FACTORS INFLUENCING ADHERENCE TO ANTIRETROVIRAL TREATMENT IN THE QUEENSTOWN REGION EASTERN CAPE (SOUTH AFRICA)

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i

Abstract

Background: Failure to adhere to antiretroviral therapy (ART) has negative consequences not only for patients themselves, but for health systems. Strict adherence to ART therapy together with modified life style will result in a positive outcome (WHO, 2003a).

Aim: The aim of the study was to describe factors that may influence adherence to ART treatment.

Method: A quantitative research approach was used to conduct a survey using an interviewer administered questionnaire in the Queenstown region in three clinics with patients on ART. A random sample of 118 was selected out of a possible 594 patients. The response rate was n=97 (80.5%). The majority were females, n=77 (79%) with most of the respondents being 35-44 years, n=46 (47.4%) and single, n=76 (78%).

Social and economic results: Respondents were economically inactive (unemployed), n= 49 (50, 5%) and n=40 (41.2%) on disability grant with no significant association between the employment status and acceptance of antiretroviral treatment. Males had higher rates for acceptance of ART and with more males n= 8/20 (40%) as compared to women n= 13/77 (16.8%) stating that they accepted their outcome (X^2=5, p=.035). High levels of emotional support were reported n= 79 (81.4%).

Health care service results: Only n=3 (3.1%) of the respondents reported to have their own transport, resulting in 72 respondents (74.2%) reporting that it was difficult to comply with treatment if they lived far from the clinic.

Condition related results: Only n= 17 (17.5%) respondents reported that they suffered from OIs in the last six months with Diarrhoea being the most common n= 93 (94.9%).

Patient related results: Only 7 respondents reported to take alcohol at an average of 1.4 bottles a week. About n=81 (83.5%) of respondents reported difficulty in taking treatment at work.

Treatment related results: The majority of respondents n= 43 (44.3%) reported to be on their current regimen for less than a year. Almost 100% of the respondents had correct knowledge of their treatment regimen and prescriptions for OIs and ART therapy. Most of the respondents (90.7%) agreed with the statement, that HIV patient's family should facilitates their intake of medication and this was significantly higher in respondents who have not accepted their diagnosis and the need to be on medication for the rest of their lives.

Conclusion: Treatment adherence management should take into consideration the factors that may influence adherence

Keywords

HIVAIDS, Antiretroviral Therapy, PLhiv, WHO-5 factors influencing adherence.

Abbreviations

AIDS   Acquired Immune Deficiency Syndrome

ART   Antiretroviral Therapy

HAART   Highly Active Antiretroviral Therapy

HCT   HIV Counselling and Testing

HIV   Human Immune Deficiency Virus

NIMART   Nurse Initiated Management of ART

NGO   Non-Governmental Organization

PEPFAR   President's Emergency Plan for Aids Relief

PLhiv   People Living With HIV

PMTCT   Prevention of Mother to Child Transmission

TB   Tuberculosis

UNAIDS   United Nations Agency for International Development

USAID   United States Agency for International Development

VCT   Voluntary Counselling and Testing

WHO   World Health Organization

Declaration

This thesis is my original work and has not been presented for a degree or other awards in any other university.
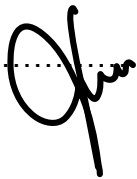
Signature: Nobuhle Magadla   Date............16|3|2018

Supervisor's Approval

Signature..Date......16|3|2018..........

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Dedication

To my loving mother, Miss Selina Nombuyekezo Magadla, who taught me the significance of discipline and determined efforts.

To my husband Vukile Magqabi for his uninterrupted support, complete attention and love.

To my children: Thandolwethu, Litha and Lonwabo for their invariable support, courage and love.

To my late sister Nosipho.

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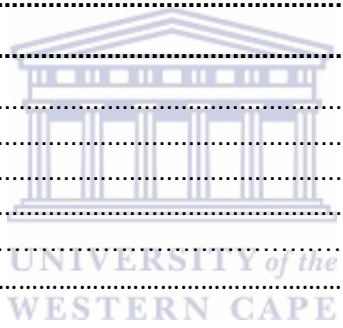
I really appreciate your tireless support throughout my studies, Molly and Mzwabantu Magadla. Thank you, Dr Loyiso and Nini Songca, for accommodating me when in Cape Town for my study sessions and transporting me to UWC all the time; you welcomed me into your family. I sincerely thank the clinics where I collected data and the staff for their assistance and time.

I would like to thank God for giving me strength and courage to study; without The Almighty none of this would have been possible.

Table of Contents

Table of Tables

Table of Figures

Chapter 1: Introduction

1.1 Introduction

Adherence is a problem in any chronic condition, especially in HIV and AIDS with the administration of antiretroviral treatment (ART). Non-adherence to treatment in chronic diseases is a global health problem and impinges on patient's health and the health systems as it causes complications, resistance to treatment and resistant infections (WHO, 2003a). The non-adherence to antiretroviral therapy (ART) regimens is a severe problem that has negative consequences, not only for patients but also for the entire society, including health providers, health plans, employers and the health industry in South Africa.
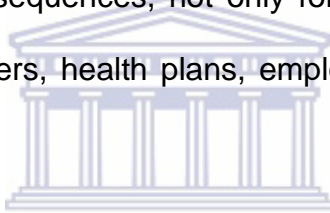
It has been noted that antiretroviral therapy has improved the quality of life for patients living with HIV and AIDS as a result there has been a decrease in HIV related morbidity and mortality in countries where ART is widely available. HIV and AIDS is now a manageable chronic illness because of ART availability. High levels of patient adherence to ART is essential hence it is important for the health care providers to identify possible barriers to adherence as soon as possible and possible solutions (Achappa, Madi, Bhaskaran, Ramapuram, Rao and Mahalingam, 2013). A high level of adherence >95% is required for the ART to be effective even in the presence of many barriers to adherence identified to both developed and developing countries (Achappa et al. 2013).

1

This chapter describes the background of the study, the aims and objectives of the study; the conceptual model provides a framework for the study while the literature highlights, retraces the identity of the research problem and refines research questions.

1.2 Background

HIV and AIDS has been a global health problem for over the last 30 years. In 2015, globally an estimated 36.7 million people were living with HIV, including 1.8 million children (UNAIDS, 2016). An estimated 25.5 million people living with HIV live in sub–Saharan Africa, with 19 million in Southern and East Africa, demonstrated by 46% of new HIV infections globally in 2015 (UNAIDS, 2016). In Southern Africa, 25 to 40% of young adults are infected with HIV and an increase in deaths and suffering among the 18-44-year age group are caused by AIDS more than any other diseases (UNAIDS, 2016).

One of the first African countries to react aggressively to the HIV and AIDS epidemic was Uganda (Ochola-Odongo, Basaza, and Kaija, 2003). HIV prevalence rates around 30%, once described as being among the highest in Africa have declined to under 10% within the last two decades. Although there was evidence of a decline in new infections in Uganda, the number of people already infected and progressing to AIDS were increasing so that by the end of 2002 the WHO had estimated that 600 000 people were living with HIV infection in Uganda (Ochola-Odongo et al. 2003). Of these 600 000 it was estimated that between 60 000 and 90 000 would need access to antiretroviral (ART) therapy on clinical grounds because of advanced HIV infection (Ochola-Odongo et al. 2003). To add to this already comprehensive response, the Uganda government then initiated an effort

http://etd.uwc.ac.za/

to offer access to antiretroviral therapy in collaboration with the Joint United Nations Programme on HIV and AIDS (Ochola-Odongo et al. 2003).

In South Africa the Provincial Department of Health in the Western Cape was the first to start issuing highly active antiretroviral therapy (HAART) in South Africa (Herman, 2006). The Western Cape Department of Health applied for external funding from the Global Fund to fight AIDS, tuberculosis and malaria in 2003 to extend its HAART programme (Herman, 2006). This resulted in the Western Cape rollout being hailed as the ART success story of the country with more than 11 000 people living with HIV and AIDS (PLhiv) receiving ART therapy by July 2005, a quarter funded by the Global Fund (Herman, 2006). It was further estimated that at the end of 2005, 65% of those in need of ART therapy in the Western Cape would have had access to ART a figure significantly higher than the South African national average of 10% (Herman, 2006).

HIV statistics in South Africa showed an estimated 5.6 million PLhiv in South Africa in 2009, more than in any other country (Stats SA, 2010). In 2009 about 310 000 South Africans died of AIDs related diseases with a prevalence rate of 17.8 % among those aged 15-49, with almost one in three women aged 25-29, and over a quarter of men aged 30-34 living with HIV (Stats SA, 2010). HIV frequency among those aged 2 years and older also differed by province with the Western Cape (3.8%) and Northern Cape (5.9%) being least affected and with Mpumalanga (15.4%) and KwaZulu-Natal (15.8%) at the upper end of the scale (Stats SA, 2010). The recent HIV statistics in South Africa stated that the total number of people living with HIV increased from an estimated 4, 94 million in 2000 to 7, 06 million by 2017. Though in 2017 approximately one-fifth of South African

3

women in their reproductive ages (15-49 years) are HIV positive. HIV prevalence among the youth aged (15 – 24 years) has declined over time from 7.3% in 2002 to 4.6 % in 2017. The rate at which the population in SA is being infected is estimated to be declining from 1, 9 % in 2002 to 0.9% in 2017(Stats SA 2017). The National Strategic Plan (NSP) 2012 – 2017 aimed to decrease and eliminate HIV and HIV-related sicknesses. The formalisation of the NSP 2012 - 2017 was to set out a target to reach 95% adherence to ART therapy for (PLhiv).

Having measured the challenges encountered and achievements from NSP 2012 – 2017 strategic plan, succeeding consultative meetings with the stakeholders, evidence based results from AIDS conference 2016 and analysis of the epidemiology of the HIV epidemic in South Africa the new NSP 2017 – 2022 was developed with the focus on the reduction of morbidity and mortality rate by providing HIV, TB and STI treatment, care and adherence support for all (South AFRICAN National AIDS Council [SANAC], 2016).

In the NSP 2017 – 2022 it is highlighted that UNAIDS suggested 90-90-90 strategy (with a key component of adherence) with the following conditions to be reached by 2020:

(a) 90% of all people living with HIV will know their status

(b) 90% of people diagnosed with HIV receive sustained antiretroviral treatment therapy

(c) 90% of people receiving antiretroviral therapy achieve viral suppression (SANAC 2016).

Heestermans, Browne, Aitken, Vervoort and Klipstein-Grobusch, (2016) highlighted that adherence to ART therapy is essential for the health of PLhiv and that taking ART therapy guarantees the virologic success of an initial regimen and is a substantial

4

determination of survival. Non-adherence is fatal as it leads to drug resistant due to failure to reach maximal viral suppression. Patients at high risk of suboptimal adherence need to be recognised earlier for prompt intervention to prevent further complications (Heestermans et al. 2016). Non-adherence to ART therapy can have serious public health implications due to the possibility of high transmission rates and increased resistance (WHO, 2003b). Studies have reported that as many as 80% of newly infected persons are resistant to one class of ART regimen and 26% are resistant to more than one class of ART regimen due to non-adherence (WHO, 2003b). ART therapy has grown rapidly in the past few years because of the importance of ART therapy adherence which is vital for both clinical effectiveness and public health (WHO, 2003b).

Prior to 2010, in 2008 and 2009 ART prices would have cost the government more than R8.8 billion to treat people living with HIV and AIDS (WHO, 2010). However, in 2010 a reduction in the price of antiretroviral drugs empowered the government to treat twice as many people as before. Following the price drop, a tender awarded to ten pharmaceutical companies resulted in costs of about 50% less than it would have (WHO, 2010). The cost reduction made ART regimens to be available to all the health facilities.

The DOH annual report for 2014 /2015 stated that SA had just over 3 million of all ages of PLhiv receiving ART by end of 2014 /2015. It is also stated that SA exceeded its NSP 2015 / 2016 target of 3 million patients on ART and this achievement can be credited to several initiatives like massive HCT campaign launched in 2010; the number of trained nurses on Nurse-Initiated Management of ART (NIMART) that increased from 10 000 in 2011 / 2012 to 23 000 by end of 2012 /2013; the change in eligibility criteria for ART

initiation from 200 to 350 in 2013 and from 350 to 500 by end of 2014 and the introduction of fixed dose combination pill (FDC) (SANAC, 2015).

To ensure improved outcomes and reach the goal, adherence rates approaching 100% are required for optimal viral suppression (Heestermans et al. 2016). Suboptimal adherence puts the patients not only at risk of HIV progression, but also at the risk of intensifying drug resistance and options for the future treatment (Heestermans et al. 2016). To improve adherence, it is thus important to understand the factors that influence adherence (Heestermans et al. 2016).

1.3 Rationale for study

Adherence had been monitored since the time of Hippocrates, when the effects of various portions were recorded with notations of whether the patient had taken them or not (Rabkin, El-Sadr ad Abrahams, 2005).Keeping patients on treatment programmes is essential and in 2003 the WHO raised concern about the rise in patients failing to follow up their ART after 36 months (WHO, 2003a). However the WHO postulated that adherence was also not just about taking "pills" on time but also a means of integrating medical and life-style approaches or simple strategies to guarantee quality of life by remaining healthy while suffering from HIV and AIDs (WHO, 2003a).

It is well understood that poor adherence leads to therapeutic failure a reduced quality of life of the patient and increase in morbidity and mortality rate (Rabkin et al. 2005). Educating patients and families can make the difference between treatment success and

treatment failure and should be a routine part of prescribing antiretroviral treatment (Rabkin et al. 2005).

1.4 Problem Statement

HIV and AIDS is a major health problem globally, but the introduction of ART contributed to the improvement of health outcomes for patients. However, poor adherence to ART among adults living with HIV and AIDS remains a major public health concern as it leads to virological, immunological and clinical failure as it increases the risk of transmission of drug resistant virus (WHO, 2008).

Due to the direct relationship between adherence and virologic failure good adherence>95% may lead to a reduction of virologic failures (WHO, 2003b). Nevertheless, ART adherence is complex and requires multiple dimensions to be addressed to facilitate adherence and to reduce treatment failure and viral resistance. Several factors have been identified as reasons for poor adherence among adults living with HIV and AIDS in South Africa (Birberck, 2010 and Dahab, 2011). These include fear of disclosure, alcohol abuse, traditional medicine use, feeling better on treatment, inadequate knowledge about the diseases and ART, stigma, transport costs, lack of social (financial and emotional) support, discrimination, depression and hopelessness, lack of food service-related factors, the burden of taking pills and drug side effects, patient's beliefs and behaviours and poor environmental factors were associated with poor adherence to ARV treatment (Sanjobo, 2008).One of the vital requirements in maintaining adherence to ART is behaviour change and though behaviour change is difficult to initiate

and maintain new patterns and practices patients must desire change (Rabkin et al. 2005).

South Africa is not exempted from this problem, but little is known about the specific factors that may influence adherence to ART among HIV positive people in different contexts. This study seeks to investigate and to evaluate the factors that may contribute to adherence in the Queenstown region in the Eastern Cape, South Africa.

1.5 The Study

1.5.1 Aim

The aim of the study was to describe factors that may influence adherence to antiretroviral therapy in the Chris Hani District Municipality Lukhanji Sub-District Queenstown Eastern Cape South Africa

1.5.2 Objectives

Objective 1

To describe the social and economic factors that may influence adherence to antiretroviral treatment.

Research Questions

I. *What are the socio-demographic factors such as gender, age, marital status and employment status that may influence adherence to antiretroviral treatment?*

II. *What are the patients' self-reported support factors (social and emotional support systems and partner support) that may influence adherence to antiretroviral treatment?*

8

Objective 2

To describe health service related factors that may influence adherence to antiretroviral treatment.

Research Questions

III. *What are the health service barriers to care that may influence adherence to antiretroviral treatment?*

IV. *What are patients' prescription problems which may influence the adherence to antiretroviral treatment regimen?*

Objective 3

To describe condition (HIV) related factors that may influence adherence to antiretroviral treatment.

Research Questions

V. *What are the patients' self-reported levels of opportunistic infections that may influence adherence to antiretroviral treatment?*

VI. *What are the levels of patient self-reported substance that may influence adherence to antiretroviral treatment?*

Objective 4

To describe treatment related factors that may influence adherence to antiretroviral treatment.

9

Research Questions

VII.   *What are patients' self-reported levels of knowledge about antiretroviral treatment?*

VIII.   *What are patients' reported complications on treatment which may influence adherence to antiretroviral treatment?*

Objective 5

To describe patients' related factors that may influence adherence to antiretroviral treatment.

Research Questions

IX.   *What are the levels of acceptance of diagnosis that may influence adherence to antiretroviral treatment?*

X.   *What are patients' perceptions about ART treatment that may influence adherence to antiretroviral treatment?*
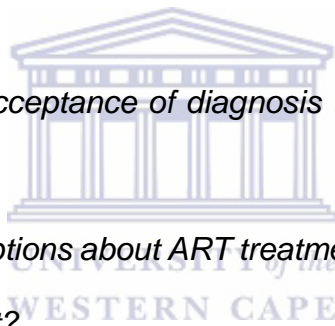
1.5.3 Hypothesis

Is there an association between demographics and other factors and treatment acceptance?

1.5.4 Terms and definitions

The following key terms are defined for the study (Table 1).

Table 1: Terms and definitions

Term	Definition
Perceptions	A settled way of thinking or feeling about something (Oxford Dictionary, 2016) *Operational definition*: In this study, individual's perceptions are the perceived feelings about taking medication for HIV Treatment (WHO, 2003b).
AIDS	Acquired immunodeficiency syndrome. This refers to a progressive immune deficiency caused by infection of CD4+ T cells with the human immunodeficiency virus (HIV) (WHO, 2010)
Barriers	Perceived barriers to positive attitude to ARV treatment include pill burden if the person is also on another chronic treatment, food restrictions, dosing schedule, side effects and stigma (Hayden, 2009). *Operational definition*: In this study, barriers are health service and prescription problems or if the patient has experienced any problems with taking medication (WHO, 2003b).
CD4 count	An antigen maker of helper/inducer T cell that recognizes antigens bound in class II MHC protein (WHO, 2010).
Condition related factors	These factors are the symptoms that are recognised in a patient on ART therapy, it includes the way the patient responds to treatment and the development of OIs (WHO, 2003b). Operational definition: In this study condition related factors demonstrate if the individual recognizes the link between the adherence to ART therapy and the viral load (WHO, 2003b).
Co-treatment	Treatment of two or more co-morbidities simultaneously (Meintjes et al. 2014).
Knowledge	Facts, information and skills acquired through experience or education; the theoretical or practical understanding of a subject (Oxford living dictionary). *Operational definition*: In this study, information on knowledge is defined using medical prescription knowledge on antiretroviral treatment (WHO, 2010). In the questionnaire for this study the knowledge on patient's treatment has been asked.
Patient related factors	Patient related factors are the factors taking place from the patient's behaviour after diagnosed with HIV infection and put on ART therapy (WHO, 2003b). Operational definition: This refers to the patient's faith on antiretroviral treatment therapy. This statement is also talking to the patient's psychological status and substance use behaviour while on ART therapy (WHO, 2003b).
Prevalence	This refers to the number of affected persons present in the population at a specific time divided by the number of persons in the population at that time (CDC, 2012).
Demographic factors	*Operational definition*: In this study these factors refer to age, gender, ethnicity, and socioeconomic factors affecting patients.
Social factors	Social factors refer to the facts and experiences that influence individuals' personality, attitudes and lifestyle (Business dictionary, 2016). *Operational definition*: In this study, social factors are the social support, treatment partner reliability, and psychosocial support related questions (WHO, 2003b).
Treatment related factors	Treatment related factors are directed to the way the patient takes the medication, how the patient understands the instructions for taking ART therapy and how the body responds to the treatment (WHO, 2003b).

11

Term	Definition
	Operational definition: In this study, treatment related factors refer to the difficulties encountered on taking treatment due to the number of tablets taken daily and when to take treatment. Patient is also affected by unpleasant side effects of treatment and vague instructions on how to take treatment including dietary restrictions (WHO, 2003b).
Undetectable viral load	The amount of HIV virus in a person's blood when it is lower than detectable level (LDL) (Medecins Sans Frontieres, 2010). Operational: The LDL of VL is important since it means that the HIV virus has stopped growing as a result of ARVs (Medecins Sans Frontieres, 2010).
Viral load	The amount of HIV virus found in a person's blood (Medecins Sans Frontieres, 2010).

1.6 Theoretical framework

The theoretical framework recommended as a foundation for this study is the WHO-5 Dimensions of Adherence (WHO, 2003b). As the concept of adherence is complex and multidimensional, this model includes five interacting dimensions affecting adherence.

1.6.1 WHO Five Dimensions of Adherence

The model has five interactive dimensions of adherence, namely social and economic, health care system, condition related, therapy-related and patient-related affecting the possibility of taking health action (Figure 1).

12
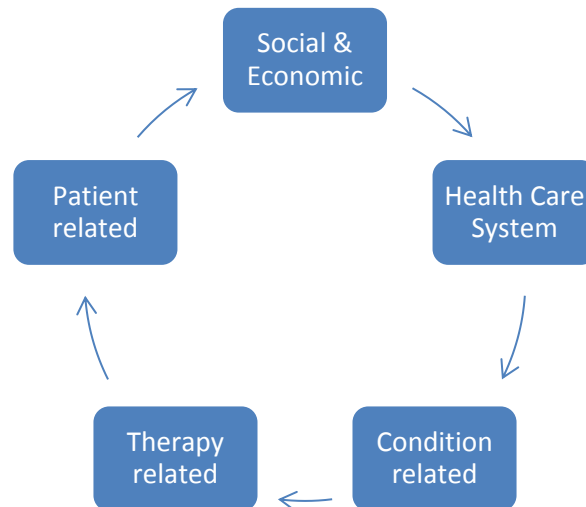
Figure 1: WHO Five Dimensions of Adherence (WHO, 2003b)

1.6.1.1 Social and Economic Factors

Economic factors: In South Africa an estimated fifty per cent (50%) of people in need of ART receive treatment in the public state health services (Department of Health, 2008). Elevated levels of unemployment and social vulnerability which predispose people to HIV infections are worsened by ill health (Department of Health, 2008). In South Africa, several types of social security grants have provided some degree of income support and social protection for children, the elderly and disabled individuals (Department of Health, 2008).

With poverty-related barriers there are also competing demands in resource-constrained settings, such as the lack of transport, infrastructure, food insecurity, the role of disability grants, and poor social support (Kagee et al. 2011). In 2008 the DOH still reported that

13

food insecurity endured, with only one in five households in the country at that time meeting their dietary energy needs (Department of Health, 2008).

Social factors: Peltzer and Pengpid (2013) defined income as an indicator of socioeconomic position which directly measures the material resources component of socioeconomic factors. Poor socio-economic status, poverty, low level of education, lack of social support networks, gender, age, marital status, employment status, unstable living conditions, long distance from the treatment centre are all social factors which can contribute to poor adherence (WHO, 2003b).The social factors also include culture and lay beliefs about illness and treatment and political and cultural barriers such as the controversies about the provision of treatment for HIV and AIDS, traditional beliefs about HIV and AIDS, poor health literacy, and gender inequalities (Kagee et al. 2011).
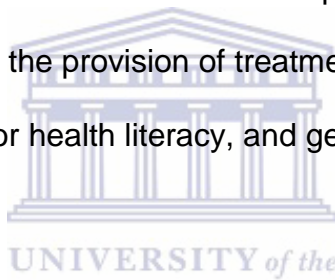
In some international studies, social factors have not been consistently found to be the main cause of poor adherence, although in developing countries low economic status impact directly on people's ability to afford health care (WHO, 2003b).

The research by Berg, Demas, Howard, Schoenbaum, Gourevitch, and Arnsten (2004) found that among both men and women, poor adherence to ARV treatment was associated with lack of long-term housing.   However, Chayiachati, Ogbuoji, Price, Suthar, Negussie and Barnighausen (2014) explained that in some settings adherence is related to behaviour and as such is affected by culture and situation.

As poor social conditions can have a negative impact on adherence, social support can have the opposite effect and is essential for adherence. A study in Tanzania (Watt,

14

Suzanne, Earp, Eng, Phillip, Golin and Jacobson, 2009) found that lack of family support contributes to cessation of treatment by PLhiv regardless of the perceived benefits. In another aspect of family support, the control of family members was so significant that relatives such as parents or husbands made treatment decisions, including the decision to break off from ART (Roura, Busza, Wringle, Mbata, Urassa, and Zaba, 2009).

1.6.1.2 Health Care and service related factors

Health care and system related factors that can influence adherence include access to health care, cost medication and logistical barriers such as overburdened health care facilities, limited access to mental health services and difficulties in providing sufficient counselling following HIV testing (Kagee et al. 2011). In addition, the relationship between the health worker and the patient is also seen as a key factor (WHO, 2003b). A lack of clear instructions from health care professionals and poor health education may have negative effect on adherence to ART, whereas good relationships including support of nurses and pharmacists may have positive effects on adherence to ART (WHO, 2003b).

1.6.1.3 Condition related factors

The condition itself, HIV, can also influence adherence. If a patient experiences a lot of symptoms or thoughts about the condition of somebody close to you living with HIV, this may influence their level of adherence through illness related demands faced by the patient (WHO, 2003b).

15

People with advanced HIV infections are exposed to other infections and malignancies that are called opportunistic infections which can take advantage of opportunity existing from a weakened immune system (AIDS*info* guidelines, 2014). AIDSinfo (2013) stated that these opportunistic infections are signs of a declining immune system and most life threatening opportunistic infections occurred when the CD4 count is below 200 cell/mm3 and when adherence has been low. The severity of symptoms of opportunistic infections may impact on the patients' risk perception, the importance of following treatment, and the priority placed on adherence (WHO, 2003b). Other PLhiv on ART complain of feeling embarrassed and discriminated by their friends, families and partners and that affect adherence negatively as others discontinue taking treatment (Azia et al. 2016). Others complain of stress as disease itself come with stress and lifelong treatment and that lead to poor adherence. Others decide to take drugs and alcohol because of difficulty in dealing with the condition (Azia et al. 2016). Other conditions, such as comorbidities and co-infections are important modifiers of adherence behaviour (Berg et al.2004).

1.6.1.4 Treatment related factors

Treatment-related factors can also affect adherence. Perceived barriers to adherence include: pill burden if the person is also on another chronic treatment, food restrictions, dosing schedule, side effects and stigma (Hayden, 2009).The treatment regimen, duration of treatment, previous treatment failures, changes in treatment, the immediacy of beneficial effects and side-effects may all impact on adherence (WHO, 2003b). Compliance factors such as pill taking reminders also may inadvertently impact on adherence (Hayden, 2009). Médecins sans Frontières (2010) stated that it was

16

imperative to try and improve adherence before switching regimens due to side effects, as these changes of regimen may lead to poor adherence and also lead to virological failure.

Side effects are more common in severely immune-compromised (CD4 <200) patients. It is recommended that health workers should caution the patient to report any side effects early and not to stop taking any drugs without consulting the health care provider first (Médecins sans Frontières, 2010). Weiser, Wolf, Bangsberg, Thior, and Gilbert (2003) in Botswana and Aspeling & Van Wyk (2008) in South Africa further support this with evidence that informed patients tolerate side effects and adhere to the therapy better than those who are not informed.
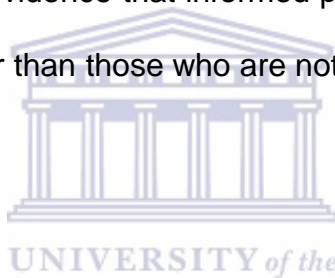
1.6.1.5 Patient related factors

Patient-related factors represent the resources, knowledge, attitudes, beliefs, perceptions and expectations of the individual patient that may influence adherence (WHO, 2003b). Patient's knowledge and beliefs about their illness, their acceptance of their diagnosis and their adherence management strategies, and expectations regarding the outcome of treatment and the consequences of poor adherence, interact in ways not yet fully understood to influence adherence behaviour (WHO, 2003b).

Alcohol is reported as one of the adherence barriers as it weakens people's reasoning and therefore affect adherence negatively as the patient may forget to take treatment (Azia, Mukumbang and van Wyk, 2016). The patient's perception of the illness and the

17

treatment may influence changes in adherence especially in serious disease like HIV and AIDS (Hayden, 2009).

It is theorised that when people believe they are at risk of a disease, they will do something to avoid contracting it and they will do the opposite if the risk is very low (Hayden, 2009). Thus patients living with HIV who believe that they are susceptible to HIV complications, would adhere to ARV treatment (Hayden, 2009). However, this theory is influenced by individual factors such as cultural beliefs or gender (Hayden, 2009). In addition, an individual's opinion of the usefulness of adopting a new behaviour in decreasing the risk of developing the complications of the disease, such as taking a medication regimen such as ART and adhere to it, is also influenced by the patients' belief that they will recover from sickness, will work again and live longer to raise their children (Hayden, 2009).
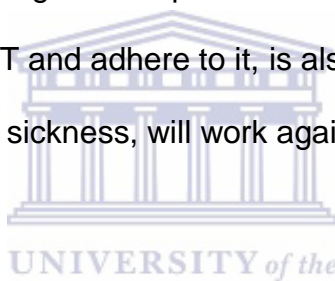
Individual socio-psychological characteristics such as spiritual and cultural beliefs may influence peoples' involvement in preventive measures such as using condoms (Glanz & Rimer, 2002). Lastly demographic variables such as gender, age and marital status may modify perceptions. For example, unmarried people may have higher adherence as they may be able to make their own decisions (Glanz & Rimer, 2002).

1.6.2 Application of WHO 5 Dimensions of Adherence to Study

Non- Adherence is an extensive problem. Adherence to ART is a critical issue for the achievement of success and the safe use of therapies, and it is clear from the literature that the factors that influence the patient's ability to adhere to treatment are multiple and complex (Mathes, Jaschinski and Pieper, 2014 & WHO, 2003b). The conceptual

framework adapted from the WHO and the literature review was done to give a deeper understanding of related concepts of adherence and the factors that influence adherence (Hayden, 2009 and Stanhope & Lancaster, 2005).The application of the WHO-5 Dimensions of Adherence is demonstrated in Table 2.

Table 2: WHO-5 Applied to Treatment Attitude

Concept	Definition	Application
1. Social & Economic factors		
Support	Influencing effect of support groups, community groups, family and friend	Influencing effect of emotional support, psychosocial support and having a treatment partner.
2. Health Service related Factors		
Access	Influencing effect of access & cost	Influencing effect of access & money
3. Condition related factors		
Symptoms	Influencing effect of Symptoms	Influencing effect of OIs
Other condition	Influencing effect of other conditions	Influencing effect of Substance use
4. Treatment related Factors		
Side effects.	Influencing effect of Side-effects and ease of treatment	Influencing effect side-effects of taking medication & ease of taking medication and accessing medication.
5. Patient Factors		
Patients perceptions	Attitudes of patients on lifelong treatment and the seriousness of the disease.	Attitudes of patients with HIV on acceptance and lifelong treatment and the seriousness of the disease.
Demographics	Influencing effect of Individual factors such as age, gender, education, employment & SES status	Influencing effect of age, gender, being alone, unemployment and socio-economic factors
Knowledge	Influencing effect of Knowledge on treatment and condition	Influencing effect of knowledge about individual ART regimens

Source: Adherence to long term therapies – Evidence for Action WHO 2003b.

19

1.7 Significance of the study

Research Significance: ART requires life-long adherence to be effective, and to prevent the development of resistant strains (Evian, 2011). Despite initial optimism for positive treatment adherence, a review in 2007 reported only 60 per cent retention of patients in antiretroviral treatment (ART) programs in 13 sub-Saharan African countries (Kagee et al. 2011). The ever-increasing provision of treatment in low- and middle-income countries necessitates a broader understanding of the reasons for low adherence and to implement effective support interventions (Kagee et al. 2011). In addition, predictive inferential two group studies are required to test for true predictive factors.

Educational Significance: Knowledge gained from this study about factors contributing to positive attitude towards antiretroviral therapy by HIV-positive patients will help in making recommendations regarding the development of appropriate health education strategies to inform patients about the importance of adherence to ART. The findings may also contribute to the review of the protocols and policies for the management of HIV-related conditions and antiretroviral therapy in adults so as to improve the clinical management of HIV and AIDS.

1.8 Summary

This chapter introduces the study, background on the study, an outline of this study including the aims, objectives, terms and the conceptual framework. In such it is the foundation on which this study is founded as it clearly states what this study involves.

Chapter 2: Literature Review

The literature for this study has been searched in medical full text sources for HIV and AIDS, adherence, antiretroviral treatment and attitudes using Google Scholar and PubMed.

2.1 Introduction

Adherence is defined as the extent to which a person's behaviour in taking medication, following a diet, and/or performing lifestyle changes corresponds with agreed recommendations from a health care provider (WHO, 2011). The person's behaviour involves health care provider recommendations and patients' decisions. However, the issues surrounding medication use are often very different from those involving attitudes to diet, to follow-up appointments, or to diagnostic testing recommendations (WHO, 2011).
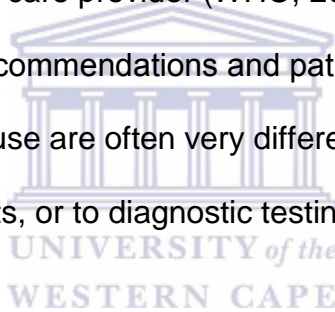
HIV infection is different from other chronic diseases because of rapid duplication and transformation rate hence it requires high levels of treatment adherence not less than 95% to suppress viral load to be undetectable (WHO, 2003b). Suboptimal adherence has been identified as one of the key reasons causing ART resistance and promoting transmission to other people (WHO, 2003b). Many researchers assumed that ART therapy would cure HIV completely, however even if the viral load is undetectable, viral duplication still continues. Therefore optimal adherence to ART therapy is required hence Paterson and colleagues discovered that if the adherence is less than 95% viral resistance is expected and opportunistic infections and admission is possible.

21

Treatment failure is predicted even with the omission of a single a dose in a 28 –day reporting period (WHO, 2003b).

2.2 HIV prevalence in South Africa

It is estimated that 12.2 % of the population (6.4 million people) were HIV positive in 2012, indicating that 1.2 million more people were living with HIV than in 2008 (10.6%, or 5.2 million) (South African National HIV Survey for 2012 & Human Sciences Research Council [HSRC] (2014).

These results differ by province, gender and other variables. The South African National HIV survey for 2012 suggested that the overall HIV prevalence differed substantially by Province (HIV HSRC of South Africa, 2014).In terms of sex, age, race, and locality type, females had a reported higher HIV prevalence than males (HIV HSRC of South Africa, 2014). The prevalence of HIV was highest among females aged 30–34 years and among males aged 35–39 years (HIV HSRC of South Africa, 2014). In the teenage population, the assessed HIV prevalence among females was 8 times that of their male equivalents, suggesting that female teenagers aged 15–19 years are more likely than their male counterparts to have sex, not with their peers, but with older sexual partners (HIV HSRC of South Africa, 2014). Further disaggregation of the data displayed that black Africans had the highest HIV compared to all other race groups, followed by Coloureds and that the prevalence for Indians or Asians and for whites was less than 1%, though the data's reliability were questioned (HIV HSRC of South Africa, 2014). In trying to comprehend the potential reasons for differential racial HIV prevalence, the

22

outcomes suggest that black Africans (39.1%) were less likely than all other races (>85%) to live in urban formal areas (HIV HSRC of South Africa, 2014) informal areas are generally under-resourced and lack some of the basic requirements such as formal housing, water, sanitation, and access to preventive health services (HIV HSRC of South Africa, 2014). The other distinctive factor among the races was marital status (HIV HSCRC of South Africa, 2014). Black Africans are less likely to mention being married than whites and Indians or Asians. HIV prevalence was found to be more in the unmarried, co-habiting population than in the married population (HIV HSRC of South Africa, 2014).

Though there are variations, overall the South African National HIV survey for 2012 showed that the epidemiological curve has moved over the 4-year period between 2008 and 2012 apparently as a result of the effects of increased ART coverage (HIV HSRC of South Africa, 2014). Peak HIV prevalence for females has moved from the 25–29 year age group in 2008 to the 30–34 year age group in 2012, whereas for males it has moved from the 30–34 year age group in 2008 to the 35–39year age group in 2012 (HIV HSRC of South Africa, 2014).

These variations were thought to be because of increased ART coverage and accessibility, knowing the HIV status through the HIV counselling and testing and a significant improvement in the attitudes towards people living with HIV since 2008 (HIV HSRC of South Africa, 2014).

2.3   The treatment of HIV

A dramatic reduction in HIV-related morbidity and mortality has been recognised in countries where ART has been made widely available (Achappa et al. 2013). ART is now accessible and international organisations are assisting many low-resourced countries to ensure that ART is affordable and accessible through the primary health care networks (Comell et al. 2007).

ART is highly active in stopping the multiplication of HIV and the highly Active ART (HAART) causes dramatic reduction in the level of HIV in the blood and many organs as it paralyses the multiplication of HIV (Evian, 2011). This process helps to stop the destruction of the immune system and allows for its recovery and an adequate immune status prevents the development of HIV-related infections and conditions (Evian, 2011). Evian (2011) states that ART therapy is a complex issue, for it to be successful it needs careful consideration and care and needs to be taken correctly and regularly, to achieve the following goals:

(i) Improved clinical condition,

(ii) Prevention of opportunistic infections,

(iii) Reduced severity or frequency of opportunistic infections,

(iv) Reduced spread of HIV via sexual and to improve quality of life and save lives(Evian, 2011).

The above goals are achieved by suppressing viral replication completely for as long as possible, using well-tolerated and sustainable treatment taken with loyalty (Evian, 2011).There are many ART guidelines that are available internationally, but there are current guidelines that have developed to address the current issues relevant to

24

Southern Africa which indicates that five classes of ARVs available in South Africa
(Table 3).

Table 3: Five Classes of ARVs

Class	Abbreviation	Mechanism of action	Specific action
Nucleoside and nucleotide reverse transcriptase inhibitors	NRTIs and NtRTIs	Reverse transcriptase inhibition	Nucleic acid analogues mimic the normal building blocks of DNA, preventing transcription of viral RNA to DNA
Non-nucleoside reverse transcriptase inhibitors.	NNRTIs	Reverse Transcriptase inhibition	Alter the conformation of the catalytic site of reverse transcriptase and directly inhibit its action
Protease inhibitors	PIs	Protease inhibition	Inhibit the final maturation stages of HIV replication, resulting in the formation of non-infective viral particles
Integrase inhibitors (also termed integrase strand transfer inhibitors)	In STIs	Inhibition of viral integration	Prevent the transfer of proviral DNA strands into the host chromosomal DNA
Entry inhibitors		Entry inhibition	Bind to viral gp41 or gp120 or host cell CD4+ or chemok (CCR5) receptors

Source: (Evian, 2011)

The most commonly used ARVs agents inhibit one of three key HIV enzymes essential
by the virus for intracellular replication:

- Reverse transcriptase- essential for the completion of the early stages of HIV.

- Replication protease – essential for the assembly and maturation of infectious viral.

- Progeny integrase – essential for the integration of proviral DNA into the host
  chromosomal DNA (Evian, 2011).

25

The ARV agents presently accessible in Southern Africa are the following (Gautam &Saha, 2008) Fixed- dose combinations (FDCs) that are progressively being made accessible, the oldest combination zidovudine (AZT) / lamivudine (3TC), but a number of other two-and three-drug FDCs are now available in the region. The FDCs decrease the problem of many pills that are being taken by patients living with HIV and may increase treatment adherence (Gautam & Saha, 2008).

2.4 History of ARVs in South Africa

According to UNAIDS (2010) South Africa today has the largest antiretroviral therapy programme in the world with a 54% coverage and 1, 5 million people on ARVs (Karim & Baxter, 2010). Years of denial, blaming, moralising and inaction finally came to an end in the watershed year of 2003, when the South African Government finally approved a national programme to make antiretroviral drugs publicly available to HIV-infected people who qualified for treatment (Karim & Baxter, 2010). Unfortunately, the damage done by the government's inaction was irreparable and many believed that the national rollout was "too little too late" and if the decision was made three years earlier, an estimated 330 000 lives could have been saved (Karim & Baxter, 2010).

The Population Council Horizons Program (2004) state that one of the foremost concerns of ARV programs is the ability of people living with HIV and AIDS (PLhiv) to maintain near perfect adherence over the long term. To achieve the goal of ART, even at undetectable levels of the virus in the blood, patients are required to maintain >95% adherence.

However, according to USAID (2010), while the government is making great progress in making ARVs available, PLhiv may lack the resources required to take their ARVs

properly and consistently. Resource limitations can influence the success of ART by affecting the availability of ARV drugs, the storage of the drugs, (refrigeration and disintegration with humidity). Drug distribution and sustained supply are other critical issues that can be affected by resource limitations (USAID, 2010).

Evian (2011) stated that the patient on ART needs to know the importance of taking the treatment correctly and regularly as negative attitude to ART promotes HIV drug resistance which is a major concern in patients on ART (Evian, 2011). Increased viral load and a decrease in CD4 count or the return of opportunistic infections may be a sign of drug resistance (Evian, 2011). He concluded that it is vital to exclude if treatment failure is due to negative attitude to ART or drug resistance (Evian, 2011).

A joint treatment relationship between health care providers and patients is the key to adherence. This can be achieved by inviting the patient to be part of regimen selection and dosing schedules (WHO, 2003b). Health care providers should educate the patients about the treatment side effects and discuss patient's readiness for the lifelong treatment, possible treatment barriers and workable solutions to those barriers (WHO, 2003b).

2.5 Adherence

According the Centre for Disease Control (CDC, 2013), the HIV pandemic is one of the most serious health crises the world faces today. Poor adherence has been found to be catastrophic in fighting HIV with ARV therapy, leading to an increased mortality rate. Minggu (2013) cited that highly active antiretroviral therapy (HAART) has dramatically

27

changed the course of HIV diseases, reducing both morbidity and mortality rates. Adherence to treatment and remaining in care are necessary to optimise clinical outcomes in PLWH.

Adherence to treatment regimens is crucial to improve health, increase survival, and prevent the spread of HIV to partners and offspring. ART lowers the amount of the virus in the body; an estimated 77% of patients in the United States taking ART have suppressed viral loads. Still, only half of persons with HIV are in care and only 28% of all persons with HIV have virus levels that are fully suppressed. Because having a lower viral load decreases the risk of transmission to others, it is essential that clinical providers and community-based HIV prevention specialists encourage adherence to ART and help persons with HIV to identify practical strategies to maintain positive attitudes to ART adherence over the long term (CDC, 2013).

HIV infection is different from other chronic diseases because of rapid duplication and transformation rate requiring95% levels of treatment adherence to suppress viral load to be undetectable (WHO, 2003b). Treatment failure is predicted even with the omission of a single a dose in a 28 –day reporting period (WHO, 2003b).Sub-optimal adherence has been identified as one of the key reasons causing ART resistance and promoting transmission to other people (WHO, 2003b).   Azia et al. (2016) cited that patients are to adhere for at least 95% to their prescribed long term ART to be able to see the benefits of using ART, however evidence has shown that this level of adherence is rarely attained because of multilevel and sometimes linked numerous aspects.

Adherence to ART is defined as a patient's willingness to follow a treatment plan, take medication at prescribed times and frequencies, and follow restrictions regarding food and other medication. Both patients and healthcare providers face significant challenges with respect to positive attitude to ART (USAID, 2010). Once initiated, HAART is a life-long treatment that consists of multiple medications to be taken two to three times a day with varying dietary instructions (USAID, 2010). These medications also have side effects, some of which may last for a brief time while others may be more permanent requiring change of treatment (USAID, 2010). Poor adherence to ARV treatment is associated with detectable viral loads, declining CD4 counts, disease progression, episodes of opportunistic infections and poorer health outcomes (USAID, 2010).

Taking treatment faithfully and correctly as prescribed is the key to maintain the positive health of HIV-positive people. Non-compliance does not only include the drug therapy, but also failure to obey the instructions and other aspects of health care such as taking other drugs like Ritonavir with meals. Patients on ART treatment benefit from the treatment (Muller et al. 2011). However, the issues surrounding medication adherence are often very different from those involving attitudes to diet, to follow-up appointments, or to diagnostic testing recommendations (WHO, 2011). Missing one or two doses a week can have a significant impact on the chances of unbeaten treatment, but, taking every dose, will get much better results. However, as it is also recognized that extremely high levels of adherence to ART (at least 95%) are needed to ensure optimal benefits, and that this may often be complex in terms of the pill burden, dietary restrictions and dosing frequency.

29

There are three types of non-adherence to ART (Grenard, Munjas, Adam, Suttorp, Maglione, McGlynn and Gellad, 2011):

- Non-fulfilment, in which providers write prescriptions but it is never filled. In this case, providers have made recommendations about a course of therapy that patient ultimately does not initiate. Often the patients fill the first prescription for a new medication but never take it.

- Non-persistence, in which patients decide to stop taking medication after starting it, without being advised by the health professional to do so; and

- Non-confirming which encompasses ways in which medications are not taken as prescribed; this behaviour can range from skipping doses, to taking medication at incorrect times or at incorrect doses, to even taking more than prescribed (Grenard et al. 2011).
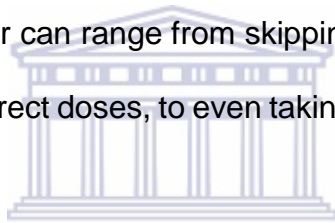
Legg (2016) highlighted that the total life expectancy of PLhiv adherering to ART in best health, not doing drugs and free of other infections may live up to their late 70s (Legg, 2016). Adherence in South Africa is sub-optimal. Van Dyk (2010) study of self-reported ARV treatment adherence showed only 40.1% of the ARV users who participated in the study reported adherence levels of more than 90% (Van Dyk, 2010). The finding that only 40% could reach the target for optimum adherence to ART as set out by the World Health Organization confirms suggestions by other researchers that rates of adherence to ART are probably like the rates of adherence to other chronic diseases treatment (Van Dyk, 2010). Although the results of the study cannot be generalised to the South African population of ARV users ,it provides some indication of what has happened in South Africa since the national ARV rollout in 2004 (Van Dyk, 2010).

http://etd.uwc.ac.za/

2.6 Promoting adherence to ART

As the WHO (2003) has highlighted that the antiretroviral (ARV) medication for people living with HIV is among the most efficacious, and the most life-transforming of therapeutic innovations of recent years, the need for adherence rates approaching 100% are required for optimal viral suppression (WHO, 2003).

Rougemont, Stoll, Elia and Nganga (2009) indicated that adherence to ARV therapy is the key to guarantee viral suppression, to reduce the risk of disease progression and to prevent the occurrence of drug resistance. However, studies have shown that it is not easy to measure adherence accurately, which is reflected in the number of contradicting reports that are available on the response to ART in people living with HIV and AIDS (Rougemont et al. 2009). It has been recommended to find simple and reliable methods of assessing adherence, treatment attitudes and the influencing factors to channel effective public-health measures (Rougemont et al. 2009).

HIV drugs will work only if a patient keep a stable minimum level of each drug in their body (Minggu, 2013). Patients need to develop a schedule for taking medication, even if they take only one pill twice a day. It is important to take medication precisely on time (Minggu, 2013). Individualised measurement and support for adherence are vital for patients to be successful with ART (Mingqu, 2013).

Heestermans et al. (2016) further stated that patient's strong belief on the significance of ART and understanding the meaning of ART contribute to adherence. Treatment attitude assessment is most successful when conducted in a positive, non-judgemental atmosphere. The patients should recognise that the provider understands the challenges

related to taking ARV regimen (Heestermans et al. 2016). Fear of discrimination and stigma were seen as factors contributing to non-adherence. Engaging in a trusting relationship may help a provider to learn what is really happening with the patient's attitude to ART rather than what the patient thinks the provider wants to hear (Heestermans et al. 2016). It is imperative to evaluate CD4 cell counts and HIV viral loads as they will indicate the effectiveness of ART in suppressing viremia, an indirect indicator of adherence. Health improvement on ART like being able to go back to work increases confidence on medication (Heestermans et al. 2016).

2.7 Measuring adherence

In a sample of South Africans only 57% of patients who reported 100% adherence achieved an undetectable viral load, that is <50 copies/ml (Nachega, Edward, Mills & Buchan, 2006). Assuming a high negative correlation between reported adherence and viral load, this inequality recommends that these patients were unable to truthfully report treatment attitude levels.

One of the key ways to ensure adherence is through the assessment of adherence. Nachega et al. (2006) stated that there is no gold standard for measuring ART adherence. Assessment of the adherence to every visit asking questions in a simple, non-judgemental, structured format and listening to the patient to encourage honesty about issues that may affect attitude to ART is important (Table 4).

Table 4: Assessing adherence and monitoring of ARV treatment (Muller et al. 2011)

Assessing Adherence	
Assessment Tool	Effectiveness/Reliability
Patient self-report	Counsellor interview, health care provider examination, entries in the patient card and the clinic record. Convenient routine and inexpensive. Less accurate, assessment over time improves the accuracy.
Pill count	May be more accurate than the self-report. Already incorporated in the system.
Pharmacy records/prescription refill monitoring	Objective measure, but presumptive – collection of drugs does not necessarily mean that patients are consuming them correctly. May serve to improve adherence when combined with telephone prompts on due visit dates.

The various methods now used by researchers include self-report, patient attendance at scheduled visits, clinical assessment, pill count, plasma drug levels, electronic bottle monitors and pharmacy- based records. In each of these methods advantages and disadvantages have been identified. Other common methods that are used to measure treatment attitude are the following; drug level monitoring and various self-report instruments (Gill, hammer, Simon, Thea, and Sabi, 2005).

Adherence to ART is monitored by self-reporting, and pill count and calculated by the formula below talking to adherence to assess if the patient's adherence is > 95% (high), 80 – 95% (moderate) or < 80% (low)(Table 5) (Muller et al. 2011).This formula has been extracted from Muller et al. (2011).

$$Adherence = (\frac{dispensed - returned}{\exp ected\ to\ be\ taken}) * 100$$

Table 5: Positive and Negative adherence to ART (Muller et al. (2011)

Rate of adherence	Interpretation
100%	Took all medication
>95%	Fewer than 3 doses missed in a period of 30 days.
80-95%	3 to 12 doses missed in a period of 30 days
<80%	12 or more doses missed in a period of 30 days

Improved adherence to ART is 100% adherence as in cases where the patient takes all the medication, when there are no missed doses and viral load (VL) also measures adherence by demonstrating how much HIV is in the blood; when adherence to ART is 100% VL becomes lower than detectable (LTD) (Muller et al. 2011).

In promoting improved adherence to ARV treatment, a new ARV fixed dose combination (FDC) was launched by the Minister of Health, Dr A Motsoaledi and implemented on 1 April 2013. Gautam and Saha (2008) stated that this will make a big difference in improving adherence because it is a single dose. When all the patients on ARV treatment have been switched to FDC, and that will only depend on the availability of the stock at all the facilities, there will be a tremendous improvement in attitude for ARV treatment (Gautam &Saha, 2008).

2.8 Factors affecting adherence

Factors affecting adherence indicate adherence is not only about following instructions, but it requires commitment and knowledge from PLhiv. The common reasons of low adherence are theorised to be: experiencing adverse drug effects, finding the regimen too complex, having difficulty with the dosing schedule (not fitting into the daily routine),

forgetting to take the medication, being too busy with other things, oversleeping and missing a dose, being away from home, not understanding the importance of adherence to treatment, and being embarrassed to take medication in front of family, friends, or co-workers (Heestermans et al. 2016).Other contributions include attitudes towards treatment, psychosocial issues, (such as lack of social support, homelessness), psychiatric illness and active substance abuse. It is important for researchers to look for the potential barriers to adherence and focus on the action required to lay the groundwork for the optimal adherence to ART in advance (Heestermans et al. 2016). Many factors have been associated with adherence to ART and are commonly divided into intersecting categories (Reiter, Wojtusik, Hewitt, Segal-Maure, Johnson, Fisher, Zackin, Masters & Bangsberg, 2000), namely: patient variables, treatment regimens, disease characteristics, patient-provider relationship and clinical setting. These factors have been identified by the WHO (2003b) in a framework, the WHO – 5 factors influencing adherence, namely: Social and economic related factors, Health system related factors, Patient related factors, Treatment related factors and Condition related factors (Who, 2003b).

- **Social and economic related factors**: These factors play a big role in affecting adherence like hectic life experienced by mothers taking care of children and household demands makes them to forget treatment and redirect funds to be used for treatment to family needs. Low income affecting the affordability and accessing treatment, cannot travel to the facility and cannot afford to buy food and poor living

conditions also contribute to these factors. Difficulty in getting family and friends support for taking treatment. Lack of support from family and friends (WHO, 2003b).

- **Health system related factors**: Clinician-patient relationship plays a big role on adherence. Vague instructions on how and when to take treatment (WHO, 2003b).

- **Patient factors**: Positive acceptance of HIV status and patient's positive belief on lifelong treatment have a positive impact on ART therapy adherence. Hectic life and hectic work schedule contribute to missed doses and that results in poor adherence. Alcohol use and drug use have a negative impact on ART therapy adherence (WHO, 2003b).

- **Treatment factors:** Complicated medication; number of pills to be taken per day and medication side effects. Education on adherence to ART therapy (WHO 2003b).

- **Condition related factors:** Comorbidities contribute to poor adherence, development of OIs, makes the patient to take more than one regime. Mental illness also contribute to poor adherence (WHO, 2003b).

2.8.1 Socioeconomic related factors

Lack of social support, family and friends support has a negative impact on adherence. When the family has not accepted the HIV diagnoses they become reluctant to offer support that is needed for the patient to take treatment (WHO 2003b). Mothers forget taking treatment due to family demands like taking care of children and household demands and they end up using funds allocated for treatment for other things that will benefit the family. Unemployment affects the affordability and accessing treatment,

36

patients having difficulty in accessing facilities for check-ups and facilities and cannot afford to buy food. The poor living conditions also contribute to these factors (WHO, 2003b).

Emotional and social support is offered to clients by their spouses, friends, treatment partners and others. Patients with extensive social support have good adherence to treatment (Mostashari, Altice, & Friedland, 1998). The study by Williams & Friedland (1997) on the association of support and treatment adherence revealed that patients living with partners adhere better than those who live with no partner. They associated lack of support with reduced negative adherence to treatment. In addition, social support appeared as a great motivator of positive adherence behaviour. The social and emotional support received from close family, friends, and colleagues positively influenced adherence behaviour. Respondents have confirmed this: "You need a support system…you can't be on your own…you need people"; "My family, my kids make me take my meds, they help me" (Williams &Friedland, 1997).

Emotional support is one of the important types of supports that is required for someone to transition into HIV care (Cook et al. 2017). It is reported that lack of emotional support may lead to poor adherence to care and lifelong treatment (Cook et al. 2017). In addition, it has been noted that many people diagnosed with HIV take time to ask for emotional support (Cook et al. 2017). They explained further that participants pronounced that emotional support is crucial especially during that catastrophic period following the diagnosis of HIV to assist them to deal with the pain (Cook et al. 2017).

37

Kagee (2008) stated that social support for compliance to treatment is defined as encouragement from family and friends for the patient to co-operate with the recommendations and prescriptions of a health professional. The expression of concern and encouragement from others to engage in health promoting behaviours, including medication adherence, may combine with social desirability needs on the part of the patient to yield higher rates of medical co-operation. There is strong evidence that positive social support, including being married, is associated with positive adherence to ART (Kagee, 2008).

The study by Poudel, Buchanan, Amiya and Poudel-Tandukar (2015) revealed that PLhiv getting social support from their families are likely to adjust better to unpredicted events like HIV diagnosis, treatment initiation and adverse side effects. They engage easily in HIV and AIDS related knowledge and treatment and use that to maintain ART adherence (Poudel et al.2015).
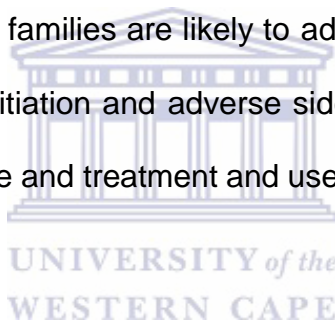
ART therapy requires high level (>95%) adherence. ART treatment achievement relies on sustainable positive adherence to ART, yet some of HIV-infected patients do not reach high levels of positive adherence to ART treatment and this can result in distressing public health problems (Wakibi et al. 2011)

Peltzer and Pengpid, (2013) revealed that income as an indicator of socioeconomic position most directly measures the material resources component of socioeconomic factors. In addition, data was searched electronically to identify studies concerning socioeconomic status and HIV and AIDs patients on ART. However, it is not clear what

effect socioeconomic factors have on adherence to ART among patients in low- and middle-income countries (Peltzer & Pengpid, 2013).

The higher the position the more discreet the workers are about their HIV status. The availability of ART regimen simplification with a once-a-day ART regimen will improve adherence to ART of employed people. The Tanzanian study revealed that PLhiv are prevented from taking ARV treatment as prescribed by work schedules, a busy life schedule, travelling out of town for work and long hours of absence from home (Watt et al. 2009). This research also focuses on the association of socioeconomic status (SES) with adherence to ART of patients with low, middle and nil income (employed, on disability grant and unemployed) in the Queenstown region area. A significant association is not clear between the employment status and the adherence; further research can be of assistance in this matter (Watt et al. 2009).
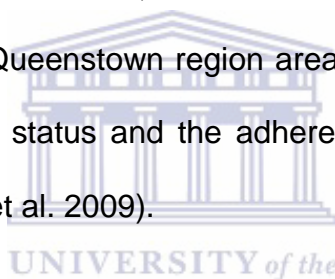
Furthermore, rural Zambian clinics identified 255 eligible patients (mean age, 39.7 years; 44.3% male; 56.5% married; and 45.5% with only primary school education) when they conducted a retrospective chart review on ART clinic patients treated during the first 12 months after clinics opened in rural Zambia to assess adherence to ART and assessed adherence based on clinic attendance (Birbeck et al. 2010). Disclosure was less likely among women (27.5% versus 49.6%, P = 0.0005); 36.5% had "clinic buddies" to provide adherence support. Adherence rates were good for 59.2%. Disclosure of HIV status to ones' spouse (P = 0.047), knowing spouse's HIV status (P = 0.02), and having a clinic buddy (P = 0.01) were associated with good adherence. Social support is a key patient-

level resource impacting positive attitude to ART adherence in rural Zambia. Limited spousal disclosure affects women more than men (Birbeck et al. 2010).

A study in Tanzania (Watt, Suzanne, Earp, Eng, Phillip, Golin, and Jacobson, 2009) revealed that lack of family support contributes to cessation of treatment by PLhiv, regardless of the assurance of better health and a high level of personal motivation. In some case, the control of family members was so significant that relatives such as parents or husbands made treatment decisions, including the decision to break off from ART (Roura, Busza, Wringle, Mbata, Urassa, & Zaba, 2009).

2.8.2 Health system related factors

A positive Health care provider and patient relationship has a positive impact on adherence. Atkinson, Nilsson Schonnesson, Williams, and Timpson, (2008) argued that an aspect of social support, namely the relationship between the doctor and the patient, has also been shown to be strongly associated with compliance to treatment. Medical providers indeed often view communicating with patients about adherence as an essential component of the health care service. While the provider-patient relationship may ostensibly constitute an example of social support, it also extends beyond this. The health worker is often seen as a person in authority, in possession of specific expertise, and in whom the patient can put hope for assistance in the recovery process (Atkinson et al. 2008). In health system related factors Mathes et al. (2015) mentioned that facility care services, co-payments and medication costs had negative effect in all systemic reviews (Mathes et al. 2015).

2.8.3 Patient related factors

Patients who have negative attitude to HIV status and a negative belief to ART therapy are unlikely to adhere to treatment. Patients' negative attitudes and poor adherence to ART treatment remains a serious problem (Dimateo, Lepper, & Croghan, 2000). Hectic life ad hectic work schedule contribute to missed doses and that results in poor adherence. Alcohol use and drug use have a negative impact on ART therapy adherence. The results from the study done by Berg et al. (2004) suggest that alcohol use may have an extremely high impact on antiretroviral adherence in women. The study also found that the finding that depression was not significantly associated with worse adherence was unusual and was most likely due to limited statistical reliability. Patient's beliefs play a big role in treatment adherences. A patient's behaviour is the critical link between a prescribed regimen and treatment outcomes (Munro et al. 2007). Consequently, the most important factors influencing treatment adherences are patient related and under the patient's control, so attention to them is a necessary and important step in improving treatment adherence. Patients who believe that treatment is advantageous are able to make an obligation to long-term treatment and are confident that they will be able to take medications correctly and regularly and tend to have positive attitude to acceptance than those who do not (Munro et al. 2007).

USAID in collaboration with the Government of the Kingdom of Lesotho explains that the low status of women in society may affect the HIV-infected woman's ability to receive treatment, including ART, and to make decisions about her own care. Women are especially vulnerable to loss of social and economic support and to domestic violence

when they are HIV-infected. However, the laws that relegated women to minority status have been reviewed. The Act that was released in 2006 gave women, men, boys and girls, the equal rights (Zewotir & Maqutu, 2006).

In the Lesotho Demographic Health Survey, it is explained that violence against women is a problem; more than half the women reported having been physically abused in their lifetime, and almost one in four (24%) reported being beaten in the past year. USAID explains that the gender policy also establishes strategies in the fight against gender-based violence. Like the equality law, this policy requires an aggressive education campaign for the masses as well as enforcement. Though the studies cite information about adherence and gender, there is still no significant association between the two (Zewotir & Maqutu, 2006).

The research by Berg et al. (2004) presents gender issues without more precision on whether more men were involved in the poor adherence to ARV treatment than women. The research indicates that gender has an influence on treatment adherence and the research results on gender-stratified analysis demonstrate that different social and behavioural factors are associated with treatment adherence in men and women. Among both men and women, worse loyalty to ARV treatment was associated with lack of long-term housing, not belonging to an HIV support group, crack/cocaine use, and medication side effects. Among women only alcohol use was associated with poor adherence to ARV treatment (Berg et al. 2004).

In addition treatment adherence was assessed by, Bonolo et al. (2012) in their study on non-adherence among Brazilian patients support the idea that women are less likely to

42

adhere to ART than men. In fact, they find that there was 1.5 times greater non-adherence among women compared to men. The study also states that women living with HIV experience barriers which differ from those their male counterpart's experience, including depression, stress, stigmatisation and specific social roles related to gender (Bonolo et al. 2012).

HIV transmission occurs mainly through heterosexual contact in sub-Saharan Africa and, less significantly, through mother-to-child transmission (UNAIDS, 1999). A slight effect of intravenous drug infection and homosexual contact infection is noted on this region. The transmission from male to female occurs with more ease than female to male transmission and as a result women are more affected by HIV in sub-Saharan Africa than males. The practice of older men having sex with younger girls increase the likelihood of HIV infection of younger females aged 15 to 19 years of age (UNAIDS, 1999).

The previous research involving two studies among women only supports the opposite connection between alcohol use and treatment adherence. However research on gender differences in alcohol abuse disorders has suggested that the physical, psychological and social effects of alcohol are different in women and men (UNAIDS, 1999).

William and Friedland (1997) did not find any association between age and adherence although they revealed that as patients grow older, adherence levels become poorer over time, and the reduction is more prominent with patients that have no schooling.

Nachega, Uthman, Anderson, Peltzer, Wampold, Cotton, Mills, Ho, Stringer, Mcintyer and Mofenson, (2012) revealed that, it was estimated that by 2015 more than half of all HIV-infected individuals in the United States will be 50 years of age or older. They also explain

43

that as population ages, the frequency of non-AIDS related comorbidities increases, which includes cardiovascular, metabolic, gastrointestinal, genitourinary and psychiatric disorders. As a result, medical management of the aging HIV population can be complicated by polypharmacy and higher pill burden, leading to negative attitude to antiretroviral therapy (ART). Approach to ART is generally better in older populations when compared to younger populations; however, cognitive impairment in elderly patients can impair adherence to ART leading to worse treatment outcomes. Practical monitoring tools can improve treatment attitudes, adherence and increased rates of viral load suppression.

Johnson, Heckman, Hemsen, Kochman and Sikkema, (2009) highlighted that older people are more committed to treatment and tend to be more health-conscious than the younger group. Young adults tend to have more hectic life styles, unhealthy eating habits and experience more stigma problems (Johnson et al. 2009). De-stigmatisation of the virus needs to be emphasised in the younger generation so that adherence to treatment can be achieved (Johnson et al. 2009).

Lyon, Maureen and Angelo (2006) provided information on the challenges linked to negative attitudes to ART among adolescents; those challenges are:

- Communication with parents
- Lack of supervision/monitoring;
- Peer pressure;
- To take pills in front of other people;
- Sleeping over;
- Accepting HIV status;
- Disclosure issues;

44

- Social support; and
- Poverty (no food to take with medicine)

2.8.4 Treatment related factors

It is difficult for a Patient to understand a complicated treatment regimen.   The following effects have a negative impact on adherence to ART therapy:

- Number of pills to be taken per day

- Treatment side effects

- Lack of education about adherence to ART therapy

- Lack of clear instructions on how and when to take treatment

- Lack of prescription knowledge

It has been reported that in developing countries there has been large numbers of traditional health practices (THPs) involved in the treatment of HIV and AIDS, however concurrent use of THM and antiretroviral drugs may lead to drug interactions that may interfere with the effectiveness of HAART(Namududu, Kalyango, Karamagi, Mudiope, Sumba, Kalende, Wobudeya, Kigozi and Waako, 2011).

Patients who can recognise their medication (in their own words or in their own way) and explain the proper dosing and administration have a more positive approach to ART and higher adherence than others. Offering patient information before giving a prescription is important to ensure positive acceptance and adherence to ARV regimens (Thandar, Mon, Boonyaleepun, and Laohasiriwong 2016). Instruction can be given orally or in a written or graphic form to help the patient understands the medications and their dosages. Basic information that is required for the patient to understand the ARV regimen is the number

of pills, dosages, frequency of administration, dietary restrictions, possible adverse effects, tips for managing adverse effects, and period of therapy. Patients need to realize that adherence levels of >95% to ART treatment prevents virological failure (Thandar et al.2016).

Médicins sans Frontières (2010) informs us that ARV regimens interrupt the life cycle of HIV, so the growth of HIV is halted and it stops killing CD4 cells. The CD4 count then slowly rises, usually to a level well above 200. This can take many months or years, and will only continue if the person faithfully takes the ARVs. This level of 200 is important, since most OIs occur when the CD4 count is below 200.

Weiser, Wolf, Bangsberg, Thior, & Gilbert (2003) in Botswana, Aspeling& Van Wyk (2008) in South Africa explained that informed patients tolerate side effects and adhere to the therapy better than those who are not informed. In the information mentioned above on knowledge of treatment there is no significant association of the knowledge of ART and the treatment adherence (Weiser et al. 2003 and Aspeling & Van Wyk, 2008).

2.8.5 Condition related factors:

Comorbidities contribute to poor adherence because of pill burden. People with advanced HIV infection are exposed to other infections and malignancies that are called opportunistic infections as they take advantage of opportunity existing from a weakened immune system (AIDS*info* guidelines, 2014). Poor adherence to ART regimen has serious consequences for HIV-infected patients, including failure to stop viral duplication and greater risk than before of developing viral resistance. The immune system for PLhiv is delicate therefore opportunistic infections (OIs) usually emerge, especially if the

CD4 count is below < 200 cells/mm3. The CD4 count is the most significant laboratory indicator of immune function in patients living with HIV. It is vital that the CD4 count should be measured in all patients who have been diagnosed to be HIV-positive as it is the key factor in informing the need to initiate OI prophylaxis and the necessity to initiate ART. Although OIs commonly occur in patients with a CD4 count < 200 cells/mm3, some OIs occur in patients with a higher CD4 count (AIDS*info* guidelines, 2014). AIDSinfo (2013) explained that OIs are signs of a declining immune system. Most life threatening OIs occur when the CD4 count is below 200 cell/mm3. OIs are the most common cause of death for people with HIV and AIDS. One of the goals of HIV treatment is to lower the risk of getting OIs. Antiretroviral therapy can help by increasing the number of CD4 cells, which will help protect you from OIs. You may also take medication used to prevent diseases from occurring (This is known as prophylaxis) (AIDS*info* guidelines, 2014).
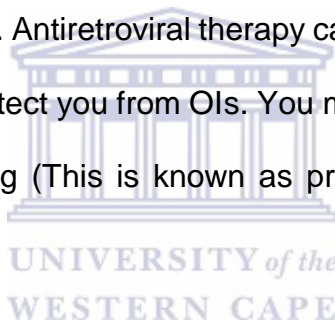
The risk of opportunistic infections (OIs) is common in HIV patients as HIV slowly weakens the person's immune system (AIDS*info* guidelines, 2014). This progressive immunodeficiency is almost always associated with an ongoing drop in CD4 count (a type of white blood cell). As the CD4 count drops, certain infections are likely to appear like TB, bacterial pneumonia, oesophageal candidiasis, STIs and more (AIDSinfo guidelines 2014).

Furthermore, tuberculosis is the primary reason of increased morbidity and death rate among HIV-infected patients (Rabkin et al. 2005). Regarding opportunistic infections and

47

adherence there is no significant association between the two and this demands more research to be done.

Médecins sans Frontières (2010) mentioned that it is imperative to try and improve adherence before switching regimens due to side effects as poor adherence may lead to virological failure. Side effects are more common in severely immune-compromised (CD4 <200) patients. In addition, ART-related side effects occur in children as well as in adults. Fortunately, they are not common in children. However, this means that they may be missed when they do occur. Vigilance and proper education given to the caregiver can help avoid this. Caution the patient to report any side effects early and not to stop taking any drugs without consulting the health care provider first (Médecins sans Frontières, 2010).

Murphy & Durako, (2001) revealed that the negative characteristics of certain medication regimens are common barriers to adherence. Youth who feel healthy before starting ARVs will be very unlikely to accept experiencing major side effects, especially if they last more than a week or two. Side effects such as diarrhoea, rashes, or jaundice may be predominantly upsetting because young people commonly worry that friends and contacts may take for granted that they have HIV. There is no significant association between the side effects and the treatment adherence (Murphy & Durako, 2001).

2.9 Strategies to improve attitudes towards treatment and adherence

National consolidated guidelines by the NDOH SA April (2015) highlighted that education on positive acceptance to comply with treatment at the beginning of the

treatment cascade is vital. A positive acceptance of the lifelong ART therapy include taking treatment as prescribed, keeping to appointments for blood tests, referrals and further investigation. Encourage disclosure to family or friends who can support the treatment plan, the strategies discussed below are to improve adherence to ART therapy, Table6.

Table: 6.**Strategies to improve treatment adherence NDOH (2015)**

Ensure quality adherence counselling: Spend time with the patient and explain HIV infection, targeted goals of ART therapy and the importance of adherence. Explain the importance of viral load (VL) suppression and the CD4 count elevation. Discuss treatment plans that will suite the patient so that she or he can understand and commit to it. Educate the patient on drug-drug interaction and the ways of avoiding it (NDOH, 2015).	**Support patient with adherence tools:** Encourage self-reporting on adherence Reinforce use of pillboxes, or a daily dosing diary. Promote support system and encourage treatment buddy that will help to remind the patient by sending sms reminder, phoning, or any method that they agreed on. Encourage caregiver participation in a support group; patient should nominate the counsellor or caregiver. Caregiver to arrange home visits with the patient (NDOH, 2015).
Impact knowledge: Equip the patient with information about ART therapy and how does the ART therapy work. Explain the importance of positive attitude to treatment. Give details on the benefits of ART therapy Explain the importance of adherence to ART therapy (NDOH, 2015). Provide clear treatment instructions **Access to Medication:**	**Modify patient behaviour:** Empower patient to manage their condition themselves. Address fears and concerns. Provide encouragement and recognition for adherence (NDOH, 2015).

Ensure easy access to a continuous medication supply (avoid "stock outs") Ensure that patients understand where, when and how to obtain medications Provide on-site pharmacies where possible Assist patients in safeguarding medications Medication "reminders" linked to daily activities, timers, beepers, alarm clocks (NDOH,2015)	

2.10 Summary

This chapter gave an overview of the importance of adherence in the effective treatment of HIV and AIDS and the factors that may influence adherence, the importance of research on the approach to antiretroviral therapy and acceptance of the ART therapy.

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50
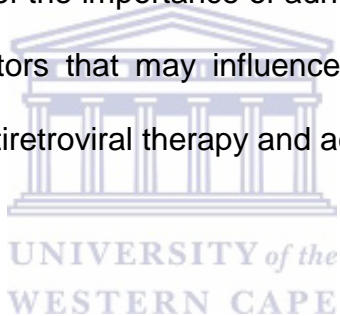
Chapter 3: Methodology

3.1 Introduction

This chapter outlines the research approach, study design, setting, population and sampling and how the data were collected and the plan for the analysis of this data. This chapter describes how the questionnaire administration guide was designed. The development of the questionnaire and the validity and reliability of the instrument is also discussed. The chapter concludes with a discussion of the ethical considerations in this study.

3.2 Research approach and paradigm

To investigate the self-reported treatment attitudes which may impact on adherence of HIV-positive people in the Queenstown Region in Eastern Cape South Africa, a quantitative approach from a positivist paradigm was used. Positivism is a position that holds that the goal of knowledge is simply to describe the phenomena that we experience. The purpose of science is to focus on what we can observe and measure (Mouton, 2006).

A quantitative approach was the appropriate approach as the objectives of the study were to describe the factors that may influence attitudes to antiretroviral treatment and the self -reported side-effects.

3.3 Study Setting

The Chris Hani District Municipality (CHDM) consists of 6 local municipalities and is one of the biggest district municipalities in the Eastern Cape. The health sub-districts are as follows: Engcobo, Sakhisizwe, Emalahleni, IntsikaYethu, Lukhanji and Inxuba Yethemba. The study was conducted in two health facilities in Queenstown, a town situated in Lukhanji local municipality which is a sub district of Chris Hani district municipality in the Eastern Cape of South Africa. The district was named in honour of the late Chris Hani, who was born in Intsika Yethu Sub district Queenstown, named after Queen Victoria, is a town in the middle of the Eastern Cape Province of South Africa, roughly half way between the smaller towns of Cathcart and Sterkstroom (Chris Hani Municipality District Profile Cooperative Governance and Traditional Affairs, 2011).

The Chris Hani district is considered a rural district since 95% of the total population is rural or semi-rural. The total population of Chris Hani District Municipality is about 822 891. Despite what looks like a prosperous district from a socio-economic point of view, wealth is not equitably distributed the overall unemployment rate is about 22% and 43 % of the population lives under the poverty line. It is relevant to mention that although the male population surpasses the female one, the majority of households are run by women (Household survey, 2001).

The district has 110 fixed clinics (local and provincial authorities), 20 health centres, 9 mobile clinics and 9 district hospitals. Human resources are scarce and capacity is poor. The combination of unequal distribution of material and human resources with poor health

systems results in poor health outcomes for the population of the district (Chris Hani District Municipality Health Systems Trust, 2016).

According to Stats SA (2015) the Eastern Cape has a HIV prevalence of 12.6% Table 7 displays HIV prevalence per year and the number of people living with HIV, 2002–2015 Table 7.

Table 7: HIV Prevalence 2002—2015((Stats SA 2015)

Year	Women 15–49 yrs	Adults 15–49 yrs	Youth 15–24 yrs	Total population	Incidence 15–49 yrs
2002	16,69	14,50	6,75	8,8	1,65
2003	16,85	14,58	6,35	9,0	1,63
2004	16,93	14,62	6,07	9,1	1,65
2005	17,01	14,65	5,91	9,2	1,67
2006	17,22	14,82	5,82	9,4	1,65
2007	17,52	15,10	5,76	9,7	1,58
2008	17,81	15,39	5,71	10,0	1,50
2009	18,09	15,66	5,69	10,2	1,43
2010	18,29	15,87	5,70	10,4	1,38
2011	18,42	16,01	5,64	10,6	1,34
2012	18,53	16,14	5,61	10,7	1,31
2013	18,67	16,29	5,60	10,9	1,28
2014	18,85	16,46	5,59	11,1	1,23
2015	18,99	16,59	5,59	11,2	1,22

The district has 110 fixed clinics (local and provincial authorities), 20 health centres, 9 mobile clinics and 9 district hospitals (Health Systems Trust Chris Hani District, 2016).The facilities used for the study are Hewu hospital and Nomzamo facility. Hewu Hospital is the provincial government-funded hospital in Whittlesea, Eastern Cape in South Africa. The hospital includes an emergency department, medical services, paediatric ward, maternity ward, outpatient's department, surgical services, operating theatre and CSSD Services, pharmacy, anti-retroviral (ART) treatment for HIV/AIDS, post-trauma counselling services, laboratory services, X-ray services, laundry and kitchen services. Nomzamo clinic is in Ezibeleni location in Queenstown Chris Hani District, Eastern Cape and

provides the following services: HIV Treatment, Medical male circumcision and Paediatric services, but are not limited to these services.

3.4 Methodology

3.4.1 Study Design

The study design used a quantitative descriptive research survey study design with a researcher administered questionnaire. A survey design was used as the study collected information on factors that may influence treatment attitudes to ART among HIV-positive people that on antiretroviral treatment in the Queenstown Region in Eastern Cape South Africa.

3.4.2 Population and Sampling

3.4.2.1 Population

The population of this study was all HIV-positive patients aged 25 years and above on antiretroviral treatment in the two clinics at the time of the study (N=594)**.** The total population per clinic was estimated as the average of patients attending HIV clinics from January 2009 to January 2010, 256 patients for Hospital Clinic and 338 patients for PHC clinic. At the time of the data collection for the study the two clinics used were the one seeing big numbers of PLhiv on ART.

3.4.2.2 Inclusion and exclusion criteria

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Inclusion criteria:

- Patients on ART on the clinical record of the facility at the time of data collection

- Aged from 25 years old and older;

- On ART for at least one year.

Exclusion criteria:

- Patients on clinic record but not on ART;

- ART defaulter patients and the patients who were lost during follow up (defaulted on treatment for more than 90 days.).

- Patients who stopped ART due to medical reasons;

- Patients who were on ART for Prevention of Mother to Child Transmission (PMTCT).

3.4.2.3 Sample size

A sample size of n=118 was calculated assuming that the distribution of people living with HIV with a positive attitude to ART was normally distributed and the confidence interval was 95% which presumes that $Z_{\alpha/2} = 1.96$; the power is 80% and margin error (d) was estimated between 5% and 7% .It was also assumed the prevalence (π_g) was 17% (Statistics South Africa, 2009) and design effect (D) of two was used.

$$n = \frac{1.96^2 * (1 - \pi_g)}{d^2 * \pi_g}[1 + Deff] = \frac{1.96^2 * (1 - 0.17)}{0..69^2 * 0.17}[1 + 2] = 118$$

Figure 2: Sample size formula

Sample sizes were determined for each strata that is to determine the number of participants per clinic (see Table 8). Each clinic was identified as a stratum. This meant that 51 patients in the Hospital clinic facility out of 256 patients and 67 out of 338 patients in PHC facility were selected.

Table 8: Stratified sample

Facilities	N	Sampled(n)
Hospital clinic	256	$n_1 = \frac{256 * 118}{594} = 51$
PHC clinic	338	$n_2 = \frac{338 * 118}{594} = 67$
Total	N=594	n=118

3.4.2.4 Sampling technique

A systematic sampling technique was used to select the participants per facility. Systematic sampling is one of the sampling methods that can be applied to select a representative sampling from a large research population.

Burns and Grove (2011) declared that systematic sampling refers to a sampling technique which entails the selection of participants in a systematic and orderly format. Subsequently the remaining participants are then selected at a constant interval. This means that every *k*th respondent on an ordered/specific list of the total population for a specific research study, are selected randomly after a randomly selected starting point

56

has been identified. An alphabetical list of all the respondents was compiled. Thereafter the first respondent on the list was selected using the random number and thereafter the rest of the respondents were selected by using a constant interval, k= N/n; the selection process continued until the exact number of respondents were selected as indicated by the computed sample (Burns & Grove, 2011). Thereafter the first respondent on the list was selected using the random number and the constant interval (k=594/118=5) was five; therefore, every second respondent was selected to obtain a representative sample at each institution. For the purpose of this study respondents were selected from clinics (Burns & Grove, 2011).

3.5 Instrument

A researcher administered questionnaire was used to collect quantitative information through structured closed questions (see Appendix 1).
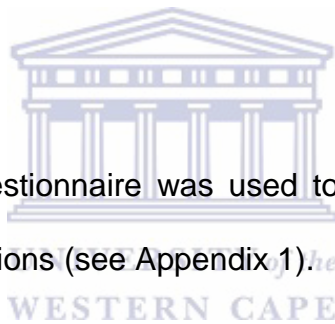
3.5.1 The questionnaire

The questionnaire was developed following a detailed literature review on studies published by WHO and other similar studies.The questionnaire was divided into five sections noted as Section A, B, C, D, E and F.

Section A: Demographics: Section A collected information to describe the respondents' demographics in the following order of the following variables: age, sex, marital status and level of education and socioeconomic status of the respondents (occupation, substance use and transport availability) (see Section A Q1 - 8).

Section B: Medical Prescription Knowledge and Adherence: Section B contained two sections: 1) treatment knowledge; and 2) prescription problems. Section B1 assessed the knowledge of the respondents about his or her regimen. In Section B_1, the respondents were asked to tick an answer they thought was correct. A respondent were classified as having good knowledge of medical prescriptions if all his/her answers to questions 3 and 5 of Section B_1 matched the physician's prescription. When at least one of the answers in Section B_1 did not match with the physician's prescription, the respondent is classified as having weak knowledge about the medical prescription. In Section B_2, respondents were asked to indicate if they had suffered from problems with taking prescribed medicines.

Section C: This section includes two parts. Part on (C1) measures the level of acceptance of the condition when diagnosed. The second part includes the patients' perceptions towards treatment (C2) using 11 questions to establish the extent to which a respondent "agreed" or "disagreed" with beliefs on treatment.

Section D: Opportunistic infections: The opportunistic infections as a possible influence on treatment attitude were explored in Section D. Respondents were asked to indicate the last time they suffered from opportunistic infections. The questions were also meant to link the existence of severity of OIs to negative attitude to ART). Five options were listed (times that a respondent suffered from OIs) from which the respondents were to select; these were: (1) Within the past 3 months; (2) Within the past 6 months;(3) Within the past year;(4) Within the past two years; (5) Within the past five years. It also included a question on opportunistic infections (indicating Yes or No). This question could function

58

as a proxy for ART treatment attitude (OR HAART negative attitude (AOR= 5.28, 95% CI 2.52-11.08) (Iroezindu, Ofondu, Hausler, & Van Wyk, 2013).

Section E: Social support: Question E assessed if the respondent were getting any kind of support from the community group as a possible influence on ART treatment attitude. Section E includes three sections: Section E1: emotional support, Section E2: Friends support; and Section E3 Significant other support related questions.

Section F: Substance for recreation and Treatment Perception: There were four questions on substance abuse in Section F of the questionnaire. The purpose was to assess any element contributing towards missing tablets. Respondents were asked to tick an option that best related to their situation and to also provide the interviewer with more information where it was indicated.
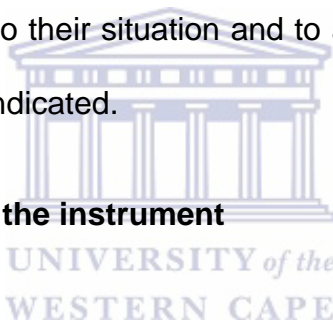
3.5.2 Validity and reliability of the instrument

3.5.2.1 Reliability of the instrument

The reliability of the instrument refers to the degree in which the instrument gives the same results if the procedure is repeated in the same way (Babbie and Mouton, 2001). One way to measure reliability is through internal consistency, calculating a Cronbach's Alpha. In this study, the Chronbach's alpha for the treatment perceptions (11 items) was α=.699 which indicated reasonable consistency in measuring the individual perception or attitude towards adherence to ARV treatment (Table 9). In addition, all other sections showed good consistency (Table 9).

59

Table 9: Chronbach's Alpha of support and treatment scale

Items	Cronbach's Alpha	Item numbers	Decision
Treatment perceptions	.699	11	Acceptable
Emotional support	.70	3	Acceptable
Friends supports	.89	2	Acceptable
Significant others	.92	2	Acceptable

3.5.2.2 Validity

The validity of the instrument refers to the degree in which a test measures what is intended to measure (Babbie & Mouton, 2001). Validity is the most important consideration in test evaluation. The concept refers to the appropriateness, meaningfulness, and usefulness of the specific inferences from the test scores.

- Face validity is purely a subjective, superficial assessment of whether the measurement procedure you use in a study appears to be a valid measure of a given variable or construct (Mouton, 2006).To ensure the face validity of the current instrument, the questionnaire was submitted for face validity to an expert in HIV.

- Content validity refers to the extent to which a measure reflects a specific domain of content, it is particularly important for test of knowledge (Table 10).

Table 10: Content Validity

Model	Research Question		Questionnaire
Social & Economic Factors	I.	What are the socio-demographic factors such as gender, age, marital status and employment status that may influence adherence to antiretroviral treatment?	A1-5
	II.	What are the patients' self-reported support factors (social and emotional support systems and partner support) that may influence adherence to antiretroviral treatment?	E1, E2 & E3
Health Service	III.	What are the health service barriers to care that may influence adherence to antiretroviral treatment?	A: 6-7, C2: 8,9
	IV.	What are patients' prescription problems which may influence the antiretroviral treatment regimen?	B2, C2: 6
Condition factors	V.	What are the patients' self-reported levels of opportunistic infections that may influence adherence to antiretroviral treatment?	B: 4-5, A8, D
	VI.	What are the levels of patient self-reported substance that may influence adherence to antiretroviral treatment?	D, F: 1-4
Treatment factors	VII.	What are patients' self-reported levels of knowledge about antiretroviral treatment?	B1:1, 3,5
	VIII.	What are patients' treatment regime which may influence adherence to antiretroviral treatment?	B1:1,2,4
Patient related	IX.	What are the levels of acceptance of diagnosis that may influence adherence to antiretroviral treatment?	C1: 1-5
	X.	What are patients' perceptions about ART treatment that may influence adherence to antiretroviral treatment?	C2:1-11

When the researcher was developing the instrument, content validity was established by specifying the content area covered by the phenomenon when developing the construct definition (Terre Blanche, Durrheim and Painter, 2006) as determined by the conceptual framework, and the objectives measured in the questionnaire (Table 10).

61

3.6 Data collection

Data collection was done over a period of two months from July 2009 to August 2009. Data collection presented a challenge as the clinic did not have space such as a spare consulting room to give to the researcher. The waiting period for the patients coming for reviews before they see the health care provider and going to the pharmacy to collect medication was long and the patients took more than an hour before coming to the researcher. In addition, the process of getting informed consent was long and complicated. The tool used was a questionnaire for quantitative information was collected through a structured questionnaire with closed questions, (See Appendix 1).

3.7 Statistical analyses

As the aim of this study is to investigate the factors that may influence adherence to antiretroviral treatment of HIV patients on ART in the Lukhanji Municipality Chris Hani District Queenstown. The study aims to address the questions "What are the factors that may affect adherence to ART among HIV-positive patients living in the Lukhanji Municipality Chris Hani District Queenstown of South Africa.

The analysis has three major sections: 1) describing the sample; 2) describing the five factors or dimensions of adherence; and 3) investigating possible associations between factors. Descriptive statistics were calculated for all variables. Relevant non-parametric tests were conducted to test for associations. In addition a regression analysis was conducted to determine which factors predicted acceptance of diagnosis.

Acceptance of diagnosis and long term treatment was calculated by recoding the item into acceptance and not ready. Acceptance was recorded and coded in option 1 as accepted and ready, where the respondent accepted and was ready for treatment.

Not ready was recorded and coded in options 4 and 5, where the respondent in option 4 knew he or she had to but was not ready and in option 5 the respondent did not accept and was not ready at all, the results were then tested against all the factors using non-parametric statistics.

3.8 Ethical considerations

For any research, the research process starting with identification of the study to publication of the findings should stick to ethical standards of research. This means that the rights of the research institution, respondents" rights and the rights of others in the setting are protected. This should include aspects such as informed consent, confidentiality, anonymity, respect and dignity. Research integrity was also maintained (Burns & Grove, 2011).

Permission to carry out the research study was obtained from the University of the Western Cape (UWC). The Department of Health (DoH) Research Committee from the Eastern Cape granted the permission to use the facilities in Queenstown for the research. Participation of the respondents in the study was voluntarily and written informed consent was given by the respondents, it was explained to the respondents that they have a right to withdraw anytime when they feel they no longer want to participate. Confidentiality, anonymity and privacy were fully guaranteed during data collection and data analysis. The anonymity of the respondents was ensured through a coding system known only to

the researcher. One respondent was allowed in the consulting room to participate in the interview. In this study, the following were done to ensure ethical standards of research: protection of the rights of the respondents and the institution; maintenance of scientific integrity of the research and dissemination of the research findings.

3.9 Summary

This chapter described and discussed the methodology and the research design used in this study, including population, sample and sample technique, validity and reliability. It explained quantitative research as a method used to collect and analyse data. It explained how the data was collected using an interviewer administered research. The ethical consideration process discussed above was taken into account for the purpose of the study. The results of the analysis are discussed in the next chapter.
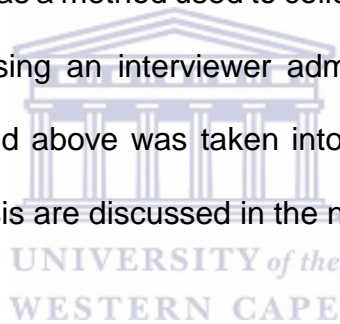
Chapter 4:   Results

4.1 Introduction

This chapter presents the findings on the factors influencing adherence to ART of the patient living with HIV. This chapter discusses the results in three major sections:

- Describing the respondents;

- Describing the profile of factors of the WHO-5 Adherence Model in this respondent group;

- Testing the hypothesis of possible associations between acceptance and perceptions.

4.2   Description of respondents

4.2.1 Sample realisation

A total of 97 respondents out of a total of 118 HIV patients completed the questionnaires, resulting in a response rate of 80.5%.

4.2.2 Demographic profile

Out of 97 respondents in the sample, n= 20 (21%) were males and n=77 (79%) were females. Nearly half of the respondents were between the ages of the 35-44, n=46 (47.4%) followed by n=35 (36.5%) respondents in the age range of 25-34, n=11 (11.3%) in the age range 45-54 years and n=4 (4.1%) 55-64 years and only one respondent aged between 65 and 74. There were no young people aged 15-24, only young adults (aged 25-34) (Table 11). In the sample, none of the respondents were widowed, n= 20 (21%) were married, n=76 (78%) were single and only one were divorced. There was high

65

proportion, n=76 (79%) of single people in the sample, followed by married patients n=20 (21%) (Table 11).

Table 11: Demographic profile of respondents (n=97)

Demographics	Number (%)
Gender	
Male	20 (20, 6 %)
Female	77 (79.4%)
Age	
25-34	35(36.1%)
35-44	46 (47.4%)
45-54	11 (11.3%)
55-64	4 (4.1%)
65-74	1 (1.0%)
Marital status	
Married	20 (20.6%)
Single/divorced	77 (79.4%)
Employment Status:	
Employed	8 (8.2%)
Unemployed	49 (50.5%)
Disability grant	40 (41.2%)

4.3 Factors which may influence adherence

Using the WHO-5 framework, the factors that may influence adherence are described below; namely social and economic factors, health service related factors, condition related factors, treatment factors and patient related factors.

4.3.1 Social and economic factors

To address objective 1 which is to describe the social and economic factors that may influence adherence to antiretroviral therapy, the factors were described under three broad areas, namely the socio-demographic factors (as described in sample description), economic factors and social and psychological support factors.

66

4.3.1.1 Economic factors

The respondents reported that they were not economically active with only n= 8 (8.2%) of the respondents being employed, n=49 (50.5%) reported that they were jobless and n=40 (41.2%) received disability grants (Table 11).

4.3.1.2 Social and psychological support

The social support profile in this sample was measured with questions on the types of support available to the respondents such as social support groups and support from treatment partners (Chronbach α=.71), and question on psychosocial support (Chronbach α=.70).

Social support

Only one (1) respondent reported that they belonged to a social support group. Though n=77 (79.4%) reported that they were on their own, most of the respondents n=89 (97.8%) reported that they had treatment partners and n=75 (82.4%) indicated that they were staying with their treatment partners. Of the treatment partners n=80 (87.9%) were family members such as a sibling or spouse. The treatment partners provided a range of support as most of the respondents reported seeing the treatment partners regularly, n=83 (91.2%). Support included reminding them to take medication n=89 (97.8%) and talking to them about their treatment problems n=89 (97.8%).

Psychological support

Psychosocial support (Chronbach α=.70) was measured through question on emotional support (Chronbach α=.69), friend support (Chronbach α=.89) and significant other

support (Chronbach α=.92) (Table 12).

High levels of emotional support were reported with more than three quarters of the respondents n=79 (81.4%) stating that they get the emotional help and support they need to adhere to ART therapy from their family. Similarly, n=76 (78.1%) stated that they talk to their family about stresses that can affect their adherence to ART therapy similarly, and n=77 (79.4%) that their family supported them with taking medication and clinic appointments (Table 12).

Friend support were higher with n= 78 (80.4%) of respondents reporting that they can count on friends' support about their health worries and concerns involving medication and can talk to friends about problems that may be barriers to adherence to ART therapy (Table 12). The highest psychosocial support was reported from significant others with n=84 (8.6%) of the respondents stated that there is special person who is around when they needed someone to motivate them regarding their ART therapy and n=85 (87.6%) respondents stated that there was a special person who was around when they needed someone to motivate them about being on life time treatment for HIV and AIDS (Table 12).

Table 12: Psychosocial support

Emotional Support	Agree n(%)	Support Score m[95% CI]
I get the emotional help and support I need to adhere to ART therapy from my family.	79(81.4%)	3.4[3.1-3.6]
I talk to my family about my stresses that can affect my adherence to ART therapy.	76(78.4%)	3.4[3.1-3.6]
My family supports me with taking medication and clinic appointments.	77(79.4%)	3.4[3.1-3.6]
Friends' Support		
I can count on my friends support about my health worries and concerns about my medication.	78(80.4%)	3.4[3.2-3.6]
I can talk to my friends about my problems that may be one of the barriers to adhere to ART therapy.	78(80.4%)	3.4[3.2-3.7]
Significant Others		
There is special person who is around when I am in need of someone to motivate me about my ART therapy.	84(86.6%)	3.4[3.3-3.7]
There is a special person in my life that cares about me being on treatment for HIV and AIDS for the rest of my life.	85(87.6%)	3.4[3.3-3.7]

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4.3.2 Health Service factors

To address objective 2 which was to describe the health service related factors that may influence adherence to antiretroviral therapy, barriers to care and prescription barriers were investigated.

4.3.2.1 Health service barriers

Health services barriers included access issues such as distance from clinic and means of transport to clinics and complying with their treatment if they live far from the clinics.

Table 13: Health Service and prescription barriers

Health Service barriers	Number (%)
Problems complying with treatment if they live far from the clinics	72(74.2%)
Owning a car	3 (3.1%)
Transport to clinic:	
Walking	45 (46.4%)
Public transport	39 (40.2%)
Public transport walking	13 (13.4%)
Prescription barriers	
Problems complying with treatment due to lack of money	79(81.4%)
Difficulty taking medications at work	81(83.5%)
Problems taking medication	
Swallowing	75 (77.3%)
No transport	22(22.7%)

To assess access to health services, the respondents were asked about the various modes of transport (Table 13). Only n=3 (3.1%) of the respondents had a car with n=94 (96.9%) indicated that they did not have a private vehicle or car. In describing their mode of transport to the clinic, n=45 (46.4%) of the respondents reported walking, n=39 (40.2%) used public transport and n=13 (13.4%) came for treatment by public transport and walking.

Respondents confirmed these problems with n=72 (74.2%) stating that it was difficult to comply with treatment if they lived far from the clinic, though only n=22 (22.7%) indicated that this has interfered with them taking medication (Table 13).

4.3.2.2 Prescription barriers

Prescription barriers were measured through problems complying with their treatment due to lack of money, difficulties taking medication at work and encountering problems taking prescribed medication.

Only five (5) respondents indicated that they currently had problems with taking medication, and all indicated that they would report these problems to the health staff. The most common reported problem was problems swallowing the tablets, with n=77 (77.3%) of the respondents reported that difficulties with swallowing is the most common reason for having difficulties with prescription medication (Table 13). Having to take medication at work could also be a barrier as n= 81 (83.5%) of the respondents stated that it would be difficult to take medication if at work.

4.3.3 Condition related factors

To address objective 3 which was to describe the condition (HIV) related factors that may influence adherence to antiretroviral therapy, common conditions such as opportunistic infections (OIs) and the impact of comorbidities of substance use were investigated.

4.3.3.1 Opportunistic Infections

Though only n=17 (17.5%) of the respondents reported that they suffered from OIs, nearly all reported some OIs in the last six months, with diarrhoea being most common n=93 (94.9%) (Table 14). Other OIs experienced were oral thrush, swollen glands, Tuberculosis (TB), Sexually Transmitted Diseases (STIs) and shingles n=91 (93.8%).

Table 14: Opportunistic infections

OI	Frequency (%)
Diarrhoea within last 6 months	93(94.9%)
Oral thrush within last 6 months	91(93.8%)
Swollen glands within last 6 months	91(93.8%)
TB in last 6 months	91(93.8%)
STIs in last 6 months	91(93.8%)
Shingles in last 6 months	91(93.8%)

71

4.3.3.2 Substance use

Substance abuse was not common for respondents with only, n=7 (7.2%) of the respondents reporting that they currently drink alcohol at an average of 1.43 bottles a week (sd 0.97).

4.3.4 Treatment related factors

To address objective 4 to describe the treatment related factors that may influence adherence to antiretroviral therapy, respondents self-reported knowledge about antiretroviral therapy and reported complications of the therapy were investigated.

4.3.4.1 Knowledge about antiretroviral treatment

To test the self-reported knowledge on their therapy, respondents were asked to identify which regimen they were on and if they were on treatment for OIs, they were asked to identify the OI regimen. The researcher then checked the regimen. In addition, the respondents were asked to indicate the time on antiretroviral therapy, the time on the current regimen.

There was an even spread of duration of antiretroviral therapy duration with only n=10 (10.3%) having been on antiretroviral therapy for more than 5 years (Table 5). However, most respondent reported being on their current regiment for less than 2 years with, n= 43 (44.3%) only being on it for less than a year.

Though only 17 respondents reported being on treatment for OIs, nearly half n=46, (47.4%) reported that their health care provider has prescribed medications for the treatment of OIs.

72

Table 15: Antiretroviral treatment and self-reported knowledge

Treatment regimen	Frequency (%)
Time on antiretroviral therapy	
< 1 year	27(27.8%)
1-2 years	28(28.9%)
>2-5 years	30(30.9%)
>5 years	10(10.3%)
Time on current regimen	
< 1 year	43(44.3%)
1-2 years	40(41.2%)
>2 years	10(10.3%
Prescribed medication for OIs	46(47.4%)
Knowledge of antiretroviral treatment	
Correct regimen identified	94(96.9%)
Do not know	3(3.1%)
Correct OI treatment identified (if any)	97(100%)

Most of the respondents correctly identified their treatment regimens, with n=94 (96.9%) respondents correct in identifying their current regiment and all (100%) of the OI treatments verified as correct.

4.3.5 Patient related factors

To address objective 5 which was to describe patient related factors that may influence adherence to antiretroviral therapy, the level of acceptance of an HIV diagnosis with an implication of long term treatment and the respondents' perceptions about ART were investigated.

4.3.5.1 Acceptance of HIV diagnosis and long term treatment

An important aspect in encouraging adherence is the psychological attitude towards their acceptance of long term treatment. Just under three quarters n=71 (73.2%) did not accept their diagnosis and was not ready at all for long term treatment, and n=21 (21.6%)

73

accepted it though n=8 (8.2%) needed more time to be ready (Table 16). Only n=13 (13.4%) stated that at the time they were diagnosed they accepted their diagnosis and were ready (Table 16).

Table 16: Acceptance of Diagnosis

	Frequency (%) n=95
Accepted & was ready	13 (13.4%)
I needed a little more time to be ready	8 (8.2%)
I did not know if I was ready or not ready	3 (3.1%)
Knew I had to, but I was not ready	2 (2.1%)
I did not accept and was not ready at all	71 (73.2%)

4.3.5.2 Individual perceptions of ART

Individual perceptions treatment were measured using respondents' agreement with a series of 11 statements on treatment using a Likert scale ranging from strongly disagree to strongly agree (Cronbach's α=.69). Once the negative phrased items were reversed, for analysis purposes statements were viewed as either negative or positive perceptions of treatment.

4.3.5.3 Overall perceptions of ART treatment

A total average score of adherence towards ART therapy was computed with a mean of 2.4 (sd 0.58) out of a possible 5. The mean values reflected less adherence towards treatment. Individual item ratings can be seen in Table 17.

Table 17. Treatment perception statements

Items	Agree n(%)
1. If HIV patients feel well, they would stop taking their medications.*	26(26.8%)
2.HIV patients will get sicker if they stop taking their medications	26(26.8%)
3.In HIV patients their medications will cause opportunistic Infections*	91(93.8%)
4.HIV is a virus that causes Opportunistic Infections	27(27.8%)
5.Medications for the treatment of HIV will prevent or delay Opportunistic Infections	22(22.7%)
6.For HIV patients, it is difficult to take their medications at work*	81(83.5%)
7.It is advisable that HIV patient's family facilitates their intake of medications*	88(90.7%)
8.HIV patients have problems complying with their treatment if they live far from the clinics*	72(74.2%)
9.HIV patients have problems complying with their treatment due to lack of money*	79(81.4%)
10.Physicians and HIV patients should agree with the ARV prescriptions	91(93.8%)
11. Do you agree with your ARV treatment regimen?	96(99%)

*Items reversed in mean score. SD: Strongly disagree; D: Disagree; N: Neither agree or not; A: Agree and S:

Strongly agree

Positive treatment perception statements

The following four (4) of the 11 statements reflected a positive treatment perception with

nearly all respondents agreeing with a positive statement on treatment (Table 17).

Nearly all of the respondents agreed with their ART treatment regimen, with n=91

(94.8%) strongly agreeing with the statement, that physicians and HIV patients should

agree on the ART prescriptions (Table 17). Most of the respondents n=88 (90.7%)

agreed with the statement, that HIV patient's family should facilitates their intake of

medication and only n= 26 (26.8%) of the respondents agreed with the negative

statement that if patients feel well, they would stop taking their treatment.

However, respondents had misconceptions about HIV causation and the effect of medication with only n=27 (27.8%) agreeing with the statement that HIV is a virus that causes OIs. Similarly, only n=26 (26.8%) agreed with the statement that patients will get sicker if they stopped their medication and that medication will delay or prevent OIs n=22 (22.7%).

The rest (3) of 11 statements reflected negative perceptions about factors influencing treatment (Table 17). Most the respondents n=81 (83.5%) agreed with the statement that for HIV patients it is difficult to take their medication at work. Similarly, the majority of the respondents n=72 (74.2%) agreed that HIV patients have problems complying with their treatment if they live far from the clinics and that HIV patients have problems complying with their treatment due to lack of money n=79 (81.4%).

4.4 Associations of acceptance of the need to take ART for life

The study also investigated the association (or relationships) between the dependent variable 'acceptance' and other variables including demographics, existence of OIs and perceptions of treatment.

4.4.1 Acceptance and demographics

Gender was a factor in the acceptance of treatment for the rest of a person's life with more males (8/20, 40%) compared to women 13/77 (16.8%) stating that they accepted their outcome (X^2=5, p=.035). No other demographics were associated with acceptance.

76

4.4.2 Acceptance and treatment and condition related factors

Reporting having OIs were associated with increased acceptance of having HIV and having to take medication for the rest of their lives, with 8/17 (47.1%) respondents with OIs stating that they accepted their outcome and having to take medication for the rest of their lives as compared to only 13/80 (16.3%) who are currently not having OIs accepting their outcomes (X^2=7.8, p=.009). When asked whether a doctor has prescribed medication for OIs, an opposite pattern was seen with 5/46 (10.8%) respondents on medication for OIs stating that they accepted their outcome as compared to 16/51 (31.4%) of respondents <u>not</u> on treatment for OIs accepting their outcomes (X^2=6, p=.014).

4.4.3 Acceptance and perceptions of treatment

There was also significant difference between respondents who accepted the need to take ART for the rest of their lives compared to those who did not with much higher agreement levels for the positive perception statements (Table 18).

Respondents who had accepted their diagnosis and the need to be on medication for the rest of their lives, had significantly higher levels of agreement on knowledge statements: *HIV patients will get sicker if they stop taking their medications* (p<.001), HIV *is a virus that causes Opportunistic Infections* (p<.001), and *Medications for the treatment of HIV will prevent or delay Opportunistic Infections* (p<.001) (Table 18).

There also appears to be higher levels of dependence by respondents who have <u>not</u> accepted their diagnosis and the need to be on medication for the rest of their lives with significantly higher levels of agreement for the following statements*: It is advisable that HIV patient's family facilitates their intake of medications* (p=.017), *Physicians and HIV*

77

patients should agree with the ARV prescriptions (p=.002) and *Do you agree with your*

ARV treatment regimen (p<.001).

Table 18: Treatment perception statements and acceptance

Perception statements	Accept	Not Accept	Test (U)	Pvalue
POS HIV patients will get sicker if they stop taking their medications	4,5[3,9-5]	1,6[1,3-1,9]	5,9	<.001
POS HIV is a virus that causes Opportunistic Infections	4[3,5-4,5]	1,5[1,3-1,8]	6,5	<.001
POS Medications for the treatment of HIV will prevent or delay Opportunistic Infections	4,2[3,7-4,6]	1,4[1,1-1,6]	7,6	<.001
POS It is advisable that HIV patient's family facilitates their intake of medications	4,2[3,7-4,7]	4,7[4,5-4,9]	2,3	.017
POS Physicians and HIV patients should agree with the ARV prescriptions	4,4[3,8-4,9]	4,8[4,7-5]	3,1	.002
POS Do you agree with your ARV treatment regimen?	4,8[4,5-5]	5[5-5]	4,5	<.001
NEG If HIV patients feel well, they would stop taking their medications.	4,8[4,5-5,1]	3,8[3,6-4]	5,7	<.001
NEG In HIV patients their medications will cause Opportunistic Infections	4,5[4,1-4,8]	4,8[4,6-4,9]	3,2	.002
NEG For HIV patients, it is difficult to take their medications at work	3,5[2,7-4,2]	3,9[3,8-4]	0,3	.756
NEG HIV patients have problems complying with their treatment if they live far from the clinics	3,8[3,1-4,4]	4,1[3,8-4,5]	1,9	.064
NEG HIV patients have problems complying with their treatment due to lack of money	2,8[1,9-3,7]	4,7[4,5-4,9]	6	<.001

POS = positive perception statement; NEG: negative perception statement.

Respondents who have accepted their accepted their diagnosis and the need to be on

medication for the rest of their lives also had significant lower levels on agreement on

money being a factor hindering their adherences in statements (p<.001) (Table 18),

though no significant differences were found for taking medication at work or living far

from the clinic.

4.5 Summary

This chapter discussed data analysis and its interpretation with the use of frequency

tables and descriptive statistics. The researcher has linked the results to various studies

78

that have been discussed in the previous chapter on HIV and AIDS adherence to antiretroviral therapy.

This chapter discussed results in three major sections:

i. Describing the respondents, ii. Describing five factors of the WHO-5 adherence model, III. Testing the hypothesis of possible associations between acceptance and perceptions.

It discussed the association between adherence to ART therapy and the factors which may influence adherence using WHO-5 framework. The factors that may influence adherence to ART therapy as in WHO-5 model are the following: social and economic factors, health service related factors, condition related factors, treatment related factors and patient related factors. Tables 11 to 18 displayed results as follows: table 11 displayed results of demographic profile of respondents, table 12 displayed results in psychological support, table 13 displayed results in health service and prescription barriers, table 14 displayed results in opportunistic infections, table 15 displayed results in antiretroviral treatment and self- reported knowledge, table 16 displayed acceptance of diagnosis, table 17 displayed results in treatment perception statements, and table 18 displayed results in treatment perception statement and acceptance.

The discussion for this study will be outlined in the next chapter.

Chapter 5: Discussion

5.1 Introduction

This chapter presents the discussion of the study results. The study sought to describe the factors that may influence adherence to ART of patients who are in the Lukhanji sub-district Chris Hani Municipality Queenstown, Eastern Cape. It was anticipated that the knowledge of these factors could assist health workers in ensuring that programmes for PLhiv include specific measures to improve adherence to ART.

5.2 Discussion and verification of research objectives

The aim of the study was to describe factors that may influence adherence to ART therapy in the Chris Hani District Municipality, Lukhanji Sub-District Queenstown Eastern Cape. Although there are many factors that may influence adherence to ART therapy, this study focused on the WHO-5 factors to determine a possible influence on adherence to ART. This framework includes sociodemographic and economic factors, health services related factors, treatment related factors, condition related factors and patient related factors. This discussion used this framework but also located the discussion into factors that could hinder or facilitate possible adherence. As adherence was not directly measured in this study, *acceptance of diagnosis and acceptance of the fact that they would have to take medication for the rest of their lives*, were used to test the level of influence of the WHO-5 factors on levels of acceptance.

5.2.1 Factors that may hinder adherence

The WHO-5 factors that may hinder adherence are the socio-demographic status of patients, health service factors, patient related factors, condition and treatment factors.

5.2.1.1 Socio-demographic factors which could hinder adherence:

Demographic factors such as gender, age, marital status and socio-economic factors such as employment status which may impact on travel and cost of medication have been identified as factors which may negatively influence adherence to ART therapy. In this study, the sample population was mainly young adults (<44 years of age), female (nearly 80%), economically very poor and most of them on disability grants. This was seen in the high level of respondents who stated that they were not employed with 50, 5% unemployed and of these 41.2% on disability grants. This finding was further compounded with 78% of the respondents stating that they were single.

Impact of demographic factors: Research in ART adherence as early as 2004 by Berg, Demas, Howard, Schoenbaum, Gourevitch, and Arnsten *(*2004*)* argued that literature reviews on the factors associated with ART adherence had not recognised a consistent relationship between gender and adherence. In this study, this was strongly confirmed that gender was a significant factor in the acceptance of treatment for the rest of a person's life, with poorer acceptance in women (40% males compared to 16, 8% of the women stating that they accepted their outcome). A study by Bonolo et al. (2012) on non-adherence among Brazilian patients also supported the idea that men adhere to ART better than women with women being 1.5 times more non-adherent compared to men. The study also showed that women living with HIV experience barriers which differ from

81

those their male counterpart's experience, including depression, stress, stigmatisation and specific social roles related to gender (Bonolo et al. 2012). Berg et al. (2004) also indicated that gender-stratified analysis demonstrated that different social and behavioural factors are associated with adherence to treatment in men and women (Berg et al. 2004).

The second factor which has been identified by some literature as having a possible effect on adherence is age. However, a lot of studies did not find a relationship between age and adherence and this was confirmed in this study, with this study also did not find an association between acceptance of diagnosis and lifelong treatment and age group. As early as the 1970's it was reported that no association of age and adherence were found, though as patients grow older, adherence were reported to have become poorer over time, and the reduction was more prominent with patients that have had no schooling (William & Friedland, 1997). In opposition to this, Barclays et al. (2007) & Godin et al. (2005), reported that older people are more committed to treatment and tend to be more health-conscious than the younger group. The age median in this study was 37 years, which indicated that most of respondents were sexually active and that poor adherence to ART might expose the partners to new infections of HIV (William & Friedland, 1997). Mathes et al. (2014) study cited that higher age and middle has a positive effect on adherence, patients aged between 35 -56 displayed higher adherence (Mathes et al. 2015).

Impact of Low Resources*:* Peltzer & Pengpid (2013) mentioned that income is an indicator of socioeconomic position (SEP) that most directly measures the material

resources component. Poverty contributes to poor adherence. Indirect and direct costs are a burden on PLhiv, forcing them to discontinue treatment. Costs include those associated with transportation to service points, laboratory diagnosis, and drugs for opportunistic infections (Mekonnen et al. 2010).

In this study, the high level of unemployment raised concern in that socioeconomic position most directly measures the material resources capacity of patients (Barclays et al. 2007 & Gordillo et al.1999). At the time of the study high unemployment rate of over 50% of the respondents were not employed and 41.2% of the were on disability grants, indicating that the majority of the respondents were not receiving any form of income and that limits their affordability of HIV medication. This was confirmed in this study showed that nearly 80% of the respondents agreed that HIV patients may have problems complying with their treatment due to lack of money. This predicament may result in PLhiv not being able to afford to get required resources for their health condition and that includes travelling to the clinic for their reviews, collection of medication, having better living conditions and providing food as these competing priorities may hinder adherence to ART. PLhiv may end up using the little income on competing priorities and things that will benefit the whole family instead of using it for their treatment.

However, investigating socioeconomic factors and the impact they may have on acceptance of diagnosis and the need for lifelong ART among patients in low-and middle-income countries. The results of this study show that there is no significant association between the employment status and acceptance of treatment and that requires further research to be done to investigate the association between employment status and treatment adherence. However, the study found that respondents who have accepted

their diagnosis and the need to be on medication for the rest of their lives did not feel that money were a factor hindering their adherences (p<.001). The results are consistent with most of the studies that have investigated the effect of sociodemographic factors of respondents on treatment for HIV and adherence to ART.

5.2.2.2. Health service factors which could hinder adherence

Health service can also be a barrier to adherence as health services include access issues such as distance from the clinic and means of transport to clinics and the resultant compliance with their treatment if they leave far from the clinics.

Transport issues: Lack of resources thus also influence transport options to clinics with nearly three quarters indicating that distance to the clinic can hinder adherence to medication. This was compounded by only three of the respondents having their own transport and 46.4% of the respondents reported walking and 40.2% using public transport to the clinic. This was further supported in this study with 74.2% stating that it was difficult to comply with treatment if they leaved far from the clinic, though only 22.7 % indicated that this did affect their adherence to medication. A study by (Kagee, 2008) did not find a relationship between transport and adherence and this study also did not find an association between transport and acceptance of diagnosis although 22.7% reported to be affected by transport issues.

Access via primary health care clinics: Accessibility of the clinic is important for the respondents to honour their appointments. It is reported that ART is now accessible and international organisations are assisting many low-resourced countries to ensure that ART is affordable and accessible through the primary health care networks (Comell,

Grimsrud, Fairall, Fox, Van Cutsem, Giddy, Wood, Prozesky, Mohapi, Graber, Egger, Boulle, & Myer, 2007). In one of the research studies on adherence a dramatic reduction in HIV-related morbidity and mortality has been recognised in developed and developing countries where ART has been made widely available through accessible clinics (Achappa et al. 2013).

5.2.2.3 Condition related factors which can hinder adherence

It is commonly hypothesized that condition related factors, specifically factors related to having HIV, may influence adherence to ART therapy. These include opportunistic factors and common comorbidities such as substance use.

Opportunistic infections (OIs): In PLhiv the immune system is weakened as the CD4 count continue to drop. AIDSinfo (2013) stated that the risk of opportunistic infections (OIs) is common in HIV patients due to low CD4 count and that a poor adherence to ART regimen has serious consequences for HIV-infected patients that includes failure to stop viral duplication and of developing viral resistance. Opportunistic infections (OIs) usually develop to PLhiv when the CD4 count is below < 200 cells/mm3 as their immune system is delicate at that time. The CD4 count is the most significant laboratory indicator of immune function in patients living with HIV (AIDSinfo, 2013). The screening of patients for OIs on every visit is necessary to identify OIs while in early stages as they will have negative impact on the patient's condition. Additionally, Rabkin et al. *(*2005) stated that an OI like tuberculosis is the primary reason of increased morbidity and mortality rate among HIV-infected patients (Rabkin et al.2005).

85

Though 17.5% of the respondents stated that they suffered from OIs, nearly all reported some OIs in the last six months, with diarrhoea being the most common being mentioned by 94% of the respondents. In addition, nearly half (47.4%) reported that their health care provider has prescribed medications for the treatment of OIs. Contrasting to expectations, reporting having OIs were significantly associated with increased acceptance of having HIV and having to take medication for the rest of their lives, with 47.1% of the respondents with OIs stating that they accepted their outcome and having to take medication for the rest of their lives as compared to only 16.3% who are currently not having OIs.

Substance use: In any human being substance abuse can leads to poor concentration and forgetfulness of important matters in life resulting taking wrong decisions and in PLhiv, this is often associated with poor adherence. Kagee (2008) stated that ART adherence requires a high level of cognitive performance, impairments in this domain is likely to impact treatment outcomes seriously as a substance abuse affects attentiveness, memory, and motivation, leading to negative attitudes to treatment and poor adherence (Kagee, 2008).

In a study by Do et al. (2010) on psychosocial factors affecting treatment adherence among HIV-1 infected adults receiving combination antiretroviral therapy in Botswana, the researchers found that alcohol use, depression and non-disclosure of status to partner were associated with negative adherence to treatment leading to poor compliance to ART (Do et al. 2010). Similarly, a study done by Berg et al. (2004) suggested that alcohol use may have an extremely high impact on antiretroviral adherence in women. Thus a side-effect of substance abuse is the comorbidity of depression. Nunes, Levin, Mariani, Brooks, Pavlicova, & Cheng (2004) describe that substance abuse may lead to

86

depressive symptoms, which can result from intoxication, withdrawal, or chronic use. Minggu (2013) argued that HIV drugs will work only if a patient keep a stable minimum level of each drug in their body and that if any drug drops beneath this level, then the virus can build up resistance to the drugs, and the drugs will stop working. Furthermore, the SA HIV Clinicians' Society (2012) stated that side effects of the antidepressants often impacted on attitudes to comply with medication and thereby change prognosis of both HIV and depression.

Wright et al. (2000) also argued that depressed patients may fail to involve themselves actively in care and adherence to treatment; they may act negatively and may reflect the terrible experience that they might have had with a friend or relative.

In this study, substance abuse was low with only 7 respondents reported to be taking alcohol at an average of 1.4 bottles a week. However, depression was not measured and more research is required to study the association between the depression and treatment adherence.

5.2.2.4 Treatment related factors which may hinder adherence

Adherence to HIV treatment is the key, however the treatment itself can hinder adherence through treatment factors like knowledge of treatment, prescription problems and side-effects (Kagee, 2008). In this study, there was an even spread of duration of ART therapy, duration with only 10.3% having been on ART therapy for more than 5 years and with most of the respondents reported being on their current regimen for less than 2 years and 44.3 % only being on ART for less than a year.

87

However, challenges may be experience with treatment. In this study, respondents described that over three quarters of them had problems swallowing tablets. This was supported in other studies which confirmed the shape and size of ART being a hindrance (WHO, 2003b).

HIV attacks the immune system and the virus multiplies fast hence adherence to ART therapy is crucial and complicated, therefore Minggu (2013) explained more about adherence discussing that HIV drugs will work only if a patient keep a stable minimum level of each drug in their body at all times (Minggu, 2013). If any drug drops beneath this level, then the virus can build up resistance to the drugs, and the drugs will stop working (Minggu, 2013). Thus it may be important to take medication on a routine schedule resulting in a second problem, namely the challenges of where to take medication. Having to take medication at work is a barrier with 83.5% of the respondents, stating that it would be a problem to take medication at work.
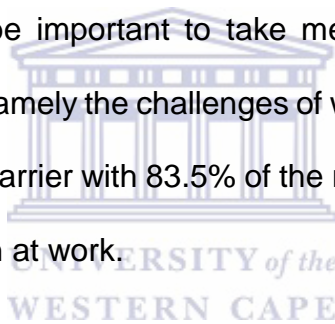
5.2.3 Patient related factors that may influence adherence

Factors that may influence positive adherence include patient's related factors of acceptance of HIV diagnosis and positive perceptions of the condition and knowledge of condition.

5.2.3.1 Acceptance of Diagnosis and the need for long term treatment.

Moitra, Herbert, & Forman (2011) argued that acceptance is related to behaviour, the way you react to the new diagnosis of HIV and your thoughts and feelings of the current diagnosis without running away from the reality that, HIV is there for life with lifelong

treatment (Moitra et al.2011). Nam, Fielding, Avalos, Dickinson, Gaolathe and Geissler (2008) who found that acceptance of HIV-status, the ability to avoid internalising stigmatising attitudes and identification of an encouraging confidante were key factors related to good adherence (Nam et al.2008).

In this study nearly three quarters of the respondents did NOT accept their diagnosis and was not ready at all for long term treatment. Gender (being male) and having previously had OI were strongly associated with acceptance of their diagnosis and the need for long term treatment. Murray et al. (2009) cited that acceptance of HIV condition and life time treatment by people living with HIV is difficult for women, especially for married women as they are often scared that their husbands will leave them when they disclose. Similarly, others were embarrassed thinking that people will judge them and label them. PLhiv found it difficult to hide treatment and that led to poor acceptance of treatment (Murray et al. 2009).
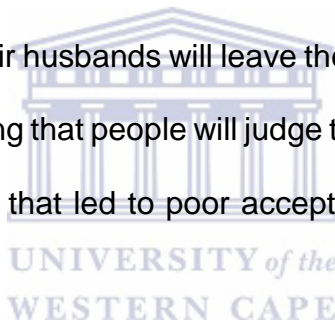
The factors that played a big role in PLhiv not to accept HIV and treatment and also contribute to hindering adherence to ART therapy according to Murray et al. (2009) were stigma, church rules, depression, hopelessness, side effects, hunger, culture, interpersonal relationships especially to husbands and wives. In addition Moitra et al. (2011) stated that for adherence to be successful it should be linked to acceptance of stresses related to HIV and lifelong treatment and acceptance of stigma associated with HIV. Therefore there is a need for direct intervention to improve acceptance of diagnosis and PLhiv need to learn to accept that their HIV status is not going to change so they need to be committed to lifelong treatment (Moitra et al. 2011).

89

5.2.3.2 Knowledge of treatment regimen

ART therapy is one of the most distinguished treatments that need optimum adherence as the HIV virus multiplies fast as compared to other chronic diseases (WHO, 2003b). It is imperative that patients understand their treatment and agree with the Doctor on their prescriptions and the more patients know their treatment and its relationship with the viral load the better as that will improve adherence (WHO, 2003b). Clinic staff need to be open to the patients and dedicate enough time for education about HIV and lifelong treatment and counselling to promote acceptance (WHO, 2003b).

Knowledge of treatment is important as Thandar et al. (2016) recommended that to get optimum adherence patients should recognise their medication on their own way, on how to take it and show acceptance of the lifelong treatment. To ensure good adherence it is important to offer information about the prescription (Thandar et al.2016).

Oral or written instructions assist the patient to understand the medication and their dosages, the number of pills to be taken, dosages, frequency of administration, dietary restrictions, possible adverse effects, tips for managing adverse effects, and period of therapy (Thandar et al. 2016).

When the patient understands how optimum adherence of >95% to ART treatment relates to viral load taking of treatment as prescribed will improve (Thandar et al. 2016).

In this study, the respondents from the selected clinics in Queenstown Chris Hani District correctly identified their treatment regimen. As this study indicated nearly 100% of the respondents have correct knowledge of their treatment regimen and prescriptions for OIs.

It was also found that respondents who had accepted their diagnosis and the need to be on medication for the rest of their lives, had significantly higher levels of agreement on knowledge statements relating to HIV patients getting sicker if they stop taking their medications, HIV being a virus that causes OIs, and that medications for the treatment of HIV will prevent or delay OIs. This was further supported by almost all the respondents (93.8%) agreed with their ARV treatment regimen and that physicians and HIV patients should agree on the ARV prescriptions, though this was higher in respondents who have not accepted their diagnosis and the need to be on medication for the rest of their lives.

The results were consistent with what was found in the literature review by Weiser et al. (2003) in Botswana, Aspeling & Van Wyk (2008) in South Africa explaining that informed patients tolerate side effects and develop good adherence to ART therapy better than those who are not informed. The study by Minggu (2013) agreed with the fact that adherence to ART treatment is important hence the patient must have clear knowledge about treatment. They need to develop a schedule for taking medication, even if they take only one pill twice a day. It is important to take medication precisely on time (Minggu (2013).

According to USAID (2010) PLhiv who lack knowledge about HIV and have common theories about the cause and treatment of HIV they develop negative perception and become less interested in treatment and for example in Ethiopia, religious PLhiv drink holy water as treatment instead of taking ART therapy. (USAID, 2010). It was however of concern that this study did find that 27.8% of respondents had misunderstandings about HIV causation while 26.8% of the respondents did not have sufficient knowledge about the effect of medication. It must be however declared that limitation in data

collection does not allow the researcher to identify whether this was a true finding or whether this finding was related to a measurement error on the data collection tool rating scale (positive and negative statements) as this finding is inconsistent with other data on knowledge.

5.2.3.3 Positive perceptions of treatment

In this study, there was significant difference between respondents who accepted the need to take ART therapy for the rest of their lives compared to those who did not with much higher agreement levels for the positive perceptions about ART treatment statements.

Dimateo, Lepper and Croghan (2000) explained that among general medical patients, depressed patients were three times less likely than non-depressed patients to have positive attitudes to ART and comply with medical treatment as most important factors that may influence attitude to ART are patient related and under the patient's control, so attention to them is a necessary and important step in improving treatment attitude.

Chesney et al. (2000) argued that openness and good communication between the patient and the healthcare provider improves the attitude of the patient and motivates the patient. Communication is vital in every patient-practitioner relationship (Chesney et al. 2000). Therefore, improved provider-client communication will develop positive perceptions to ARV treatment, patient education and improved health care provider communication skills will contribute to positive attitude to ARV treatment (Chesney et al.

92

2000). In this study, all the respondents indicated that they would communicate with the health workers if they were to have problems taking their treatment.

How a person perceives and accepts HIV condition and lifelong treatment is likely to affect how they perceive themselves both individually and when with others and that is bound to affect their adherence to ART therapy. Hence Wright et al. (2000) stated that a depressed patient, whose perceptions may be affected, does not feel enthusiasm or a desire to be treated. Often when a physician experiences that his patient is not motivated to take care of herself or to adhere to treatment generally, depression is the common source of the problem. Depression may be caused by external factors but it may also be an intrinsic aspect of the patient's individual personality (Wright et al. 2000).

Positive perception about antiretroviral therapy (ART) are crucial to ART adherence, yet many people living with HIV do not attain the level of perception that is required.

The study by Wright, Frey, Templin, Naar-King, Jeffrey, Parsons, and Phebe (2000), Brew, Nurrie & McArthur (1997) stated that Motivational interview (MI) counselling was discovered to be successful in changing many health behaviours towards positive attitude to medication and adherence. Motivation acts on the verge limit of psychological disturbance.

5.2.3.4 Social and psychosocial support

Psychosocial support contributes to good adherence and identifying support factors like psychosocial support, treatment partner support, emotional support, friends support and

93

significant others associated with family support may positively influence adherence to ART therapy. It is believed that having support for the lifelong treatment may have positive influence on the HIV and treatment perception and acceptance.

Social support: In terms of social support, it is of concern that only ONE respondent reported belonging to a social support group. The study by Williams & Friedland (1997) agreed with the importance of support on improving adherence. However though nearly all did not belong to social support groups and nearly 80% stated that they were on their own, nearly all of the respondents (97 %) reported that they had treatment partners and 82.4% indicated that they were staying with their partners which provided them with emotional support. Prominent levels of emotional support were reported with more than three quarters of the respondents (81, 4%) stating that they get the emotional help and support they need to adhere to ART therapy.

Emotional and social support can be offered to clients by their spouses, friends, treatment partners and others. Therefore Mostashari, Altice, and Friedland (1998) argued that patients with extensive social support have good adherence to treatment. While the study by Williams & Friedland (1997) on the association of support and treatment adherence revealed that patients living with partners adhere better than those who live with no partner. They associated lack of support with reduced negative adherence to treatment. In addition, social support appeared as a great motivator of positive adherence behaviour. The social and emotional support received from close family, friends, and colleagues positively influenced adherence behaviour. Respondents have confirmed this: "You need a support system…you can't be on your own…you need people"; "My family, my kids make me take my meds, they help me" (Williams & Friedland, 1997). The study by Cook

94

et al. (2017) revealed that emotional support is required by the respondents following an HIV diagnosis to promote linkage and engagement in care. In addition it is stated that emotional support ensures ongoing reassurance and comfort. However emotional support also ensures the acceptance HIV diagnosis and ART therapy (Cook et al. 2017).

Treatment partner support: In this study, most support was received from treatment partners, namely; significant others followed by friends and families. Significant others can also help to reduce threats and barriers to action by improving communication with the patients and supporting positive actions (Kozier et al. 2008). These results were consistent with what had been predicted in the study by Do et al. (2010) in Botswana on psychosocial factors affecting treatment attitudes among HIV-1 infected adults receiving combination antiretroviral therapy. The study by Do et al. (2010) also revealed that non-disclosure of status to partner were associated with poor adherence rates. In this study on significant others, most of the respondents reported having special person who is around when in need of someone to motivate them about treatment. In this study respondents also agreed that there is a special person in life that cares about them being on ART therapy for life and that statement agrees with Do et al. (2010) on the value of support to improve adherence.

Family support: Kagee (2008) stated that social support for compliance to treatment is defined as encouragement from family and friends for the patient to co-operate with prescribed treatment. Kagee (2008) stated that the support from others to engage in health promoting behaviours, including medication adherence, may combine with social desirability needs on the part of the patient to yield higher rates of medical co-operation.

There is strong evidence that positive social support, including being married, is associated with positive adherence to ART (Kagee, 2008).

In this study, most of the respondents (90.7%) agreed with the statement, that HIV patient's family should facilitates their intake of medication and this was significantly higher in respondents who have not accepted their diagnosis and the need to be on medication for the rest of their lives. This was supported by a Tanzanian study which found that a perceived lack of family support led some PLhiv to drop out of treatment, despite evidence of improved health and an important level of personal motivation (Roura et al. 2009). In some cases, the influence of family members was so significant that relatives such as parents or husbands made treatment decisions, including the decision to interrupt ART (Roura et al. 2009). In this study patients reported that they get all the support they need from their families, partners and friends.
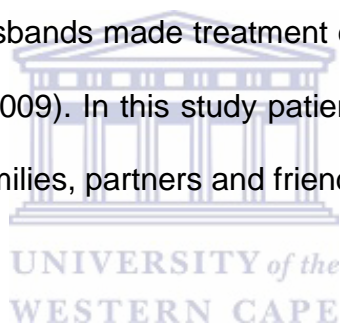
5.3 Summary

The study sort to answer the question what are the factors that may influence adherence to ART therapy. Adherence is complicated in HIV treatment therefore for PLhiv to achieve optimum adherence and a suppressed viral load factors such as patient related factors, treatment related factors, condition related factors, health system related factors and socioeconomic related factors need to be addressed.

The discussion on this chapter and previous studies revealed that optimum adherence is important for the PLhiv. Therefore adherence strategies need to be strengthened by health care providers and patients need to be involved when planning their regimen to

promote acceptance of the HIV and lifelong treatment. This study identified and discussed the contribution of gender, emotional and psychosocial support, knowledge and transport towards adherence. In this study respondents had high knowledge of their treatment, this could be explained by the fact that 96.9% had correct knowledge of their treatment. The WHO-5 frame work used for this study can be used as a foundation to predict factors that may influence to adherence to ART therapy.

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97

Chapter 6

Recommendations, Conclusion and Limitations

6.1 Introduction

The study intention was to describe and discuss factors that may influence adherence to antiretroviral therapy in the Chris Hani District Municipality Lukhanji Sub-District Queenstown Eastern Cape South Africa.

The objectives of the study were:

- To describe the social and economic factors that may influence adherence to antiretroviral treatment

- To describe health service related factors that may influence adherence to antiretroviral treatment

- To describe condition (HIV) related factors that may influence adherence to antiretroviral treatment

- To describe treatment related factors that may influence adherence to antiretroviral treatment

- To describe patients' related factors that may influence adherence to antiretroviral treatment

This chapters sets out to summarize the context that is the importance of adherence to ART and the factors that may influence adherence, the key findings of the study, limitations of the study, key recommendations and a concluding statement.

6.2 Key findings on the factors that may influence ART adherence

According to WHO, (2003b) adherence has been described as how the patient takes the prescribed medication on following the instructions given and how is the behaviour of the patient related as to treatment. Adherence is taken as the most important part of managing HIV and AIDS effectively. Therefore, it is important to describe the factors in specific context that may influence adherence

In this study the population of this study was all HIV patients on ART therapy aged 25 years old and above in two clinics in the Chris Hani District Municipality Lukhanji Sub-District Queenstown Eastern Cape South Africa at the time of the study.

The theoretical framework used as a foundation for this study was the WHO-5 Dimensions of Adherence (WHO, 2003b). This framework includes five interrelating dimensions that may influence adherence, briefly summarised below with highlights of the key findings in each of these domains.

6.2.1 Social and economic related factors:

Demographic factors such as gender, age and socio-economic status can affect adherence. Unemployment limits affordability and that makes it difficult to access treatment as it involves travelling to the facilities (WHO, 2003b). This also has an impact on living conditions, and diet as they will be affected negatively by unemployment therefore that will affect adherence negatively (WHO, 2003b).

Key findings:

- Gender was a significant factor in adherence with women having lower levels of acceptance of their diagnosis and the need for long term medication.

- Poor socio-economic status or unemployment was high (only 8% employed) with the concomitant effects on cost of treatment, access to health services, competing needs all having potential impact on adherence.

These risks for adherence were contrasted through social support. Studies have shown that social support may be effective to other psychosocial problems and that patients with support from family and friends adhere to treatment better that those without support (WHO, 2003b).

Key findings:

- Low use of social support groups with only one respondent belonged to a social support group.

- Though nearly 80% of respondents were on their own, nearly all of the respondents confirmed to have treatment partners with most of them regularly.

- Most common treatment partners were family members like siblings and spouses who offered support on how to take their medication and also were willing to listen to their treatment challenges.

- The results on emotional support revealed that more than 79 (81.4%) stated that they get emotional assistance and support they need from their families to adhere to their treatment.

100

6.2.2 Health system related factors:

WHO, (2003b) explains that health system factors include accessibility of the facilities and stock outs of medication have a negative influence on adherence; and clinician-patient relationship and monitoring of adherence (WHO, 2003b). If the factors that strengthen communication relations between patients and clinic staff are poor, patient education on the importance of adherence will be affected, that will leave the patient frustrated and confused with complex treatment, and that also will lead to decreased adherence. If there are no systems in place for the clinical staff to monitor adherence and consider new diagnoses adding to the existing HIV condition will decrease adherence (WHO, 2003b).

Key findings:

- One of the factors discussed that may influence adherence was on health service barriers focusing on transport where the study revealed that nearly half of the respondents had to walk to the clinic and a further 40% use public transport.
- Respondents all reported that they would communicate with the health workers about their condition and side effects. Further positive relationships with health workers were reported in the positive statements about the agreement about treatment regimens.

101

6.2.3 Treatment factors:

Medication is complicated as it is linked to the life style of the patient with pill burden contributing to difficulty in taking medication as prescribed especially if the patient is also taking medication for OIs like TB, where the treatment is taken for a long time (WHO, 2003b). The number of pills for ART therapy and the number of pills for OIs contribute negatively to adherence. Treatment side effects may also have negative influence on adherence (WHO, 2003b).

Key findings:

- Swallowing pills were reported by respondents as a key challenge.
- OIs were common and nearly all had an OI at some stage of their diagnosis. However, having an OI was strongly associated with acceptance of diagnosis and the need for long term treatment.
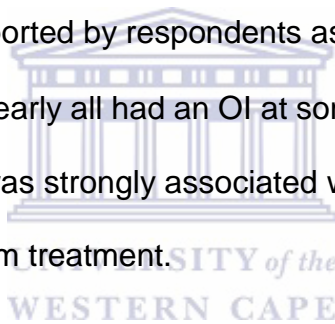
6.2.4 Condition related factors:

Development of OIs, makes the patient to take more than one regimen hence it is important to screen OIs at every visit as they will affect adherence negatively if not treated (WHO, 2003b). A second factor related to the condition was mental illness, such as depression and substance are one of the conditions contributing to poor adherence (WHO, 2003b).

102

Key findings:

- Substance abuse report did not suggest any form barrier to adherence, as only 7 respondents disclosed taking alcohol.

6.2.5 Patient factors:

Patient's behaviour is very important in addressing good adherence to ART therapy, other contributing elements that need to be addressed include hectic life and hectic work schedule that may lead to decreased adherence as the patient will have missed doses (WHO, 2003b & Azia et al. 2016). Patient factors includes knowledge, perceptions on treatment and acceptance of the condition. A patient may experience depression due to negative perception and acceptance of the lifelong treatment and that may decrease adherence to ART therapy (WHO, 2003b & Azia et al. 2016).

Poor adherence in a complicated condition like HIV leads to resistance to medication, hence the patient needs to accept the condition and treatment or the treatment should be delayed until the patient is ready (WHO, 2003b & Azia et al. 2016). Assessing the patient's willingness to adhere to lifelong treatment and the willingness to overcome adherence barriers will have positive results on adherence (WHO, 2003b & Azia et al. 2016).

Key findings:

- This study found that over three quarters of the respondents were not willing to accept their diagnosis, (HIV condition) and were not ready for the lifelong treatment. However, males were more likely to accept their diagnosis than women,

showing that gender is a factor in the acceptance of treatment for the rest of a person's life with more men accepted their outcome as compared to women.

- The study found good levels of knowledge and mostly positive perceptions on treatment.

6.3 Recommendations

Recommendations are discussed in terms of the following: Recommendations for Practice, Recommendations for Education and Recommendations for further research.

6.3.1 Recommendations for Practice

In winding up, given the complex collection of factors linked to poor adherence to ART therapy no single approach is likely to be successful for every respondent.

- It is suggested that patients be targeted with individualised involvement employing a behavioural education approach to advance capability to fit therapy to own lifestyles, based on the individual factors that may improve adherence.

- It is important to recognise that PLhiv with poor socio-economic status may need to be identified for additional support to improve adherence.

- These results suggest that it is important to assess patient's acceptance of their diagnosis and willingness to start treatment as this may have an impact on their adherence.

- PLhiv should be monitored for side-effects of the condition and the effects of treatment to improve their adherence by preventing negative impact on adherence.

104

- Other factors that will promote good adherence is the regular availability of stock for ART therapy especially the new Fixed Dose combination Pill (FDC) as it easy to take it because you take one pill once a day

- It is essential to identify each individual's level of social support, not only whether they are in a relationship or not. Identifying support groups, treatment partners and family can significantly improve adherence.

6.3.2 Recommendations for Education

- It is recommended that the use of a theoretical structured model to assess the factors that influence adherence may be beneficial to be included in nursing education programmes

6.3.3 Recommendations for Research

- Additional research is required on the prevalence of depression in this population group.

- Research linking actual adherence to each of these factors in this population will enhance the value of this framework.

- Moreover, research is recommended to explain factors that may influence adherence to ART therapy among patients receiving ART therapy from the clinics in rural areas.

6.4 Limitations

The limitations of the study related to the descriptive nature of the study and the need to conduct analytical research linking these factors to actual adherence.

Further limitations are linked to measurement bias. This included possible errors in questionnaire in the use of both positive and negative perception statements which might have led to incorrect completion of the perceptions. In addition, the space at the clinic for conducting the interviews and the availability of clients to participate in the study due to long waiting periods before they can be attended to by the health care professional may have impacted on the study.

A further limitation may be the profile of the clients at the clinics used for the study who were patients who are generally adhering to ART therapy as indicated by the clinic staff.

6.5 Summary

This study was an effort to investigate and describe the factors that may influence adherence to antiretroviral therapy in the Lukhanji sub-district Chris Hani Municipality Queenstown area. There is a scarcity of studies on the factors that may influence adherence to ART in resource-poor settings. There is, therefore, a need for multidisciplinary research on this topic to identify the ways of involving the community in the approach to improve adherence not only the factors that may influence adherence to ART but to treatment of all other chronic diseases.

106

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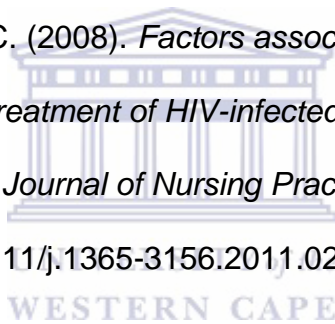
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107

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110

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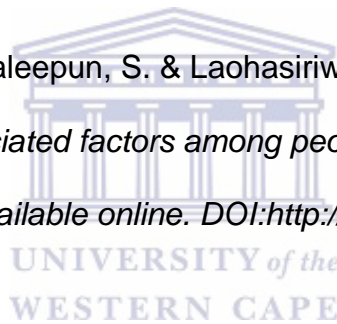
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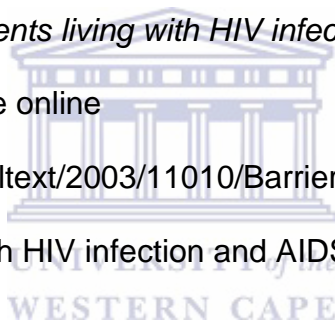
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Appendices

Appendix 1: Questionnaire

NOTE: This questionnaire has been amended following the pilot.

Questionnaire

Igama lam ndingu Nobuhle Magadla; ndenza imfundo enoMsila kwezokonga kwi Dyunivesithi yase Ntshona Koloni. Enye yemfuno zale mfundo inomsila (Masters) kukwenza uphando ngokubhala lo mqulwana. Ndikhethe ukuphanda nzulu ngokutya amachiza entsholongwane kagawulayo kwii kliniki ezi kwisithili saku Komani e Mpuma Koloni. Ndingathanda ukucela ixesha lakho siphendule lemibuzo ilandelayo. Zonke inkcukacha ezithatyathiweyo ziyakuba yimfihlo zisetyenziswe ngokufanelekileyo negama lakho alisokuze lisetyenziswe. Ndingathanda ukuba siqalise ukubuzana imibuzo.

Questionnaire

The focus of this questionnaire is to describe the *factors that may influence adherence to* Anti-Retroviral treatment and in addition, to measure the individual perceptions of susceptibility.

The questionnaire is divided into five sections noted as Section A, B, C, D, E and F.

Section A: Demographics: Section A with the following order the following variables: age, sex, marital status and level of education and socioeconomic status of the respondents (occupation, transport and availability) (see Section. A Q1 - 8).

Section B: Medical Prescription Knowledge and Treatment Perception: Section B contained two sections: 1) treatment knowledge; and 2) prescription problems.

Section C: Perception and acceptance of treatment: In section C of the questionnaire eleven questions are asked in order to establish the extent to which a respondent agrees or disagrees with the situation

Section D: Opportunistic infections: The respondents are asked to indicate the last time they suffered from opportunistic infections.

122

Section E: Social support: Question E to asses if the respondents are getting any kind of support.

Section F: Substance for recreation and Treatment perception: The purpose is to assess any element contributing towards missing tablets.

Section A: Personal Information

NOTES: This section is seeks to collect information on the demographics of the respondent

INSTRUCTIONS (*Questions 1 – 8): Tick where appropriate*

1. Gender

Male	Female

2. How old are you?

3. Marital Status.

Single	Married	Divorced	Widowed	Other

4. What is your home language?

(1) Xhosa	(2) English	(3) Other

5. Are you working?

(1) Yes	(2) No	(3) Disability grant

6. Do you have a car?

Yes	No

7. (If no to no.6) how do you come to the clinic?

(1) Public transport	(2) Walking	(3) Hired car

8. Have you suffered from any Opportunistic Infections?

Yes	No

Section B: Medical Prescription Knowledge and Perception

NOTES: A patient is classified as having strong Knowledge of Medical Prescriptions if all his answers to Questions 3 and 5 match the Physicians prescription. When at least one of the answers does not match with the Physicians prescription, the patient is classified as having weak knowledge about the Medical Prescription.

Section B1: Knowledge and Treatment Perception
INSTRUCTIONS *(Questions 1 –5):* *You tick under the correct answer; like number of the years on treatment.*
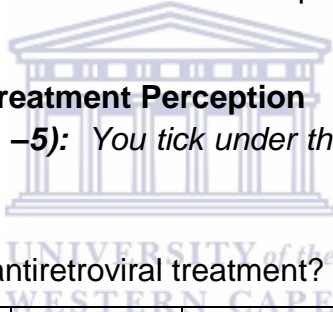
1. How long have you been on antiretroviral treatment?

0- less than 1year	1-<2 years	2- 5 years	More than 5 years

2. How long have you been on the regimen that you are using now? (To check if the regimen was changed and reasons for changing).

(0- less than 1year	1-<2 years	2- 5 years	More than 5 years

3. Which Regimen are you on? (Interviewer to check prescription)

(1) Correct answer	(2) Incorrect answer	(3) Do not know

124

4. Has your healthcare provider prescribed medications for treatment of opportunistic infections? [*For respondents who answered "yes" on Question 8 Section A only*]

(1) Yes	(2) No	(3) N/A

5. What is (was) your Prescription for the Opportunistic Infection(s) that you have (had)?
  (Check with the Prescription)

(1) Correct answer	(2) Incorrect answer	(3) Do not know

Section B2: Prescription problems, perception and acceptance

B2.1 Have you encountered any problems with taking prescribed medicines?

Yes	No

B2.2 If you have encountered problems with taking medication have you reported it to the clinic Sister?

| Yes	No

125

B2.3   If yes to B2.1, which one of these responses best describes the problems encountered?

Swallowin g	Being	No transport	Not granted permissio	Lack of	Cannot take medicines	Other reasons

Section C: Perception of ART Treatment

NOTES: For each of the following questions we invite the respondent to respond according to what best represents their view toward the statement presented in the question. With the following 11 questions we wish to know to what extent you agree or disagree with the situation that helps or limits HIV patients with their treatment compliance as indicated by physicians. [For analysis purposes: a result of 4 or 5 is classified as a positive attitude and a result of 1-3 is classified as a negative attitude]
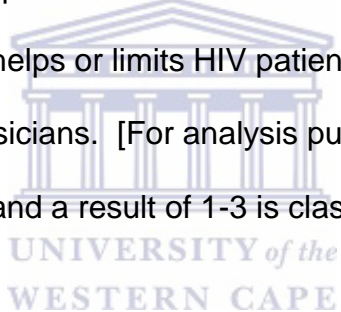
INSTRUCTIONS *(Questions 1- 11): Tick in the appropriate box.*
Section C1: Psychological acceptance

Which response best describes what came into your mind or how you felt   when you were told you are going to take ARV's for the rest of your life?

1. A accepted & was ready	2. I needed a little more time to be ready	3. I did not know if I was ready or not	4. I knew I had to, but I was not ready	5. I did not accept and I was not ready at all

Section C2: Treatment perception

	Strongly agree	Agree	Neither Agree OR Disagree	Disagree	Strongly disagree
1. If HIV patients feel well, they would stop taking their medications.	1	2	3	4	1
2. HIV patients will get sicker if they stop taking their medications	5	4	3	2	1
3. In HIV patients their medications will cause Opportunistic Infections	1	2	3	4	5
4. HIV is a virus that causes Opportunistic Infections	5	4	3	2	1
5. Medications for the treatment of HIV will prevent or delay Opportunistic Infections	5	4	3	2	1
6. For HIV patients, it is difficult to take their medications at work	1	2	3	4	5
7.It is advisable that HIV patient's family facilitates their intake of medications	5	4	3	2	1
8. HIV patients have problems complying with their treatment if they live far from the clinics	1	2	3	4	5
9. HIV patients have problems complying with their treatment due to lack of money	1	2	3	4	5
10. Physicians and HIV patients should agree with the ARV prescriptions	5	4	3	2	1
11. Do you agree with your ARV treatment regimen?	5	4	3	2	1
TOTAL SCORE					

Section D: Opportunistic Infections and Treatment Acceptance
NOTES: Questions on opportunistic infections to assess the attitude to treatment through

severity of the OI's

INSTRUCTIONS:[*For respondents who answered yes on Section A Question 8 section A only] Indicate the last time you suffered from opportunistic infections and* (For severity of OI's showing negative attitude to ARV treatment) How many times have you suffered from OI's?. Options to select from are: (1. within the past 3 months; 2. within the past 6 months; 3. within the past year; 4. within the past two years; 5. within the past 5 years).

Opportunistic Infections (OI's) one of the complications of negative attitude to ARV's.	Indicate the last time you suffered from opportunistic infections	(**For severity of OI's showing negative attitude to ARV treatment**) How many times have you suffered from OI's?
Diarrhoea for more than two weeks		
Oral thrush		
Swollen glands		
TB		
STI's		
Shingles		
Other		

Section E: Support and Treatment Acceptance

NOTES: Section E has the following Sections: E1 (A Question on Social support and treatment attitude), and E2 (Questions on treatment partner reliability).

Section E1: Social Support and Treatment Acceptance

1. Are you attending any support group in your community? (*This question is for assessing if the client has accepted his or her new status and if is getting any kind of support from the community group).*

1.Yes	2. No

http://etd.uwc.ac.za/

Section E2: Treatment Partner and Treatment Perception

NOTES: This SECTION is for assessing the reliability of a treatment support.

	1.Yes	2. No	Other response (specify)
1. Have you got a treatment partner?			
2. Are you staying together with your treatment partner?			
3. Is your treatment partner a family member: like your sibling or spouse?			
4. Do you see each other regularly?			Specify (weekly, monthly etc)
5. Have you got some-one to remind you to take tablets?			
6. Do you talk to your treatment partner about your treatment problems?			

Section E3: Psycho-Social support related questions

NOTES: This section is for assessing the strength of the client's support and the kind of Psycho-social support do you have?

INSTRUCTIONS *(Questions 1 -)***:** *To what extent do you agree or disagree with the following items?*

	SA	A	D	SD
Section E3.1: Emotional Support				
E3.1.1 I get the emotional help and support I need to improve treatment attitude from my family.				
E3.1.2 I talk to my family about my stresses that can affect my treatment attitude.				
E3.1.3 My family supports me with taking medication and clinic appointments.				

129

	SA	A	D	SD
Section E3.2: Friends' Support				
E3.2.1 I can count on my friends support about my health worries and concerns my medication.				
E3.2.2 I can talk to my friends about my problems that may be one of the barriers to positive treatment attitude.				
Section E3.3: Significant Others				
E3.3.1 There is a special person who is around when I am in need of someone to motivate me about my attitude to ARV treatment.				
E3.3.2 There is a special person in my life that cares about me being on treatment for HIV/AIDS for the rest of my life.				

Section F: Substance for recreation and treatment perception

NOTES: *To assess any element contributing towards missing tablets.*

INSTRUCTIONS (Questions 1 – 4): Tick where appropriate and provide more information where indicated

	1. Yes	2. No	Other Response (Specify)
1. Do you drink alcohol?			
2. How many bottles do you drink a week			
3. Have you tried to quit drinking before?			Specify approx.
4. If you have tried to quit before, what method did you use?			

Appendix 2: Permission

Eastern Cape Department of Health

Enquiries   Vuyokazi Poswayo   Tel No: 063 378 1789

Date: 7 July 2009
E-mail address   vuyokazi.poswayo@empilo.ecpro.gov.za

Dear Ms Nobuhle Bakumeni

RE: FACTORS INFLUENCING ADHERENCE ON ANTIRETROVIRAL TREATMENT IN THE QUEENSTOWN REGIO (EASTERN CAPE)

The Department of Health would like to inform you that your application for conducting a research on th abovementioned topic has been approved based on the following conditions:

1. During your study, you will follow the submitted protocol with ethical approval and can only deviate from it aft having a written approval from the Department of Health in writing.

2. You are advised to ensure observe and respect the rights and culture of your research participants and maintai confidentiality of their identities and shall remove or not collect any information which can be used to link th participants. You will not impose or force individuals or possible research participants to participate in you stud Research participants have a right to withdraw anytime they want to. However, you shall be responsible dealing with any adverse effects following the research treatment provided in your study.

3. The Department of Health expects you to provide a progress on your study every 3 months (from date yo received this letter) in writing.

4. At the end of your study, you will be expected to send a full written report with your findings and implementab recommendations to the Epidemiological Research & Surveillance Management. You may be invited to th department to come and present your research findings with your implementable recommendations.

5. Your results on the Eastern Cape will not be presented anywhere unless you have shared them with th Department of Health as indicated above.

Your compliance in this regard will be highly appreciated.

EPIDEMIOLOGICAL RESEARCH & SURVEILLANCE MANAGEMENT   DATE 7/07/2009

131

Appendix 3: Ethics

**OFFICE OF THE DEAN
DEPARTMENT OF RESEARCH
DEVELOPMENT**

Private Bag X17, Bellville 7535
South Africa
Telegraph: UNIBELL
Telephone: +27 21 959-2948/2949
Fax: +27 21 959-3170
Website: www.uwc.ac.za

23 October 2008

To Whom It May Concern

I hereby certify that the Senate Research Committee of the University of the Western Cape has approved the methodology and the ethics of the following research project by:
Ms. Nobuhle Bakumeni

Thesis title: Factors contributing to poor adherence to anti-retroviral treatment among HIV positive women in Queenstown (Eastern Cape).

Registration number: 08/8/25

Henk Swater
Research Development
University of the Western Cape

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http://etd.uwc.ac.za/

Appendix 4: Consent

Project Title: *Factors Influencing Adherence to Antiretroviral Treatment in the Queenstown Region Eastern Cape (SA)*

What is this study about?

This is a research project being conducted by Nobuhle Magadla at the University of the Western Cape. We are inviting you to participate in this research project because you are an HIV-positive woman aged between 25 and 49 years old who has a clinic record in this clinic and has agreed to participate in this research. The purpose of this research project is to determine the factors influencing adherence to ART Therapy at the clinics in the Chris Hani District Queenstown. The aim of this research is to use the information to improve adherence on ART Therapy

What will I be asked to do if I agree to participate?

You will be asked to answer the questions directed to you about your HIV status, your treatment and your support financially and socially. Interviews will take place at your clinic at the time convenient to you, using your own language. It will take about 40 to 45 minutes. You are allowed to withdraw anytime when you feel that you do not want to continue with this research.

Would my participation in this study be kept confidential?

We will do our best to keep your personal information confidential. To help protect your confidentiality, all the information will not be permissible to anyone out the research team and we will never mention your name in our records. Your information will be kept in a lockable cabinet and no one will have access to it except me as a researcher. I will not use your names I will be using codes for this data collected and during analysis we will be using codes.

If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

There are no known risks associated with participating in this research project.

What are the benefits of this research?

The benefits for you will be to identify the causes of poor adherence and to the people at clinic like sister in charge or a social worker to try and help you if possible to improve on adherence.

This research is not designed to help you alone, but the results may help health care providers to improve the services being offered to you to improve adherence to ART, so everybody including the community will benefit. The researcher will also learn more about ART therapy and

133

adherence. We hope that, in the future, everybody might benefit from this study through improved understanding of Adherence.

Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalized or lose any benefits to which you otherwise qualify.

Is any assistance available if I am negatively affected by participating in this study?

Counselling will be offered if you are negatively affected by the research.

What if I have questions?

This research is being conducted by Prof J Chipps as Head of Department at the University of the Western Cape. If you have any questions about the research study itself, please contact Prof L Chipps at: UWC. At 021 – 959 3923 jchipps@uwc.ac.za

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:
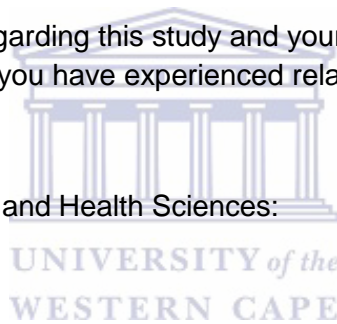
Head of Department:

Dean of the Faculty of Community and Health Sciences:

University of the Western Cape

Private Bag X17

Bellville 7535

This research has been approved by the University of the Western Cape's Senate Research Committee and Ethics Committee.