ADHERENCE TO HAART: EXPERIENCES OF MEN AND WOMEN LIVING WITH HIV IN THE WESTERN CAPE PROVINCE, SOUTH AFRICA

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A mini-thesis submitted in partial fulfilment of the requirements for the degree of Magister Psychology in the Department of Psychology, Faculty of Community and Health Sciences, University of the Western Cape

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ABSTRACT

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The aim of this study was to explore how HIV positive people understand and describe their experience of taking antiretroviral treatment consistently in a strictly organised regimen. Eight participants were recruited from Ikhwezi Clinic. The participants were interviewed using an in depth interview guide. A Phenomenological data analysis was employed through which six themes emerged. The themes are forgetting and memory aids, fitting treatment into daily routine, belief in effectiveness of medication, experiences of side effects, disclosure and social support and relationship with the health care provider. The health belief model and the self-efficacy theory were applied in the study. These theories helped to understand that the decision to take treatment is not only based on the individual experiences and beliefs but the interaction with the social and environmental factors as well. Family, community and health care factors are all interconnected and play a vital role in the decision to commence and continue with HAART. The study revealed that PLWHA can adhere to antiretroviral medication if they believe in the benefits of doing so. Furthermore it became clear that experiences of men and women differ when it comes to HAART. The involvement of the in-laws as experienced by the women in this study had a negative influence in the participants' adherence routine. Further studies are needed to explore the influence of culture in decision making by women with regards to their health.

August 2010

DECLARATION

I declare that "Adherence to HAART: Experiences of men and women living with HIV in the Western Cape Province, South Africa is my own work, that it had not been submitted before for any degree or examination in any other university, and that all sources I have used or quoted have been indicated and acknowledged as complete references.

Name: Nomonde Ngada Date: August 2010

Signed: ....

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Definition of key terms

HAART: a combination of drugs that suppress HIV, the virus that causes AIDS; it usually consists of taking three drugs of different types at the same time.

ARV: Anti-retroviral

PLWHA: People living with HIV/AIDS

Adherence: a person's ability and willingness to follow recommended health practices, making and keeping periodic medical and dental appointments, using seatbelts and engaging in other behaviours that coincide with the best health advice available.

Viral load – a concentration of a virus, like HIV in the blood

CD4 count: a blood test that is done to measure the protective cells in one's immune system

Regimen - a regulated course, as of diet, exercise, or manner of living, intended to preserve or restore health or to attain some results.

CHAPTER ONE

1. INTRODUCTION

The introduction of highly active antiretroviral therapy (HAART) has transformed the treatment of HIV infection by improving the clinical course of the disease and substantially reducing HIV related morbidity and mortality (Barclay et al., 2007). However, research has shown that the successful treatment of HIV infection requires that adherence be nearly perfect (95%) in order to reduce viral loads and prevent the emergence of drug resistant variants (Abaasa et al., 2008; Chesney, 2003; Paterson et al., 2000). Adherence to medical regimens is defined as the degree to which patient behaviour is consistent with medical or health advice (Balfour et al., 2006).

According to Nischal, Khopkar and Suple (2005), adherence rates vary not just between individuals but also within the same individual over time. Numerous factors that can influence adherence to HAART include its lifelong duration, side effects, the complexity of the regimen, social aspects such as the lifestyle patterns of the patient, financial support, family support, the motivation to start and continue therapy and the ability to adhere to therapy (Nischal et al., 2005).

Other factors that affect adherence to HAART are more cognitive and relate to how the patients perceive their health and medication, whether they believe medication will prolong their lives and whether they will be able to handle taking medication for the rest of their lives (Gonzalez et al., 2004; Gordillo, Del Amo, Soriano, & Gonzalez-Lahoz, 1999). Interpersonal relations between the patient and the health service provider have also been associated with adherence patterns (Fehringer et al. 2006; Schneider, Kaplan, Greenfield, Li, & Wilson, 2004).

Adherence to medication is difficult under any circumstances, but the unforgiving nature of viral replication, the complexity of ART regimens and the associated toxicity of medicines all pose difficult challenges for the patients (Wood, Tobias, & McCree, 2004). Therefore, understanding peoples' experiences of taking HAART can assist in identifying and overcoming the factors that reduce adherence.

1.1. HIV/AIDS prevalence

Sub-Saharan Africa is the global nucleus of HIV/AIDS (UNAIDS, 2006). Even though the population of Sub-Saharan Africa constitutes just over 10% of the world's population, the region is home to an estimated 63% (24.7 million) of the 39.4 million people living with HIV (PLWHIV) worldwide (UNAIDS, 2006). Sub-Saharan Africa represents 77% of women living with HIV, 79% of AIDS deaths as well as 92% of the world's AIDS orphans (Mills et al., 2006). An estimated 2 million people died of HIV/AIDS in this region in 2005, while an additional 2,7 million people became infected with HIV (UNAIDS, 2006). Worst hit among the African regions is Southern Africa, accounting for 32% of people infected and 43% AIDS deaths (UNAIDS, 2006).

In South Africa, on the other hand, the epidemic appears to have stabilised and may even be declining, for example, among teenage girls, the rate fell from 16.1 in 2004 (Shisana et al., 2005) to 12.9 in 2007 (HSRC, 2009). Additionally, the researchers estimate that 10.9% of all South Africans over 2 years old were living with HIV in 2008 (HSRC, 2009), this figure was 11.4 and 10.8 in 2002 and 2005 respectively which indicates a degree of stabilisation.

Earlier projections suggested that about six million South Africans would be infected with HIV/AIDS and that without intense adherence to antiretroviral medication, the mortality rate of HIV/AIDS will reach 800 000 deaths by the year 2010 (Nachega et al., 2005). Therefore, the introduction of ARV and access to treatment could decrease the morbidity and mortality; thus changing the trends of HIV/AIDS deaths.

The degree of HIV infection varies across different geographic regions in South Africa. Of the nine provinces, Kwazulu-Natal has the highest prevalence at 15.8%, while the Western Cape remains the province with the lowest level of infection at 3.8% (HSRC, 2009). The African population remains the highest in infection rate with a prevalence of 13.6% in 2008 (HSRC, 2008).

1.2. The HAART program in South Africa

South Africa's approach to AIDS has been influenced by persistent antipathy on the part of the former President, and his Health Minister towards antiretroviral therapy. According to Nattrass (2006) the questioning of the science of AIDS and resistance to implementing programs using anti-retroviral treatment by the former President increased antagonism against antiretroviral therapy. Moreover, the Health Minister continued a war of attrition by portraying antiretroviral treatment as poison and by supporting and protecting suppliers of scientifically untested alternatives (Nattrass, 2006).

Despite all those efforts, the parliamentary cabinet approved antiretroviral treatment for public health patients and the government released its Operational Plan to have 54,004 people on treatment by March 2004 (National Department of Health South Africa, 2004). The previous Health Minister continued to procrastinate, the result being a slow start and poor performance in relation to the planned targets. It was only from late 2004 and into 2005 that the rollout gathered pace (Nattrass, 2006). By the end of 2005, the number of people on treatment in the public sector was still less than 30% of the original planned total. Rather than actively supporting the rollout, the Health Minister constantly pointed to the side effects of antiretroviral therapy whilst highlighting the benefits of nutrition (notably garlic, lemon and olive oil). This has resulted in AIDS patients being reluctant to take antiretroviral treatment because they feared that they were poisonous (Nattrass, 2006).

Even though the number of people taking HAART in South Africa increased extensively from less than 200 in 2003 to almost 200 000 by the end of 2005, South Africa's performance in terms of coverage remains poor in comparison to other countries and the targets set out by the government's own operational plan. Furthermore, the public sector roll out has been uneven across South Africa's nine provinces (Nattrass, 2006).

1.3. Research setting

The study was conducted in a Western Cape public health care facility located in Lwandle Township, Cape Town. Lwandle Township is situated approximately 4km south of Somerset West. It has easy access to the road and transport networks connecting into Cape Town via the National Road (N2). According to the Lwandle Hostel to Homes Revitalization Project, it is a poverty stricken township, originally built for migrant labourers in the 1960s. It has since grown due to migration of people largely from the Eastern Cape. Approximately 60% of the people are unemployed with a majority of the people making a living from selling vegetables, meat and other foodstuffs on the street side, selling a minimal amount of locally produced goods in the arts and crafts centre, and selling alcohol in shebeens.

1.4. Aim

The aim of this study was to explore how HIV positive people understand and describe their experience of taking antiretroviral treatment consistently in a strictly organised regimen.

1.4.1. Objectives

- To explore the participants experiences of taking HAART daily
- To understand the participants' challenges that threaten adherence to HAART
- To investigate the participants' source of support or social support network and how that influences adherence to antiretroviral therapy.

1.5. Outline of the study

Chapter one has introduced the topic, described the aims and objectives of the current study, chapter two will discuss reviewed literature and the theoretical framework applied in the study. Chapter 3 details the research procedure which includes the recruitment of participants, procedure, data collection and analysis, reflexivity and ethical considerations. Chapter four provides a discussion of the results and ends with the summary of the results. Chapter five provides the conclusion of the study including limitations and recommendations for future research.

CHAPTER TWO

2. LITERATURE REVIEW

2.1. Introduction

Although HIV and AIDS is still considered a serious condition, the invention of HAART has reduced morbidity and mortality and increased the possibility of living longer productive lives for HIV infected people (Heyer & Ogubanjo, 2006; Kleerberger et al., 2001; Llabre et al., 2006). However, long-term effectiveness of HAART is dependent upon strict adherence to the prescribed regimen (Kleerberger et al., 2001; Llabre et al., 2006; Roge et al., 2004; Trotta et al., 2002).

Antiretroviral therapy requires an adherence rate of 95% or more to achieve viral suppression, to slow the time to treatment failure and subsequent development of resistance to antiretroviral therapy (Kleerberger et al., 2001; Llabre et al., 2006; Roge et al., 2004). However, non-adherence to medication may have detrimental effects on the patient's health and quality of life. Moreover, consequences of poor adherence include not only diminished outcome for the patient, but also the public health threat of a multi-drug resistant HIV and widespread transmission of a drug resistant virus (Heyer & Ogubanjo, 2005).

This chapter examines the notion of adherence to antiretroviral therapy. It discusses literature located on antiretroviral therapy and adherence. It provides research evidence of how people living with HIV and AIDS (PLWHA) adhere or not to antiretroviral therapy including the challenges and enablers to adherence.

2.2. Factors affecting adherence

HAART is usually complex and inconvenient with a lot of pills to take under a very stringent time schedule, and the pills frequently provoke side effects (Perreti-Watel et al., 2006). These conditions sometimes make it difficult for HAART patients to adhere. Therefore, understanding factors associated with poor adherence could empower both the patient and health care worker to take steps to manage adherence better, thus the patient will get maximum benefit from the treatment.

If a patient understands the treatment he/she is taking, the purpose, how to take it and the benefits thereof, it can have a profound influence on adherence. Chesney (2000) stated that patients' attitudes and cultural beliefs influence their trust in Western medicine, their degree of skepticism about the medical establishment and the extent to which they believe myths about antiretroviral medication. On the other hand, healthcare providers need to understand what each patient expects from antiretroviral treatment and the degree to which they have confidence in their efficacy, and establish if the patient's motivation is high enough to optimize his/her health (Tsasis, 2001).

Numerous factors combine to make adherence to HAART particularly difficult. The factors that influence individual's adherence or non-adherence to the HAART regimen are diverse but can be categorized into four: patient-related, health care provider related, treatment-related and social factors (Goudge, Ngoma & Schneider, 2004).

2.2.1. Patient-related factors

2.2.1.1. Demographic factors

The literature commonly demonstrates that personal attributes such as age, gender, social class and religion are not strong predictors of adherence (Barclay et al., 2007; Goudge et al., 2004; Valerie & Stone 2000). However, some studies have shown that adherence increases with age with young people less likely to adhere compared to older people (Barclay et al., 2007; Gordillo et al., 1999). These researchers associated the adherence patterns of older adults with the fact that medication requires less alteration in lifestyle unlike the younger adults who,often have to change their lifestyles dramatically to fit the treatment requirements.

Poppa et al. (2004) stated that poor adherence cannot be restricted to a particular social class. It is only when a group of demographic variables are joined, for example gender and social class that their combination shows a stronger association to adherence (Sarafino, 2002). Moreover, levels of adherence differ within the same person over time; adherence can therefore be best understood as a variable behaviour not as a characteristic of an individual, as people may sometimes exhibit high and low adherence (Poppa et al., 2004).

2.2.1.2. Socioeconomic factors

Lower socioeconomic status (SES) has been shown to contribute to decreased adherence (Barclay et al., 2007). Research has shown that the components of lower SES associated with decreased adherence include unstable or poor housing, low income and low level of education and lack of medical insurance (Golin et al., 2002; Gordillo et al., 1999).

Gordillo et al. (1999) found that low income may prevent patients from easily accessing care in terms of purchasing medication, transport fare to medical services, hiring help for child care and food restrictions that come with treatment. In the South African context where HAART is free in public health care centres, transport fare and lack of food may result in non-adherence. A study by Barclay et al. (2007) reported that younger participants who were financially supported by others were less likely to be adherent with only 28% classified as good adherers compared with 46.7% of participants with independent financial resources.

Poor housing may either contribute directly to lower adherence by preoccupying the patient with more immediate concerns or become an indirect indicator where a patient does not have a stable support system (Barclay et al., 2007). A lot of variables come to play when one does not have a stable home. For example, Gebo, Keruly, and Moore (2003) found that patients who had unstable living situations were likely not to adhere, especially if they lived with extended family due to privacy issues with medication, as well as lack of a safe place to leave their medication. Patients should be made aware of the consequences of non-adherence and be informed that once drug resistance develops, treatment options become limited (Chesney, 2003). In South Africa there are only two regimens; therefore options are very limited which poses a challenge to non-adherent patients.

2.2.1.3. Substance use/abuse

HAART requires that one keeps a standard treatment schedule and that means being in control at all times. However, substance use may affect adherence directly or indirectly because it may lead to impaired judgment, loss of short term memory and a decline in cognitive functioning (Halkitis, Kutnick, & Slater, 2007). Furthermore, research has shown that concurrent use of illicit drugs and HAART results in lower adherence levels (Halkitis et al., 2007; Peretti-Watel et al., 2006; Chander, Himelhoch & Moore, 2006). Illicit drug use has often been proven as an independent risk factor for non-adherence (Gebo et al., 2003; Holzemer, Henry, Portillo, & Miramontes, 2000). Therefore, substance use may lead to a disorganized lifestyle that can make adherence to HAART difficult or directly impair judgment about behaviour (Halkitis et al., 2007). Substance users are reported as unreliable when it comes to adherence to HAART, they may forget to take medication at required times or fall asleep due to drugs before taking the medication (Halkitis et al., 2007; Peretti-Watel et al., 2006). Substance users may also have more side effects because of drug interactions with HAART (Parsons, Rosof, & Mustanski, 2007). Illicit drug users have been reported to take treatment breaks in order to alleviate side effects (Parsons et al., 2007).

In addition to drug use, Parsons et al. (2005) found that the amount of alcohol consumption predicts whether or not someone will adhere to their medication, regardless of the problems caused by the drinking. Frequent drinkers could also be more concerned about potentially harmful interactions between alcohol use and their HAART medication, and thus choose not to take medication when they had taken alcohol. This is in line with the existing literature on alcohol which indicates that the altered state induced by alcohol may cause heavy drinkers to forget or lose sight of the importance of taking medication (Cook et al., 2001; Halkitis et al., 2005). A study of predictors of adherence to combination antiretroviral medication reported that patients who drank alcohol were significantly less adherent compared to those who did not (Parsons, Rosof, Punzalan & DiMaria, 2005).

2.2.1.4. Behavioural factors

Mental health problems, particularly mood disorders, are common among patients living with HIV and may pose a threat to adherence (Chander et al., 2006). Research has shown lower rates of HAART adherence among those with mood or anxiety disorders (Gonzalez et al., 2004; Rao, Kekwaletswe, Hosek, Martinez, & Rodriguez, 2007). Depressed individuals tend to be less motivated to take their medication; they may have impaired cognitive functioning that makes it difficult to remember to follow through with treatment recommendations or may have a pessimistic outlook about the effectiveness of treatment (Parsons et al., 2005).

Medication taking itself can cause depression (Barclay et al., 2007). Participants in one study stated that taking medication consistently was depressing such that one participant reported that she got fed up and threw the medication away (Rao et al., 2007).

In addition to mood disorders, forgetting has also been associated with non-adherence and it has often led to alteration of the treatment schedule (Chesney, 2003; Chesney, 2000; Kleerberger et al., 2001). Forgetting has been reported as more prevalent when individuals regain well being, return to work, and resume other activities (Chesney, 2003; Chesney, 2000). Furthermore, Fogarty et al. (2002) reported that people who had difficulty with concentrating and those who had inadequate information about ART frequently reported forgetting to take medication and therefore adhered poorly. Higher levels of apathy were also found to be associated with sub-standard adherence for participants (Barclay et al., 2007).

2.2.1.5. Self-efficacy

Adherence to medication can be thought of as a decision-making process involving the consideration of the pros and cons of change, an evaluation of self-efficacy to change, and attitudes held about the efficacy of treatment (Parsons et al., 2007). Self-efficacy involves a degree of confidence patients have in their ability to adhere to HAART and assumes that patients who manage to adhere to their medication experience a sense of control (Lewis, Colbert, Erlen & Meyers, 2006). Patients who have a greater level of confidence in being able to carry out a doctor's instruction are likely to engage in such activities to a greater extent than those who do not (Kagee, 2004). This can also be attributed to patients' perceived success at adhering in the past and attributing that success to their own efforts.

Several factors interact with self-efficacy include patients' level of comfort with interacting with the health care system, their relationship with the medical personnel and the complexity of the treatment regimen (Fehringer et al., 2006; Li & Wilson, 2004; Schneider, Kaplan, Greenfield). Together with health literacy, the competing demands of daily living and limited financial resources, these factors impact on adherence self-efficacy in a manner that may be unique to primary health care patients residing in historically disadvantaged South African communities

(Kagee, 2004). Radical change in the current health care system is needed in order to change the focus from that of the health care provider being 110% responsible for the recovery of a patient to allowing joint partnership between the patient and the health provider (Kagee, 2004).

2.2.1.6. Health beliefs

Beliefs that people hold about their own health can affect their ability to take medication (Reynolds, Neidig, Wu, Gifford, & Holmes, 2006). Health behaviour is a function of an individual's personal beliefs about the perceived threat of a disease and an assessment of the risks or benefits of the recommended course of action (Brannon & Feist, 2004). For instance, the decision to take HAART is more likely if the individual perceives HIV as a threat to their health and that the benefits of taking HAART outweigh the barriers (Halkitis et al., 2005). Within the broader agenda of adherence research, health beliefs have been identified as being significant predictors of adherence. Specifically, perceived threat as a health belief has received considerable attention in compliance and adherence research for multiple perspectives in patient populations (Carpenter, 2005).

Patients who believe in the effectiveness of their HAART medication are more likely to adhere, whereas non-adherent patients tend to perceive fewer benefits of HAART (Wagner, et al., 2003). Patients' subjective beliefs and adherence are influenced by the experience with medication over time; thus, the discordance between the initial expectation about the effectiveness of HAART and actual experience may have a negative influence on adherence (Reynolds et al., 2006).

2.2.1.7. Cultural beliefs

It is common practice to consult a traditional healer and spiritual healers in Africa at the onset of illness (Banerjee, Harries, Nyirenda, & Salaniponi, 2000; Cambanis et al., 2005; Pronyk, Makhubulele, Hargreaves, Tollman, & Hausler, 2001; Van Dyk, 2005). This is propelled by traditional beliefs in things like witchcraft and evil spirits (Cambanis et al., 2005; Edginton, Sekatane, & Goldstein, 2002; Wandwalo & Morkve, 2000). Therefore, cultural aspects of the patients' belief system and life goals may be influential in treatment adherence.

Furthermore, insensitivity to health beliefs, values and practices, lack of knowledge about the culture of black South Africans among health care providers may contribute to failure of treatment programmes (Van Dyk, 2005). Cultural differences are a significant determinant of non-adherence in South Africa. For instance, the consultation of traditional healers should be viewed from results of TB studies which revealed the belief of the presence of 'other' diseases with similar symptoms (Banerjee, Harries, & Salaniponi, 2000; Edginton et al. 2002; Jaramillo, 1998). These diseases have their own local and traditional terminology and are commonly associated with breaking cultural rules (Edginton et al., 2002). Also important is that these diseases can only be cured by traditional healers; therefore the people immediately seek health from them when they see symptoms (Banerjee et al., 2000). It is therefore important to understand the traditionally held beliefs in causes and characteristics of diseases like HIV for facilitating communication about the disease to the population and to reduce the related stigma. A person without symptoms is not expected to take medication in traditional African culture, but in asymptomatic diseases such as HIV, such a belief can have catastrophic consequences for the patient (Edginton et al., 2002).

2.2.2. Health-care related factors

2.2.2.1. Patient-provider relationship

A quality patient-provider relationship has been cited as an important source of support to promote adherence to HIV medication (Fehringer et al., 2006; Schneider et al., 2004) and an important source of support (Parsons et al., 2007). Important aspects of patient-provider relationship include trust, consistency and continued interaction (Reynolds et al., 2006). Patients who dislike their physicians or who have trouble talking openly with them are more likely than other patients to be non-adherent (Brannon & Feist, 2004).

Patients who are dissatisfied with their providers are less likely to comply with treatment recommendations than those who feel they are involved in a collaborative relationship in which they are an integral part of the decision-making process (Fehringer et al., 2006). Johnson et al. (2006) stated that the need for trust of the physicians was commonly identified by participants.

For these patients, trust in their health care providers meant more confidence in their treatment regimen and higher likelihood of disclosure regarding missed medications, leading to discussions about their struggles with adherence.

Communicating clearly with the patient about the purpose of treatment, the duration and the intervals between doses with clear instruction of food intake before or after taking HAART, as well as expected side effects can promote adherence. For example, communication problems such as language barriers are common in South Africa where HIV patients are speaking another language which English speaking doctors may not understand. Miscommunication can also start when the physician asks patients to report on their symptoms and fails to listen (Brannon & Feist, 2004). Kagee (2004) suggests clear instructions to patients such as the presentation of oral and printed material. However, the printed material should be presented in a manner that is appropriate to the reading level of the patient.

Physicians need to be aware of cultural norms and traditions because they can have a powerful effect not only on compliance but even on what constitutes compliance. A study by Edginton et al. (2002) on the effect of health beliefs in Limpopo province discovered that there is a strong belief that tuberculosis is the result of breaking cultural rules and that people with this curse can only be treated by traditional healers. The impact of beliefs like these can be dreadful for adherence to antiretroviral therapy. The infected person might decide to conceal his/her status and therefore have to hide treatment and the consequence of this could be skipping doses.

Health care providers may ask closed questions which do not give space to the patients to express their concerns about medication (Fehrringer et al., 2006). When the participants in Fehringer et al. (2006) were asked about concerns regarding adherence, several patients who told providers that adherence was going well, shared a different story. Some participants indicated that they had tried to discuss issues with the practitioners but they did not receive productive or supportive feedback. Therefore, the patient-provider relationship is crucial, particularly when managing adverse reactions.

2.2.2.2. Health care system factors

The elements of the health care system, including its culture and environment, have an impact on adherence (Nattrass, 2006). Such factors include policies, organisation, resources and financial arrangements impacting on the availability, accessibility, and acceptability of health care services (Nattrass, 2006). For example, opening times of the health centres may not be suitable for some patients, especially the working class. Taking time off work to go to clinics for low income workers cost the whole family a day's salary (Johnson & Folkman, 2004). Health care facilities should be brought closer to patients because long distance travelling could be a barrier to adherence especially if the patient is unemployed. Poppa et al. (2004) suggests the 'one stop shopping' approach to medical care which includes mental health care services, case management, social support, and other services readily available when patients visit the facility to avoid back and forth movement. This includes the availability of HAART medication in local pharmacies because any delay could result in missed doses.

2.2.3. Treatment-related factors

2.2.3.1. Regimen complexity

The number of pills that a person takes, timing and food restrictions have been cited as factors that lead to poor adherence to antiretroviral therapy (Heyer & Ogubanjo, 2006). Patients living with HIV take a complicated array of drugs which makes daily life adjustment necessary to ensure efficacy (Chesney, 2003). Participants in Remien et al. (2003), stated the number of pills that had to be taken, the size and the taste of pills, the frequency of dosing and how the pills can get in their way of life as a cause for them to switch the times or even take a break in taking medication. The number of pills per day becomes a problem especially if one is taking other medication at the same time, for example TB medication or has another chronic illness (Murphy, Roberts, Martin, Marelich & Hoffman, 2002). In Golin et al. (2002) dose frequency was associated with adherence although the total number of antiretroviral pills prescribed was not.

In addition to the pill burden and timing of doses, multiple daily doses with food restrictions greatly influence the individual's willingness to adhere to HAART (Bartlett, DeMasi, Quinn, Moxham, & Rousseau, 2000). While some drugs require no food intake to assure effectiveness, others are best taken with food to improve gastrointestinal tolerance (Adam, Maticka-Tyndale & Cohen, 2003; Remien et al., 2002).

2.2.3.2. Side effects and toxicity

Drug adverse effects are often a focal point of patient concern (Max & Sherer, 2000). HAART is characterised by adverse side effects including nausea, vomiting, diarrhoea, fatigue, sleep disturbances, body fat redistribution, and skin problems (Johnson & Folkman, 2004) which influence willingness to take medication and are consistently associated with poor adherence (Ammassari et al., 2002; Chesney, 2000; Heyer & Ogubanjo, 2006). Research has shown that people intentionally stop taking medication as a means of alleviating side effects; some would adjust their medication regimen in response to actual or anticipated side effects (Adam et al., 2003; Remien et al. 2002).

Moreover, concerns about potential future side effects such as lipodystrophy - a syndrome characterised by loss of fat in the face, limbs and buttocks and fat accumulation in the midsection and neck and by breast enlargement which result in poor adherence (Max & Sherer, 2000). Some people have seen lipodystrophy as disclosing their HIV positive status to the general public and those who perceive this syndrome to be severe stop taking their antiretroviral treatment (Duran et al., 2001; Reynolds et al., 2006). The impact of lipodystrophy is particularly strong among women, because they are judged by their appearance (Max & Sherer, 2000).

2.2.3.3. Alternative therapies

About 80% of Africans utilise services of a traditional healer (Van Dyk, 2000). Health care providers need to be aware of cultural norms and traditions because they can have a powerful effect on adherence. Beliefs that are culturally based, for example, that TB is caused by breaking cultural rules (Edginton et al., 2002), if not explored and addressed can negatively impact adherence to antiretroviral therapy.

The use of alternative therapy is not unique in Africa, some participants in Remien et al. (2002) in the United States of America indicated that they do not trust western medication; they used eastern medication to treat HIV or to alleviate symptoms of the side effects. Remien et al. (2002) raise concerns when it comes to these alternative medications since there is limited information available about the side-effects, food interactions and the effect of toxic quantities. The ARV guidelines of the National Department of Health South Africa (2004) emphasizes that patients need to be questioned about the use of any herbal medicine before commencing ART.

2.2.4. Social factors

Poor social relationships and activities can be associated with lower adherence in several studies (Gonzalez et al., 2004; Parsons et al., 2007; Rao et al., 2007). Support from family and friends provide psychological resources to help HIV positive individuals cope with the stressful aspects of taking HIV medication (Rao et al., 2007). The involvement of family members is crucial in the treatment planning because it can be used as a source of encouragement and support (Bernard & Krupat, 1994). This is more important with antiretroviral therapy because of the long-term nature of treatment which can lead to fatigue and despair. Some patients are reported to even reach a point of taking treatment holidays (Rao et al., 2007). It is no surprise that lack of social or family support and fear of stigmatisation are commonly associated with non-adherence to antiretroviral therapy (Gonzalez et al., 2004; Parsons et al., 2007).

Social support is directly associated with disclosure of HIV status. Studies have shown concealment of HIV status is common among people who feel discriminated against and those people have difficulties in taking medication in the presence of other people whether it is friends or family (Gonzalez et al., 2004, Ware, Wyatt & Tugenberg, 2006). As a result, where a person feels that he/she cannot successfully hide the treatment they skip doses.

Contrarily, HIV positive people who live with partners and have disclosed their status are more likely to adhere because their daily routines tend to be stable and they have support within the home (Davies et al., 2006; Rao et al., 2007). The involvement of partners may assist with identifying adherence barriers like child care, reminders and transport money and eliminating them by doing things for the partner who is taking treatment. On the other hand, stigmatisation, whether perceived or real, can lead to the concealment of the HIV positive status (Halkitis et al., 2007).

Some studies looked at the construct of perceived quality of support and concluded that quality of support is more consistently associated with adherence than is quantity of support (Gonzalez et al., 2004; Rao et al., 2007). Therefore one of the strongest predictors of adherence is the level of social support one receives from family and friends (Brannon & Feist, 2004). In general, people who are isolated from others are more likely to be non-adherent while those whose lives are filled with close interpersonal relationships are more likely to develop a routine, supported by family and friends, and adhere to medication (Gonzalez et al., 2004; Rao et al., 2007).

In addition to social support, the use of adherence aids such as reminders and pill boxes have been associated with better adherence (Golin et al., 2002). In their analysis Golin et al. (2002), reported that patients who used aids were more adherent. These findings were congruent with the findings of a randomised study of an on-line paging system (Safren, Boswell, Johnson, Salomon & Mayer, 2001). In that study, patients receiving paged medication reminders improved their adherence significantly more than the control group over a period of four weeks.

2.3. THEORETICAL FRAMEWORK

Research has shown that adherence to HAART is a complex subject that encompasses the social circumstances, locus of control and the psychological functioning of the individual. Therefore a single theory may not provide a fair examination of the cognitive reasoning behind taking and maintaining treatment for an HIV infected person. Based on this explanation, the health belief model (HBM) and the self-efficacy theory were selected for the current study.

2.3.1. The health belief model

The Health Belief Model (HBM) is a psychological model that attempts to explain and predict health behaviours by focusing on the attitudes and beliefs of individuals. It views health behaviour change as based on a rational appraisal of the balance between the barriers and the benefits of action (Rosenstock, 1990). The key variables of the HBM are: (1) perceived threat, which include one's perceived susceptibility of contracting a health condition, and perceived severity which refers to one's feelings concerning the seriousness of contracting an illness and of leaving it untreated; (2) perceived benefits, like belief in the effectiveness of the strategies designed to reduce the threat of illness; (3) Perceived barriers which include the negative consequences that may result from taking particular health actions including physical, psychological and financial demands; and (4) Cues to action which involve events either bodily or environmental that motivate people to take action (Brannon & Feist, 2004; Crepaz & Marks, 2002). The HBM also take cues to action (e.g. written reminders) as important elements in eliciting or maintaining patterns of behaviour.

The HBM has been widely used in adherence research to understand general constructs of HIV including knowledge, perceived barriers and perceived efficacy of antiretroviral therapy (Tuldra & Wu, 2002; White et al. 2006). The perceived benefits and perceived barriers influence the perception of the effectiveness of health behaviour, while the demographic and socio-psychological variables influence both perceived susceptibility and perceived barriers to action (Armitage & Conner, 2000; Stroebe, 2000). According to Armitage and Conner (2000), perceived threat is influenced by cues to action, which can be internal or external. Engagement to the recommended behaviour can be increased by high perceived threat or high perceived benefits. The HBM relates largely to the cognitive factors predisposing a person to health behaviour (Crepaz & Marks, 2002).

2.3.2. The Self-Efficacy theory

Self-efficacy, which forms part of the social cognitive theory, refers to peoples' beliefs that they can perform those behaviours that will produce desired outcomes in any particular situation (Bandura, 1986). The social cognitive theory assumes that humans have a capacity to exercise some control over their lives (Bandura, 1986). This control, however, is influenced by the environment in which the person lives. Bandura (1997) suggests that human action results from the interaction of behaviour, environment and the person factor. Self-efficacy is part of the person factor in the social cognitive theory. Bandura (1986) suggested that self-efficacy can be acquired, improved or reduced through one of four sources, which are: (1) performance, or enacting behaviour; (2) vicarious experience or seeing another person with similar skills perform a behaviour; (3) verbal persuasion or listening to the encouraging words of a trusted person; and (4) physiological arousal states such as feelings of anxiety, which ordinarily decrease self-efficacy. The combination of self-efficacy and outcome expectation plays an important role in predicting behaviour.

Self-efficacy has been used to predict adherence to a variety of health recommendation. For example, one study on social support, positive state of mind and HIV treatment adherence (Gonzalez et al. 2004) found that positive state of mind increased self-efficacy which in turn was strongly related to good adherence. According to Lewis et al. (2006) self-efficacy involves a degree of confidence patients have in their ability to adhere to HAART and assumes that patients who manage to adhere to their medication experience a sense of control.

2.4. Summary of the chapter

This chapter reviewed literature on Adherence to HAART. Four key factors that impact on adherence were discussed. The literature search covered the patient-related factors, health-care related factors, treatment-related factors and social factors. In patient-related factors, the researcher discussed demographic factors, socio-economic factors, substance abuse, behavioural factors, self-efficacy and cultural beliefs. The health care related factors focused on the patient-provider relationship and the health care system factors. The treatment related factors looked at the regimen complexity, the side effects and the alternative therapies that people use concurrently or in replacement of HAART. In the social factors the researcher discussed the support systems and their contribution in adherence to HAART. The two theories, the Health Belief Model and Self-efficacy Theory that the researcher has applied in the study were discussed in depth.

The following chapter details the research method that the researcher followed in conducting the study.

CHAPTER THREE

3. METHODOLOGY

A qualitative phenomenological research method was chosen for the current study because, according to Sankar, Golin, Simoni, Luborsky and Pearson (2006), qualitative investigation still remains underused in adherence research. This argument is supported by Remien et al. (2002) and Goudge et al. (2004), who stated that although quantitative studies have identified factors associated with medication adherence, no single variable or combinations of variables are sufficiently consistent to apply to any individual or group of people, therefore qualitative studies can be used to complement the quantitative studies.

The few South African studies that the researcher located from the literature search were mostly quantitative (Coetzee et al., 2004; Nachega et al., 2005; Orell, Bangsberg, Badri & Wood, 2003; Skogmar et al., 2006), with only one narrative qualitative study that looked at the psychological experiences of women with young children that are on antiretroviral therapy in Masiphumelele, Cape Town (Brandt, 2005).

The origins of phenomenology can be traced back to Kant and Hegel, but Edmund Husserl is regarded as the fountainhead of phenomenology in the twentieth century (Valle, 1998). Husserl rejected the belief that objects in the eternal world exist independently and that the information about objects is reliable. He argued that people can be certain about how things appear in, or present themselves to their consciousness (Eagleton, 1983). Furthermore, Husserl argued that to arrive at certainty, anything outside immediate experience must be ignored, and in this way the external world is reduced to the contents of personal consciousness. Realities are thus treated as pure phenomena and the only data from where to begin. Husserl named his philosophical method, phenomenology: the science of pure phenomena. (Eagleton, 1983).

Phenomenology therefore refers to knowledge as it appears to consciousness, the science of describing what one perceives, senses and knows in one's immediate awareness and experience. The basic assumption in phenomenology is that experiences are constituted by consciousness and thus could be rigorously and systematically studied on the basis of their appearance to the consciousness (Valle, 1998). Researchers working in this tradition assume that peoples' subjective experiences are real and should be taken seriously, that we can understand others' experiences by interacting with them and listening to what they tell us (Creswell, 1998).

According to Groenewald (2004), the operative word in phenomenology is 'describe'. The aim of the researcher is to describe as accurately as possible the phenomenon, refraining from any pre-given framework, but remaining true to the facts (Groenewald, 2004). A researcher applying phenomenology is concerned with the lived experiences of the people (Kvale, 1996). Creswell (1998) stated that the phenomenologists are concerned with understanding social and psychological phenomena from the perspective of people involved.

Therefore, the researcher found the phenomenological research method fitting this study because she wanted to explore how individuals living with HIV and AIDS (PLWHA) describe, in their own words, their experiences of taking HAART and the challenges that are posed by having to take a strict regimen. The phenomenological research method was preferred because the psychological approach in phenomenology focuses on individual rather than group experiences (Creswell, 1998). Individual perception is regarded as the primary source of knowledge (Moustakas, 1994).

The following section discusses the process followed by the researcher to recruit participants, collect, store and analyse data.

3.1. Recruitment of participants

According to Hycner (1999), the phenomenon dictates the method including the type of participants suitable for the study. The researcher chose purposive sampling to identify participants. The selection of participants was based on the purpose of the research. The aim was to locate participants who have had experiences related to the phenomenon being researched. The recruitment and screening of potential participants was carried out at the IDC (Infectious Disease Clinic) in Ikhwezi Community Health Centre which was identified as a research site. The researcher was assisted by the professional nurses working in the IDC to identify suitable candidates. Eight Xhosa-speaking HIV positive patients between the ages 23 to 34 were selected.

Participants consisted of five females and three males. In phenomenological research, two to ten subjects are regarded as sufficient to reach saturation (Creswell, 1998). The choice of mixed sexes was based on research that has proven that no association was found between adherence and demographic characteristics (Goudge et al., 2004; Barclays et al., 2007).

3.1.1. Participant profile

Participant No.	**Age**	**Gender**	**Period on HAART**
1	28	Female	27 months
2	31	Female	14 months
3	28	Male	17 months
4	34	Male	49 months
5	29	Female	41 months
6	32	Female	51 months
7	33	Male	41 months
8	23	Female	20 months

3.2. Procedure

The researcher started by getting an ethical clearance letter from the University of the Western Cape (see appendix A). She wrote a letter of application to collect data at Ikhwezi Clinic to the Eastern Sub-District manager of the City of Cape Town's Department of Health. The Sub-

District Manager replied in writing and gave authorization for data to be collected (See appendix B). After getting the authorization letter from the Sub-District Manager, the researcher approached the facility manager to request access to the facility. The facility manager introduced her to the doctor in charge of the ARV clinic which is referred to as the Infectious Disease Clinic (IDC). The researcher informed the IDC doctor of the purpose of the study and requested assistance with identifying suitable potential participants. Participant eligibility was verified through clinical records by the professional nurses within the clinic using the specified criteria and all identified participants qualified. The criteria indicated that participants should be 18 years and above, not currently diagnosed with any mental disorder and should have been on treatment for six months and beyond.

After checking the eligibility of the client, the clinic sisters informed the participants of the study and when the patient agreed to participate, they were sent to the researcher. The researcher informed the participants that she is a student at the University of the Western Cape and outlined the purpose of the study using the information leaflet that participants had to sign as an indication that they understand the purpose of the study and the role they will be playing (See appendix C). When the participant agreed to participate, the researcher made an appointment with him or her specifying the venue, date and time at which the interviews would take place.

Participants gave their contact details and the researcher gave her contact details and informed the participants that they can contact her should they have a problem or if they have changed their minds. All participants honoured the appointments for the interviews.

3.3. Data collection

In phenomenology, investigation is conducted through long, in-depth interviews (Creswell, 1998). The phenomenological interview involves an informal, interactive process and utilises open-ended comments and questions (Creswell, 1998; Moustakas, 1994; Valle, 1998). According to Creswell (1998) the phenomenological investigator writes questions that explore the meaning of that experience for individuals and asks the individual to describe their everyday lived experiences. This information is collected through a lengthy person-to-person interview that focuses on a bracketed topic and question. A follow up interview may also be needed (Moustakas, 1994).

Based on the above explanation, the researcher collected data using a semi-structured phenomenological interview guide (See appendix A). The interviews were held over a period of three days in a designated room within the IDC at Ikhwezi Community Health Centre. Each interview session took 45 to 60 minutes.

According to Moustakas (1994), phenomenological interviews often begin with a social conversation aimed at creating a relaxed and trusting atmosphere. The interviewer is responsible for creating a climate in which the research participant will feel comfortable, thus responding honestly and comprehensively. Therefore, the researcher in the current study opened the interview by engaging in small talk with the partcipant. It involved questions around where the participant is originally from and their clan names. This helped to ease the tension that some participants felt in the beginning and to create rapport as all participants were happy to talk about themselves and their backgrounds. Fortunately all the participants were Xhosa-speaking, which is the home language of the researcher as well.

The interviews were conducted in isiXhosa, the language that participants understood best. This afforded the researcher an opportunity to understand what it meant for participants to describe their experiences, feelings and perceptions about taking HAART and it helped to stimulate cooperation. It also made it easy for participants to explain and clarify their viewpoints using a language they are comfortable with. However, some participants mixed Xhosa and English in their responses.

3.4. Data analysis

3.4.1. Bracketing

Phenomenologists, in contrast to positivists, believe that the researcher cannot be detached from his/her own presuppositions and that the researcher should not pretend otherwise (Hammersely, 2000). Therefore, since the researcher has prior experience working with HIV positive people as a counsellor, she attempted to follow the guidelines of the phenomenological design (Creswell, 1998; Moustakas, 1994; Valle, 1998), which states that the researcher should "bracket", or hold her preconceived expectations about the data, and thus approach the interviews with an untainted perspective regarding what might unfold. Kvale (1996) remarks with regard to data capturing during the qualitative interview that it involves an interchange of views between two persons conversing about a theme of mutual interest, where the researcher attempts to understand the world from the subjects' point of view, to unfold meaning of peoples' experiences. At the root of phenomenology, the intent is to understand the phenomena in the respondent's own terms, to provide a description of human experience as it is viewed by the person him/herself and allowing the essence to emerge (Kvale, 1996).

Interviews were transcribed verbatim. Transcription was followed by the phenomenological data analysis as described in Creswell (1998). After transcribing the interviews, there were unclear statements from two participants. Therefore the researcher made follow up appointments to clarify those statements and get some additional information; the follow up interviews took 15 to 20 minutes.

3.4.2. Delineating units of meaning

Delineating units of meaning is a critical phase in phenomenological data analysis in that statements that are seen to illuminate the researched phenomenon are extracted or isolated (Creswell, 1998). The researcher started analyzing data by listing all the participants' expressions that are relevant to the experience. Following that, the researcher started the process of elimination, that is, to determine the invariant constituents. According to Creswell (1998), an expression can only be a prospect of the experience if (i) it contains a moment of the experience that is necessary and a sufficient element for understanding, and (ii) it is possible to abstract and label it. Expressions that do not meet these two requirements are eliminated. Groenewald (2004) further states that, for the researcher to be able to delineate units of meaning she has to consider the literal content, the number (significance) of times the meaning was mentioned and also how it was stated.

The researcher went through all the participants' statements and eliminated those which did not meet the requirements. Overlapping, repetitive and vague expressions were also eliminated. Groenewald (2004) cautions that during this stage of data analysis, the researcher is required to make a substantial amount of judgment calls while consciously bracketing his/her own presuppositions in order to avoid inappropriate subjective judgments. In this study, the researcher constantly reminded herself of the purpose of the study while doing the analysis, she read the interviews several times, bracketing her preconceived ideas and looked at the interviews objectively.

3.4.3. Clustering of units of meaning to form themes

Clusters of themes are formed by grouping units of meaning together (Creswell, 1998; Moustakas, 1994). With the list of the units of meanings, the researcher is again expected to bracket his/her presuppositions in order to remain true to the phenomenon (Groenewald, 2004).

The researcher rigorously examined the list of meanings of units, eliciting their essence within the holistic context (Moustakas, 1994). She followed the specified process and grouped similar or related meanings together to form themes which represented the experiences of taking HAART by PLWHA.

3.4.4. Validation

The final stage of data analysis was the validation. According to Creswell (1998), this is where the researcher checks the invariant constituents and their accompanying themes against the complete records of the research participants. The purpose is to establish if they are expressed explicitly and are compatible with the complete transcription. The researcher checked the statements against the transcriptions to ensure that the final document is a true reflection of the said experiences.

3.5. Reflexivity

According to Bless and Gigson-Smith (1995), researchers as human beings can never be neutral, particularly when dealing with social sciences. The researcher had worked with HIV positive people in a non-governmental organization before. Even though she never had an opportunity to explore how they were taking ARVs, she was exposed to general comments about treatment taking. However, she tried by all means to avoid leading the participants and remained as neutral as possible throughout all the interviews and also during the data analysis and interpretation of results.

3.6. Ethical considerations

During recruitment, the researcher introduced herself and explained the purpose of the study to each participant. An informed consent form was explained to all participants and they were asked to sign (see appendix 2). Participants were also informed that they have a right to refuse participation. The researcher made it clear to participants that they have a right to withdraw from the study at any time and if a participant decides to withdraw from the study, he or she may request the destruction of his or her information and that will not affect the continuous care he or she is receiving from the clinic. The researcher requested contact details of the participants so that she could arrange the time and venue for the interviews.

Permission to use a tape recorder was requested from the participants beforehand. Participants were assured that their information will be kept safe in a lockable cupboard and the only people to have access to the information are the researcher and the supervisor. They were further reminded that participation in the study is voluntary and they have no obligation to participate.

Participants were assured that their information will be kept anonymous by disguising their names and omitting anything that might lead to the disclosure of the participants' identity. It was also explained to the participants that the researcher will write notes as the interviews continue so that she may be able to ask questions for clarification. Participants were assured that the recordings will be deleted from the tape recorder as soon as the study is finished and that the transcriptions will be destroyed.

Each interview was assigned a code. Codes were Interview 1 up to interview 8. The researcher opened a folder in her computer in order to save the transcriptions. She transcribed the interviews and saved each interview in the folder. Transcriptions were later printed and put in a file for analysis. All the printed transcriptions and the notes taken during the interviews were kept safe in a lockable cupboard at the researcher's home office.

3.7. Summary of the Chapter

This chapter discussed the process that the researcher followed in recruiting the participants, data collection, data analysis, reflexivity and ethical considerations. Phenomenological data analysis was a tedious process because the researcher started with listing all the statements from each participant and removed the repetitive ones. From there, she scrutinized all the statements from all the participants through a process called delineation of the units of meanings. She later formed themes using the units of the meanings and finally she scrutinized the final analysis and went back to the original transcriptions to check for validity. This was a learning process not only about the content of the study but also how to do a phenomenological data analysis. The following chapter will detail the themes as they emerged from the clusters of meaning.

CHAPTER FOUR

4. RESULTS AND DISCUSSION

4.1. Clusters of themes

After rigorously examining the list of meanings of units, six major themes emerged from the study. Those themes are; Forgetting and use of memory aids, fitting treatment to daily routine, belief in the efficacy of medication, the experience of side effects, social support and disclosure and the relationship with the health care provider.

4.1.1. Forgetting and use of memory aids

Forgetting has been reported as one of the major causes of poor adherence and it has often led patients to alter medication times without informing the medical provider (Kleerberger et al., 2000; Chesney, 2000; Chesney, 2003). Therefore, similar to previous studies (Golin et al., 2002; Kleerberger et al., 2000), participants in this study reported that they sometimes forgot to take medication on time.

> "In the beginning, I was always late for my treatment. The thing is, I am unemployed; therefore I don't wake up at the same time every day. Sometimes I

would take them at eight [o'clock] or sometimes at nine [o'clock]. I did not have a fixed time." (Participant 3)

Forgetting to take treatment may lead to anxiety.

> "I forgot to take my medication and I remembered I think it was after two hours. I was so frustrated; I called the counsellor and asked what to do." (Participant 7)

Additionally, the participants in this study reported that in order to reduce chances of forgetting medication, they used electronic devices like cell phones and other forms of alarms to assist them to remember to take medication on time. The HBM suggests that cues to action are important elements in eliciting or maintaining patterns of behaviour (Brannon & Feist, 2004). Some participants reported that they used the personalized please call me message (a free sms text message that is available from all cellular networks) to remind their treatment partners about the time. Contrary to Adam et al. (2003), none of the participants found the reminders intrusive. All participants were happy to have them as an additional reminder for them not to forget medication

> "I set my phone alarm to remind me of my ARVs every morning. And, just to make sure I don't forget again, me and my treatment supporter send each other a '*please call ipilisi*' every morning and evening." (Participant 1)

However, participants reported that using cell phones as the only source of reminder was a risk because of different personal experiences. Some participants reported that they missed doses because when the time to take treatment came, the cell phone was not with them. Fifty percent of the participants reported that they lost their cell phones during the period they were on treatment.

4.1.2. Fitting treatment into daily routine

According to Ammassari et al. (2002), the extreme complexity of HAART regimens requires patients to alter their daily routines in order for them to be able to adhere to treatment. The participants in the current study reported that when they started taking HAART, they did not have fixed times to wake up in the morning nor did they have fixed meal times.

> "The ones in the evening were a problem. I take them with meals. So I would take them after supper and in my place we alternate cooking responsibilities. It depends on who is cooking and what time the meal will be ready. I can't say when." (Participant 2)

However, the participants in this study reported that when they changed their daily routines they were able to take treatment on time. Among the changes implemented by the participants was to establish new routines like meal times. The participants reported that changing the daily routine was guided by the treatment requirements because some of their ARV pills are taken on an empty stomach and others are taken with meals. Therefore, in addition to consistency with the

ARV treatment timing, establishing stable routines assisted participants with adhering to the requirements that come with the medication.

> "Unlike before when we just had dinner anytime it was ready, things have changed. We now have our dinner at 7:30 everyday when we're watching news on TV so that by 8pm I can take my treatment. So even if I'm not at home, come 7:30, I am hungry and I know it's time to go home." (Participant 8)

Changing the daily routine required the ability to take control of one's own life and to take responsibility of his/her own health. Self-efficacy Theory states that people can perform those behaviours that will produce desired outcomes in any particular situation if they believe they can. Therefore participants who were able to change their lifestyles to fit HAART demonstrated the ability to take control of their lives. Additionally, patients who believed in the efficacy of the medication willingly changed their lifestyles because their focus was on the desired outcome of their behavior which is improved adherence to HAART. Belief in self control made it easy for participants to take life changing decisions and establish new daily routines which were conducive to their treatment taking habits. Lewis et al. (2006) stated that self-efficacy involves a degree of confidence patients have in their ability to adhere to HAART and assumes that patients who manage to adhere to their medication experience a sense of control.

Moreover, developing new habits required commitment to the changes that one had made into his or her lifestyle. The participants recognized the need to regain control over their lives and their health.

> "I wanted this treatment to work. I was prepared to do anything to make sure that I live longer. My child needs me." (Participant 2)

However, it must be noted that although the participants reported that they succeeded in maintaining high levels of adherence once they changed their daily routines, occasionally doses were missed if the routines was disrupted. In their study on adherence practices among people living with HIV, Adam et al. (2003) stated that memory is supported by routine and any disruption to the routine might lead to poor adherence. For example, some participants in this study reported that they experienced challenges with adherence if something that required them to be away from home occurred. The female participants reported that when the child was sick or if they had to take care of something else which was not part of their usual routines, they forgot to take medication with them and as a result they missed some doses.

> "I remember my child got sick in the middle of the night. I went with her to hospital. I did not think about medication until late that day." (Participant 5).

According to Adam et al. (2003), disruptions to routine may be associated with weekends, sleeping in, partying and travelling. The male participants in this study reported challenges with adherence over weekends especially with the evening dose. This is because they would either be visiting friends or have friends coming over. On the contrary participants in Lewis et al.'s (2006) study reported that they recognized the need for personal accountability and accepted that there are things that they had to give up in order to succeed with antiretroviral treatment. Therefore they took control of their lives, and made sure that nothing stands in their way of achieving 100% adherence to HAART.

4.1.3. Belief in the efficacy of medication

Patients who believe in the effectiveness of their HAART medication are more likely to adhere than those who perceive fewer benefits of taking their medication (Wagner, et al. (2003). As assumed by the health belief model, participants in the current study, who believed that they would benefit from taking HAART, reported making every effort to adhere to medication. The confidence in the effectiveness of the ARV treatment paid off because participants developed pride in their accomplishments of managing their illness and medications. They described an experience of feeling triumphant when they could see improvement in their physical appearance.

> "I was able to look at myself in the mirror again. It was… I can't even explain it. You would think I won a lotto. I screamed with joy. I looked good." (Participant 1)

Another participant explained:

> "My hair was thin and falling but now. Now I can do braids. You know what, I am human again."

The participants further explained that seeing improvement in their health made it possible for them to dream of the future again.

> "I want to go back to school to finish my matric. I want to be a nurse and I know that with ARVs, I can do that. They [ARVs] have changed my life for the better." (Participant 6)

Female participants frequently referred to their children and they used that as a motivating tool to encourage themselves to continue with medication.

> "When I feel down and tired of taking ARVs, I look at my children and say, I will live for them. I tell myself that this is my only hope to see my children grow." (Participant 5)

Additional to personal observation of health improvement, medical reports about the increased CD4 count and decreased viral loads confirmed and enhanced the participant's beliefs in the efficacy of the medication.

> "Within nine months my viral loads was undetectable. From then on, there was no reason not to take my medication. It works." (Participant 4)

However, participant number seven reported that he hated taking ARVs because they were a constant reminder he is HIV positive. He reported that when he initially took the treatment from the clinic, it dawned to him that he really is going to live on treatment and that was something he was not prepared to do. As the HBM assumes, he focused on all the barriers that would make it impossible for him to live on treatment and decided that it was a mistake to accept the pills. He explained:

> "You know, I felt, what's the use of taking this treatment? Once you have AIDS, you are going to die, so why torture yourself with pills every day. I did not follow any of the things the doctor and counsellor said. I just did not take them."

However, the severity of the disease forced some participants to take ARV medication. Two of the participants in this study took medication when they we hospitalized because of the HIV complications. The HBM states that the severity of the disease may encourage the person to adhere to health behaviour (Brannon & Feist, 2004).

> "I ignored these pills until I was in hospital. I could not walk by myself. I was carried to hospital but within two weeks of taking the treatment regularly I saw the difference. They changed my life." (Participant 7)

Belief in the effectiveness of medication may be influenced by the information one has either for or against treatment. For example, one participant in the current study reported that he believed that ARVs kill people. He reported:

> "I heard that this treatment was a poison. It kills people. So I decided not to argue with the doctor, I took it home, but I never swallowed one pill until I became worse and was admitted in hospital. I was afraid"

Similar to the findings of Remien et al. (2003), participants in the current study reported taking breaks without informing the health care provider. For some participants, taking breaks was based on previous experience of taking TB treatment. They therefore ignored the instruction to take ARVs daily and felt that they were entitled to weekends off.

> "You know what; I thought that it was okay not to take treatment on weekends. This is what I used to do when I was on TB treatment. I didn't see anything wrong with it really" (Participant 4).

Remien et al. (2003) warns that health care providers should be aware that previous experience informs medication taking habits. Patients will always use the previous experience as a benchmark for taking medication which could have detrimental effects in strict regimens like HAART.

On the other hand, even though participants recognized the benefits of antiretroviral medication, some participants were unhappy with their lives being centered on taking ARVs. Participants reported intrusive worries about the possibility of not being able to take their medications due to unforeseen illnesses, or having uncontrolled side effects. Some participants expressed concerns about the possibility of treatment not working after using it for a long time.

> "The only thing that makes me unhappy is, I am always thinking about this medication all the time. I don't know what is going to happen when. Am I going to live long or the treatment is going to stop working at some point? It's frustrating to deal with something you don't know." (Participant 2)

4.2.4. Experiences of side effects

Similar to previous studies (Adam et al., 2003; Duran et al., 2001; Roge et al. 2004; Reynolds et al., 2006 & Remien et al., 2003), side effects that participants commonly mentioned in the current study were nausea, vomiting and headaches, fatigue and bad dreams especially during the first weeks of starting treatment. The consequences of the ARV side effects differed from person to person depending on the severity of the discomfort and perceived outcome of the symptoms. Some participants in the current study reported instances where they would intentionally skip doses as a means of alleviating side effects.

> "When I started treatment, I was always nauseous; I felt like there is a lump in my throat all the time. I couldn't eat the whole day such that, I think on day 3 I decided not to take treatment then I took it the following day. I did that on and off I think for two weeks." (Participant 1).

However, contrary to the findings of Remien et al. (2002), none of the participants in this study reported completely stopping treatment due to side effects. Despite those who skipped doses due to side effects, most participants reported that they were able to tolerate the side effects. This confirmed the theory of the HBM which stipulates that beliefs in the benefits of a health enhancing behaviour must outweigh the beliefs in the barriers of the behaviour for adherence to be successful (Brannon & Feist, 2004).

> "The truth is, even though the counsellor had told me what side effects to expect, the actual experience was too much. Walking around with nausea and a headache was not easy. But I could not stop taking my treatment. My life depended on it." (Participant 6)

Max and Sherer (2000) support the notion of informing patients about side effects even before they are given the first prescription. These researchers argue that informing patients about possible side effects helps them to take informed decisions on whether to start treatment or not and it also enhances adherence because, with enough information, patients are likely to continue with treatment despite the side effects. One participant in the current study reported that she never experienced any side effects. She explained:

> "I never experienced any side effects. Never, I just took my medication and nothing changed."

On the other hand, participants who had taken treatment for two years and more reported different challenges than when they started taking treatment. These participants reported that they were starting to experience long term side effects and that brought doubt as to whether they should continue with treatment or not. Similar to the findings in Alfonso et al. (2006), these participants reported feeling exhausted by the efforts of managing their own health. One participant who had taken ARV treatment for five years had developed kidney problems which the doctor attributed to long term ARV therapy. She reported that the doctor instructed her to drink five or more litres of water per day. She explained:

> "I sometimes feel that I should stop taking this treatment. But, I know how I was before I started on ARVs. I don't know what to do."

Most participants in the current study reported that they were adherent despite the unpleasant side effects, including those who skipped doses when they started treatment. Participants were aware of the limited treatment options in South Africa and they wanted to delay going to the second line regimen as long as possible. The continuation of the participants to take treatment despite the side effects could be explained through the HBM's perceived benefit of following a healthy program (Brannon & Feist, 2004). The perceived benefits (improved health) of taking ARVs outweighed the experienced barriers (side effects) and the belief in the effectiveness of treatment encouraged the participants to continue with treatment.

4.2.5. Disclosure and Social support

According to Klitzman et al. (2004), taking antiretroviral treatment can facilitate disclosure which in turn can promote adherence while failure to disclose HIV status may affect adherence to treatment and may lead to stress. Persons desiring to avoid the experiences of stigma may use whatever means at their disposal to avoid disclosure, including skipping doses, dissembling or disguising the fact that one is taking medication for HIV/AIDS (Ware Wyatt and Tugenberg, 2006). Some participants in the current study reported that initially they concealed their status from the family members because of the fear of stigma. The concealment of HIV status meant that the participants must hide their medication which was not always possible especially if one lives with the whole family.

> "I kept my ARVs in my suitcase where I know, nobody will see them. I remember, when the time comes, I had to find the reason to go to the room alone

> so that I can quickly take my treatment. You know, I even learnt a skill of swallowing treatment without water." (Participant 5)

The reaction of participants in this study towards fear of discrimination is similar to previous studies (Gonzalez et al., 2004, Ware, Wyatt & Tugenberg, 2006). People who feared being discriminated against in Gonzalez et al.'s (2004) study reported that they concealed their status and had difficulties in taking medication in the presence of other people, some had to sacrifice taking medication in the presence of friends and others removed the labels and lied about the medication they were taking. In this study, when participants were confronted with the dilemma of being with other people at dosing times, they had to weigh their chances of getting away with treatment without being noticed or skipping the dose. These were hard decisions to make because of the awareness of possible viral mutations and drug resistance.

> "When I started [taking medication], I missed my doses when my friends were around. You know mos, men don't just take medication. There must be something really wrong. So I would sit around and chat hoping that as soon as they leave I will take it but sometimes it would be so late that I missed that dose." (Participant 3)

Adherence and being a member of the family became competing priorities rather than co-existing. For example, married female participants whose HIV status was not known by their in-laws reported that adhering to medication was a challenge when they visited or got visited by their in-laws. These participants reported that they were not prepared to disclose to their in-laws because they feared that they might be accused of bringing HIV into the family. The participants reported that the in-laws have specific expectations for a woman who marries into the family, one of which is that she must bear as many children as possible for the family to grow. This increased the fear of disclosing because the participants feared that they might lose their husbands due to pressure from the in-laws about their inability to give them what they want.

> "They could see that I am sick but they did not care. All they wanted is for me to have children (crying). With my third baby, I was on ARVs but she is positive. I could not take them; I was afraid they will see them and chase me away." (Participant 6)

In extreme cases, participants consciously decided not to take treatment to avoid disclosure.

> "I stayed without medication for the whole weekend. I was frustrated, but I could not risk disclosing our status. My sisters in-law are the worst monsters. They would make sure that I suffer if they found out." (Paericipant 8)

According to Banerjee et al. (2000), it is important to understand traditionally held beliefs in causes and characteristics of diseases like HIV for facilitating communication about the disease to the population and to reduce the related stigma. The decision not to take treatment can be understood from the foundation of Self- Efficacy Theory which states that physiological arousal states such as feelings of anxiety decreases self-efficacy (Bandura, 1986). For these women, it was easier to defer treatment than to face the questions of the family about the nature of the medication they were taking.

However, living far from home reduced the pressure of disclosing to family for most participants. Some participants reported avoiding family gatherings.

> "I haven't gone home [Eastern Cape] for four years now. I am afraid that after a few days people will notice the alarm and the treatment. I am not ready to explain that I am HIV positive let alone being on ARVs." (Participant 2)

Nonetheless, taking ARVs may inadvertently disclose the infected individual (Klitzman et al., 2004). Participant in the current study acknowledged that it was possible that most people who knew what they looked like when they were sick, know that they are HIV positive. The improvement of their health due to ARVs was reported as a possible disclosure on its own.

> "I think my neighbours know. They can see that I am no longer carried by people to hospital now, I can walk by myself. People know these days that there is treatment. But, I don't mind as long as I feel better." (Participant 6)

Moreover, ARVs side effects were seen by some participants as promoting stigma against PLWHA. Participants acknowledged that people who know about ARVs will notice body changes and attribute that to ARVs. Therefore some participants reported that they had to accept that people will eventually find out that they are HIV positive. In some cases they saw how people looked at them and they knew that they are suspicious of the treatment they are taking.

> "I used to have a great [physical] structure, but now my legs are thin, my breasts have grown big, I just look funny. I don't wear short skirts anymore. People who know about ARV side effects will put one and one together.... I'm fine with that as long as I feel healthy." (Participant 8)

On the other hand, similar to other studies (Alfonso et al., 2006; Remien et al., 2003), one participant who had disclosed to family members, reported misunderstandings regarding her emotional needs. The response from family was not as she had expected which she expressed as to be encouraged to take treatment and to be left to make her own decisions. Instead, she reported that she was treated like she cannot think on her own and some decisions were taken on her behalf. She complained:

> "They talk about me as if I'm not there. I mean, they take decisions on my behalf. My mother would go on; No, [name] cannot do that, she is sick. I can speak for myself. I'm not dead I am just HIV positive. That really irritates me"

However, consistent with previous research (Gonzalez et al., 2004; Remien et al., 2003) which state that the perceived quality of support that participants received was associated with less depression and it enhanced good adherence to ARV treatment, most participants in this study reported that the positive support they received from family and friends encouraged them to adhere to medication.

> "My mother is my pillar of support. When I told her that I am going to take ARVs, she sat me down and told me that she will support me no matter what. You know, she always wants to know how I am doing and she tells me that I look good since I started treatment. That is really encouraging" (Participant 2)

Rao et al. (2007) and Davies et al. (2006) found that HIV positive people who live with partners and have disclosed their status are more likely to adhere because their daily routines tend to be stable and they have support within the home. The involvement of partners may assist with identifying adherence barriers like child care, and transport money. It also reduces the anxiety of hiding treatment from the partner.

> "I and my husband are both on treatment. This makes life easy because we take treatment at the same time. We support each other." (Participant 2)

The study on social support, positive states of mind and HIV treatment adherence in men and women living with HIV/AIDS by Gonzalez et al. (2004) found that perceived quality of social support was significantly associated with medication adherence. Even in the current study, participants who had their close family members' support reported that adherence for them was fairly easy.

Additionally, in support of the assumption of Self-Efficacy Theory which states that the vicarious experience of seeing another person with similar skills perform behaviour strengthens the ability to pursue a similar behaviour, joining a support group of PLWHA was reported as beneficial by most participants in the current study. They reported that support group members that were on HAART were more supportive and understanding than family. Participants who were unable to disclose to anybody at home reported that belonging to a support group filled the gap. Attending a support group gave them a sense of belonging.

> "They understand how I feel, what I am going through, everything. You know there are days when you feel you are really tired of the ARVs. But when I go to the support group; I come back with new hope that I can live." (Participant 3)

Conversely, some participants reported a different form of concern about taking ARVs. They referred to the fact that ARVs are advertised everywhere and they believed that a lot of people know what the pills look like. Participants reported that they also take note of somebody who takes treatment at particular times especially if they try to hide it or if an alarm rings before they take treatment. As a result some participants reported delayed or missed doses when they were in public places.

> "Just the other day, not long ago, my alarm rang in a taxi. I decided not to take the treatment immediately because I was afraid people will notice. I knew I was supposed to take my treatment otherwise I would be late. But I did not. I took them, I think, twenty minutes late when I got out of the taxi. This life is not easy my sister." (Participant 7)

4.1.6. The relationship with the health care provider

The quality of care offered by professional staff can promote adherence to HIV medication (Fehringer et al., 2006; Schneider et al., 2004). In the current study, positive and caring relationships between the participants and the health care providers promoted adherence. One participant reported:

> "The doctor and the nurses care a lot. In fact, even the counselors. Every time I come for treatment they always want to know if I am happy with the treatment or if I want to know anything more. I like that because it makes me free to talk."

The positive relationship between the health-care provider and the patient may increase the patient's ability to adhere to HAART. The self-efficacy theory assumes that verbal persuasion or listening to the encouraging words of a trusted person increases the person's belief in the ability to perform behaviour. Therefore a doctor or a nurse plays an important role in increasing the patients' confidence in the effectiveness of the medication. How they ask questions and their physical reactions to the patients' efforts can act as an enhancer to adherence (Fehringer et al., 2006). Kagee (2004) suggests clear instructions to patients such as the presentation of oral and printed material.

However, some participants in this study were not satisfied with the way in which some health care providers dealt with them. They reported that, as ARV patients, they were judged and accused of non-adherence whenever they came to the clinic for something else.

> "The other day I came here because I had flu. Now, because I am on ARVs they started asking a lot of questions about treatment and how I am taking it. When you are on ARVs you are treated like a fool here. You cannot be sick otherwise

> you will be accused of defaulting. It's like; I am no longer human because I have HIV. They treat you like a virus or some kind of animal." (Participant 3).

Studies have shown that patients who are satisfied with their providers are more likely to comply with treatment recommendations than those who feel they are not (Fehringer et al., 2006). The impact of the health care professional's attitude can have a detrimental effect in adherence to HAART. The way health care providers address the patients may lead to poor adherence (Fehringer et al., 2006). None of the participants complained about waiting in the queues to get treatment.

4.2. Summary of the chapter

This chapter discussed the results of the study. Six themes are discussed in detail. The first theme described the PLWHA's experiences of forgetting and how that impacted on their adherence practices. Forgetting occurred mostly during the initial stages of taking. The researcher detailed how the participants derived means to reduce forgetting. The use of memory aids like cell phones and alarms and also treatment supporters to enhance adherence is mentioned in this chapter. The second theme looked at how participants attempted to fit treatment into their daily routine. The researcher looked at the participants' experiences of changing their lifestyle in order to accommodate ARVs. The discussion referred to the participants' attitudes towards changing their lifestyle and the benefits they derived from fitting treatment into regular daily activities.

The third theme focused on beliefs in the efficacy of the ARV medication. Positive attitudes towards the medication encouraged participants to follow adherence procedures and the benefits of adhering to the treatment resulted in health improvement which in turn promoted adherence to HAART. The fourth themes centered on the participants' experiences of ARV side effects. The discussion is about how participants experienced side effects and the actions they took to alleviate the discomfort. The fifth theme discussed disclosure and social support. In this theme the researcher discussed participants' experiences of both positive and negative social support. The participants' perceptions of the outcomes of disclosure and the decisions they took are referred to in this chapter. The sixth theme discusses the influence of the relationship between the participant and the health care provider in adherence to HAART.

CHAPTER FIVE

5. CONCLUSION

According to Murphy et al. (2000), the structures of everyday life have major impacts on consistent adherence to pill-taking regimens. Reports from the participants in this study revealed that taking ARVs is not easy, especially during the initial stages. Chances of forgetting treatment become increased as participants are not used to a regulated regimen which in most cases does not fit into their daily routines. Therefore, taking ARV treatment is similar to introducing a new habit and it requires that one modify his or her lifestyle in order to accommodate the medication. Similar to previous research (Adam et al., 2003; Murphy et al., 2000), the current study revealed that linking antiretroviral treatment to regular daily routines especially waking times and meal times improves adherence to ARV treatment. However, participants also acknowledged that adherence to HAART is not only about taking pills every day but also about taking it at the same time daily. As a result changing their lifestyle to fit treatment included fixing meal times so that they can be able to adhere to treatment timing as well.

Because HAART is a lifetime commitment, a positive attitude towards treatment was reported as a motivating factor to adherence. Positive attitudes were highly influenced by the belief in efficacy of the treatment. According to Adam et al. (2003), perception of the effectiveness of medication has the potential of leading to self-reinforcing processes where belief confirms adherence and adherence better ensures effectiveness. The participants in this study confirmed this statement because they reported that once they observed improvement in their health they were even more motivated to take their treatment. This motivation was enhanced by medical reports which showed improvement in their CD4 counts. Health improvements made it possible for the participants to start focusing on future plans which further encouraged them to adhere to ARV treatment.

However, perceived ineffectiveness may generate a lack of trust in medications which in turn may diminish adherence and thus potential effectiveness (Adam et al., 2003). This was demonstrated by a participant in the current study who failed to take the medication because of negative beliefs that ARVs are poisonous.

Previous studies have shown that medication side effects were one of the primary reasons for people stopping their medication regimen (Murphy et al., 2003). In this study participants reported skipping doses in order to alleviate the side effects but none of the participants reported completely stopping medication. Most participants were able to tolerate the side effects and they attributed that to the information they were given about possible side effects even before they were initiated on the treatment. Max and Sheerer (2000) support the notion of informing people about side effects even before their first dose so that they take informed decisions as to whether to continue with treatment or wait until they are ready. Additionally, the belief in the long term benefits of taking ARVs encouraged participants to continue with medication despite the side effects.

As Ware et al. (2006) stated, participants in their study felt that being seen with pills risk disclosure to a person living with HIV. Rather than taking that risk, some participants in the current study chose to compromise their adherence. According to Ware et al. (2006), when health and social interests are experienced as being in conflict, social interests may well take precedence. Similar responses were reported in this study where participants would delay taking treatment in the presence of friends which sometimes ended in a total miss of the dose because of the fear of stigma and discrimination. However, positive support from family and friends promoted adherence to HAART. Some participants who had disclosed to their partners and family received support; family members acted as treatment reminders and were able to take care of things that would have been barriers to adherence.

Participants who were attending a support group received additional support from people they could identify with. Through the support group, the participants reported that they did not only receive support from other HIV positive members but they also found space to be themselves without the fear of being judged by others. The support group also helped as a measuring yardstick for those who were due to start treatment to see that ARVs can improve people's lives by looking at the physical appearance and the sharing of information that happened there which included advice on how to deal with side effects and any other infections that come with the HIV positive status. Participants also got an opportunity to support others and to motivate themselves to continue with treatment.

Nonetheless, some participants were unable to disclose to extended family members. The study revealed that disclosure and adherence were a challenge for married women because of the pressures and expectations of the in-laws. However, it was not always possible to completely hide antiretroviral therapy. As stated in Klitzman et al. (2004), antiretroviral therapy can facilitate HIV disclosure. For example, participants reported that people suspected that they are on ARV therapy when their health, and their physical appearance, improved. They endured being gossiped about.

Finally, most participants were satisfied with the quality of care they received from the health care facility. Research has shown that patients who are satisfied with the service they receive from health care practitioners are more likely to comply with the treatment recommendations than those who are not (Fehringer et al,, 2006; Schneider et al., 2004). However, the attitudes and the language the health care providers use may not be sensitive to clients and may lead to poor adherence. For example, in relationships with health care provider, participants voiced his dissatisfaction with the attitude of health care providers to ARV patients. The participant felt that he was falsely accused of non-adherence because he got sick while on treatment and he reported that he was not sure if he wanted to go back to the facility again. This may impact on his treatment because going to another facility may break his adherence because he will have to go through preparation sessions before accessing treatment.

5.1. Limitations

Participant selection undertaken through a method of purposive sampling, therefore the results of the study cannot be generalized to other populations. The selection could have been biased because the researcher depended on the patients referred to her by the clinic staff. Although the criteria were clear and discussed with the clinic staff, patients may be influenced by the staff member or the choice could be of those the staff member thought were adherent. Moreover, the study is cross sectional; therefore participants that were selected were those who came to the clinic during the period of the research. This limited the diversity of participants that a researcher could have interviewed.

Furthermore, the researcher realized during the data analysis that the target group was wide. The study could have brought better results if it was focused on one target group: either men or women. Although studies are indicating that there are no significant differences in the experiences of men and women in terms of adherence to ARVs, issues between the two in a cultural context may be different. Lastly, the exploratory, phenomenological nature of this study limits drawing any causal conclusions.

5.2. Recommendations

The findings from this study suggest implications for practice and research. Health care professionals may assume that a person living with HIV/AIDS has accepted his or her HIV status before accepting HAART but the study has shown that this assumption may not be true. The fact that ARV treatment is a reminder that a person is living with HIV may have negative effects in adherence and may quickly lead to treatment fatigue. Therefore health care practitioners need to probe into what other motivating factors patients have for taking treatment. Follow up sessions after the initiation of the treatment may have to focus on the purpose of taking HAART and how that is used as a reminder for adherence.

Most importantly, this study revealed that disclosure is a challenge when it comes to married women and their in-laws. Cultural expectations and positive living with HIV have a potential of clashing because the expectations of in laws may not match with the health needs of the women married into the family. Further studies are needed to explore the influence of culture in decision making by women with regards to their health. Because many black people who live in the Western Cape come from the rural Eastern Cape, possible linkages should be made between health care facilities so that the community health care workers are able to provide further support to people who live in the Western Cape and visit the Eastern Cape or vice versa. Lastly, more awareness campaigns focusing on the benefits of taking ARV could help to de-stigmatize ARVs and to encourage disclosure.

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TO WHOM IT MAY CONCERN

UWC Research Ethics Clearance: UWC Project Number: 07/7/2 : "Adheren to HAART: Experiences of Men and Women Living with HIV in the Western Cape Provin South Africa."

Principle Investigator: Ms Nomonde Ngada
Supervisor: Ms Maria Florence.

This is to certify that the above project has received research ethics clearance and has be registered as a research project of the University of the Western Cape.

Yours faithfully

Renfrew Christie

PROFESSOR RENFREW CHRISTIE
Dean of Research
27 June 2008

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CITY HEALTH

6 JULY 2008

Ms Nomonde Ngada
Student number: 2646236
University of the Western Cape

Dear Ms Ngada

RE: YOUR REQUEST TO CONDUCT RESEARCH AT IKWEZI CLINIC

Your request dated 23rd April 2008 to conduct research on "Adherence to HAART: Experience Men and Women Living with HIV in the Western Cape Province, South Africa" refers.

I hereby authorise you to collect the relevant data for the above research project as outlined in y research protocol.

This authority is only for Ikwezi clinic and any other relevant clinic operated by City Health in Eastern Sub-district, City of Cape Town, and only for the purposes stated in your resea protocol.

We shall also ask you to present your findings either or during at the conclusion of your research

Regards

DR PAUL NKURUNZIZA
MANAGER HEALTH: EASTERN SUB DISTRICT
CITY HEALTH

UNIVERSITY *of the* WESTERN CAPE

DEPARTMENT OF PSYCHOLOGY

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Appendix C1

Information leaflet and informed consent to participate in a research study

Dear Sir/Madam

I am Nomonde Ngada, a Masters research student at the University of the Western Cape. Presently I am engaged in the research project titled: Adherence to HAART: Experiences of man and women taking HAART in the Western Cape Province.

The purpose of the study is to understand how people Living with HIV/AIDS describe their daily experiences of taking HAART.

You are invited to participate in this research project because you are on HAART treatment. If you accept the invitation, you are agreeing that I will meet you on the agreed date, time and location for an interview that will last for almost 60 minutes. During the interview, I will be taking notes to keep track of the discussion. In order to get all the information you will be sharing I will use a tape recorder. The audio tape will be analysed by me, the researcher.

During the interview, questions will be asked about your experience of taking antiretroviral therapy. Some of these questions may bring back difficult memories. However, please be assured that you may stop the interview at any time or you can refuse to answer specific questions. You are also free to discontinue participation at any time and this will not affect your ongoing treatment at the clinic. Should you choose to discontinue, you can request that all data collected about you, including tapes and transcriptions of tapes be destroyed. If you participated in the study and you are interested in the findings of the study, they will be communicated to you as soon as they are available.

I undertake to ensure anonymity of your name by disguising your real name and any other information that might reveal your identity. The information from the transcribed tape may be accessed by my supervisor since she will be assisting me with writing up the research.

I ………………………………………… have discussed the above with the participant. In my opinion, I am convinced that the participant understands the benefits, risks and obligations involved in participating in this research project.

…………………………………… ……………………

Signature of interviewer Date

CONSENT FORM

I …………………………………………… understand the information in this leaflet. I am aware that participation is voluntary and that I may withdraw from the research anytime without repercussions. I understand that participation in this study is not related in any way with accessing health care services from my clinic and my withdrawal will not affect my care.

………………………………………..   …………………………….

Signature of participant   Date

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Appendix C2

Uxwebhu lwengcaciso nesivumelwano sokuthabatha inxaxheba kwimfuna lwazi

Mthabathi-nxaxheba obekekileyo

Igmam lam nguNomonde Ngada. Ndingumfundi kwiziko lemfundo enomsila uDyunivesithi yase Ntshona Koloni. Ndenza izifundo zemfuna-lwazi esihloko sithi malunga nendlela abaziva ngayo abantu abasela iipilisi zokuthomalalisa intsholongwane kagawulayo. Ngesilungu isihloko sale mfuna-lwazi sithi: Adherence to HAART: Experiences of man and women taking HAART in the Western Cape Province.

Uyamenywa ke ukuba uthabathe inxaxheba kule mfuna-lwazi kuba wena usitya ezi pilisi zokuthomalalisa intsholongwane kagawulayo. Ukuba uyasamkela esi simemo, uyavuma ukuba uza kudibana nam ngosuku, ixesha nendawo esizakuvumelana ngayo ukuze sibe nodliwano ndlebe. Udliwano ndlebe luyakuthatha malunga neyure enye. Xa sisenza udliwano-ndlebe, ndizakubhala amanqaku phantsi ukuze ndizokwazi ukuba besithetha ngantoni. Ukuze ndikwazi ukufumana konke eskube sithethe ngako ndakusebenzisa isishicileli. Iyakuba ndim ndedwa oyakusimamela isishicileli.

Xa sisenza udliwano ndlebe, imibuzo iya kuba malunga nendlela ozisela ngayo iipilisi. Mhlawumbi eminye imibuzo iya kubuyisa iingcinga ezingemnandanga. Kodwa ke ndifuna ukukuqinisekisa ukuba ungayeka nanini na ukuthabatha inxaxheba. Kunjalo nje ukuyeka kwakho ukuthabatha inxaxheba akusayi kuchaphazela ubudlelwane obunabo neziko eli lezempilo. Xa kunokwezeka ugqibe kewlokurhoxa ukuthabatha inxaxheba unalo ilingelo lokucela ukuba yonke into ebisele ishicilelwe malunga nawe itshitshiswe. Ukuba onawo umdla wokwazi ziphumo zale mfuna-lwazi, unganxibelelana nomfundi lo ukuze yena akwazise nje ukuba agqibe ukuzihlela.

Ndiyafunga ukuba ndiyakuqinisekisa ukuba akukho bani waziyo ukuba ngubani pthabathe inxaxheba kule mfuna-lwazi ngokuthi igama lakho ndiligquke kwaye ndigquke yonke into enokwenza ukuba kukrokreleke ukuba nguwe. Qaphela ukuba umfundisi-ntsapho ondiphetheyo uzakwazi malunga nale ngxoxo kuba nguye ondincedisayo ukuhlanganisa le mfuna-lwazi.

Mna .... ndimcacisele umthabathi-nxaxheba ngayo yonke le nto ibhalwe ngentla. Ngokokwam ukuqonda, ndiqinisekile ukuba umthabathi-nxaxheba uyazi malunga nenzuzo, ubungozi kunye nezobophelelo ezihamba nokuthabatha inxaxheba kule mfuna-lwazi.

....

Umfundi Umhla

ISIVUMELWANO

Mna ………………………………………………… ndiyayiqonda ingxam yokubhalwe kewli phepha. Ndiyazi ukuba ndithabathe inxaxheba ngokuthanda kwam kwaye ndingarhoxa kule mfuna-lwazi nanini na ndifuna akukho sibophelelo sizakundijikela. Ndyazi ukuba ukuthatbatha kwam inxaxheba kolu dliwano-ndlebe alunanto yakwenza nobudlelwane bam neziko lezempilo kwaye aluzukuphazamisana nonyango lwam.

…………………………………..

Umthabathi-nxaxheba

……………………………..

Umhla

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Appendix D

INTERVIEW GUIDE

A. Background Information

1. When did you start taking ARV treatment
2. How long have you been on treatment

B. Interview questions

1. Describe how you take your ARV treatment
2. How do you remember to take your medications?
3. Have you had any problems with your medication?
4. Have you had any problems with collecting your medication?
5. Do you have any other form of support?