitment. On recruitment, the participants were recruited at the ARV clinic during the normal routine and follow-up visits. The participants were sampled from a total population of patients, whether male or female, irrespective of colour or race, or their state of socio-economics. The members of the support groups have to be PLWHA however the health care providers qualify by the virtue of being knowledgeable and providing service to the PLWHA about ARVs.

3.1.8. Population

Population is the term used to describe the total number of cases that forms the subjects of the study and it can consist of objects, people or even events (Walliman, 2005). Furthermore, a population is defined as a complete set of persons or objects that possess some common characteristics, which are of interests to the researcher (Brink 2011). Similarly, McDaniel & Gates (1998) define population as a total group of people whom information will be obtained from. In this study, the population under study consisted of support group members linked to the Victoria Hospital ARVs-site. The participants were restricted to a manageable number due to the cost implication and also for easier accessibility by the researcher. Based on the ethics of the study the participants shared every experience and almost everything that the researcher wished to know through the guidance of an interview schedule. The participants were all confident and comfortable enough to talk about their HIV status openly.

3.1.7 Instruments

An interview guide was used to facilitate both the in-depth interviews and focus group discussions in order to allow for a free flow of information, communication as well as a smooth transition from one question to the other. The interview guide enables the researcher the appropriate questions to ask, when to ask such questions, in what form/manner/ order and in an in-depth manner guided by both University ethical clearance. The advantage of the research guide is to guide the researcher to abide and not go out of context.

3.1.10. Data Collection Method and Procedure

Data collection refers to the methods which researcher uses in the process of information or data collection (Welman et al. 2005).

In this study, data collection was conducted at the Victoria Hospital ARV clinic, Eastern Cape Province. The researcher had made several visits before the data collection process to ensure that all the preparations were in order to have permission to conduct the interviews for the study at the hospital. Other activities include meeting the potential samples and explaining to the participants the objectives of the study as well as the possible benefits of the study to the University, the country at large and possibly to the PLWHA themselves. This was important for the participants to make informed decisions as to whether they could be included in the study. Consent forms were handed out to the participants so that they could explain whether they want to be part of the study or withdraw willing if they were uncomfortable at any point in time of the investigation. Ground rules were laid down to control the participants for the study. The researcher read simple questions from the interview guide for the participants to give answers to or respond to and this was done to allay any fear pertaining to giving answers to questions the participants were cleared of or sure of. Participants were also encouraged to share their views and experiences. This encouraged participants too openly to the researcher and others without any fear of intimidation. Participants were encouraged to give support to one another and engage with others as they were all candidates of taking ARVs. The study area was the conference room of the ARVs' site located within the Victoria Hospital. The conference room served as an ideal environment for the discussion and engagement. The researcher provided refreshments and some scones to the participants after the study to avoid participants' departure as an excuse to quench their hunger or thirst. Each of the participants was given a pen and paper to write down important questions and points to ask during the discussion.

3.2.0 In-depth interviews

Participants as the selected samples at the ARVS site clinic at the Victoria hospital, Eastern Cape Province were asked in-depth questions during the interview. The research tool used for the study was an in-depth interview through questionnaire where the participants were asked semi structured 'open-ended questions which allowed participants to communicate their experiences in their own words without any restrictions.. The use of open-ended questions was intended to gain an insight into the experiences, feelings and opinions of the PLWHA in an in-depth manner guided by both University ethical clearance/ guidelines as well as .the interview guide and as such the researcher abided by the ethical issues and regulations governing the conduct of research in the University. The researcher also assured the participants' of information confidentiality. A copy of the Ethical Clearance approved for the study is attached as Appendix 1.

3.2.1 Advantages of in-depth interviews

According to Boyce and Neale (2006), in-depth interviewing can be referred to as a qualitative research method, which entails conducting intensive interviews with a small number of participants to exploring their perspectives on a particular idea, program, or situation. Furthermore, the primary advantage of in-depth interviews is that it offers detailed information than other data collection methods. It is information being collected within a more relaxed atmosphere, and lastly, in-depth interview can be used in place of focus groups if the participants are not comfortable talking openly in a group.

3.2.2. Focus groups

The study also used focus group discussion (FGD) to complement the in-depth interviews with the questionnaire. About 18 people were interviewed. Focus group discussion is a method used for data collection within qualitative research where a researcher leads a discussion with a small group of participants. The purpose was to allow participants to bring out their views/opinions about a topic of discussion. The group discussions lasted for two hours. The aim of the discussion was to find the determinants of adherence for PLWHA who are linked to ARVS medical regimen protocol site of the Victoria hospital in Eastern Cape Province.

Observably, the use of focus group discussions proved useful as the participants brought out their views on the topic for discussion. This proved to be cost effective as it was done over a short period of two days within the patients' schedule of visits to the clinic. The shortcomings of the focus group discussion included the tendency of having less control over the group which might lead to loss of time and inability to resolve some relevant issues. The researcher's active and leadership prowess contributed to the control to lead and facilitate the discussions.

3.2.3 The Role of a researcher

According to Creswell (2009), the researcher has roles to fulfil when conducting a research project. He/she is the driver and in qualitative researcher, he/she is the primary data collection instrument. This means that his/her views, experiences, interpretations become important in the final results of a research undertaking. He/she is responsible for putting the data in a manner that the reader can understand the topic better and make sense of the research results satisfactorily. The final role of the researcher is also to assure the participants' of information confidentiality. The researcher has to ensure that all the conditions pertaining to the rights of the participants and their comfort are appropriate. He/she has to ensure that the study happens within an environment that is institutionally and legally correct. For example, he/she has to ensure the ethical clearance is availed before the study kicks off (Creswell, 2009). It would be against the law of the land if the researcher does not abide by all the ethical and legal protocols of a research process.

3.2.4 The Research Domain and Justification of Choice

The Victoria hospital ARV site located in Eastern Cape Province was selected because it was the domain from which ARVS were administered and dispensed off to the PLWHA. Also, the nurses who had experience of administering and dispensing the ARVs worked there. The study targeted people living with HIV and those who were placed on ARVs for six months and longer.

3.2.5 Ethical and Legal Considerations

The study also considered the ethics and pertinent conditions that needed to be fulfilled while undertaking such investigation. Critically and legally, researchers need to consider the basic human rights of the study participants/respondents. This was because research undertakings proved to violate the human rights of the participants as well as cause major harm to their social, psychological and emotional wellbeing sometimes in a huge way. Therefore, researchers were advised to obtain all the legal and ethical requirements before undertaking in any study. For instance, the research goals and objectives of the study must have been explained to all the participants and if they were comfortable to be involved, they need to sign an informed consent form. Afterwards nobody would be investigated without being given the rights conditions to make informed decisions.

The researcher needs to tell the research participants that their involvement in the study was voluntary and there would no intimidation from any quarter. The participants have the free will to quit and no one should feel obligated to continue in the research proceedings. Equally, the study also has the right to terminate the participant’s involvement at any given time. The researcher has the right to protect the rights of the participants’ (De Vos, et al., 2011). According to De Vos et al., such rights includes, the right to privacy, the individual’s right to decide when, where, to whom, and what extent his or her attitudes, beliefs, and behaviour would be revealed; the rights to remain anonymous, which implies that participants would identify each other after the termination of the contract between them; and the right to confidentiality. Within the study, the researcher must assure the participants’ utmost confidentiality and anonymity so that no one attaches them to any information. The researcher achieved the maintenance of privacy so that no one has access to any data collected instruments such as the scribed note pads, and transcribed materials except the researchers. To avoid any unforeseen harm whether psychologically, emotionally or physical, the researcher must assure the research participants that no one would be left harmed in all aspects.

3.2.6 Data Analysis

.This is where the researcher organises data info file folders, index cards, or computer files, and also convert the files to appropriate texts units for example a word , a sentences, or a full story (De Vos et al., 2005). The information that the researcher got from the participants was haphazard and ad hoc, hence the information that the researcher collected was organised into computer files. A file was opened for each participant to ensure better management of the data.

3.2.7 Reading and writing memos

After organising and conversion of data, the researcher continued with the analysis by getting a feel for the whole data base (De Vos et al., 2005). The various pieces of transcripts were translated since data had been collected using IsiXhosa language. It needed a double translation to English. This is because all the reports about the study had to be in English.

3.2.8 Conclusion

This chapter has focused on various components of research methodology, the research design, methods of data collection and data analysis. It has also discussed the research instruments as well as ethical consideration. The next chapter will focus on the analysis and interpretation of the data.

Chapter 4

4.0 Data Analysis and Interpretation and Presentations

4.1. Introduction

The previous chapter elucidated all the components of the research methodology that has been used to guide the whole of this study. The sample comprised of individuals living with HIV/AIDS who are on ARV treatment and linked to the Victoria Hospital. The research utilised in-depth interviews in private room within the ARV site. The main aim of this study was to investigate the lack of adherence to antiretroviral treatment for people living with HIV/AIDS linked to Victoria Hospital, Alice, Eastern Cape. The study had the following objectives.

- To explore the factors contributing to non-adherence to ARVs by PLWHA linked to Victoria Hospital, Eastern Cape.
- To establish the effects of non-adherence to ARVs.
- To explore support systems for the PLWHA to enhance adherence.
- To investigate by gender who are likely to adhere to treatment.

The following are the results that emanated from the research process:

4.2. Demographics and Personal Details

This section presents the findings related to the biographical information of the participants in the study.

4.2.1 Individual in-depth interview participants

The participants were asked to briefly tell the researcher who they were, their age, and marital status, number of children and status of employment.

Table 1 Demographics and Personal Details of Individual in-depth interview participants

Pseudonames	**Age**	**Marital status**	**Education**	**No of children**	**Employment**
Kondile	44	Married	Grade 4	4	Unemployed
Mkondeleli	29	Single	Grade 12	1	Student
Nokuku	37	Single	Grade 11	1	Employed
Almen	41	Single	Grade 6	3	Employed
Fifi	51	Married	none	6	Employed
Mpopoli	31	Single	Grade 12	2	Student
Ntombizakhe	39	Married	Grade 9	4	Employed
Bhovuza	29	Single	Grade 12	2	Unemployed
Noxabiso	39	Single	Grade 8	3	Unemployed

Lulama	56	Divorced	none	5	Unemployed
Hamile	33	Grade 12	Grade12	None	Unemployed
Xolo	49	Grade 5	Grade 5	3	Employed
Ahlumile	26	Single	Grade 12	None	Employed
Nomvuzo	25	Married	Grade 11	2	Unemployed
Qobo	27	Cohabitating	Grade 12	None	Employed
Noluvo	23	Single	Grade 11	1	Employed
Xolile	40	Single	Grade 9	1	Employed
Zibula	38	Single	Grade 12	1	Employed

Gender

Table 2 Gender of participant

Sex participant	**Frequency**	**Percentage**
Female	15	68.18%
Male	7	31.82%
Total	22	100

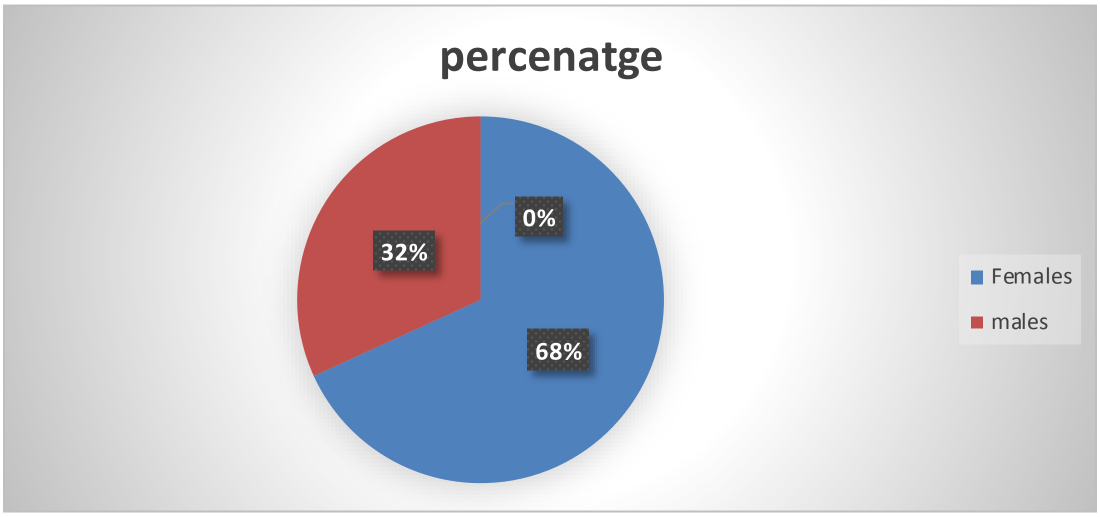

Figure 1 Percentage of sex of participants

The study revealed that a higher percentage of females (68.18 %) participated in the study than the males. This could perhaps point to the direction that the females are more vulnerable to infections of HIV/AIDS; they are also the ones who are more responsive to issues pertaining to HIV/AIDS; and more of them than males have known their seropositive status and therefore were benefiting from ARVs more than males.

Age

Table 3 age of participants

Age	Frequency	Percentage
20-35 years	8	36.4
36-45 years	10	45.4
46-60 years	4	18.2
Total	22	100%

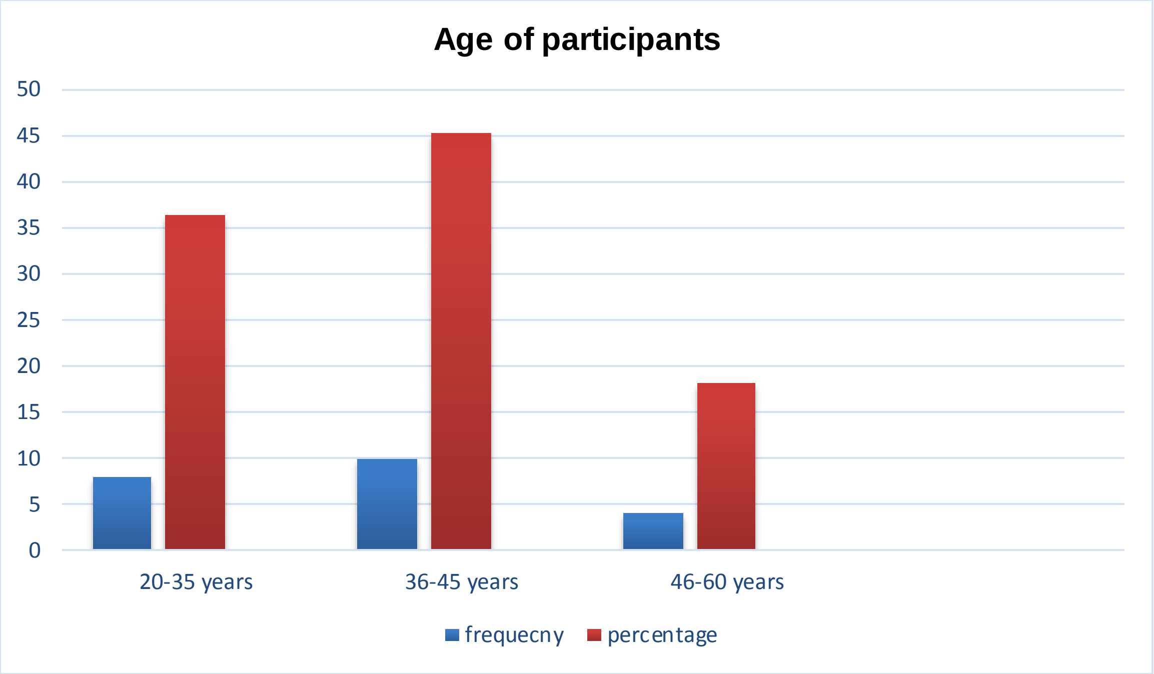

Figure 2 Age of participants

On age, the analysis showed that the middle aged persons (36-45 years) participated in the study on a higher percentage of 45.4%, than the relatively elderly individuals of 46-60 years whose participation scored a low percentage of 18.2%. These findings would imply that having many participants aged between 36-45 created a challenge on adhering to the treatment of HIV/AIDS. This is because at this age, individuals of 36-45 are also handling many life chores such as nurturing children and generally running households.

Education

Table 4.1.4 Education of participants

Education level	**Frequency**	**Percentage**
None	**2**	**9.1**
Grade 4-7	**4**	**18.2**
Grade 8-12	**16**	**72.7**
Total	**22**	**100**

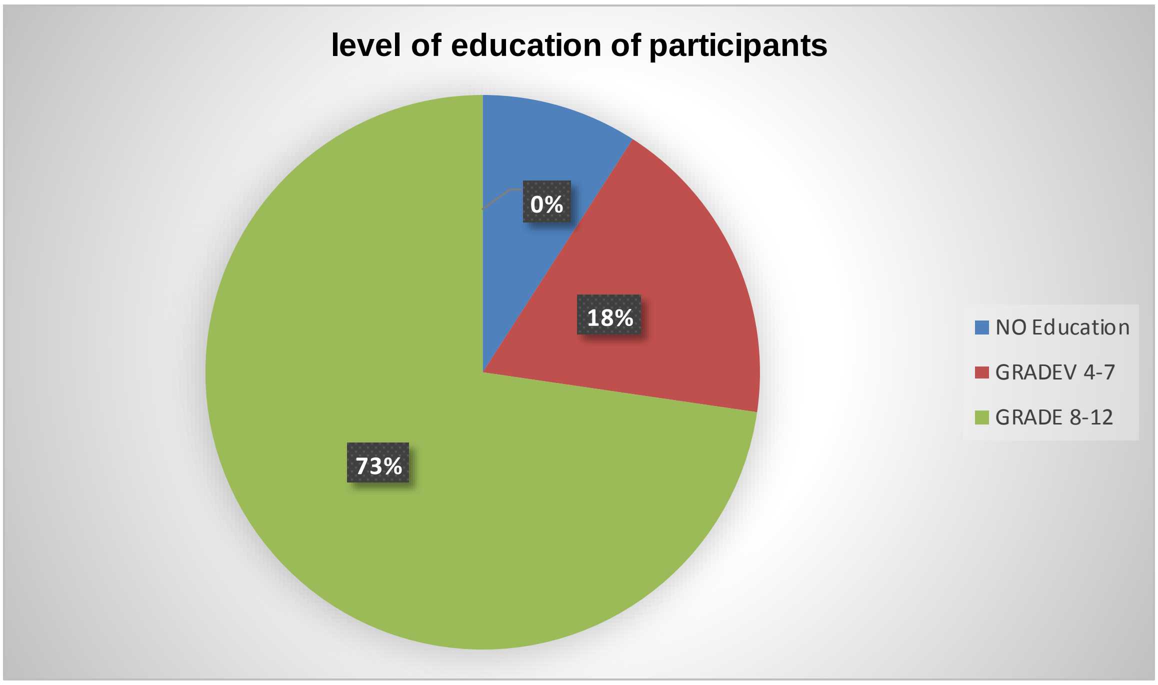

Figure 3 Level of education of participants

On education, the analysis above reveals that the literacy rate in Alice is high and most have advantage of using their education in terms of adherence. This is because individuals with relatively good literacy levels are likely to understand the dynamics associated with ARV adherence.

Marital status

Table 4 marital status of the participants

Marital status	**Frequency**	**Percentage**
Single	10	45.5
Married	8	36.4
Widow	1	4.5
Cohabitating	2	9.1
Divorced	1	4.5
Total	22	100

The results drawn from table indicate that 46% of the participants are separated from their partners; and 36.4% were married. As far as adherence was concerned, those who were married and living with their partners would be expected to get some psychosocial support that would help in adherence. With 46% being separated, this was a population whose capacity to adherence was at stake.

Employment status

Table 5 Employment Status of participants

Employment	**Frequency**	**Percentage**
Employed	12	54.5
Unemployed	8	36.4
students	2	9.0
Total	22	100

Findings revealed that more than half of the PLWHA respondents were employed. This was a positive score as far as an environment to contribute to adherence was concerned. However being unemployed and perhaps living in a state of poverty prompts state of apathy which creates a fertile environment for non-adherence.

4.2. Focus Group Participants Demographics and Personal Details

Table 6 the demographics and personal details of focus group participants of the study.

Pseudonym	**Age**	**Marital**	**Profession**	**No of children**
Nomalizo	47	Married	Nurse	4
Kayone	44	Married	Caregiver	3

Mbali	39	Cohabitating	Caregiver	2
Bongo	37	Single	Male nurse	3

Gender

Findings indicated that most participants were females. This indicates a higher tenacity and motivation for women to be engaged in HIV/AIDS issues. This perhaps make this researcher to think that perhaps factors such as culture and societal attitudes were deterrent to male involvement in HIV/AIDS issues.

Marital status

The marital statuses of participants were different; two were married, one single and one cohabitating. With marital status, people were assumed to be giving one another a conducive environment to adherence; while it is assumed that those who were single missed a good support system to facilitate adherence.

4.3. Themes That Emerged During Data Analysis

4.3.1. Poverty of the PLWHA negatively influence adherence

The participants emphasised the importance of two particular needs, namely nutrition, and intimacy. Nutrition was cited as being a very important for adherence, immunological development, and treatment success. Participants expressed that most people who are taking ARVs at Victoria Hospital were living in abject poverty that negatively affected their capacities to adhere to ARVs. They felt that there is a strong correlation between HIV and AIDS and poverty. This is because they said that HIV and AIDS increases poverty and poverty also offered an environment conducive to being infected by HIV/AIDS. This is because poverty easily attracts people to engage in high-risk sexual behaviour, which makes them vulnerable to HIV/AIDS infections. Since high risk behaviours could lead to other viruses getting into some one's body that could easily affects one's body biology and hence making the current ARVs not effective. This could easily lead to a faster progression of AIDS. Participants also mentioned that it is not only the HIV that suppresses the immune system and makes PLWHA susceptible to a host of opportunistic infections, but also hunger. The participants felt that after being attacked by opportunistic infections, an HIV-infected individual may have a poor adherence to ARVs. These opportunistic infections may interfere with the activities of daily living. The above finding was supported by the following sentiments.

> *In Alice, I feel we [nurses] are going nowhere in the fight against the epidemic, because of poverty. Poverty has promoted prostitution, and prostitution has increased the prevalence of HIV and other sexually transmitted infections, and, as such, provision of ARVs will do little to improve the lives of the people. We should find out how we need to deal with the problem of hunger first, before giving ARVs.*

> *"It is a pity, because we educate people about a balanced diet, yet some families cannot afford even a plate of porridge. How do we expect them to afford the luxury of a balanced meal three times a day? Maybe government can do something, like offering some incentives in the form of food or money, to alleviate the problem of hunger".*

> *"It's because of lack of food that makes me not adheres to the treatment".*

This implies that the ART programme may just be a drain of the public coffers if the government does not work hard to address the poverty of the PLWHA. Since the cost of ARVs are very high, perhaps equipping the PLWHA with skills or funding them to kick-start some income generating projects could be central.

4.3.2 Incentives critical to PLWHA

Findings indicated that some PLWHA cried foul that the incentives that were received before should be resuscitated in order for the PLWHA to afford a good diet in order for the ARV medication to work adequately. However, some felt that the incentives were making people irresponsible and lazy as well as encouraged non adherence so that their CD4. Can meet the criteria for the incentives. The above findings were supported by the following sentiments:

> *"Kwiminya edlulileyo kwakukho imali eyayifumana ngabantu abaphila nentsholongwane kagawulayo xa Icd4 count ingaphantsi ko 200, kodwa ke kwaye kwafunyaniswa abantu abaphila nentsolongwane abayilandeli imiqathango kagqirha ngenjongo yokuba Icd4 count yehle,bazokwazi ukufumana isibonelelo kurhulumente,kuba urhulumente ebesasikhupha isibonelelo ngeyingekho indlalala nook wbantwini abaphila nentsholongwane".*

> *"In the previous years there was financial incentives for PLWHA with a low CD4 cell count of 200 and less, but it was discovered that the PLWHA were deliberately failing to honour the drug protocol so that their CD4 cell count could be below 200 so that they meet the criteria of the incentive. The mere fact that the government is providing incentives means that it is rewarding them [PLWHA] for being HIV-positive, and people will deliberately infect*

> *themselves. If government provides incentives, it has to provide them for all other chronic illnesses".*

The majority of the participants finally reached consensus that adherence was negatively affected by lack of food incentives. They demanded that the government should give them the incentives as it used to do some times back. Otherwise, having the ARVs on an empty stomach may just be a defeatist affair of providing people with ARVs.

4.3.3 ARV dispensing was not friendly to the rural dwellers

Study findings indicated that although the dispensing of the ARVs was free, the administration and dispensing of the ARVs was still centralised and therefore disadvantaging the rural dwellers that had to travel long distances to access the drugs. This was heart breaking and provided opportunities for some failing to get the drugs timeously. This was an opportunity for non-adherence. The finding was supported by the following sentiments:

> *"ARVs are available only in referral hospitals, which are far away for some of the people. There is a need to train nurses, so that they have the capacity to give these drugs at the clinic level and have mobile clinics to take care of those far away".*

The issue of considering the ease of administering the ARVs as well as dispensing is key. It is critical that the government consider training the local nurses so that they can be skilled enough to be able to dispense and administer the drugs. This would reduce chances of some PLWHA failing to adhere because of lack of transport to get the ARVs to the centralised dispensing points.

4.3.4 Stigma associated with being a PLWHA

Study findings indicated that some PLWHA felt stigmatized and deprived of love by their families and community members in general. They indicated that the situation made them feel unwanted and helpless. It also made them feel hopeless of living. Such states made them to fail to adhere, especially when engulfed with negative feelings of the heralding imminent death coming by. The finding above was supported by the following sentiments.

> *“Akakho umntu onokwamkela xa wena ungazamkeli”*
>
> *"No one can accept you before you accept you.”*
>
> *“Yonke into ebendiyenza, nalapho bendihamba khona, bendiba lusizi xandisiva abantu bethetha, besithi mjongeni uphila nentsholongwane”*
>
> *"Everything I did, everywhere I went, I felt ashamed to hear a person saying, “Look at her. She is positive."*
>
> *“Xa sise patini abantu baye bangafuni kutya ngezitya esitya ngazo thina bantu baphila nentsholongwane,bangavumi noba sisele nge glasi abasela ngazo”.*
>
> *"They do not want to eat in the dish when you use it, they will never share the glass with you”*

> *“Ndiyaqumba yaye ndoyike ukuhamba nabahlobo bam xakufuneka ndihambe nabo sizakuhlala endaweni enye”*
>
> *I was feel so sad and then I become so afraid to go with my friends and go and sit with them"*
>
> *“Ndacinga ngokuzibulala ngenxa yempatho mbi kubantu ebendibathemba”*
>
> *"I even thought of committing suicide."*
>
> *“Yhhhooo xa kuzawulalalwa bafuna ulale ngaphandle,abafuni noba ndombathe ngengubo ezi bazisebenzisayo endlini.”*
>
> *"You sleep maybe they want you outside. They do not want you to use their blanket in house."*
>
> *“Xa uthewagutyungelwa lilifu elimnyama izihlobo ziyabaleka,ngoba mna ndabalekwa nazizihlobo zam ekaya nditsho udade wetu”*
>
> *“When my days were dark she wasn't there for me”*

The above scenario indicates that the challenge pertaining to adherence was to remain as long as stigma was not subdued. It is therefore critical that government strengthens anti-stigma campaign.

4.3.5. Challenge associated with inadequate transport

Study findings indicated that most PLWHA defaulted in their adherence process because of lack of transport to get the ARV timely from the dispensing points. This is because many were poor and unemployed, posing huge challenge to afford transport to the dispensing points. This was particularly the case for those who were living in deeper rural areas. They indicated that if there was government transport facility, or some sort of government subsidy for those going to get ARVs that would help in boosting chances of ARV adherence. The following sentiments support the findings.

> *"I am working at forest, so sometimes I take my treatment after my work schedule, because the forest manager does not provide transport as he is not sick. I have to wake up very early in the morning and walk long distance before I reach to transport point in a distant village".*

> *"My village is very far from the ARV clinic, the transport requires cash then I end up walking to the hospital".*

Apparently, perhaps the administration of the ARVs need to factor this challenge because it is real that those who comes from faraway places get disadvantaged as far as fetching ARVs is concerned. There ought to be better mechanisms to help all to conveniently fetch the ARVs. Otherwise, transport challenge can easily form a fertile ground for no adherence.

4.3.6. Inextricable relationship between people's socio-economic status and adherence

Participants stated that people's state of socio-economic status reflected their possibilities and probability of affording adherence to ARVs. This state of socio-economic status was informed by lack of employment, having many children, widowhood etc. With people who had better living conditions, they were likely to live positively and therefore with less stress. Such people are therefore able to think straight and adhere with ease. Such people are also likely to enjoy some significant social support. For those who are in poverty, life usually presents other ramifying situations making them to think about other problems other than the issue of taking drugs. Once can easily forget about medication altogether. This finding was supported by the following comments:

> *“Money leads to poor nutrition, poor living conditions, and poor access to healthcare, which are all breeding grounds for HIV people”.*

4.3.6. Alcohol and Drugs use negatively influences adherence

This study finding indicated that PLWHA state of adherence was negatively influenced by alcohol abuse. Participants owned the knowledge that alcohol abuse made those taking the medication to forget taking their medication. Furthermore, most of the participants mentioned that sometimes they fear taking the drugs while under the influence of alcohol and are therefore forced to default until they are sober. The following finding finds support from the following sentiments.

> *“I experience a problem of taking my medication when I have consumed alcohol. I become scared of mixing it with alcohol and tobacco. Therefore, when I have alcohol, I do not take my medication”.*
>
> *“When I thought I had recovered fully from the disease, I stopped taking my medication in the right way. I went back to alcohol. Therefore, when I am drunk, I’ am unable to take my treatment”.*
>
> *“When I’m under the influence of alcohol, I forget the times of taking the medication. Therefore, I end up not being consistent in taking my medication”.*

The scenario above indicates a possible inextricable relationship between drug abuse and non-adherence to ARVs. This underscores the fact as long as the PLWHA are abusing alcohol, chances of successfully following the drug regimen is slim. Perhaps the HIV/AIDS campaign needs to seriously incorporate advocacy against the abuse of alcohol and other drugs.

4.3.7 Inadequate awareness campaign pertaining to adherence

All participants mentioned that awareness campaigns addressing issues of adherence on ARVs are limited. They therefore wished if the government can deploy nurses to the communities to conduct awareness campaigns on how adherence can be bolstered among the PLWHA. The finding finds support from the following comments:

> *"We need to have awareness campaigns that will address issues of adherence because we lack information*"
>
> *"Awareness campaigns can assist us and our families to be informed about our states of health and how to stay health in our treatment"*
>
> *"Ukuba ndandikwazi ukufunda ezi pilisi, ngendisindile kugawulayo, ngoba umntwana wam akazange andixelele ba utya ipilisi zantoni, nam ke ngelixesha agulayo bendimhlaba ndingafaki zikhuseli"*
>
> *"If I was educated, I couldn't be affected by virus, my daughter never disclosed her status and I had to wash her without protection"*
>
> *"I feel that HIV and AIDS education can reduce HIV-infection and people can stay updated about the epidemic".*

Perhaps it is critical that community awareness campaigns generally are intensified on the HIV/AIDS campaign, its aetiology and epidemiology, as well as how to maintain and manage adherence for those living with HIV/AIDS. It is apparent that lack of education and awareness was becoming a recipe of disaster and therefore increasing chances of HIV/AIDS infections, as well as opportunities for non-adherence.

4.3.8. PLWHA usually suffered pangs of Anger and Despondency

Many participants owned the fact that having to live with the virus was a difficult and arduous task that usually drives them into a state of anger and despondency stated. They further indicated that the states of anger were exacerbated by how their partyers were treating them and also by states of stigma they were subjected to by community members. They further said that most of the conflicts with their partners revolved the question of who infected the other, with each one of them tending to point a finger to the other. The following findings are supported by the following sentiments

> *"It is painful to be reminded about ones HIV status. At times, I ask myself whether it is my fault to be infected with HIV"*
>
> *"I am angry because now I am pregnant and HIV positive, how can my partner expose me to such state of danger".*
>
> *"There are things that are not going on well in my life. Right now, I'm going through a divorce, and I do have a problem, because we are just fighting on the phone. Otherwise, I just want to be positive about life. There are bad things that happened in my life, like one day, I was about to commit suicide because I was so hurt and felt that things were not going well, But through. God's Grace, I am surviving. I had that situation in my life, but now everything is good and I have committed myself to God".*

Apparently, living with HIV/AIDS should be viewed as a complex phenomenon that requires concerted interventions. Because of the social, emotional and psychological challenges, perhaps the government and the NGOs should deplore as many psychotherapeutic professionals to be always available to cool the tempers of the PLWHA. Giving them hope and love is also central.

4.3.9 PLWHA being prone to Separation and Rejection

Some female participants shared that they were being rejected by their partners after they disclosed their status. This is because the male partners unfairly and unfaithfully insisted that their female partners were not faithful and that they were the ones who had brought the virus to them. The following finding finds support from the following sentiments.

> *"Emva kokuba ndilixelele okokuba ndichaphazelekile yintsholongwane kagawulayo iqabane lam landishiya" ("After I disclosed my status my partner left me")*
>
> *"Saphela sisohlukana neqabane lam emva koba ndimxelele ukuba ndichaphazelekile"*
>
> *"After I disclosed my status to my husband we ended up separating. However, the one that I have now is so supportive"*

Perhaps the campaign to own sero-positivity to be a real phenomenon is critical in South Africa. Also the campaign to de stigmatize the disease so that people reduce chances of denialism is critical. HIV/AIDS should be viewed in a normal way just like any other disease. Perhaps the poor campaign especially in the rural areas has made people to view the disease as a dreadful one and refusing to accept living with the loved ones who are infected.

4.3.10 Health workers breaking confidentiality of the PLWHA

Many participants indicated they were unhappy with the way the nurses dispensing the ARVs were breaking the ethics of confidentiality by disclosing the information about who and who is living with the virus. This had made the PLWHA very angry in that some people knew their sero-positivity and yet that was supposed to be a secret affair. Such phenomenon was a painstaking one and made adherence a huge challenge. This is because some people were refusing to go for medication

> *"Ndiyoyika ukumxelela umlingane wam, ngaske angayiva nasekuhlaleni ngoba ndoyika sohlukane yaye nasekuhlaleni andifuni bayazi okokuba ndiyagula,ndisoyika ndinjalo umkumxelela umlingane wam, amanesi aye angayigcini iyimfihlo wona izigulo zethu ngouyoze ufika ephunga ngathi kwezi lali sihlala kuzo waziwe nangu thatha ba uyagula"*
>
> *"I am scared to disclose to my partner, I so wish she can never hear about my status and my community members I do not want them to know that I am HIV positive".*
>
> *Sometimes our community and partners are not aware about our HIV status because, they still perceive HIV/AIDS as moral condition not diseases that they are going to get information from the local nurses where we get our medication".*

It is pertinent that the health workers know that they are under oath to protect the secrecy and confidentiality pertaining to the state of clients they handle. Otherwise, they should know that breaking confidentiality of a client is punishable by law. Perhaps more legal sensitization of the health workers pertaining to maintaining ethical standards as provided for by both the medical policy and legal provisions is central.

4.3.11 Apathy and hopelessness

All the participants who were part of the research felt hopeless, apathetic and despondent. Some thought they would never live long but die soon. They also felt abandoned by their families. They echoed the following sentiments

> *"I deprived to sit with my family at lounge watch television, I cannot even use a spoon that they are using at home, and even if I want to assist with something my family does not allow me to assist"*
>
> *"Andivumelakanga ndihlale ne femeli yam ndibukele no mabona kude, naxa ndifuna ukuncedisa kwimisebenzi yasendlini abandiniki thuba, andinathemba lakuphila ngcono".*
>
> *"I am a laughing stock to my friends and family they are gossiping about me and I feel so hopeless and my self-esteem is very low".*
>
> *"Ndiyinto yohlekisa kwizihlobo ne femeli yam, andinathemba, ubu mna bam buhle tuu".*

The above scenario indicates that the environment in which the PLWHA lived in drove them into a state of apathy and therefore created a fertile ground for various kinds of stresses, despondency. This was an environment that would easily compromise the states of adherence. Any successful campaign, therefore, would have to address the challenge of unconducive environment of the PLWHA. Their economic upliftment is critical.

4.3.12. Lack of Knowledge

Study findings had some participants owning the fact that they were ignorant of the knowledge packages pertaining to HIV/AIDS generally. The information pertaining to ARVs was particularly lacking. This attracted the following comments:

> *"Mna azange ndifumane ngcaciso malunga namachiza kagawulayo ngoba ndandihlukumezekile engqondweni, ndahlolwa kwafumanekiswa ba iCd4 count yam isezantsi ndanikwa amachiza kwa ngoko*.
>
> *"I never get enough information about the treatment coz I tested and sisters had to give me treatment on the same day because my cd4 count and my viral load were very low"*
>
> *"Ndizitya na xesha liphi ipilisi zam andinaxesha lithitheni, ukuba ndizityile qha andibinangxaki, ngoba umongikazi wathi ndingaze ndiphose suku"*
>
> *"I take my treatment anytime as long I am not skipping even a day, I do as I was told by a nurse".*
>
> *"Ndizitya mihla le ipilisi ndizicinge ebusuku ndivuka ndizitye ngoba umongikazi wathi ndingaze ndiziphose, xa ndithe ndaziphosa ndiye ndizidibanise ngosuku oluladelayo".*
>
> *"I take my medication every day, even if I forgot at night, I wake up and drink them, because the nurse told me so, if I forget I take them all following day".*

The above scenario indicates that some PLWHA challenge pertaining to adherence emanated from the fact that some were ignorant about HIV/AIDS aetiology, transmission and the working of ARVs. This points to the need for the government to stage continuous awareness session campaigns on ARVs if adherence was to be strengthened.

4.3.13. Labelling

Findings indicated that people living with HIV/AIDS were labelled, making them fear the communities and longing to be alone. This negatively affected their capacity and motivation to adhere. They were also called derogatory names such as prostitutes, gays and lesbians. This attracted the following sentiments.

> *"Siyazi sonke imvelaphi kagawulayo yayisaziwa nje ngesifo sesini esifanayo, kunye nabathengisi ngomzimba yaye kunzima ngoku kuthi isuke ingqondweni lanto siyaziyo malunga nogawualayo. Mhlambi ekuhambeni kwamaxesha iyasusuka ke lonto".*
>
> *"Abanye abantu abaziva bonwabile kukuchaphalezeka yintsholongwane bayoyika nokuthetha ngayo ngoba bacinga ukujongelwa phantsi nokubizwa ngamagama uba ulihule uziphethe kakubi".*
>
> *"Some of the people don't feel comfortable being HIV. And they are afraid being called by names, e.g. you are hoe, yeah.*
>
> *"To speak to others cause they think they would be judged and labelled by others".*

Since labelling was making the lives of the PLWHA, sometimes running away from the people who could be of assistance to them, it would be critical if education generally pertaining to HIV/AIDS was strengthened in the communities

4.3.14 Support mechanism

Findings revealed the importance of support system and the well-wishers to people living with HIV in their homes and communities. Any psychosocial support availed to them for example made people living with HIV/AIDS feel loved and to enjoy positive living. To this end, two participants mentioned that:

> *"Andifuni theta ubuxoki ifamily yam lindixhase kakhulu ingakumbu ngexesha ebendigula ngalo lonke ixesha ibindivelela nasesi bhedlela indinika ithemba kwakunye no thando".*
>
> *"I do not want to lie, my family gave me support more special at that time I was in hospital, they had payed visit every time, gave me love and hope".*
>
> *"Oww abantu basekuhlaleni bandixhase kakhulu babubonisa ubuntu kum, nam ndatsho ndaziva ndingumntu nangona ke bekhona abo bebendihleba kodwa uninzi lwabo belundixhasa".*
>
> *"Oww my community members supported me big time, they showed spirit of ubuntu and I felt I am a human being, although there was those who were gossiping but most was on my side".*

From the above scenario it is critical that communities accept to embrace and share the challenge of PLWHA in the communities. It would be in the spirit of ubuntu for our communities to give support and love to them. Moreover, it gives them the conviction that they are part of our communities and they live in and it will not be a challenge for them to accept their statuses.

4.4 Conclusion

The data analysis process and interpretation of findings enabled the researcher to conclude that although the ARV treatment improves the quality of life of PLWHA, the challenges that make the fail to adhere are many and needs the concerted efforts of different stakeholders to help them out. Availing them the requisite psychosocial support is critical.

CHAPTER 5

Discussion of the findings, Conclusions and Recommendations

5.1 Introduction

This chapter seeks to discuss the research findings and to bring to conclusion the study on exploring the lack of adherence to antiretroviral treatment for people living with HIV/AIDS linked to Victoria Hospital, Alice, Eastern Cape. This chapter therefore discusses the findings by pitting them against other literature and research findings. This is to ground the study in a strong theoretical frame and lay bare the development of new knowledge. This chapter also draws conclusion and recommendations emanating from the themes and subthemes that emerged from the study. It is believed that overall objectives of the study have been met and the research questions have been succinctly answered.

5.2. Demographic data

The following discussions were made in consistent with the demographic data of the interviewed respondents

.5.2.1. Age

Study findings revealed that the ages of the respondents ranged from 36-45 years of age. It was found that middle aged and relatively elderly individuals faced more challenges of adherence. Perhaps the fact that they are involved in various domestic chores and other life demanding events could explain the phenomenon. Literature in many countries suggest that it is becoming common features for middle age people to no-adhere on their treatment because they are mixing alcohol and treatment (UNICEF 2004).

5.2.2 Gender

On gender, findings from the study revealed that there were more females than males who were investigated. This mirrors many studies pertaining to HIV/AIDS in which saw many women constituting a larger population of the interviewees. For example in a study on caregiving in Botswana, virtually 90% of the caregivers were females (Kang'ethe, 2011). In this research study, it was apparent that more women than men were prone to stick to the protocol of adherence. In another study in Botswana by Kang'ethe (2012), many women indicated their challenge of adherence because of heavy alcohol intake

Kang'ethe, S.M.(2011). Gender discrepancies abound in Community Home Based Care

5.3 Education

Study findings indicated that most respondents were formally educated. Education is a basic human right in people's lives and the absence of education among the participants might result in poverty. This because the state of the inadequate education in many life settings informs the level of returns, remuneration of tasks and assignments, as well as promotion in job settings (Campbell, 2008). The study findings showed that the minimal education is also contributing to the states of non-adherence. Lack of education could mean that people living with HIV could not get involved in complicated and well-paying businesses (Bird, Shepherd, Butaumocho and Scott, 2002). This researcher is of the opinion that that since education is a tool of empowerment and has a mentally liberating and emancipating effect to all, the government should attempt to avail opportunity for adult literacy education especial in the rural areas (Khan and Baillie,2003).

5.4 Marital status

Study findings revealed that 45.5 percent were single participants, though 36.4 percent were married. However, it is assumed that those who were married and perhaps in better and cordial relationships were likely to have a better social environment that is conducive to adherence. However, single people are usually associated with loneliness and lack of support. This situation is likely to gravitate to situations that could raise chances of non-adherence. The study reveals that although a few respondents adhere on treatment they needed that support from their families and communities.

5.5 Unemployment

The study findings revealed that although participants were employed, but there was still respondents who were not employed and the income was not enough because they were working on farms. This indicates that probably most were poor and living a life of financial struggle. In a state of poverty, remembering issues of drug protocol and therefore adherence may be an arduous and an uphill task. Perhaps this is why research by Kang'ethe (2012) in Botswaba indicated an inextricable relationship between poverty and possibilities of non- adherence.

5.6 Poverty

Findings indicated an inextricable relationship between it and non-adherence. According to Pelzer (2011), successful ARV treatment is dependent on taking correct dosage, timeously and on time and n in the correct way. Furthermore, Peltzer suggested that adherence has to be 95% if the treatment has to be effective. Linking poverty and non-adherence, Maokisa (2011) attest that people in rural areas do not adhere to their treatment because they either have to walk long distance or live in poverty, emphasising that although ARVs is available free of charge, follow-up visits and refill may pose a challenge because of poverty. This extreme poverty and hunger becomes principal reasons why PLWHA fail to adhere on ARVs.

5.7 Side effects

In the issue of side effects, Heyer and Obunbanjo (2006) agree that adverse drug effects impact the patient's willingness to take medication, hence, non-adherence to ART. Similarly, Vienot, Flicker, Skinner, Mc Clelland, Saulnier, Read and Goldberg (2006) point out that women's personal experiences with the shift of body fat (lipodystrophy) caused anxiety and as a result, patients stopped taking their ARV treatment. They further argue that the side effects also contribute immensely to adherence because, some PLWHA when they experience side's effects, they tend to stop taking the treatment. That is serious and can lead to severe illnesses and death.

5.8 Alcohol abuse

Findings indicated that excessive alcohol intake was compromising the adherence rate. The association between substance abuse and adherence to ART may be a result of forgetfulness caused by impairment in cognition, conscious skipping of treatment due to excessive alcohol intake and the state of apathy that usually goes with the phenomenon (Kekwaletswe 2011). Once under the influence of alcohol, PLWHA may have tendencies to deny their health status and continue to practice unsafe sex (WHO, 2006). According to Molina, Happel, Zang, Kolls and Nelson

(2010), alcohol abuse impacts negatively on the gastrointestinal and respiratory tract immune system, and thereby resisting the ARVs from effective functioning against opportunistic infections. For example, in a quantitative study conducted in the Cape Metropolitan area, South Africa, of all the participants who had TB status, 14% reported harmful use of alcohol and other drugs compared to11% that did not have alcohol and drug problems (Kader, Seedat, Govender, Koch, & Parry, 2013

Study findings also indicated that the PLWHA rate of adherence was influenced by their ignorance about HIV/AIDS generally and in particular pertaining to the taking of ARVs. To this end, Aspeling et al (2006) indicate that the patients understanding of their medical conditions and treatment recommendation is a strong predictor of ARV treatment adherence. As such, information sharing need to be well timed as bad timing may result in patients forgetting important information. If patient are not allowed enough time to get accustomed to their HIV sero-positivity, they are likely to default as they were coerced to take treatment. In addition, Moratia (2012), explains that disruption to social routine like sleepovers makes it difficult adhere to ART.

Study findings indicated that the state of adherence was negatively influence by societal state of stigma and discrimination against PLWHA. The study conducted by Moratoia (2012) is consistent with these research findings in that patient’s fear of discrimination in their communities make them sometimes miss their refill because they do not want to be seen in ARV clinics, and that lead to non-adherence. On the other hand, Williams, Burgess, Danvers, Malone, Winfield and Saunders (2005), contend that family support has been shown to affect adherence, as negative public opinions and beliefs on PLWHA MAY cause rejection of patient of patients.

5.9 Transport

Study findings indicated that most PLWHA defaulted in their adherence process because of lack of transport to get the ARV timely from the dispensing points. This is because many were poor and unemployed, posing huge challenge to afford transport to the dispensing points. This was particularly the case for those who were living in deeper rural areas. They indicated that if there was government transport facility, or some sort of government subsidy for those going to get ARVs, that would help in boosting chances of ARV adherence. In rural areas there are limited ARV sites, PLWHA travel long distance to and from treatment sites, resulting to non-adherence (Wasti,Simkhanda,Randall, Freeman, and Van Teijlingen, 2012). The study by Jogleker,Jain, Rhang,Reddy and Sahay (2011), support that people living with HIV/AIDS have a challenge with regard to adherence on treatment and in accessing treatment centres, since they do not have transport and there are no mobile clinics to access the treatment.

5.10 .Support mechanism

Study findings indicated that lack of various support by either family members or employers posed a challenge that could compromise the state of adherence. The phenomenon is likely to drive PLWHA into a state of hopelessness, helplessness, and coping challenges. In addition, many of the female patients reported that when they disclose their HIV status to their sexual partners, were rejected and some relationships and marriages collapsed as their partners dumped them. However the researcher found out that some patients who received support, especially from their partners and family, had self-efficacy and positive outlook in life generally and they were adhering to their ARVs.

5.11 PLWHA being prone to Separation and Rejection

Study findings indicated that most women were likely to suffer state of rejection and possible divorce in the event of disclosing their status. They therefore had to remain silent that compromised their state of adherence. For instance they could not take medication when there are other people around. In addition study conducted by Moratoia (2012), reveals that separation and rejection in their communities, sometimes create a gap of adherence and missing of refills to PLWHA because they do not want to be seen in ARV sites. And that lead to non-adherence .Porter,Hao,Bishai,Serward, Wawer, Lutalo, Gray and Rakai (2004) also reveal in their study that separation is more common among HIV infected women. Women are therefore vulnerable to non-adherence on ARVs and may not disclose their HIV status because they protect their marriages or relationships.

5.12 Health workers breaking confidentiality of the PLWHA

Study findings indicated that some health workers were breaking the confidentiality of the PLWHA. This made them hurt and discouraged to visit the clinics. This was likely to compromise their adherence to ARVs. In KwaZulu Natal the Department of Health offered a mobile clinic services which made monthly visits to the area, but this proved to be insufficient as people complained that they needed frequent visits. Some patients cannot afford transport costs and if they do afford those costs, chronically ill patients are often treated and turned back home due to shortage of hospital beds (Campbell, Nair, Maimane, & Sibiya, 2008). As the rate of HIV persons increases and as they experience opportunistic infections, the demand of health care services also rises up (Ehlers, 2006). With the unavailability of resources, PLWHA are also faced with HIV-related illnesses. In South Africa, access to many medications to treat symptoms associated with HIV infection is limited to the hospital and inpatient setting (Shawn, Campbell, Mnguni, Defilippi, & Williams, 2005).

Pierret, (2007), states that it is now widely accepted that effective available medical technologies such as antiretroviral drugs have transformed HIV/ AIDS from a severe life threatening condition to an established chronic disorder within a list of other such conditions that can be effectively managed. According to Westburg and Guindon (2004), this has resulted in a shift in emphasis from preparing people to die, to prepare them to live positively with the virus, the drugs and the required life-style changes.

There have been accounts of PLWHA who have been brought back from near-death (Persson, 2004).There were large number of PLWHA who died before the existing of ARV treatment. According to Sharma, Singh, Laishram, Kumar, Nanco and Armed (2006), PLWHA benefit better when in a relationship with their relatives and friends and when they adhering on ARV treatment. Aleksandra (2006) believes that effects on ARV adherence can be in a form of personal and emotional resources, suggesting that patients who received both personal and emotional resources will benefit from HIV and live a better life for a number of years. He goes on to say that when the PLWHA adhere to the ARV treatment their CD4 counts increase and their viral load decrease, this contributes towards their emotional stability. The following strategies and mechanism a can be used to support PLWHA adhere better to the drug regimen.

Study findings indicated that most PLWHA were of poor socio-economic status that provided a fertile ground for non-adherence. Concerning the socio-economic status of PLWHA in South Africa, participants stated that poverty in Alice is a common phenomenon. This is confirmed by the Second National Multispectral HIV and AIDS Strategic Plan (2006-2008), which states that the majority of people in the country (69%) are classified as poor (that is, living below the poverty line, possibly due to poor distribution of available resources and rising unemployment, which is estimated 90%. Although South Africa has enacted Millennium Development Goal No.1, which is aimed at eradicating poverty and hunger, and health sector funding has improved from 7.9% of the national budget in 2007-2008, to 10.6% in 2008-2009, and 17% in 2009-2010 (which is above the 15% minimum stipulated by the Abuja Declaration), the problems of poverty and hunger still exist. Okello (2008) pointed out that there is a vicious cycle of poverty and HIV in South Africa. First an individual gets sick, then he or she gets laid off from work, then the individual will lack money to buy food, and he or she will become a beggar, will stop taking medication, and will get sicker.

The study revealed that some of the participants were not conversant with the term “adherence”. To them it meant just taking medication any time, as long as the medication is taken daily. The term “adherence” was explained to them. When they were asked if they were adhering to their medication schedule, they expressed that they faced many challenges, which caused them not to adhere. The challenges mentioned by the participants were failure to adhere due to lack of knowledge.

5.13 Discrimination and Rejection

Study findings indicated that PLWHA suffered immense discrimination and rejection. They were also labelled and called derogatory names. Although some participants stated that ARVs have helped reduce discrimination associated with HIV and AIDS, some participants mentioned that ARVs have increased stigma and discrimination. This shows that stigmatisation and discrimination against PLWHA is still pervasive in

Alice, and it is a major cause of non-adherence to ART and consequently lowers self-esteem. It was also identified that discrimination against PLWHA in Alice leads to PLWHA being afraid to disclose their HIV-positive status, failure to use risk-reduction practices, and social isolation. Discrimination and Rejection is at the heart of many failed efforts to deal with HIV and AIDS over the years, and many HIV prevention, care, support, and treatment interventions have not been that effective, as a result of HIV-related stigma (World Council of Churches 2005).

5.13. PLWHA usually suffered pangs of Anger and Despondency

Study findings indicated that PLWHA found them drifting into a state of anger and despondency

5.14. Labelling

Findings indicated that people living with HIV/AIDS were labelled, making them fear the communities and longing to be alone. This negatively affected their capacity and motivation to adhere.

5.15 Inadequate awareness campaign pertaining to adherence

All participants mentioned that awareness campaigns addressing issues of adherence on ARVs are limited. There is a study showed that negative attitudes and perceived discrimination towards PLWHA were related to lacking knowledge of ARVs, lack of history of testing and having discussions about HIV (Becky, Hlauka, Konda, Maman 2009).Also there are findings by Dlamini et al (2009) whish state that knowledge about HIV was found to be predictor of adherence, and with patient inadequate knowledge being associated with non-adherence. Lack of knowledge can therefore, be a challenge for PLWHA which result to non-adherence.

5.16 Conclusions

The study explored the lack of adherence to people living with HIV/AIDS particular focus was given to PLWHA in Alice Eastern Cape AIDS. The main aim of the study was to explore the challenges faced by people living with HIV .The study goal helped the researcher to investigate the real problems that lead PLWHA to non-adherence The study intend to achieve the following :

- To explore the factors contributing to non-adherence to ARVs by PLWHA linked to Victoria Hospital, Eastern Cape Province.
- To establish the effects of non-adherence to ARV's
- To explore support systems that can help PLWHA to enhance adherence.
- To investigate by gender who are most likely to adhere on treatment.

The first objective was to explore factors contributing non-adherence to ARVs by PLWHA. The study was focused on bringing out the different challenges are faced by PLWHA. The challenges are poverty, inadequate of education, Lack of knowledge and lack of transport which affects their adherence.

The second objective was to establish the effects of non-adherence to ARVs. The aim of this objective was to examine on how the challenge identified in the above objective effects. According to the research study, most PLWHA the adherence affects their lives and well-being. The study concluded that this challenge affects even their health and hinder the living conditions. This therefore prompts the need for nurses to conduct awareness and proper education on ARVs.

The third objective focused on investigating the support systems that can help PLWHA to enhance adherence. The main aim of this objective was to bring the out the whether families, communities do offer support to these people, if so ,what kind of support is being provided in order to enhance adherence to people living with HIV/AIDS, According to the findings , PLWHA are provided by emotional support, financial and social support by different people. The study finding reveals that there is no much support provided by community and families as well.

The last objective to investigate by gender who is most likely to adhere on treatment. The study findings reveal that most people who adhere on treatment are females, because they are the one who help each other and dominate in the support group even in the site roll.

5.17 Recommendations

The government of South Africa needs to be acknowledged for its formidable efforts to put prevention strategies in place. The national roll-out of the antiretroviral (ARVs) drugs has given many disadvantaged communities who happen to be the most vulnerable to the disease such as HIV/AIDS pandemic new leases of life and a better future. Although such initiatives by government prove to be helpful, but it is an open secret that there are other aspects or factors such as poor socio-economic challenges that happens to hinder every possible action that is present in the fight against HIV/AIDS pandemic.

5.12.1 Strengthen education

Awareness campaigns that will focus on educating communities about the limitations of HIV/AIDS pandemic in the 21st century, treatment literacy initiatives in order for people to be aware about the dangers of treatment default and drug resistance are critical. Perhaps different health practitioner s can be utilized by the government to strengthen education. Such practitioners include: pharmacists, peer educators, volunteers, case managers, nurse practitioners. The researcher should call upon government to make policies that will make change towards non adherence to PLWHA.

5.12.2 Strengthening support mechanism

Strengthening families and communities through equipping them with skills and ways of coping with people living with HIV/AIDS especially those who badly sick. There is need to provide lessons or skills through training and support particularly to those who are denial. Practitioners can also put more focus in supporting caregivers' well-being. Support can be offered financially and professionally to avoid stress burnout.

5.12.3 Maximization of coordination within communities

Coordination mechanism at every level is vital in ensuring that government, care providers and community member's work together effectively to prevent social ill to people living with HIV/AIDS. This connection will help all people who are living with HIV to keep close to each other.

5.13 Suggestions for future studies

The basic philosophy and utility of research lies in the ability to use other peoples research findings to either refine their research or incredibly extend the value of the research by looking at it from another angle, different area, and different subjects. Making research findings for other researchers is viewed as an ethical obligation in the research field and thus making recommendations for future researchers becomes imperative.

It was acknowledged that undertaking the research from a qualitative study perspective was in itself a limiting factor given widespread occurrence of the phenomenon under study. It is thus the recommendation that the future studies should emulate to refine these findings through quantitative or use mixed methods. This has been found to be important as it can give statistical evidence regarding the extensiveness of the case. Also conducting the research through oral interviews could be noted as limiting factor.

5.14 Conclusion

The research study was meant to investigate the lack of adherence to antiretroviral treatment to people living with HIV/AIDS in Victoria Hospital, Alice Eastern Cap. The researcher has consulted different literature to investigate about the problem of adherence in other countries. The aims and objective of the research study were achieved though qualitative research interviews. However, the people living with HIV/AIDS should consider adherence as a good thing to do to enhance their chances of living. It is critical that government turn an blind eye to the needs of PLWHA, and communities as well should support them by everything so that they cannot feel discriminated and isolated.

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University of Fort Hare
Together in Excellence

Dear Participants

I am a 2nd year master's year level and conducting a study exploring the lack of adherence to antiretroviral treatment for people living with HIV/AIDS linked to Victoria hospital, Eastern Cape. There are no right or wrong answers. May you therefore answer these questions with honest as no other person will access the information? The information you share with me will be treated with confidentiality as you will remain anonymous. Please do not write or reveal your names.

Section A

Participant number [ ]

Age in years [ ]

Gender

Male [ ] Female [ ]

Marital status

Single [ ]

Legally Married [ ]

Divorced [ ]

Not legally married but staying together [ ]

Section B

1. What are the challenges of living with HIV/AIDS and for how long you have been taking the ARV treatment?

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2. What could be the reasons for PLWHA not to adhere to ARV treatment?

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3. Can you explain if you have experienced any form of discrimination after you disclosed your HIV status to your family, friends and church?

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4. How do your sexual partner(s) support you adhering to the ARVs?

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5. Can you explain the type of support system you get from family, friends, Health care workers and community members?

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6. Have you ever defaulted (i.e. stop taking the ARVs)? Please elaborate.

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7. How have the ARV treatment (i.e. adherence) helped you?

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8. How do you keep your immune system resistant to opportunistic infections (i.e.STIs,TB etc.)?

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9. Describe any side effects that you experienced when you take the ARV treatment?

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10. How best PLWHA in rural areas can be assisted in terms of accessing their ARVs.

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Thank you

University of Fort Hare
Together in Excellence

ETHICAL CLEARANCE CERTIFICATE
REC-270710-028-RA Level 01

Certificate Reference Number: KAN031SMBO01

Project title: **Exploring the lack of adherence to antiretroviral treatment for people living with HIV/AIDS linked to Victoria Hospital, Eastern Cape**

Nature of Project: Masters

Principal Researcher: Yandisa Mboto

Supervisor: Prof S.M Kang'ethe
Co-supervisor:

On behalf of the University of Fort Hare's Research Ethics Committee (UREC) I hereby give ethical approval in respect of the undertakings contained in the above-mentioned project and research instrument(s). Should any other instruments be used, these require separate authorization. The Researcher may therefore commence with the research as from the date of this certificate, using the reference number indicated above.

Please note that the UREC must be informed immediately of

- Any material change in the conditions or undertakings mentioned in the document
- Any material breaches of ethical undertakings or events that impact upon the ethical conduct of the research

The Principal Researcher must report to the UREC in the prescribed format, where applicable, annually, and at the end of the project, in respect of ethical compliance.

Special conditions: Research that includes children as per the official regulations of the act must take the following into account:

Note: The UREC is aware of the provisions of s71 of the National Health Act 61 of 2003 and that matters pertaining to obtaining the Minister's consent are under discussion and remain unresolved. Nonetheless, as was decided at a meeting between the National Health Research Ethics Committee and stakeholders on 6 June 2013, university ethics committees may continue to grant ethical clearance for research involving children without the Minister's consent, provided that the prescripts of the previous rules have been met. This certificate is granted in terms of this agreement.

The UREC retains the right to

- Withdraw or amend this Ethical Clearance Certificate if
    - Any unethical principal or practices are revealed or suspected
    - Relevant information has been withheld or misrepresented
    - Regulatory changes of whatsoever nature so require
    - The conditions contained in the Certificate have not been adhered to
- Request access to any information or data at any time during the course or after completion of the project.
- In addition to the need to comply with the highest level of ethical conduct principle investigators must report back annually as an evaluation and monitoring mechanism on the progress being made by the research. Such a report must be sent to the Dean of Research's office

The Ethics Committee wished you well in your research.

Yours sincerely

Professor Gideon de Wet
Dean of Research

02 February 2015