

**ADHERENCE TO ANTI-RETROVIRAL TREATMENT:
PERCEPTIONS OF CHALLENGES AND EXPERIENCES
AMONG PEOPLE LIVING WITH AIDS**

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Key Words: adherence, compliance, antiretroviral, morbidity, regimens, non-adherence, medication, side-effects, resistance, health-provider.

Abstract

New antiretroviral therapy has given hope to HIV-infected people, but the medication requires strict optimal adherence if suppression of HIV is to be maintained. Successful long-term treatment of HIV/AIDS requires at least 95% adherence to ARV medication in order to prevent emergence of drug-resistant HIV variants that lead to regimen failure and limit options of future therapy. Barriers to successful adherence to medication include patient-related, provider-related, regimen-related, disease-related, and systems-related factors. This study focused on the understanding of participants' perceptions of challenges and solution to adherence to antiretroviral medication. In-depth interviews, using semi-structured schedules, were conducted with 10 HIV positive males and females between 18 and 30 years old, and on ARV treatment at a clinic in Crossroads. From the qualitative data, study deracinated a number of patients' perceptions of challenges and experiences they face in their battle with HIV/AIDS. These include patients' self-efficacy to take doses as prescribed, beliefs about taking medication, knowledge about HIV, counselling and education, denial, lack of food and hunger, stigma, perceived social support, side-effects, patient satisfaction, privacy and confidentiality, the challenge of alcohol, depression, and relation to health providers. The findings of the study indicate that effective adherence to medication requires long-term commitment and easy access to medication and HIV/AIDS education programmes to minimize the stigma of the disease. An important implication of the study is that programmes that identify and address barriers to adherence should be aligned with professionals who provide clinical care. The study further recommends that a longitudinal study that tracks adherence for some time,

together with evaluations should be performed to identify lapses in adherence, treatment failure, non-adherence, and reduced quality of life for HIV positive people.



DECLARATION

I declare that this thesis, from conception to execution, except where indicated, is my own work. All sources used or quoted in the text have been acknowledged.



ACKNOWLEDGEMENTS

I would like to thank the Almighty Father, for without His Guidance and His grace I would not have achieved the goals that I have accomplished. I would also wish to express sincere gratitude to the following people who contributed to this study and who made it possible through their continual support and understanding

- My supervisor, Prof Kevin Mwaba, for his valuable time, guidance and support
- The respondents who participated in this study
- The provincial Department of Health, for allowing participation in this study
- Ms Sharyn Spicer, for her constant motivation, support and encouragement.
- Prof Malcolm, the Head of the Department of Psychology, who made it possible for me to access financial resources
- Lastly, I would like to extend a word of gratefulness to my colleagues, for their constant support and friendship.



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CHAPTER ONE

INTRODUCTION

1. Background to the study

1.1.1 HIV/ AIDS prevalence in South Africa

Sub-Saharan Africa is the global nucleus of HIV/AIDS, and still the most affected place in the world. Although with just over 10% of the world's population, the region is home to more than 60% (24, 5 million) of HIV-infected people (UNAIDS, 2006), and it represents 77% of women with HIV, 79% of AIDS deaths as well as 92% of the world's AIDS orphans (Mills, Nachega, Buchan, Orbinski, Attaran, Singh, Rachlis, Wu, Cooper, Thabane, Wilson, Guyatt & Bangsberg, 2006). In 2005, about 2 million people died of HIV/AIDS in the region, while an additional 2, 7 million people became infected with HIV (UNAIDS, 2006).

South Africa, on the other hand, is presently experiencing one of the most severe HIV/AIDS epidemics in the world, and the disease has caused a lot of suffering in the country (UNAIDS, 2006). Approximately 1, 700 people are newly affected everyday and about 4. 2 million South Africans are infected, making the country with the highest figure of HIV-infected people in the world. Earlier projections suggested that about six million

South Africans would be infected with HIV by 2005 and that without intense adherence to antiretroviral medication, the mortality rate and of HIV/AIDS will reach 800 000 deaths in a year by 2010. However, increasing access to antiretroviral therapy, which has the potential to decrease morbidity and mortality, could change the trend substantially (Nachega, Lehman, Hlatshwayo, Mothopeng, Chaisson & Karstaedt, 2005).

In South Africa, there are discernible societal and cultural features of 'the endangered groups', with mostly black or coloured, mostly urban or suburban, mostly young (between 15 and 40 years), and more men than women. The major fact is that young men, already living in the big cities, most often in poor townships, shanty-towns or squatting areas, or young migrant workers or unemployed youngsters, from inside South Africa or the neighbouring countries, are certainly the most endangered section of the population (UNESCO, 1999).

Degrees of HIV infection vary across different geographic regions in South Africa. Of the nine provinces, KwaZulu/Natal has the highest prevalence. Contrarily, the Western Cape, whilst remaining the province with the lowest level of infection, indicates a sharp increase in infected population. For instance, Khayelitsha, a township in Cape Town with a population of 400 000 inhabitants had a HIV seroprevalence of 24,9% in public-sector clinics in 2002, with 25 patients placed on ART each month (Coetzee, Boulle, Hildebrand, Asselman, van Cutsem & Goemaere, 2004).

For each person living with HIV in South Africa and everywhere else, it does not only affect their lives, but also emotionally affects their families, friends, and wider communities (UNAIDS, 2006). The HIV/AIDS epidemic has also negatively changed the lives of many in South African in the townships. Most of the people who live with HIV/AIDS are the socially weakened, with their means of survival include migrating, enduring gender violence, and they are thus confined to living in the margins of society (Le Marcis, 2005).

1.1.2 The ART programme in South Africa

Since the launch of WHO's '3 by 5' initiative in 2003, sub-Saharan countries began to establish national antiretroviral treatment (ART) programmes. Although the target was never achieved, about 1.3 million people in low- and middle-income countries had access to treatment (UNAIDS, 2006). However, South Africa's national HIV treatment programme has been the topic of much debate. The government of South Africa was initially cynical about providing antiretroviral treatment to HIV-infected people ((Nachege et al, 2005), and the country's AIDS policy has always been suspicious of antiretroviral therapy. Further, the Ministry of Health refused to accept the introduction of ART for people suffering from HIV/AIDS (Natrass, 2006).

Despite the furore caused, global and local interventions and initiatives have allowed the South African government to create a plan to offer ART free of charge to HIV-positive patients who receive health care in the public sector ((Nachege, Stein, Lehman,

Hlatshwayo, Mothopeng, Chaisson, & Karstaedt, 2004). Thus, a combination of drug price reductions, private donations, and improved access to antiretroviral treatment, alongside the establishment of the Global Fund to Fight AIDS, Tuberculosis and Malaria, reduced the financial barriers in South Africa and Africa at large (Nachega et al, 2005).

It was, then, only in 2003 that an ART treatment plan was launched, with rollout of antiretroviral treatment beginning in 2004. The plan aspired to treat all South Africans who need antiretroviral therapy by 2009 (Nachega et al, 2004)). Since then, the public sector rollout of ART gradually gained momentum, although it was irregular and continued to be characterized by discernible absence of political will at high levels (Natrass, 2006).

The number of people taking antiretroviral medication in South Africa rose extensively from less than 200 in 2003 up to almost 200 000 by the end of 2005. Yet South Africa's performance in terms of ART coverage is poor both in comparison with other countries and the targets set out by the government's own Operational Plan. Further, the public sector 'rollout' has been uneven across South Africa's nine provinces (Natrass, 2006).

Despite the removal of all structural barriers, ART programmes can still fail if health care providers do not adequately address behavioural factors influencing adherence (Gill, Hamer, Simon, Thea & Sabin, 2005). For example, there are concerns that black African patients, with many of them living in dire and abject poverty lack formal education, experience suboptimal adherence to ART, leading to the development and spread of drug

resistance (Mills et al, 2006). As a result, some ART programmes in South Africa have presently reported mediocre or poor adherence, and among longitudinal studies, declining adherence over time (Gill et al, 2005).

Furthermore, many health systems in South Africa presently lack the capacity to provide basic health care to their communities, let alone the additional burden of scaling up antiretroviral therapy. Thus, HIV/AIDS creates a challenge for health systems that differs from all other problems they ever faced. The burden of transforming a deadly disease into a manageable chronic one turns millions of people into chronic patients, in need of life-long regular follow-up. Besides, putting many people on ART has reduced the load caused by HIV/AIDS on the health services, but the increasing workload related to maintaining thousands of patients on ART compensates all this. Moreover, the burden will increase as the epidemic is growing and as long as the prevalence of HIV infection is not dramatically reduced; and even then the case-load will continue to increase due to the delay between reduced transmission and a decreased need for ART (van Damme, Kober, & Laga, 2006).

When it comes to access to healthcare, two systems are operational. There are consumers of health care who have formal professional employment and who have medical aid plans and may thus access the private health care system. On the other hand, most HIV-positive black South Africans are unemployed, under-employed and are below a sustainable income threshold, who may attend primary health care clinics that are often overcrowded, under-resourced and staffed by overworked health care providers (Kagee, 2004).

1.2 Statement of the problem

The widespread introduction of combination antiretroviral therapy (ART) in 1996 for the treatment of HIV/AIDS has led to a dramatic reduction in HIV-related illness and death (Nachega et al, 2004). The focus of HIV treatment changed from comforting care to maintenance, restoration, or improvement of health of people with HIV infection (Schonnesson, Diamond, Ross, William & Bratt, 2006). However, treatment efficacy relies on constant adherence, which becomes a serious challenge to those receiving antiretroviral treatment (Mills et al, 2006).

Thus, utmost sustainable control of HIV viral replication below detection is essential to achieve these biological and clinical objectives. To achieve success requires almost perfect adherence to combination ARV regimens, and that involves the taking all pills in the correctly prescribed doses, at the right time, and in the right way (Carter, 2005). Such optimal adherence, along with lifestyle changes, is a solution to viral load and preventing multi-drug-resistant HIV strains from widespread transmission. In cases where there is complete patient adherence to the treatment regimen, the probability that antiretroviral therapy may reduce viral load and improve immune system functioning among people infected with HIV is high (Tsisis, 2001).

However, optimal adherence to such therapies may be complex in terms of pill burden, dietary restrictions, and dosing frequency, are prerequisite to ensure optimum treatment benefits. Furthermore, adherence does not only involve the act of taking prescribed

medication (Poppa, Davidson, Deustch, Godfrey, Fisher, Head, Horne & Sherr, 2004), but also focuses on behavioural and cultural norms, perceptions, and attitudes that influence the patient's expected likelihood to conform to medical advice (Kennedy IV, 2000). It may also be influenced by practical factors, such as ensuring there is a reasonable match between the requirements of medical regimens and the day-to-day lifestyle. Others are more cognitive and relate to how the patients perceive their health and medication – whether they believe their treatment will be beneficial (Schreider, & Stein, 2001). For instance, adherence to treatment tends to decline; as the number of prescribed regimens increases, particularly when there are three or more daily medications, as dosing frequency is four or times daily, and when the duration of the treatment is prolonged (Godin, Cote, Naccache, Lambert & Trottier, 2005).

Furthermore, the challenge of adherence despite the presence of potential viral resistance, treatment failure, disease progression and the spread of drug-resistant virus to HIV-positive patients is a great concern (Furtado, Callaway, Phair, Kunstman, Stanton, Macken, Perelson, & Wolinsky, 1999). Failure to sustain adequate adherence may result in antiretroviral antibodies not being maintained at sufficient concentrations to suppress HIV replication in infected cells and to lower the plasma viral load (Chesney, 2000). While conscientious treatment adherence is difficult under any circumstances, the unforgiving nature of viral replication, the complexity of the ART regimens, and the associated short- and long-term toxicity of the medicines, all pose particularly difficult challenges for the patient). Thus, adherence to ARV treatment is a critical issue (Palella, Delaney, & Moorman, 1999) and, identifying and overcoming the factors that reduce

adherence to combination antiretroviral agents is of paramount importance for prolonged viral suppression (Chesney, 2000).

1.3 Rationale

There is strong evidence to suggest that patient non-adherence to antiretroviral treatment is prevalent in South Africa. Research studies also indicate that there is scarcity of quality data on adherence to ARV treatment in the country, and thus, solutions to the problems of adherence will continue to elude healthcare providers. The concern is that research on adherence, conducted elsewhere in the world may be considered to be applicable in the South African context (Kagee, 2004).

Moreover, little has been published about the patients' viewpoint of their illness and treatment (Meystre-Agustoni, Dubois-Arber, Cochand & Telenti, 2000), and few studies have examined the knowledge, expectations, and assumptions about HIV and ART among HIV-positive patients in a country with limited resources or whether there are plausible barriers to treatment adherence. The previous studies in the 1990s that assessed perceptions and knowledge about patients attending clinics for sexually transmitted diseases (STDs) and family planning indicated inadequate awareness among at-risk of the mode of HIV transmission as well as of cure for AIDS (Nachega et al, 2005).

It is, thus, crucial in the case of a chronic illness such as HIV/AIDS where the level of uncertainty and the role of the imagination and individual beliefs are considerable. For

example, in describing how patients 'construct' the different dimensions of HIV/AIDS like progression, treatments, psychological consequences, etc, and the understanding how their knowledge, beliefs, and their experiences influence medical follow-up and adherence to treatment in particular (Meystre-Agustoni et al, 2000).

The illness perception approach begins with the patient's experience of their HIV illness, with emphasis on the patient's own model of the disease. Just as representations of the external world, to explain and predict events are individually constructed; patients develop similar cognitive models of bodily changes that reflect transient symptoms and chronic illnesses. The approach may offer an opportunity to identify the critical factors in patients' adaptation to illness. It can also facilitate the development of interventions that modify or embrace specific patient cognitions such as beliefs about the cause or potential for control or cure of HIV/AIDS, with the patient taking a more active and informed role. Thus, the exploration and identification of the patients' perceptions from the beginning provides the opportunity to minimize or avoid later difficulties such as non-adherence to treatment and recommended behaviour changes. Furthermore, such an understanding of the patients' perceptions is crucial for effective patient management, and consequently, enormous potential for research and practice in the area of psychosocial research (Weinman & Petrie, 1997).

1.4 Research objectives

The main aim of the study was to find out what promotes or inhibits adherence to ARV treatment among people living with HIV/AIDS. Such an understanding may encourage research in a number of critical areas including, but not limited to cross-cutting principles of motivating adherence in studies aimed at developing models of adherence, treatment, and rehabilitative strategies to enhance adherence to them.

Furthermore, the study may help develop methods of adherence that promote incremental change to sustain the benefits of adherence, how differential patterns of adherence to various components of combined interventions influence outcomes. It may also help identify the general principles of motivation most effective in encouraging adherence, and identifying the emotions, attitudes, states, or beliefs, such as negative emotions, or positive attitudes like an enhanced self-image that are most centrally associated with adherence behaviours. Lastly, studies of how factors underlying adherence in one domain, for example, interventions aimed at HIV disease, other sexually transmitted diseases and tuberculosis, might inform adherence to interventions aimed at mental disorders.

CHAPTER TWO

LITERATURE REVIEW

2.1 Introduction

This chapter examines the notion of adherence with prescribed medications, particularly antiretroviral regimens. Williams (2000) holds that non-adherence to medication may have detrimental effects on the patient's health and quality of life, and may also lead to further morbidity or mortality. Despite the evidence that HIV/AIDS is still regarded as a serious condition, the perception that AIDS is no longer a serious disease since the development of antiretroviral medications may be associated with poor adherence. Therapeutic benefits may not be realized if patients are not properly adherent to their antiretroviral regimens (Godin et al, 2005).

However, a perfect intervention to encourage adherence to antiretroviral therapy has yet to be developed. Hitherto, interventions have either been ineffective or of short-term benefits. An explanation may be that single interventions fail to take account of the full range of enablers of, and barriers to, optimal adherence. Research has improved the understanding of the psychology of adherence and identified some of these enablers and barriers. It thus suggests that adherence interventions are more effective when they adopt a multifactorial approach, taking account of the patient's perceptions and the practicalities of taking treatment (Poppa et al, 2004).

The section below reviews literature in order to provide a series of evidence-based recommendations for provision of adherence support interventions in clinical and community-based settings.

2.2 Factors affecting adherence

By understanding factors associated with optimal adherence, both healthcare provider and patient can take steps to prevent and manage adherence difficulties, control viral replication and minimize the risk of resistance. What a patient understands about a specific regimen, such as the purpose of different medications, and each medication's food and liquid requirements, can have a profound influence on adherence. On a broader level, 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 medications (Chesney, 1999).

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 or her health (Tsasis, 2001). Moreover, numerous factors combine to make adherence to HIV therapy particularly difficult. The factors that influence individuals' adherence or non-adherence to prescribed are diverse and multifaceted in nature (Molassiotis, Lopez-Nahas, Chung & Lam, 2003; Tsasis, 2001). Yet, they can be broadly classified into five categories: patient-related, provider-related, regimen related, disease-related (Tsasis, 2001), and systems factors

(Sarafino, 2002). The combined effects of several of these factors, as discussed below and their level of interference with normal life are main issues contributing to poorer adherence with antiretroviral medication (Molassiotis et al, 2003).

2.2.1 Patient-related factors

The Health Belief Model makes an effort to explain reasons for adherence and non-adherence to medical advice and clarify health-related behaviours, such as whether patients are likely to adhere to medication or use health services. Thus, a patient who feels threatened by HIV/AIDS and believes the benefits of ARV regimen outweigh the barriers is likely to adhere to his/her healthcare provider's advice. But those who do not feel threatened by HIV/AIDS or assess that the barriers of the regimen, e.g. side effects, outweigh the benefits are unlikely to adhere (Sarafino, 2002). Patient factors that influence adherence are discussed below.

2.2.1.1 Demographic characteristics

The literature constantly demonstrates that demographic characteristics such as age, gender, social class, race and religion are not strong predictors of adherence since people are inconsistent in their individual adherence behaviours (Straub, 2002). However, this does not mean that these factors do not affect adherence, for each is not by itself strongly related to adherence (Sarafino, 2002). For instance, low adherence cannot be restricted to a particular social class, but is extensive and unpredictable (Poppa et al, 2004). It is only

when they are joined, for example gender and social class, that their combination shows a stronger association to adherence (Sarafino, 2002). Additionally, the levels of adherence vary not just between people, but within the same individual over time. Adherence can therefore, be best understood as a variable behaviour rather than a stable characteristic of an individual, as people may sometimes exhibit low and high adherence (Poppa et al, 2004).

2.2.1.2 Socioeconomic factors

The notion that poverty and disease are inextricably linked is widely acknowledged, with the link being extended to HIV/AIDS in South Africa. Two approaches are used in the link: the behavioural or lifestyle approach, and the material or structural conditions approach. Both of these viewpoints concur that different levels of poverty, either individual, household or community, and corresponding characteristics, such as lack of education, knowledge or information about the risk of infection and resources to act on this knowledge, ability to negotiate sex, together with low marketable skills and high population mobility, create a 'fertile terrain' for diseases to flourish (Tladi, 2004).

Thus, the patient's economic status can have an impact on adherence and choices of activities (Castro, 2005), with factors like financial constraint being related to non-adherence. Not having enough money, for example, may mean that patients may not heed to recommended food requirements (Reynolds, 2004), while patients with jobs may have work schedules that conflict with clinic hours (Castro, 2005). Thus, such people may

miss clinical appointments, and as a result, have generally poor levels of adherence (Reynolds, 2004).

Furthermore, the soaring unemployment levels in South Africa contribute to high HIV infections. For example, people might stop taking their antiretroviral medication solely to remain eligible for the disability social grant, since HIV/AIDS positive people have to be in poor health or disabled to qualify for the grant. Thus, taking their medication as prescribed may pose a threat to eligibility for social grant, due to the positive effect it tends to have on the individual's health (Tladi, 2004). Similarly, lower income patients may drink and smoke more than their higher socio-economic counterparts. Their quality of life, partly mediated by material circumstances, may also moderate motivation to adhere to medication (Murphy & Bennett, 1994).

2.2.1.3 Knowledge about treatment regimens

Knowledge about HIV/AIDS, the impact of adherence and about the purpose of medication regimens (Starace, Massa, Amico, & Fisher, 2006; Tsasis, 2001) is an important predictor of adherence (Wahl et al, 2004). Patients may need, for example, information on factors that constitute correct antiretroviral medication use and adequate adherence, specific side effects that may occur with one's regimen, and potential drug interactions (Starace et al, 2006), including what the medicine does and what it is for, how to take it and related precautions (Howes, 2005). Therefore, patients who know about the effectiveness of medication and understand that poor adherence promotes viral

resistance and treatment failure; are more able to adhere to their medications (Starace et al, 2006).

The type of information resources patients are exposed to regarding their illness is influential to adherence behaviour. Although there is a variety of information to HIV patients through the South African media, internet, and community and provider resources, evidence suggests that patients may not be provided with enough information about their antiretroviral medications (Reynolds, 2004).

While education alone is not sufficient to promote adherence, it is a vital component (Reynolds, 2004). Patients also need to know about the disease, including the cause and implications for quality of life and the undesirable consequences. Their knowledge base should include, for example, the meaning of viral load and CD cell count and how ART will help them change the natural course of illness (Garcia et al, 2003). Such information is vital to help patients concretize the purpose of the medications (Howes, 2005). Thus, lack of knowledge about adherence, dosing requirements, knowledge and information about HIV medications, a lack of understanding of HIV disease and low levels of literacy are always associated with poor adherence (Williams 2000). If, for instance, patients are surprised by the side effects of the medication, they are likely to be non-adherent. Similarly, the consequences of non-adherence, including treatment failure, disease progression, and death should be understood (Chesney, 2003), especially if the symptoms are asymptomatic (Howes, 2005).

Patients should also be made aware of the consequences of non-adherence, for example that once drug resistance develops, treatment options become limited (Chesney, 2003) as they may not be aware of the link between non-adherence and the development of resistance (Simoni, Frick, Lockhart & Liebovitz, 2002). They may also not fully understand the treatment regimen, or how to take their antiretroviral treatment, and that lack of knowledge can lead to an inability or lack of motivation to complete a regimen (Mills et al, 2006).

2.2.1.4 Motivation

Motivation refers to the patient's desire to be treated, which invokes values that reason transforms into willpower (Garcia et al, 2005). On the one hand, personal motivation to adhere to medication is influenced by one's attitudes and beliefs about the potential outcomes of optimal and suboptimal adherence. On the other hand, social motivation involves one's perceptions of support for adherence from significant others, and one's motivation to comply with significant others' wishes. These values, beliefs and attitudes guide and control human behaviour, establishing a life project and motivating the effort required for achieving established goals. Critical here is that motivation does not involve only accurate information, wherein one is motivated to follow what one understands to be one's prescribed regimen irrespective of whether that understanding is accurate, nor does accurate information imply high motivation, wherein one is entirely accurate in understanding the requirements of one's regimen and still feel unmotivated to fulfill those

requirements. In effect, a relation between adherence-related information and motivation cannot be assumed (Starace et al, 2006).

Moreover, lack of motivation to adhere to antiretroviral regimens may occur if, for example, patients have many competing priorities in their lives such as substance abuse, homelessness, sickness from other diseases (e.g., TB), and taking HIV medication may not be considered a priority by the patient (Garcia et al, 2005).

2.2.1.5 Personal control

People differ in the degree to which they feel they have control over their lives. Some people believe they have a great deal of control, while others think they have almost none. Those who believe they have control over their successes and failures are described as possessing an internal locus of control. That is, the control of events lies within themselves - they are responsible. On the other hand, those who believe that their lives are controlled by forces outside themselves, for example, by luck, have an external locus of control. Certainly, it is unrealistic for people to assume everything in their lives is under their control. But the degree to which they attribute responsibility to themselves, versus other forces, determines their locus of control (Sarafino, 2002). Thus, beliefs about personal control are related to feelings of mastery and confidence, and their perceived ability to determine outcomes of an occasion. When patients' taking of medication is perceived as causally linked to outcomes, perceptions of control emerge (Bruhn, 1988)

However, when the result cannot be tied to the behaviour, it is more difficult to believe that there is control (Bruhn, 1988). Patients may, consequently, experience stress over a long period of time and feel that nothing they do really matters (Sarafino, 2002). They may also experience helplessness, trapped and unable to avoid negative outcomes (Sarafino, 2002) and the devastating effects of believing that one cannot control what happens (Bruhn, 1988).

Such an experience may, in turn, be exacerbated by the desire to regain total control over their HIV/AIDS status, and thus, respond poorly to both psychological and medical treatment. Guided by the belief that HIV corresponds to a physical problem, patients with loss of control may perceive that their visits to clinics will help them solve their organic cause of the disease and it will completely disappear. Yet, the wish may not be realised, given the impossibility of gaining absolute control over HIV/AIDS (Moreno, Garcia, & Pareja, 1999). The sense of control, which becomes stronger the longer the period of successful adherence to antiretroviral medication, may also be threatened when individuals encounter a high-risk situation, like drinking at a party. Hence, high-risk situations may increase the risk of relapse to non-adherence (Stroebe, 2000).

Self-efficacy, another important aspect of personal control, is the belief that people can succeed at specific activities they want to do (Sarafino, 2002). It involves the degree of confidence patients have in their ability to adhere ARV treatment (Marcus, Bock & Pinto, 1997), and assumes that patients who manage to adhere to their medication experience a sense of control (Stroebe, 2000). This association is due to the patients' perceived success

at adhering in the past and attributing that success to their own efforts (Christensen et al, 1997). However, patients with low self-efficacy about their participation in adherence behaviour are less likely to maintain behaviours needed for the success of their medication regimens (Marcus et al, 1997).

2.2.1.6 Health beliefs

Beliefs that people hold about health can affect their ability and desire to take medication (Reynolds, 2004). For example, beliefs about health and sickness, particularly about the necessity of medication to fight HIV/AIDS, and concerns about its potential adverse events may be influential in HIV disease (Poppa et al, 2004). Furthermore, the patient's perception of how beneficial or detrimental the treatment regimen would be in affecting HIV/AIDS outcomes is always linked to adherence to ARV medication. This includes the patient's beliefs about his or her ability to follow medication, beliefs about real and perceived side-effects, and any beliefs about taking regimens generally (Tsasis, 2001).

Patients who believe in the effectiveness of a treatment are more adherent, while those who are sceptical or wary are less likely to be adherent. Moreover, patients' subjective beliefs and adherence are influenced by their experience with treatment over time. Thus, discordance between the patient's initial expectations about the effectiveness of antiretroviral medication and actual experience may have a negative influence on adherence (Reynolds, 2004).

2.2.1.7 Cultural beliefs

Cultural aspects of patients' belief system and life goals may be influential in treatment adherence (Jani, 2002). Thus culture, which Mazrui (in Airhihenbuwa & DeWitt Webster, 2004) defines as "a system of interrelated values active enough to influence and condition perception, judgment, communication, and behaviour in a given society", plays a crucial role in determining the level of health of the individual, the family and the community. This is particularly relevant in the South African context, where values of the extended family and community significantly affect the behaviour of the individual, a cultural factor with strong implications on sexual behaviour, HIV/AIDS prevention and control efforts (Airhihenbuwa et al, 2004).

Furthermore, cultural differences also play a significant determinant of non-adherence in South Africa. For example, insensitivity to health beliefs, values and practices, lack of knowledge about the culture of black South Africans among healthcare providers and consequent failure to operate within it, including the inability to translate the rationale of Western HIV perception and treatment across cultural boundaries, may be cultural bases for the failure of treatment programmes (Greene, 2004).

Such cultural factors include practices that impact on adherence and clinical care (Hubbard, 2006) and outline misconceptions about HIV transmission and reframing of conceptualization of HIV illness among communities (Jani, 2002), which is likely to influence views regarding the aetiology and treatment of HIV/AIDS (Ross & Deverell,

2004). For example, 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 disastrous consequences for the patient (Page, 2005).

2.2.1.8 Substance use

Substance abuse, including intravenous drug use, alcohol and smoking is always associated with lower rates of adherence (Reynolds, 2004; Magura, Loudet, Mahmood, Rosenblum & Knight, 2002). Substance users are too unreliable to take these medications, particularly in the early stage of their recovery from drug abuse (Mallow, McPherson, Klimas, Antoni, Schneiderman, Penedo, Ziskind, Page & McMahon 1998).

Substance use may affect medication adherence both directly and indirectly. It may lead to a disorganized lifestyle that can make adherence to a medication regimen difficult, or directly impair judgment about health behaviours. It may also function as self-medication, substituting the use of antiretroviral medications that may be perceived as less effective, slow to act, or having more side effects. Substance users may decline medication because of denial of illness, preferring to ascribe their symptoms solely to substance misuse rather than to HIV/AIDS because the latter is more stigmatizing; and medication, even if accepted initially, is used only temporarily. (Magura et al, 2002)

For instance, HIV patients who abuse alcohol, particularly, are more likely to have aggravated HIV symptoms and co-occurring conditions like hepatitis C. In some cases, the biological interaction of alcohol and HIV may produce the poor health outcomes. Further, alcohols' behavioural effects may also be influential, particularly affecting patients' adherence to complicated antiretroviral medication and their access to health care (Magura et al, 2002). Alcohol abuse in patients may signal a disregard for health and decreased adherence to disease management (Chesney, 2003) and they may forget to take their medications on time because of altered thinking or being distracted by social functions at bars and parties (Reynolds, 2004).

2.2.1.9 Cognitive and psychological form

Mental health problems, particularly mood disorders and depression, are common among patients living with HIV and may pose threats to adherence (Parsons, Rosof & Mustanski, 2007). Such cognitive and psychological disturbances may affect patients' interpretation of their illness (Reynolds, 2004), as hopelessness and negative feelings reduce motivation for self-care (Chesney, 2003). Furthermore, HIV involvement of the central nervous system can affect memory and patients may experience confusion or memory loss. AIDS related dementia, which is characterised by abnormalities in cognitive and motor function, is also common among patients with advanced HIV disease. These cognitive deficits impact negatively on adherence to antiretroviral medication, and even if cognition is unimpaired, it may difficult to remember to take

medications (Cournos & Wainsberg, 2001). Research also indicates lower rates of adherence to medication among those suffering from these mental conditions (Parsons et al, 2007).

Depression, for example, may prevent patients from achieving optimal adherence, and existing tension and a patient's perception of stress can further diminish adherence (Cournos & Wainsberg, 2001), and can result in non-adherence as patients 'give up' and may even refuse treatment altogether. Depressed individuals also tend to be less motivated to take their HIV medications, may have impaired cognitive functioning that makes it difficult to remember to follow treatment recommendations or may be pessimistic about the effectiveness of treatment (Parsons et al, 2007). They may also be at risk of non-adherence to a treatment programme for concomitant diseases (Bender, 2004), and the more chaotic a patient's life is, the more difficult it is to maintain consistent medication-taking behaviour (Cournos & Wainsberg, 2001).



When a patient is not motivated, sometime as the real problem is that he or she is depressed because motivation is the threshold limit of psychological disorder, and depression is a major impediment to motivation. Thus, a depressed patient does not feel any enthusiasm or desire to be treated. Depression may be caused by external factors but it may also be an intrinsic aspect of the patient's individual personality. It is common and

almost everyone has experienced a period or a moment of low motivation or even a more profound depression (Garcia et al, 2003).

Thus, psychologically disturbed patients may have difficulty organising themselves and maintaining sufficient motivation to follow their treatment plan, and this may signal erratic adherence (Bender, 2006). Accurate medication management requires numerous cognitive components, including comprehension of medication instructions, organisation of the individual medications into a medication plan and temporal sequence that integrates multiple medications and doses, retention of the medication plan, and remembering to take medication at planned times (Bender, 2006). Therefore, the identification and treatment of mental health issues, particularly depression, may be a potential way to address and reduce non-adherence (Parsons et al, 2007).

2.2.1.10 Social support

Social support is always associated with adherence to antiretroviral medication, although the relationship is not straightforward. It can be construed as a multifaceted construct, a practical, emotional, or information (Parsons et al, 2007) support from friends, partners, family and organizations (Reynolds, 2004), or unidimensional construct of support generally (Parsons et al, 2007). For HIV positive people, social support and adherence to medication play a role not only in the HIV progression, but also in the quality of life, as an understanding of ideal health behaviour is crucial in planning adherence (Gaede,

Majeke, Modeste, Naidoo, Titus & Uys, 2004). Adherence is also enhanced when patients can depend on friends or family members for help and support, as well as for reminders to take medication (Walsh, Pozniak, Nelson, Mandalia, & Gazzard, (2002).

As a result of stability, predictability and control, social support may provide psychological resources that can help HIV-infected people cope with the nerve-racking aspects of taking antiretroviral medication. Conversely, social networks may interfere with adherence because of unplanned social activities, which can disrupt doses, or because of issues complicated by stigma, disclosure and non-support associates in the social network (Parsons et al, 2007; Reynolds, 2004). However, any measure that improves a patient's social support is likely to improve adherence (Walsh et al, 2002).

2.2.2 Disease-related factors

Characteristics of HIV/AIDS itself also affect people's ability to start and maintain antiretroviral treatment. The HBM identifies individuals' perceived susceptibility to illness or its consequences as an important factor in the ability to change behaviours related to illness. Thus, people must believe that they suffer from HIV/AIDS and that the benefits of taking their medication outweigh costs (Stretcher, Champion & Rosenstock, 1997).

Disease severity, the duration of HIV infection, and associated opportunistic infections may influence adherence to treatment. HIV/AIDS, like other chronic diseases, generally

exhibit a lower rate of adherence to treatment than non-chronic diseases, with a significant decline of medication adherence over the course of treatment (Tsasis, 2001). Even the most motivated patients find it increasingly difficult to remain adherent, over time (Hubbard, 2006). However, such diseases require long-term therapy; involve complex lifestyle changes which may consequently be difficult to adhere to (Bernard & Krupat, 1994).

Furthermore, HIV positive individuals often remain asymptomatic for a long time, limiting clear treatment adherence benefits, resulting in declining adherence rates (Tsasis, 2001). This, in turn, may result in deterioration of health status and well-being because of concomitant medications side-effects and disruptions in daily routine (Hubbard, 2006). Furthermore, once patients no longer feel sick, they often think they can discontinue taking their medications and their symptoms can improve dramatically during the initial phase of treatment - the first 8 weeks (Sarafino, 2002). This is consistent with the HBM which postulates that people are less likely to take action if they perceive that their diseases are mild rather than serious (Bernard & Krupat, 1994).

Conversely, symptomatic patients may show a higher adherence rate than their asymptomatic counterparts (Tsasis, 2001). The effect of symptom experience about medication may be complex, as symptoms may sometimes be perceived as stimulating taking medication by acting as a reminder or reinforcing beliefs about its necessity. However, patients' expectations of symptoms relief are also likely to have an important effect. This could be effective if expectations are unrealistic, or whether treatment is

prescribed for asymptomatic disease, as is frequently the case with HIV infection (Poppa et al, 2004).

2.2.3 Treatment characteristics

A variety of aspects related to HIV treatment can impact adherence. These include the complexity of the regimens, side effects associated with taking antiretroviral medication, and the use of complementary or alternative medications (Hubbard, 2006). For example, adherence to a regimen declines as the number of medication treatments, frequency of dosage and length of the treatment regimens increases (Reynolds, 2004; Tsasis, 2001; Hubbard, 2006; Patel & Patel, 2006; Tsasis, 2001).

As with other chronic diseases, the complexity of ART includes dosing frequency, pill burden, dietary instructions, convenience, and the ability to incorporate a treatment regimen into the patient's daily life (Hubbard, 2006). While it may be difficult to achieve even on a single-drug regimens, adherence to multi-drug medication may be even more problematic (Ferguson, Steward, Funkhouser, Tolson, Westfall & Saag, 2002) because the more complex the procedures required to manage or cure HIV/AIDS, the less likely patients will be adherent (Bernard & Krupat, 1994).

People taking combination antiretroviral therapy experience a variety of problematic short and long-term side-effects such as increased fatigue, headache, nausea, diarrhoea, insomnia, memory loss, sexual dysfunction and metabolic combinations. The number and

severity of the side-effects and the person's perception of their tolerability are prominent factors in non-adherence or premature discontinuation of antiretroviral regimens. Even seemingly minor side-effects may reduce the patient's adherence to the regimen as patients commonly miss doses of antiretroviral medication as a strategy to manage aversive treatment-related symptoms (Reynolds, 2004).

Thus, failure to manage these treatment factors may result in patients skipping doses, and consequently failing to fully adhere to their medication regimens (Tucker, Orlando, Burman, Sherbourne, & King, 2004) and follow the treatment plan (Tsasis, 20001).

2.2.4 Patient-provider relationship

A quality patient-provider relationship is another important factor influencing adherence to treatment (Reynolds, 2004; Crossley, 2000) and an important source of support (Parsons, et al, 2007), as such a relationship is critical for motivating taking and adhering to complex antiretroviral medication (Chesney, 2000). Important aspects of patient-provider relationship include trust, consistency, continued interaction, (Reynolds, 2004), together with the perception of healthcare provider as respectful, open, empathetic and showing genuine interest (Parsons, 2007).

Such a relationship is crucial, particularly when managing adverse medication reactions. Patients have to believe that their healthcare providers are truly working in their best interest to manage toxicities and to change regimens, if necessary. Fostering a rapport

with patients makes it possible to ask open-ended questions about missed doses and find ways to help work through problems with drug regimes (Tsisis, 2001).

Communicating clearly with the patient about the purpose of the medication, providing requisite instructions on the proper use of prescribed medication, as well as what to expect while taking the medication, further enhances patient adherence (Tsisis, 2001). Medication adherence is also affected when the healthcare provider is consistently available to answer questions, has a non-judgemental attitude, reinforces the treatment regimens, provides positive feedback, and assists the patient to incorporate the treatment into his or her lifestyle (Roberts, Towell & Golding, 2001).

Further, communication problems such as language barriers may be further compounded by unsympathetic attitudes of healthcare providers who do not understand the cultural location of the illness within the community, including the norms or traditional cultural values of other groups (Roberts et al, 2001). For example, in South Africa many people with HIV use a language other than English, and most healthcare providers cannot speak any of the home languages of the majority of the people living with HIV/AIDS. Language is commonly accepted as a barrier to effective communication (Ross & Deverell, 2004).

Thus, a patient's trust in his or her healthcare provider makes it easier for a patient to discuss issues when medication is causing difficulties (Tsisis, 2001). Further, patients who are not satisfied with their healthcare providers are less likely to adhere to their

medication and adhere to the treatment recommendations than those who perceive they are involved in a collaborative relationship in which they partake in the decision-making process (Parsons, 2007).

2.2.5 Systems factors

Elements of the healthcare system, including its culture and environment, have an impact on adherence (Poppa et al, 2004). Such factors include policies, organization, resources, and financial arrangements impacting on the availability, accessibility, and acceptability of health care services (Murray & Callahan, 2003). For instance, access to medical providers is crucial and must include multi-disciplinary services – the ‘one-stop shopping’ approach to medical care. (Poppa et al, 2004). Of importance here is the distance patients have to travel to obtain medical care, availability of transportation to the healthcare centre, and thus, improving the infrastructure for communication about medication between patients and providers (Murray & Callahan, 2003).

Furthermore, adherence to a medication regimen is generally enhanced when mental health services, case management, social support, and other services are readily available. This also requires that antiretroviral medications be stocked in the local pharmacy, because any delay can cause missed doses (Poppa et al, 2004).

2.3 Theoretical Framework for Medication Adherence

There are health-behaviour theories and models that suggest methods to explain patient adherence and what influences behaviour change towards adherence to treatment regimens. Awareness of these elements of behaviour change theories will assist HIV/AIDS healthcare providers in optimizing the effectiveness and efficiency of their interactions with patients (Elder, Ayala, & Harris, 1999). However, there is no clear-cut model that adequately addresses all issues related to behaviour change, and adherence (Inungu, Beach & Skeel, 2003).

2.3.1 The health belief model

The Health Belief Model (HBM) was developed in the 1950s by social psychologists Godfrey Hochbaum, Irwin Rosenstock and Stephen Keyes. The model was developed to understand the failure of tuberculosis health screening programme, but has been adopted and applied to general changes in behaviour related to health care. The initial model included only four concepts: perceived susceptibility, how likely people feel they are to get the disease; perceived severity, how severe the disease will be; perceived benefits, how adherence to medication will provide benefits and; perceived barriers, what will make it challenging to quit drug use (Inungu et al, 2003).

To account for people's readiness to act, the concept of cues for action, or environmental factors that trigger behaviour change, was added. Finally, the concept of self-efficacy, confidence in one's ability to successfully perform a specific type of action, was added to address the challenge of habitual unhealthy behaviours. The HBM has two weaknesses: First, individuals have many beliefs. Beliefs compete with other beliefs and attitudes to

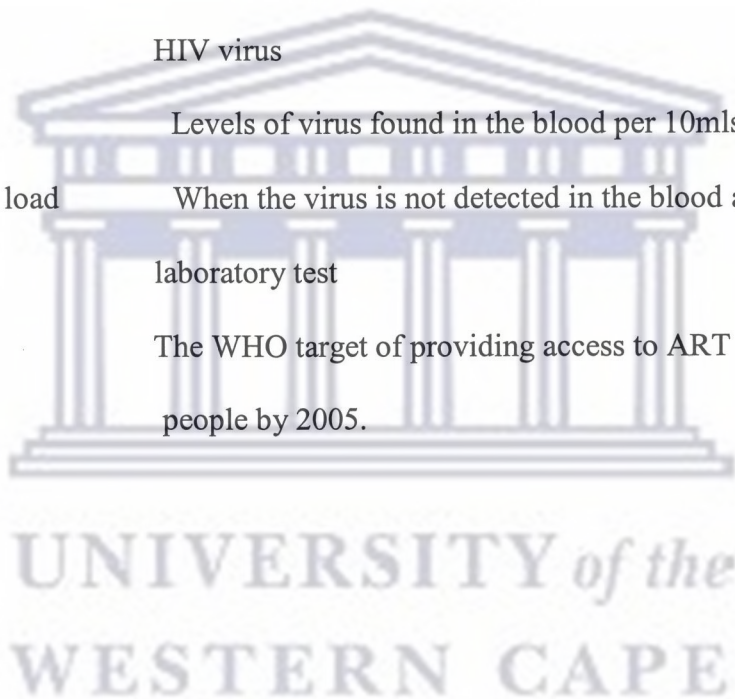
influence behaviour. Second, there is little research evidence showing that belief formation always precedes behaviour change. In fact, the formation of a belief may actually follow a behaviour change (Inungu et al, 2003).

2.4 Summary of the chapter

Adherence to antiretroviral treatment is the outcome of dynamic process of clinical and behavioural interactions. The chapter discusses factors influencing this process and emphasises the fact that people living with HIV/AIDS who are receiving antiretroviral medication should strictly adhere to multi-drug regimens to achieve optimal treatment responses. The perspective that emerges from the chapter suggests that adherence is a dynamic phenomenon; that is, any patient, at any point in time, may encounter difficulties with the medication regimens. Thus, focus should not be limited to the individual paradigm aimed at the patient that leads to a value judgement, but on a more comprehensive examination of factors related to adherence. There is a variety of factors impact on the patient's ability to adhere to prescribed medication and are apparent at the patient, provider and treatment level. Together with the characteristics of HIV disease and therapies, these factors make adherence to treatment difficult.

2.5 Definition of key concepts

Adherence	Taking medication exactly as recommended
HIV	Human immunodeficiency virus
AIDS	Acquired immunodeficiency syndrome
Antiretrovirals (ARVs)	Medicines designed to suppress the progression of HIV/AIDS, consisting of double or triple combination of ARV drugs.
Antiretroviral therapy	Treatment involving the use of triple combination of ARVs
Complex regimens	Drugs that have been manufactured to suppress the HIV virus
Viral load	Levels of virus found in the blood per 10mls
Undetectable viral load	When the virus is not detected in the blood after a laboratory test
'3 by 5' initiative	The WHO target of providing access to ART for 3 million people by 2005.



CHAPTER THREE

RESEARCH METHODOLOGY

3.1 Introduction

In this chapter, the methodology and the procedures used in the collection and analysis of data are discussed. Mark (1996) points out that methodology should involve decisions about population, sample, research design, data collection and analysis methods and the methodology that will be followed in this chapter will focus on these aspects. Mcauley (2003) states that when the focus is on people, their biographies and perceptions, the researcher will become more aware of the role of agency, power and culture in shaping how people utilize or fail to employ local structure.

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Furthermore, Strauss and Corbin (1990) posit that studies that attempt to uncover the nature of people's experiences with illness, usually lend themselves to qualitative types of research. Thus, the methodologies used in this study are applicable to understanding perceptions of challenges and solutions to adherence among people living with HIV/AIDS in South Africa. Denzin and Lincoln (1994) believe that such rich descriptions of the social world and details are valuable.

3.2 Methodological considerations

The qualitative research approach helped to structure the issues around perceptions of challenges and experiences of adherence to antiretroviral therapy among participants, and assessed these holistically. Denzin and Lincoln (2003) argue that qualitative researchers focus on the socially constructed nature of reality, the intimate relationship between the interviewee and what is studied, and the situational constraints that shape inquiry. They also seek answers to questions that highlight how social experience is created and given meaning. Thus, researchers come up and confront against the constraints of daily life, getting valuable, 'thick descriptions' of the social world.

3.3 Data collection

3.3.1 Interviews

In-depth interviews, which provided a flexible tool to collect narrative data describing participants' perspectives (Rapley, 2003), were used to investigate their perceptions of challenges and experiences to antiretroviral therapy.

The use of interviews, which were conducted in isiXhosa, the language best understood by the participants, provided an opportunity for the researcher to understand what it meant for the participants to understand their experiences and challenges of adherence to ARV treatment. This made it easy for them to have exchanges with the researcher, giving

opportunity to clarify and explain their viewpoints from their own perspectives. It also provided, as Rosnow and Rosenthal (2002) advocate, an opportunity to establish rapport with the participants and to stimulate the trust and cooperation often needed to probe sensitive issues around HIV/AIDS and adherence to antiretroviral medication.

The interview session was used to learn about the participants' perceptions of challenges and experiences about adherence to ARV treatment and to provide an opportunity for the researcher to understand the lives of people living with HIV/AIDS. Experiences of adherence were explored, as well as in reference to, relationships with healthcare providers, peers, spouses, family members and other clinic staff. Participants were also asked to reconstruct some particularly gruesome days or times when problems with adherence were experienced. The self-reflection was painful for some participants and required empathy and concern on the part of the researcher.

The dimensions of their experiences were explored at first, using open-ended questions, not in any particular order but with more personal questions being asked after rapport and trust was established. For example, one question required the participants to tell as much as possible about the challenges and experiences of adhering to antiretroviral treatment, from time they discovered that they are HIV positive until the present moment, reflecting on these challenges and experiences of about their adherence to ARV treatment, how it affected them, and what it means to them.

Later, participants were provided with a summary of the taped interviews and given time to review and reflect upon the material. They were given an opportunity to add further information, to elaborate on any statement or to clarify an idea. It was again made clear that they had the right to withdraw from the study at any time during the interview.

3.3.2 Planning and pilot-testing the interview

During the testing phase, the researcher located some of the potential interviewees and tried out the questions on them. Rosnow and Rosenthal (2002) believe that this requires patience because the researcher may need a longer series of interviews with many randomly selected individuals to find the appropriate participants.

Before going into the field, the researcher pilot-tested the interview schedule with two researcher-friends, and made modifications wherever necessary. Rosnow and Rosenthal (2002) point out that this ensures that during the interview questions come out promptly to avoid a frequent interruption of the flow of the narrative. This also gave the researcher the opportunity of setting time limits. Each interview was of approximately 90 minutes as an effort to avoid making the interviews too long, lest the interviewees became bored and fatigued and thus, losing interest in the study. Seidman (1991) affirms that this process allows participants the opportunity to “reconstruct their experience, put it into context of their lives, and reflect on its meaning.” Further, although the interview session may seem too long, it was long enough to make them feel that they are taken seriously.

The researcher also used a tape-recorder because he wanted to interact with the interviewees without spending much time head-down and writing, thus distracting the process by noting down only issues that seem to interest him and excluding responses which may be more pertinent to participants. The use of the tape-recorder also provided a much more detailed record of the verbal interaction that ensured that nothing is missed during the interview, more than any amount of note-taking or reflection could offer. This meant that the researcher can also play and replay the tapes, produce transcripts and then selectively draw on these to provide demonstrations of arguments.

3.3.3 Recruitment of interviewees

Recruitment and screening of potential participants was undertaken in a community clinic serving HIV-positive patients at Crossroads. With the help of the superintendent and interviewees themselves, the researcher managed to find 10 Black HIV-infected participants. After signing a written informed consent, all clinical records were screened by the clinical staff and they identified as eligible for the study. Madden, Quick, Ross-Degnan, and Kafie (1997) concur that assessing the perceptions of patients to investigate various health-related activities has previously been used successfully.

The choice of mixed sexes is based on the fact that “there is little or no association between adherence and demographic characteristics” (Sarafino, 2002). The participants were between 18 and 30 years old and were also prescribed antiretroviral medication for at least six months. With the help of the clinical staff, all the eligible patients were

contacted by phone and letters. However, some could not be reached by phone and some were homeless, and some did not qualify as they had changed to other clinics for their care. Those who qualified were compensated R30 to defray traveling costs and received food parcels worth R50.

The initial contact with the participants was important for the establishment of good rapport and level of trust for the interview process. Both the researcher and individual participants had to decide on the location for future meetings, determine whether the individual was truly interested, that he or she fully understood the nature of the study. This provided an opportunity to review in person the consent agreement and all other aspects of the study so that at the interview participants fully understand the process. It was also provided that researcher the chance to determine whether the individual was appropriate for the study, and time to record all basic data about each potential participant. Rapley (2004) agrees that the process of finding interviewees and setting up interviews is central to the outcomes of the research.

3.3.4 Bracketing interview

It was vital that during the interviews and throughout the study the researcher keep a reflective journal in order to be continually aware of, and bracketing his or her own values. Hutchinson (1988) asserts that bracketing is a process where the researchers become aware of their own personal values and preconceptions and then setting them aside in order to view the situation from a new and neutral perspective. Polio, Henley and

Thompson (1997) state that a bracketing interview sensitize researchers to any requests they might make of participants during the interviews or in later interpretation. Further, the researcher became the participant in the interview; a researcher-friend was the interviewer. This process helped the researcher gain insight into what it is like to be interviewed regarding the perceptions of challenges and experiences to adherence to ARV treatment, and brought him understand any personal assumptions about it.

3.3.5 Debriefing participants

The participants were given the opportunity to engage in extended discussion with the researcher about the purpose of the study. The debriefing session, Rosnow and Rosenthal (2002) argue that it provides the researcher an opportunity to remove any misconceptions and anxieties that the participants might have, so that their sense of dignity remains intact and do not feel that their time has been wasted.

3.4 Data analysis

3.4.1 Transcription of interviews

After all steps of the research process had been recorded, the analysis of recorded data required transcription, converting the medium from audio to text during and before the analysis process. This was, by its nature, a time-consuming and tedious exercise, which involved a considerable time and energy. Nevertheless, the interviews were accurately

transcribed and thoroughly documented along with reflections about the interview and the data gathering experiences. Strauss & Corbin (1990) agree that the mode of operation in grounded theory analysis is that the first interviews be entirely transcribed and analysed before going on to the next interviews. Thus, the early coding gave guidance to the next interviews, as discussed later in the study. The process of transcribing data also provided an opportunity to revisit the interview process, with the researcher recalling what the interviewee has said and reincarnating the picture of the body language and the lamenting voice of the interviewee.

Later, as the theory developed, the researcher listened to the tapes, and transcribed only the sentences, passages, and paragraphs that relate to the evolving theory. This was necessary because early in the study the researcher was not certain what is relevant and what is not. So, it was better to transcribe everything, lest important data is missed. The bottom line was that the theory was guided not only what the researcher looked for and when he went to the field, but what to look for in the data. This allowed the researcher to collect data, especially near the end of the study when the analysis informed him about holes in the theoretical formulations that needed closing, and that further data collection was needed to close them.

3.4.2 Theoretical sensitivity

Theoretical sensitivity, or the personal quality of the researcher, is crucial for a study that deals with sensitive data around participants' perceptions of challenges and experiences

of adherence to ARV treatment. The researcher's many years of working within the education system, both as a teacher and a school counsellor provided him with attributes of having insight, the ability of giving meaning to data, the capacity to understand, and the capability to separate the germane from that which is not. Strauss & Corbin (1990) affirm that theoretical sensitivity allows the researcher "to develop a theory that is grounded, conceptually dense, and well integrated – and to do this more quickly than if this sensitivity is lacking".

3.4.3 Data coding

Transcripts of the translated interviews were coded and the data was analysed for patterns of consensus, contrast, and variability. However, with grounded theory, analysis began early, and the emerging data was coded as it was being collected. Throughout coding, the researcher started defining and categorizing data and began to interact with the data. As the researcher broke data down into discrete parts, he closely examined it, compared for similarities and differences, and asked questions about perceptions of challenges and solutions to adherence to ARV medication as reflected in the data. Throughout this process, the researcher's own and participants' assumptions about their perceptions were questioned and explored, and this helped to gain new perspectives on the material and to focus on further data collection, which led the researcher in to unforeseen directions. As Charmaz (2003) advocates, unlike quantitative research that requires data to fit into preconceived standardized codes, the researcher's interpretations of data shaped the emergent codes.

Thus, coding started with a chain of theory development, developing of as many codes as possible, which helped summarize the differences and similarities between ‘incidents’ in the data. Incidents are data bits or chunks that the researcher discerned as being distinct entities. Codes that accounted for the data took form together as emerging theory that, in turn, explained these data and directed further data gathering.

Then, coding proceeded throughout the researcher’s examining each line of data, defining each line of data, and then defining actions or events within it. This process of line by line coding kept the researcher studying his data. In addition to starting building ideas inductively, the researcher was deterred by line-by-line coding from imposing extant theories or his own beliefs on the data. Charmaz (2003) notes that this form of coding helps researchers to remain attuned to participants’ views of their reality, rather than assume that they share the same views and worlds.

Line-by-line coding helped sharpen the use of sensitizing concepts, that is, those background ideas that informed the overall research problem which offer ways of seeing, organizing, and understanding experience, that are embedded in researcher’s disciplinary emphases and perspectival inclinations. Although sensitizing concepts deepened perception, they provided starting points for building analysis, not end points for evading it. The researcher used these sensitizing concepts only as points of departure from which to study the data. Line-by-line coding also led to refining and specifying any borrowed extant concepts. Throughout the coding of participants’ statements line by line, the researcher created codes and later developed them into categories. Charmaz (2003)

argues that this process keeps the researcher thinking about what meanings he made of his data, asking himself questions of it, and pinpointing gaps and leads him to focus on during subsequent data collection, while keeping the codes active. Such action codes give the researcher insight into what people are doing, and about what is happening in the setting. Charmaz (2003) further postulates that generating action codes facilitates making comparisons, a major technique in grounded theory.

While the emphasis in open coding was on stimulating ideas rather than documenting evidence, axial coding, as Dey (2003) suggests, became a method of integrating analysis through making connections between a category and its subcategories. Strauss (1991) asserts that axial coding consists of intense analysis done around one category at a time. The focus was on specifying conditions that gave rise to the category, its context, the social interactions through which it was handled, and its consequences. The purpose was to make emerging theories denser, more complex, and more precise. The concept of dimensionality was then developed to recognize and account for complexity beyond one meaning of a property or a phenomenon. Charmaz (2003) professes that this process allows the researcher to divide properties into dimensions that lie along a continuum. In turn, the researcher developed a “dimensional profile” of the properties of a category.

Once categories were integrated through axial coding, coding became increasingly selective. As Dey (2003) suggests, selective or focused coding used initial codes that reappeared frequently to sort the large amount of data. This coding was more directed and, typically, more conceptual than line-by-line coding. These codes accounted for most

of the data and categorized them most appropriately. Charmaz (2003) maintains that making explicit decisions about selecting codes may allow the researcher to check for correspondence between the emerging theoretical framework and the empirical reality it explains.

The categories for synthesizing and explaining data arose from the researcher's focused codes which, in turn, shaped the developing framework. Charmaz (2003) asserts that categories often subsumed several codes. For example, the researcher's category of "social support" included positive events and relieved negative events. Thus, categories may turn description into conceptual analysis by specifying properties analytically.

With selective coding, the "conditional matrix", which Strauss and Corbin (1990) perceives as an analytic diagram that maps the range of conditions and consequences related to the phenomenon or category, was used. It is a series of circles in which the outer rings represent those conditions most distant from actions and interactions and the inner rings represent those closest to actions and interactions. The researcher created matrices to sensitize himself to the range of conditions conceivably affecting the interviewees' perceptions of challenges and experiences of factors affecting their adherence to ARV treatment and to the range of hypothetical consequences. Such matrices tended to sharpen the researcher's explanations of predictions about interviewees' perceptions of challenges and experiences of their adherence to ARV treatment.

Finally, as Dey (2003) recommends, the procedure of grounded theory sets out a framework for conducting systematic data analysis directed the analysis, with prominent shifts from ‘open’ through ‘axial’ to ‘selective’ coding. However, the researcher took note of the suggestion by Strauss and Corbin (1990) that the lines between each type of coding are artificial, as the different types do not necessarily take place in stages. Thus, in a single coding session, the researcher, quickly and without self-consciousness, moved from one form of coding to another, especially between open and axial coding.

3.4.4 Memo writing

Memo writing, which Charmaz (2003) describes as an intermediate step between coding and the first draft of the completed analysis, was prioritized because memos provide a record of theory development and, as Strauss and Corbin (1990) advocate, are kept “orderly, progressive, systematic and easily retrievable for sorting and cross referencing”. This step helped to spark the researcher’s thinking and encouraged him to look at the data and codes in a new way. It also helped the researcher define led for collecting data, both for initial coding and later theoretical sampling. Through memo writing, the researcher elaborated processes, assumptions, and actions that are part of codes created, leading the researcher to explore more codes, and expanded upon the processes the researcher identified or suggested. Thus, the codes took on substance and structure for sorting data.

The action codes, as illustrated above, spurred the writing of useful memos because they helped the researcher see corresponding processes rather than static isolated topics. As

the researcher detailed the properties of actions taken in memos, the researcher linked categories and defined how they fit into the larger processes. Charmaz (2003) asserts that by discussing these connections and defining processes in memos early in the research, the likelihood of getting lost in mountains of data was reduced, as memo writing kept the researcher focused in the analyses and involved in the research. Furthermore, memo writing helped the researcher in linking analytic interpretation with practical reality. The researcher brought raw data right into the memos for the maintenance of those connections, which were examined directly. Charmaz (2003) points out that raw data from different sources provides the grist for making precise comparisons, fleshing out the researcher's ideas, analyzing properties of categories, and seeing patterns.

Thus, memo writing helped the researcher grapple with ideas about data, including redefining categories, defining the relationship among various categories, and to gain a sense of confidence and competence in their ability to analyse data.

3.4.5 Theoretical sampling

As the researcher refined the categories and developed them as theoretical constructs, gaps in the data and holes in the theories were identified. The researcher then went back to the participants to collect the missing data to fill in those conceptual gaps and holes. For the session, the researcher chose to sample only specific issues, looked for precise information to shed light on the emerging theory. Dey (2003) defines theoretical sampling as a process of collecting data collection for generating theory whereby the

researcher collects, code and analyze data and then decides what data to collect next and where to find them, in order to develop his theory as it emerges. Charmaz (2003) states that the aim of this sampling is to refine ideas, not to increase the size of the original sample. Thus, theoretical sampling helped the researcher identify conceptual boundaries and pinpoint the fit and relevance of the categories.

Charmaz (2003) further postulates that theoretical sampling is a critical part of the development of formal theory. The level of abstraction of the emerging theory has explanatory power across substantive areas because the processes and concepts within it are abstract and generic. Thus, the researcher would sought comparative data in substantive areas through theoretical sampling to help tease out less visible properties of concepts and conditions to limit of their applicability. For example, the researcher addressed “depression” in several analyses of the experience of HIV illness. The researcher refined his concepts by looking at depression in other situations, such as bereavement and unemployment. Further, comparative analysis of people who experience unanticipated ego gains, such as unexpected job promotion, may also require conceptual refinements.

Strauss and Corbin (1990) assert that the necessity for the researcher to engage in theoretical sampling meant that a solid grounded theory could not be produced through one-shot interviewing in a single data collection phase. Instead, Charmaz (2003) suggests that theoretical sampling demands that the researcher completes the work of comparing data with data and develop a provisional set of relevant categories for explaining data. In

turn, these categories took the researcher back to the field to gain more insight about when, how, and to what extent are they important and useful.

Strauss (1991) maintains that theoretical sampling may help the researcher to define the properties of the categories; to identify the contexts in which they are relevant; to specify the conditions under which they arise, are maintained, and vary; and to discover their consequences. Thus, the emphasis on studying the process together with theoretical sampling to delineate the limits of the categories also helped the researcher to define gaps between categories. Through using comparative methods, the researcher specified the conditions they are linked to other categories. After deciding which categories best explain the process of the study, the researcher treated them as concepts. Thus, these concepts were useful in helping the researcher understand many incidents or issues in the data. As Charmaz (2003) recommends, theoretical sampling was conducted later in the study so that relevant data and analytic directions emerge without being forced. Otherwise, as Charmaz (2003) further suggests, early theoretical sampling may bring premature closure to the analysis.

Strauss and Corbin (1990) argue that grounded theory researchers take the usual criteria of “saturation” of their categories for ending the research, by fitting new data into the categories already devised. Chamberlain (1999) further states that when no new categories that relate to the central issue or processes being researched are found, and the theory can account for all the data that have been obtained, saturation of the theory is considered to have occurred. To affirm this, the researcher examined negative instances

or cases that did not fit the theory and tried to incorporate all disparities. Then, data collection ceased when there were no new gaps in the theory and all categories were linked meaningfully together to provide a comprehensive explanation of the participants' perceptions of challenges and experiences of adherence to antiretroviral medication.

3.4.6 Ethical considerations

Formal application for ethical clearance to conduct the research was sought from the Senate Research Committee of the University of the Western Cape before data collection. All the data were collected anonymously and confidentiality was upheld for all participants. Informed consent was obtained from all participants before their participation. The names of all 10 participants and the centre chosen as a research site were kept confidential in the report, and will remain confidential in all publications emerging from this research project.

3.5 Summary of the chapter

The chapter described the methodology applied in the study, which involves the use of qualitative methods in collecting and analyzing data. In-depth interviews were used in the collection of data, with the grounded theory used to analyse the data. The chapter systematically follows the trajectory the researcher was involved in when collecting and analyzing the data. The researcher started off by providing information about the sample, establishing rapport with the participants, preparing for the interviews and setting out

questions. Then the analysis of data began while the data was being collected, using grounded theory. It went through to the coding of data, with line-by-line examination in search for themes. The fact that the researcher re-visited the participants for further interviews, ascertained that the researcher filled in gaps of data whenever, necessary. The last stages of the analysis, memo writing and theoretical sampling, required that the researcher have a deeper insight and understanding of the data being dealt with.



CHAPTER FOUR

RESEARCH FINDINGS

4.1 Introduction

This chapter discusses the findings of the study relating to the participants' perceptions of challenges and experiences of adherence to ARV medication. The first section focuses on introducing the findings of the participants' perceptions of challenges and experiences of adherence to antiretroviral medication from the data analysis process in the previous chapter. The second session focuses on excerpts of participants' self-reports of their perceptions of challenges and experiences, with the findings from in-depth interviews with participants to highlighting similarities and contradictions in the findings.

4.2 Overview of the results

The findings suggest that patients experience problems in their efforts to attain optimal adherence rates, although they may be highly motivated to take antiretroviral medication as prescribed. The results of the coding process began to reflect theoretical categories that explain how the participants living with HIV/AIDS conceptualised their perceptions of challenges and experiences of adherence to antiretroviral treatment. The research outcomes revealed that constraints such as patients' self-efficacy to take all doses as prescribed, beliefs about taking medication, knowledge about HIV, counselling and

education, denial, lack of food and hunger, stigma, perceived social support, side-effects, patient satisfaction, privacy and confidentiality, the challenge of alcohol, depression, and relation to health providers. However, despite these health system constraints, the perceived quality of care among participants is relatively good.

Hereunder, the researcher provides excerpts of participants' self-reports that explicitly exhibit the most commonly statements perceptions of challenges and experiences of ARV adherence.

4.2.1 Patients' self-efficacy

Patients conceptualized their construct of self-efficacy as an their confidence in the ability to adhere to antiretroviral medication as well as the belief to adhere in the face of situational temptation not to adhere to medication. However, some participants voiced their lack of confidence in taking their prescribed medication. For instance, when a 25-year old female respondent was asked how he was tempted to miss medication, she answered:

I am not sure that I will stick to this medication treatment when side effects interfere everyday with my daily activities...

and a 26 year old male counterpart had this to say:

Sometimes I doubt that I will take the ARV medication for a long time. I can't say that I will take them irrespective of whatever....sometimes conditions will determine whether to take them or not...

4.2.2 Beliefs about taking medication

A considerable number of participants expressed various beliefs about antiretroviral medication. Most patients had positive beliefs about the effects of the medication, although some expressed their negative feelings about the medication. For example, a 23 year old semi-professional young participant had to say:

The medication always helps me stay in good shape

And

The tablets always reduce the chances developing side effects

But, a 28 year-old unemployed female mentioned that:

The medicines are the main cause of my side-effects

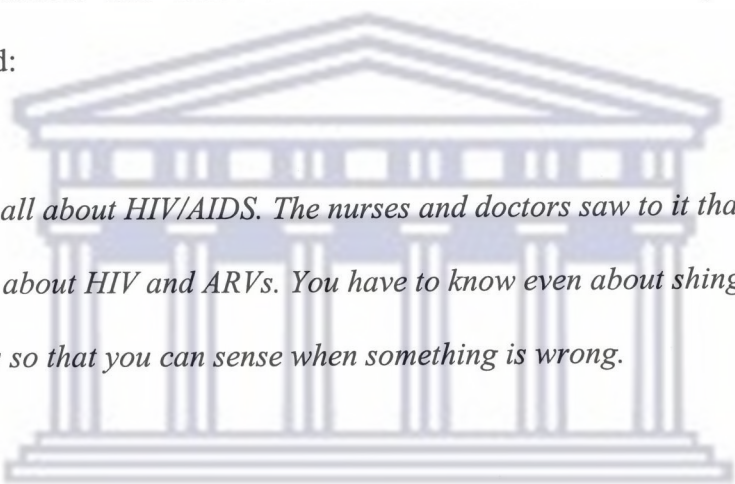
As a result of these fears, some people reported delaying taking their medications, even when they had the opportunity to do so. As one 28 year-old woman declared:

I never wanted to take the pills. At first they were saying, why don't you

take ARVs? I said no way, I will not take them. I had that belief until 2005 and yet I was told about ARVs long ago.”

4.2.3 Knowledge about HIV

All participants were impressive with their vast knowledge about HIV/AIDS and its terms. They learnt all aspects of the illness. They confessed that they attended counseling and informative classes and learnt all about the illness. One 19 year-old female respondent boasted:



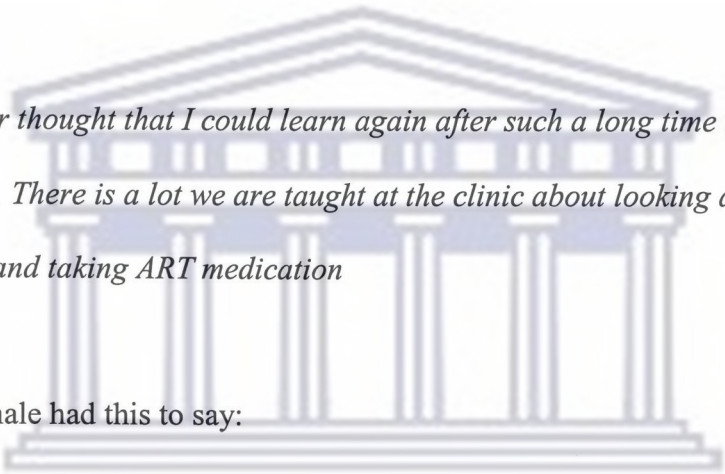
We learnt all about HIV/AIDS. The nurses and doctors saw to it that we know everything about HIV and ARVs. You have to know even about shingles and side effects so that you can sense when something is wrong.

However, not everybody seemed to know all about adherence. All that some knew about well was eating good food, but not about all the psychosocial aspects required for optimal adherence. A 23 year-old male respondent confessed:

We were not told all about adherence, not everything. We sometimes depend on the others and ourselves for guidance. If you do not have family or friends who care, you will not know sometimes whether what you're doing is right or wrong.

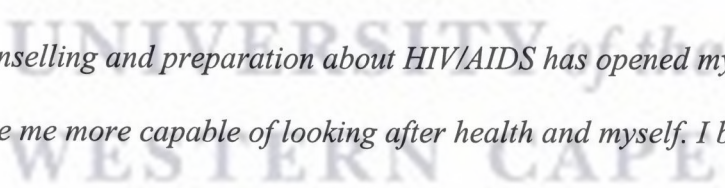
4.2.4 Counselling and education

Most patients expressed their satisfaction with the high quality of counselling and education they receive from their healthcare providers and the counselling team. They mentioned that sometimes they would be like school children sitting in a classroom where they would be taught about the need to accept their state of health and about the importance of adherence to antiretroviral medication. One 22 year old female participant had to say:



I never thought that I could learn again after such a long time that I left school. There is a lot we are taught at the clinic about looking after our health and taking ART medication

and a 29 year old male had this to say:



Counselling and preparation about HIV/AIDS has opened my mind and made me more capable of looking after health and myself. I became a better person after the counselling meeting. Otherwise I had given up on life. Now I take my antiretroviral medication responsibly.

4.2.5 Denial

Feelings of denial and isolation were common among the participants. Most participants described the time before acceptance of their HIV-positive status and beginning taking antiretroviral treatment as a period of denial, fear, shock and disillusionment about life. For example, a young female of 19 years, had to say:

I did not want to be around anybody; I wanted to be all by myself

and a 30 year old male lamented:

I was not true to myself, I wasn't facing that I had it; I was in denial for a long time

and a 21 year old girl added:

I didn't want to understand it; I tried to hide myself from others, including myself.

4.2.6 Lack of food and hunger

The issue of lack of food and hunger was mentioned at every interview, and several patients believed that medication must be taken with food. The participants felt that lack

of food disrupted the daily schedule for taking their treatment. One 26 year old male respondent, who mentioned that he was unemployed had to say:

I have to eat every time, I must eat before taking the treatment, but sometime there is nothing to eat.

Some went to further to express the belief that it is unhealthy to take medication without food, as a 27year old female said:

If you take the pills an empty stomach, you feel as you are going to die. Sometimes you find that it is difficult to breathe properly at that time.

Among the respondents, a lack of food grant is a very real concern. One 25 year old female respondent expressed that:

The main problem is that all or most of the patients are poor like me. We don't have money to buy food, and we don't have food at home right now.

4.2.7 Stigma

Almost all participants reported on their experiences of stigmatisation and discrimination. Some participants mentioned that after disclosing their HIV-positive status they had lost their jobs. Fearing such stigmatisation, ARV users often decide to hide their HIV status

from colleagues, friends and others. The fear of stigmatization is illustrated by one 23 year-old male below:

I cannot take my pills when people are watching. I always go and hide somewhere when I take them. Otherwise people will start whispering about you all the time.

However, ARV users are very much aware of the important role they can play as role models in encouraging people to open up, disclose their HIV status and seek treatment. One 30 year old male participant mentioned that:

We – HIV positive people - we get back and tell them about the ARV medication. When they look at some of us and see how we were and how we look after taking ARV medication, they become bold enough to ask us what has helped to make us look better.

Other participants expressed that people learn to overcome stigmatization and are encouraged to start using antiretroviral medications through hearing the testimonies of people who are already on ART, as a 22 year old female ardent reader had to say:

Reading the column in Sunday Times called 'You know someone else' helps people to come out from stigma."

and she also mentioned that:

(We have) our own networks in our community and Lovelife for People Living with AIDS. Whenever we gather people are forced to ask why (we attend) the meeting and as a result we tell them about the medicine.

Patients also report that their re-integration into society is difficult, or even impossible, and this despite their good health. They wonder if it is really worthwhile to sacrifice so much in order to stay healthy when their HIV-positive status continues to mean social death.

4.2.8 Perceived social support

All participants perceived social support as an essential component of their daily survival. They believed that support is built from relationships and interactions that provide participants with assistance or feelings of attachment. Among various types of support, namely, emotional, informational, appraisal, and instrumental, emotional support was reported as the main concern and immediate need. The excerpt below from a 25 year old female illustrates a common thread found among the participants:

If people understood what HIV/AIDS is all about they would treat those who have it differently. Sometimes all it takes is a little love, caring, patience to make a big difference. If I had been supported I could take my

medications better. It's true, HIV is a lonely person's disease. I don't have any kind of help or support

A 30-year old man who had been on antiretroviral treatment for 3 years whispered in pain:

I have to keep this feeling with me...I do not tell anybody... in effect nobody seems interested in helping me.

In contrast, a 19 year old patient taking ARV medication was very optimistic:

I told my mother, my brother, my sisters, and they all support me.

Lack of social support also made respondents fail to disclose their HIV-positive status. When they fail to disclose their status, they will not receive adequate social support and encouragement to take their antiretroviral medication regularly and on time. Children were found to be important sources of support, as illustrated in the case of a 28 year old female:

When my child saw the state I was in after getting ARVs, I called her and told her about my condition. She got encouraged and she bought me drinks and food because she was told that the drugs I am taking require food. Now my child knows very well that because of my drugs I have I have to drink enough and eat on time..

Further, most patients noted that today, the general public's interest in the problems of people living with HIV is increasing. However, they feel that the availability of antiretroviral medication has contributed to the drop in compassion by 'normalising' the disease. One 29 year old male patient expressed his feelings with relief:

Many people now know that the other people have the disease. They even help us take the medication... but you don't know whom to believe.

However, they themselves do not necessarily identify with AIDS organisations like TAC, but rather increasingly see themselves as consumers of ARV treatment who simply wish to meet others in order to exchange experiences.

4.2.9 Side –effects

Adverse side-effects of treatment were repeatedly mentioned by the participants, and the most frequently mentioned side-effects were: body rash, swollen legs, nausea, headache, increased heart rate diarrhoea and vomiting. The occurrence of side-effects was mentioned as an important reason for skipping doses. A 22 year old female told of her struggle with side-effects:

I suffered from side-effects and decided to take medication only once daily...

and a 23 year old immaculately dressed semi-professional male had to say:

I feel a lot of heat all over my body, especially after taking ARVs and profuse sweating makes one embarrassed in public. So, you feel like postponing the pills to a later time when you are not with people.

4.2.10 Patient satisfaction

The participants expressed their confidence and trust in their healthcare providers; about their personal characteristics and their perceptions of their providers' technical and interpersonal skills together with their perceptions of whether or not they are adhering appropriately to their treatment. Some even expressed their trust in their patient-provider interactions on the basis of continuity, frequency, and success of treatment, as well as for predicting the relationships between perceived trust, anxiety, tolerance of bitter medication, and perceived health outcomes. One 27 year old male respondent, seemingly effervescent, said:

I trust that the nurses are doing a good job, I love them. They are friendly and we have very good relations with them.

For some respondents, their satisfaction led them to return to their provider and related to both their satisfaction and their inclination to the interaction between the characteristics of the patient and of the clinic setting. A 28 old unemployed female participant consented by saying:

For the sake of continuity of care, I think this is one of the best

clinics around. I don't think that I will move to another place. I am satisfied with this place

For some participants, the quality of oral communication between the patient and the healthcare provider, there is, and paradoxically, patients' contentment with the provider's show of anger towards them, anger being interpreted as a reflection of a firm but fair attitude. One 26 year old respondent smilingly expressed the sentiment:

Patients love him for his show of anger. It pleases us because we know that it shows that he loves what he is doing. He loves us and he wants to save our lives. We are worried when he is on leave or away for a long time

4.2.11 Privacy and confidentiality

The majority of participants reported that although there were private rooms in which HIV-positive patients could be consulted, the fact that they had a separate section of the clinic for them made them feel vulnerable to stigmatisation and discrimination. While privacy was possible for most of the patients, it was compromised by the presence of other healthcare providers in the room. A 30 year old male, who seemed angered and concerned about this matter, did not mix his words as he said:

You sit on the bench waiting for the doctor or nurse...I don't think the nurses care about that. Everybody walks into the section freely. There is a

separate section for us...every time you walk into the section everybody knows that you have AIDS. That makes me fail to come to get medication sometimes

and one 25 year old female, who also felt demeaned by the situation, strongly mentioned that:

There is absolutely no privacy at all here, nurses just walk into the consulting room whenever they wanted to. This makes me feel uncomfortable, and sometimes I think twice about getting my tablets from the clinic.

The issue of privacy may be linked to concerns of confidentiality, which are crucial when dealing with patients with HIV/AIDS.

4.2.12. The challenge of alcohol use

Most of the interviewed participants consumed alcohol. There were reports of partying and of rowdy social gatherings among the interviewees. Some mentioned that it is not easy to get rid of the old habits. A 25 year old female, a self-confessed party-monger, had this to say:

Changing overnight is not easy...I am always tempted to go to the same old places. Sometimes I tell myself I am going to refuse drinks...but I find myself

taking a few glasses...and sometimes more than I expected.

Participants who fail to adhere to the drug regimen often do not understand the importance of never skipping a dose and always taking their medications at the same times. One 22 year old female confessed to missing doses:

It is obvious that I cannot carry my medication when going to pubs and shebeens...that means missed doses...

4.2.13 Depression

The challenge of apathy and depression was mentioned by almost every participant. They mentioned that the first step is the shock of discovering that they are HIV positive, then the feeling that you are not going to live longer anymore, and that of depending on the pills for the rest of your life. One seemingly depressed, 19 year old female participant shared the sentiment:

Sometimes I think I am going to die...too much things going in my head...

imagine a 19 year old contemplating death, knowing that she is going to die soon. It's quite depressing.

Another depressed 22 year old female, who was a victim of peer pressure, could not hold her tears as she said:

I don't know what I was doing...I have been told by friends I wanted to forget about that man. Look at me now. I don't know what to do about myself...I just feel So down and I am empty. I feel like going down and cry...

4.2.14. Relations with health providers

Some patients were unequivocal about the good relationship they had with the health providers at the facility. They expressed support from the staff of the clinic. One 29 year old male patient had to say:

I feel happy with the way that they support us; they make us feel at home when I am around them... they show a lot of compassion and heart.

However, other patients regret that consultations rarely offer the opportunity for more than a discussion of the latest examinations and the usual check-ups. One 26 year old male patient said:

I wish they would discuss effects of treatment on our social and sexual relationships; and would perhaps do so if encouraged to discuss obsessions with what goes beyond the merely medical, but I feel that they there is no place

or time for these issues with our consultations

4.3 Summary of the chapter

The chapter divulges the themes and categories that form the core perceptions of challenges and experiences people living with HIV/AIDS. The themes depict the kind of circumstances among black South Africans who live in dire poverty, and whose lifestyles and beliefs are not congruent with 'normal' ways of life expected from potentially adherent people. The categories include constraints such as patients' self-efficacy to take all doses as prescribed, beliefs about taking medication, knowledge about HIV, counselling and education, denial, hunger, stigma, perceived social support, side-effects, patient satisfaction, privacy and confidentiality, the challenge of alcohol, depression, and relation to health providers. However, those categories do not differ extensively from of people living in other developed countries.



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CHAPTER FIVE

DISCUSSION

5.1 Introduction

Adherence continues to be understood as a dynamic relationship between different aspects of the person, the medication and the social context in which they live. As previously espoused, the problem of non-adherence affects all populations, but some are more vulnerable than others. In this study the researcher examined the perceptions of challenges and solutions to adherence to ARV medication among HIV-positive people in South Africa. The findings illustrate the patients' experiences as they endeavour to attain optimal adherence proportions. Generally speaking, the participants' adherence was good, but hardly ever perfect. The general perception of the sample of HIV-positive people receiving antiretroviral medications used in the study suggest that achieving high levels of medication adherence would be challenging more than ever before. Astonishingly, however, self-reported adherence levels were equivalent to those of antiretroviral adherence among HIV-positive people generally.

A number of patients' perceptions of the challenges and experiences to antiretroviral treatment emerged from the study as factors related to the level of successful adherence that patients can achieve, and that continued to have implications on adherence to

antiretroviral medication. The research findings are discussed below, with reference to relevant literature.

5.2 Patients' self-efficacy

Some participants expressed their skepticism about their commitment in taking their medication as recommended, which indicated that they lack self-efficacy. On the other hand, self-efficacy, or confidence in one's ability to adhere, is one patient factor that is consistently and meaningfully related to ARV medication adherence. The amount of self-efficacy displayed by the participants is the paramount requisite factor for healthy adherence and, along with perceptions of treatment efficacy, is central to theories of health behaviour and adherence, including HBM. Such confidence is not expected to waver even in the face of challenges such as side effects, interference with daily activities, environmental barriers to treatment, depression, and lack of support from others.

Bandura (1997) concurs that unless people believe they can adhere to the prescribed medication by their own actions, they have little motivation to act or persevere in the face of obstacles. Thus, self-efficacy beliefs influence adherence, how much effort they invest in their adherence, and how long they will persist and adhere in the face of those barriers, and the level of accomplishment they realize. However, self-efficacy is not only an important intermediary outcome; it is an important outcome in and of itself as an increase in self-efficacy is a direct indication of treatment success. When adherence to treatment is

successful, patients themselves become increasingly confident of their ability to change for adherence to their medication. Accordingly, Bandura (1991) argues that self-efficacy measurement should be specific both to the situations in which adherence is required and the level of challenge to adhere to medication. Furthermore, research linking adherence to self-efficacy has also indicated the potential for interventions to bolster adherence self-efficacy for persons who are struggling with adherence.

5.3 Beliefs about taking medication

Many respondents expressed beliefs they held and that seemed to be supportive and some unsupportive of taking medication. For example, the intention to take medication was strongly associated with positive beliefs about clinical benefits of taking medication. Hence, participants who were positive and believed that taking medication as prescribed was important for maintenance of their health reported high levels of adherence, whereas those who reported the belief that taking medication is important only when one feels sick were less likely to take their medications as prescribed. Chesney (2000) supports the belief that taking one's medication as prescribed helps maintain health and may form the foundation on which other adherence efforts are based. Thus, the health provider's communication with patients should emphasise the importance of preventing illness through continuous efforts at taking the medication as prescribed, with education materials that assist in patient understanding that HIV remains active during periods of apparent wellness.

However, there were participants who held negative beliefs about taking their medication, who mentioned problems of gaining wait and the effect of side-effects. Treharne, Lyons and Kitas (2004) agree that patients may respond to such dilemma by trying to minimize their perceived risks by taking only part of their recommended treatment dose, as some of the participants did. Further, Treharne et al (2004) argue that people may hold negative beliefs about medicines if, although they do receive enough information from healthcare providers about treatment benefits, they often have minimal understanding of the information given.

Treharne et al (2004) further argue that harbour such negative feelings about taking medication if they feel less involved in the decisions made regarding their treatment. For instance, one participant confided that healthcare providers always encouraged them to take a more active role in their treatment plan and become more involved in the decisions that are made about their medication. Murphy et al (2000) agree that people who are more involved in their treatment plan may feel less anxious about their treatment, more in control of their decision-making about their care and consequently may have more confidence about managing their medication.

Often, some participants had problems in taking medicines as prescribed, as they believed that it is beneficial to stop taking their medication for some time to give their body a 'rest'. Reynolds (2004) states that this is common among patients who feel they are not experiencing HIV/AIDS symptoms and so they adjust or omit their dose accordingly. However, Tsasis (2002) maintains that since medication is prescribed for preventive

reasons, for those who have negative beliefs about medication, it may help them adopt a wider perspective of the benefits of taking medication, which will help enable them to feel more confident about the reasons for taking their medicines, and improve their health and quality of life.

5.4 Knowledge about HIV

The participants seemed to be well-informed about HIV and other related issues like side effects and CD4cells. They knew, for example, about information on factors that constitute correct ART utilisation and adequate adherence, specific side effects that occurred with their regimen, and potential drug interactions, what the medicine did and what it was for, how it was taken and related precautions. They were also aware of the consequences of non-adherence, including treatment failure, disease progression, and death be understood, were aware that once the medication resistance develops, treatment options are limited. Howes (2005) agrees that the type of information patients are exposed to about their illness and medications is influential in adherence behaviour. Thus, the participants' understanding of HIV/AIDS, knowledge and adequate awareness of the purpose of therapy, adherence-related information that is necessary for improved medication use (Starace et al, 2006), which led them to improved adherence to antiretroviral medication. Howes (2005), Durante (2003) and Weiser et al. (2003) further argue that if, for instance, patients were to be surprised by the side effects of the medication, it was likely for them to be non-adherent.

While some participants expressed their concern about the amount and complexity of information imparted to them, it was evident that the digestion of the information by the patient appeared to be very simple to the health provider. It was seemed extremely complex for people without a good background in education and science, as treatments became more complex even more information had to be explained to the patient. Howes (2005) agrees that such lack of adequate education can act as an impediment to adhere, and advices that the amount and complexity of such information could be tailored to the needs of the patient. This would involve the explanation of risks and benefits of treatment in a simplified way to allow patients to review points they may have missed or forgotten.

Although information and increased knowledge was necessary for the behaviour to take place, some patients felt it was often insufficient to sustain or reinforce the behaviour over time. Thus, Clark (1994) asserts that healthcare providers should communicate clearly the behaviours they want the patients to perform, with written materials to augment verbal instruction. This was especially necessary for the disadvantaged people of Crossroads, and as Fisher, Arfken, Heins, Jeffe, & Sykes (1997) agree that for individuals with low literacy skills, can benefit from tailored educational messages regarding the duration of treatment, dosage, frequency, or purpose of medication.

5.5 Education and counselling

The participants were enthusiastic when they reported about their level of counselling and education they received from their healthcare providers. They attributed their adherent

behaviour to the effectiveness of counselling they received from the clinic. Stetson, Charalambous, Dwadwa, Pemba, Baggaley, Grant and Salaniponi (2005) state that education and counselling are important initial strategies of addressing issues when dealing with care of HIV-infected individuals. Furthermore, Fisher et al, (1997) posit that educational approaches to enhancing adherence normally begin with providing the patient with a general understanding of the importance of the medical recommendations. Gracia et al, (2003) argue that while conventional patient education programmes have focused on knowledge of disease and regimen, as patients claimed to have received, Wroth and Pathman (2006) maintain that recent approaches should recognize the importance of changing patients' behaviour. The approach has integrated evaluation of individual learning needs, planning teaching or learning strategies, while identifying appropriate behavioural goals and objectives, and evaluating outcomes, with the expectation that once education occurs, regimen adherence will follow.

Most patients mentioned that the healthcare provider first nurtured a rapport with them and made it possible for them to ask questions about missed doses and find ways to help work through problems with drug regimens. The patient's trust in the provider made it easier for a patient to discuss issues when a medication is causing difficulties. Wroth and Pathman (2006) assert that trust and confidence in one's healthcare provider improves medication adherence. Furthermore, Crossley (2000) maintains that this trust is further entrenched when other themes which are also of relevance to patient encounters with health providers, for example, caring, educating, compassion, and simply witnessing their experiences, all of which are central to medical care, are discussed. Thus, Stetson et al.

(2005) argue, for counselling to be effective, patients should be able to communicate freely, and trust and willingness to participate are the foundations upon which the objectives of counselling can be achieved.

5.6 Denial

The fact that some patients expressed that they were unable to face up to that they have HIV and confessions of being in denial of the disease explained refusal to accept that they are HIV positive. Denial is an emotional state that frequently occurs in a grieving process and was a way of patients protecting themselves from the shock of the disclosure of HIV status. For these patients, denial provided the needed time to understand the diagnosis and organise more lasting and coping mechanisms. Ross and Deverell (2004) assert that there might be rejection of the HIV status itself, and its permanent impact on adherence to antiretroviral medication. People who reject their HIV status often tend to argue with healthcare providers and sometimes refuse to accept their views, thereby creating an adversarial relationship in which the healthcare provider either feels insecure about the accuracy of the diagnosis.

Alternatively, as Thomason and Campos (1997) argue, if denial persists, it may manifest itself as maladaptive coping behaviours and avoidance strategies, some patients may not confront the provider with denial, but instead either fail to go to the clinic for their medication or to follow the prescribed medication, and as non-adherence to treatment enables individuals to remove themselves from the reality of an HIV diagnosis.

5.7 Lack of food and hunger

The participants very often mentioned the problem of lack of food and hunger. Food and diet is part of adherence as well as to the overall wellbeing of persons living with HIV/AIDS, but often overlooked in primary health care settings, such as clinics. Whether healthcare providers are dealing with body's responses to medication, drug regimens, or whether the patient is experiencing weight loss or gain, or the development of opportunistic infections, all these issues involve nutrition. As Gebo, Keruly, & Moore (2003) point out, economic barriers faced by patients illustrate the situation of dire and abject poverty HIV-positive people have to face up to in South Africa. Lack of financial resources for life essentials and hunger are most likely representative of a life of poverty and social instability that need to be addressed in order to potentially increase overall antiretroviral adherence.

Gebo et al (2003) also argue that although the government is addressing the question of hunger and poverty through the introduction of disability grants for HIV/AIDS, and a national programme of child support grants for care givers, to meet basic needs for limited household resources. As some participants have mentioned, they felt that they needed money to sustain their lives. The desire to rescue themselves from poverty and hunger has resulted in some of them deliberately refrained from taking their medication. as Tladi (2006) argues, people may deliberately put themselves at risk of infection or fail to take their medication in order to qualify for disability grant.

Participants also felt it was unhealthy without any food. Patel and Patel (2006) note that the ability to take medications together with food and the avoidance of food restrictions are important factors in simplifying a patient's regimen and increasing the likelihood of successful medication adherence.

5.8 Stigma

The participants seemed to be very conscious of the effect of the stigma of HIV/AIDS as a barrier in their endeavour to adhere to their antiretroviral treatment. Some even mentioned that they may even skipped doses than taking pills in the presence of other people. The anxiety and fear of being stigmatised defined the patients' concerns for HIV stigma which are, themselves informed by a person's understanding of and attitudes towards both HIV and people living with the virus. This also included perceptions of other people's attitudes towards HIV, and experiences with expressions of fear, bias, or discrimination directed at them and other people living with HIV.

In turn, stigma concerns then affected the participants' behaviour. For instance, some of the participants mentioned that they had to navigate the potentially dangerous landscape of everyday personal relationships and decide if when, how and to whom they would disclose their HIV status. Rintamaki, Davis, Skripkauskas, Bennett and Wolf (2006) affirm that the threat of social stigma may induce negative feelings and prevent people living with HIV from revealing their status to others and thereby become a barrier to HIV treatment adherence. They further argue that knowing that bias and stigmatisation are

frequently consequences of HIV infection, people with high concerns of stigma may be less likely to disclose their HIV status to others, either out of shame or out of fear of persecution.

Furthermore, as the situation was with the participants, the HIV medication regimen complicated this process by requiring consumption at inopportune times and in environments with little privacy, such as at workplaces, restaurants, or even when entertaining company at home. As a result, accessing or consuming HIV medication produced anxiety over potentially revealing one's HIV status to others and heightened mindfulness of disease state. Rintamaki et al (2006) assert that such situations create dilemmas for people living with HIV, in which they must weigh the costs of taking their medications against others learning about their HIV status. Consequently, if people taking ARV medication do not disclose their HIV-positive status, it may affect adherence, as non-disclosure may lead to patients taking their medications secretly and irregularly.

5.9 Perceived social support

Although nearly all of the participants mentioned being 'reasonably' satisfied with the level of support they received, most often expressed the desire and need to feel loved and cared for. Thus, perceived support emerged as a patient factor in promoting or encumbering adherence. In most cases, the need for social support was positively associated with acknowledged non-adherence, although actual receipt of support was not.

While the participants did not establish any causal relationship, the outcomes suggest that a lack of support from an affirming other, an information-enhancing relationship, an empathic listener, or a spiritual relationship interfered with achieving greater adherence.

Furthermore, those participants who indicated that they have friends, family, or partners who encouraged them to take their medications reported high levels of adherence. Johnson, Caza, Remien, Rotheram-Borus, Morin, Charlebois, Gore-Felton, Goldstein, Wolfe, Lightfoot, Chesney, & the NIMH (2003) concur that the presence or absence of social support is identified as a strong and consistent predictor of successful adherence management in those with HIV/AIDS. Social support for taking antiretroviral medications may thus be closely linked to awareness of friends and family of the patient's HIV status. However, reluctance to take medication publicly or even when with friends or family are around was also reported to be a barrier to adherence.

As some participants indicated that they received their support from healthcare providers, Koenig, Ferneta and Farmer (2004) agree that social support can also be provided by the healthcare providers with patients undergoing detailed social assessment to address potential barriers to medication adherence, response to therapy, or nutrition. As some patients have confirmed that some health providers regularly made home visits to provide emotional support and ensure that patients are thriving in all aspects of life, Koenig et al (2004) agree that a healthcare provider may visit each patient at home, analyse the household's financial situation and social support network, and that a management plan is elaborated on the basis of these assessments. However, Bender (2006) argues that

healthcare providers may not be able to resolve the conflicts of dysfunctional families, but recognizing the problem can lead to referral to a mental health professional.

5.10 Side –effects

Some participants reported skipping or missing doses in order to avoid side effects and other unpleasant symptoms. Chesney (1999) agrees that patients who miss or skip one or several component regimens of their treatment usually do so in order to avoid particular unpleasant side-effects. The same is true of patients who modify the dosage of various medications in order to adapt to the treatment to their own perception of their body. Such patients may reduce the recommended dosage if, for instance, they feel that their weight is below average and therefore needs lesser amounts of antiretroviral medication. Temporary and long term interruption of treatment is also justified by the same logic: as patients want to purify their bodies or to substitute the antiretroviral therapy with another, for instance, alternative type of medication or they may resort to a religious-meditative type of approach.

In most cases mentioned by the participants, side-effects seemed to disappear over time, and some patients did not seem to have this important information about the prevalence of side-effects. By contrast, among participants who experienced side-effects and with whom side effects were discussed extensively in pre-treatment counselling, only a few of them cited them as one of the reasons for missing their medication, suggesting, as discussed above, that effective counselling increases tolerance. Hirani and Newman

(2005) argue that the symptoms or any identity patients believes to be associated with HIV/AIDS may be an important influence on taking medication. thus, if patients perceive the bodily sensations they are experiencing, for example diarrhea, are indicative of HIV side effects, they are likely to delay taking antiretroviral medication. On the other hand, once patients accept their HIV-positive status, they may become focused on their internal sensations, interpret them as reflecting their HIV condition, and become debilitated by HIV focused anxiety.

Hirani and Newman (2005) further argue that with HIV/AIDS, how people interpret and respond to the symptoms and side-effects is influenced by the intensity of the pain, previous experience with HIV/AIDS – either personal or family history – as well as whether they sought advice and support from other. Such experiences appear to be among the most important influences on the interpretation of symptoms as a serious threat to patient's health and thus influence the desire to take antiretroviral medication. Hirani and Newman (2005) further argue that beliefs about the degree and seriousness of the side-effects may also act to encourage or discourage medication adherence. For example, if HIV-positive people do not accept that they have a serious problem, they may not be likely to take appropriate action, like adhering to their antiretroviral medication to attenuate the progress of the HIV/AIDS. Thus, both physical and social impacts of side-effects are a concern for people taking antiretroviral medication and can have an adverse effect on adherence.

5.11 Patient satisfaction

Some participants were unequivocal in expressing their trust and confidence on the efficacy of the healthcare providers and the overall treatment at the clinic. Various dimensions of patient satisfaction mentioned by the participants emanated from accessibility, humanness, technical competence, and there were distinct factors within the clinic which influenced each of these kinds of satisfaction. For example, satisfaction with accessibility was related to the patients' distance to the clinic and the hours that the clinic is open. To some extent, participants attributed their satisfaction to issues such as humaneness to competence, an example of the halo effect, where the determinants of satisfaction with competence of healthcare providers were similar to those for satisfaction with humaneness. Patients also assessed competence directly through useful but imperfect indicators such as staff confusion, modernity of equipment and facilities, or the quality of data gathering or information giving to them.

Further, satisfaction with the interpersonal aspects of care, such as concern, privacy, and respect, were also related to the role discretion of the healthcare providers, or their ability to make decisions without checking with someone else first. Healthcare providers with little role discretion were perceived as concerned with patients as individuals, and less able to use personal discretion by, for example, providing them privacy. Greenley and Davidson (1988) agree that the lack of role discretion is probably the reason that highly bureaucratic healthcare facilities are often disliked by the patients. Such highly bureaucratic centres are hierarchical in nature, have written orders, have routinised

procedures, and have specialised personnel. Such specialised healthcare providers would provide referrals or seek consultations about problems outside their area of expertise. They would also have to ask permission from their superiors more often and would have to refer to written orders more often, and they would appear less flexible. All these could help explain why patients would be more dissatisfied with service in clinics where staff members have less role discretion. Greenley and Davidson (1988) argue that these characteristics negatively affect the patient's perception of the effectiveness of the healthcare provider.

However, there were those who felt that they were not satisfied about the way the clinic operates, with patient dissatisfaction leading to a variety of patient behaviours, as behaviours within the clinic and characteristics do not produce the same reaction in all patients. Further, more subtle behaviours at the clinic that provided passive barriers at the entry of the service, such as long waiting times to get an appointment or to see a provider, were related to dissatisfaction with service. For example, the dislike or distrust of the healthcare providers expressed by some participants may have been the reason for delaying between the times symptoms are first noticed and seeing a healthcare provider. Further, untreated symptoms which were present among some patients may be a way of expressing dissatisfaction with past medical care from the clinic. Some of the participants who expressed more discontent with the clinic's medical care mentioned that they have had sessions where they did not receive attention and were considering seeking medical care elsewhere. Greenley and Davidson (1988) argue that such "doctor shopping," or

consulting another healthcare provider about the same problem without a referral may be related to patient satisfaction with a healthcare provider.

Greenley and Davidson (1988) further argue that satisfaction varies by what patients expect and value and patients vary on what they expect and value. For example, one participant expressed his dislike of a large group practice because it was more bureaucratic, while another liked the same group practice because it was more efficient in processing disability grant forms. In addition, unmet expectations were another major source of dissatisfaction, and actions that angered patients and led to dissatisfaction, such as requiring people to wait a long time, are associated with lower levels of adherence. Thus, Bernard and Krupat (1994) contend, patient satisfaction results in various patient health behaviours, like adherence and non-adherence to antiretroviral medications.

Greenley and Davidson (1988) postulate that patient satisfaction with care may reflect attitudes and opinions about care that may influence other patient behaviours, such as choice of provider, amount of services used, and adherence.

5.12 Privacy and confidentiality

The participants complained strongly about lack of privacy and confidentiality at the clinic. They felt exposed to ridicule as their section was separate from other sections and thus, anyone could identify them as separate group who were HIV-positive. As a result, anybody who walked into the section and saw them sitting on the benches knew without

telling that they are suffering for HIV. Some reported that they thought twice about going to the clinic, and that they would sometimes prefer to seek help from pharmacies and informal traders where there was more privacy. Fortensberry, McFarlane, Bleaky, Bull, Fishbein, Grimley, Malotte and Stoner (2002) argue that considering the disgraceful feelings evoked by HIV and the stigma attached to the disease, that kind of management, together with the assurance of confidentiality, is especially important when dealing with the treatment of such diseases. As was the case with the participants, Moses, Ngugi, Bradley, Njeru, Eldridge, Muia, Olenja, and Plummer (1994) found most of HIV patients they studied reported getting their medication from pharmacies and informal dealers because there was more privacy in such places, among other reasons. Although most of the participants felt they had enough privacy, it was compromised by the movement of the healthcare providers who were either in the room or walked in freely.

Furthermore, the question of privacy was directly linked to concerns of confidentiality. The guarantee of confidentiality is essential when dealing with sensitive diseases such as HIV/AIDS. Giesecke, Ramstedt, Granath, Ripa, Rado, and Westrell (1991) posit that the patient-provider coordination will not be successful unless patients are assured of confidentiality, together with medical and psychosocial care. Chesney (1999) adds that patients have to be provided with the kind of confidentiality they deserve, as some participants had an enormous need for privacy around their HIV status and taking their medications. This requires greater emphasis on planning ahead for moments of privacy on a daily basis.

5.13 The challenge of alcohol use

Most participants acknowledged that they drank alcohol and that changing their habits and lifestyles was one of their greatest challenges as they felt it was not easy to drop the habit. They acknowledged that heavy drinking, on the other hand, can be construed as a lack of desire to improve one's health, and therefore, the two behaviours may be incompatible. They were also concerned about potentially harmful interactions between alcohol use and adherence to their treatment, and they mentioned that they missed their medication doses and were thus, less adherent. Meanwhile, they concurred that taking medication was an important step towards improving one's health, a desire to live and a willingness to endure the side-effects and other negative consequences that may occur as a result of non-adherence to recommended treatment.

Parsons et al, (2007) assert that alcohol consumption is common among HIV-infected persons and has an important relationship to medication adherence. The altered state induced by alcohol usually makes heavy drinkers forget about taking their medication or lose sight of their importance. Thus, alcohol consumption among HIV positive people may lead to disease progression because of impaired adherence to antiretroviral medication. People who consume alcohol are more likely to have worse adherence than those who do not drink, with non-adherence increasing with the level of drinking severity. It is not only heavy drinking that negatively impacts adherence, but moderate drinking too, is a risk factor for poor adherence. People with HIV may also have problem-level drinking, and thus face a particular challenge with adherence to

antiretroviral medication. Thus, problem drinking can be predictive of decreased, as problem drinkers more commonly report missing their medications due to forgetfulness or running out. Further, alcohol consumption is the most predictor of non-adherence among those with a history of alcohol problems, and that increased alcohol use can be associated with both non-adherence and HIV viral load suppression

5.14 Depression

One of the most prominent challenges that faced the participants and an important factor in determining readiness and adherence to antiretroviral medication was depression. Some participants expressed their disappointment with their lives and did not see any need for living, and there are multiple factors that explain why depressed patients may have more difficulty adhering to complex ARV regimens. For instance, Simoni et al (2002) argue that depressed patients may lack the physical and mental readiness to maintain high levels of adherence. Depressed patients frequently harbour feelings of hopelessness toward themselves and their future; as a result, adhering to medication regimens with the hope of future health is unlikely. As Parsons et al (2007) further argue, depression among HIV positive can result in non-adherence as patients may 'give up' and even refuse their treatment altogether. Depressed HIV positive people also tend to be less motivated to take their HIV medications, as they may have impaired cognitive functioning that makes it difficult to remember to follow through with the treatment recommendations or may have a pessimistic outlook about the effectiveness of treatment

Such feelings of depression may also be a potential mediator between the need for social support and non-adherence. Furthermore, severe appetite changes are often associated with depression and therefore, depressed patients may find adherence to special dietary instructions related to adherence particularly difficult. Thus, the identification and treatment of mental health issues, particularly depression, may be a potential way to address and reduce non-adherence

5.15 Relationship with health providers

There were numerous factors of provider-patient relationship that emerged as being significantly influential to adherence. For example, participants who had ‘open lines’ of communication and positive relationships with healthcare providers mentioned that they took their medications as prescribed, while those who characterized their communications with their providers as poor appeared to have low levels of adherence. Thus, a sound provider-patient relationship enabled the provider to understand the patient’s internal frame of reference and the necessary lifestyle changes that would promote ongoing adherence to treatment. Roberts (2002) agrees that there is enough evidence to suggest that relationships with health care providers can affect medication adherence.

In the same vein, van Servellern and Lombardi (2005) note that positive engagement by patients in the patient-provider relationship, and interpersonal component, is related to adherence. They state that patients who are more engaged with their healthcare providers

are more adherent to their medication regimens, and those who are less engaged are more likely not to follow healthcare provider advice, and thus become less adherent. Whereas good quality patient-provider relationships are associated better adherence, lesser quality relationships have a more deleterious effect on attitudes of patients about their treatment and impede adherence. Furthermore, adherent and non-adherent patients differ in their perception of provider advice, including the interpersonal manner, conduct, and overall quality of the relationship. Also stressing the importance of the patient-provider relationship, Ickovics and Meilser (1997) assert that rapport with the medical team is frequently the reason patients remain in antiretroviral treatment. On the other hand, Chesney (2003) also notes that patient-provider collaboration can result in lifestyle-tailored regimens that enhance adherence and willingness to adhere to antiretroviral medication for a long time. Furthermore, the stigma and embarrassment associated with HIV/AIDS, makes trust in the patient-provider relationship critical with regard to acceptance of and adherence to treatment.

5.16 Summary of the chapter

The chapter discussed the themes and categories and perceptions of participants as they emerged from the research. Each theme is discussed along with supporting literature evidence to give strength to them. The themes reflect on the perceptions of challenges and experiences of people living with HIV/AIDS in South Africa. Although the participants' perceptions are not unique in the sphere of HIV/AIDS and other chronic diseases, their shed light as to what healthcare providers should pay attention to when

dealing with their patients. For the mere fact that there is both national and international literature to support the points laid out by the participants indicates that the perceptions of the participants are not unique only to South African or sub-Saharan African nations, but are universal.



CHAPTER SIX

CONCLUSION AND REFLECTIONS

6.1 Introduction

The previous chapters have dealt with the review of literature, research methods, themes and categories, discussion of the theme of perceptions of challenges and experiences of adherence to antiretroviral treatment among people living with HIV and AIDS. This chapter focuses on the summary and conclusions of what has been previously investigated. Patients in the study population generally functioned well and were very vocal about their perceptions of challenges and their experiences of adherence to antiretroviral treatment.

6.2 Summary of the study

The present study reveals good knowledge among participants about HIV/AIDS, disease progression, and its transmission. However, there is a great need to educate participants that ART does not heal HIV/AIDS and that missing doses could result in drug resistance and then lead to disease progression. Adherence is complex and the management of HIV/AIDS is challenging, yet many patients do succeed. However, it is important to acknowledge that poor adherence to antiretroviral treatment is a pervasive problem in HIV/AIDS care which leads to clinically unpleasant personal and public health results.

Psychological factors such as social support, self-efficacy, mental health conditions, health locus of control, health literacy and quality of life, play a significant role in determining the degree of patient adherence. Although these factors are always associated with poor adherence, none of them are satisfactorily robust to reliably identify people at risk for poor adherence. Thus, adherence is increasingly understood as a dynamic behaviour influenced by interrelated factors that change over time. With HIV/AIDS, patient and provider assessment of adherence are unreliable predictors of success. Taking the medication properly can be problematic, even for the patients who understand the danger of non-adherence.

Overall, patients' understanding of the complexities of adherence has been incomplete than might be expected. It may not be easy to identify patients who are likely to be non-adherent, and that, for example, substance abuse may not be directly associated with non-adherence. Therefore, researchers and healthcare providers have to be careful to ask patients with histories of substance abuse about adherence. It does not follow, however, that all patients who abuse substances will be non-adherent. Similarly, homelessness, lack of education, and mental illness are not necessarily predictors of non-adherence, but might warrant extra attention and support. Furthermore, the abstinence from alcohol and drugs does not predict good adherence. Thus, as with other chronic diseases, the data supporting interventions are weak. Therefore, well-powered, rigorously evaluated antiretroviral adherence intervention trials are urgently needed.

Nevertheless, concise, frank, efficient education for the patient from the provider improves outcomes in HIV/AIDS. Success is often the result of good collaboration between the patient and the healthcare provider in identifying the specific barriers to adherence for that individual and making appropriate accommodations. Based on results in chronic diseases other than AIDS, regimens with simpler dosing strategies, for example fewer pills and fewer side effects improve outcomes, including early discussion of expected toxicities, may facilitate adherence.

On the other hand, addressing social and psychosocial issues at the outset can improve adherence, as the presence of these factors at the initiation of medication treatment does not necessarily predict long-term failure. Many patients harbour beliefs about the nature of HIV/AIDS, its treatment, and their own ability to be adherent. Exploring these beliefs briefly, but openly, can facilitate adherence treatment and success.

Furthermore, problems in the field still exist as a function of limitations of available measures of adherence. Progress in measurement methodology and analysis strategies will support needed advances in the field. While significant progress in the field has been made, clearly, considerable research efforts to better understand and improve antiretroviral adherence.

6.3 Limitations

While enlightening and valuable for the understanding of the challenges and experiences of adherence to medication among people living with HIV/AIDS, the study has several limitations. First, participants in the study were registered in an ART programme at a clinic and were therefore predisposed to a selection bias. Despite the fact that the sample was drawn from a single site, these self-reports that were used to generate the study data were thus expected to reflect the knowledge, attitudes, and beliefs of a particular sample in at a certain point in time instead of objective facts or population-based method. Furthermore, the participants in the present study had a relatively short period of antiretroviral treatment of 18 months at the time of initiation of research, which may indicate an inadvertent selection against patients with difficulties taking or consistently obtaining treatment.

Furthermore, adherence to antiretroviral medication is difficult to measure accurately and the basic technique used, self-reporting, has its own limitations. Self-reports usually reflect only short-term or average adherence and may often overestimate. Such one month self-report of adherence and non-adherence to antiretroviral medication may be subject to memory bias and possible overestimating adherence as compared to other objective measures, and likely served to ease rather than increase the strength of the research findings.

Self-reports assume, though, that patients can accurately remember their adherence behaviour and are providing honest answers as well. Furthermore, participants appeared to be honest in reporting adherence because in reporting adherence, non-adherence is negatively associated with viral load. Although the present study is only concerned about the participants' perceptions of aspects of HIV, multi-method approaches to adherence measurement such as pill counts and electronic monitoring systems could have lent further accuracy to adherence measurement. However, self-reports have the advantage of being inexpensive and flexible to design, as for example, questionnaires suited the language of the participants. It was also easy to collect data, making it easy to determine the reasons why patients are adherent or not.

The sample size of the study was also limiting because of the high level of adherence reported as most of the participants reported high levels of adherence to their medication. Thus, findings require replication in larger samples of HIV-positive people because of the small size in the current study. This requires more studies to be conducted with larger participants in both urban and rural areas, including participants who have been taking antiretroviral medication for a few years, to establish whether the high levels of adherence reported in this study could be sustained when adherence programmes in resource-limited areas are escalated. The small number of participants may have resulted in a failure to identify important associations between probable risk factors and other interesting variables that may emanate from a larger sample.

6.4 Conclusion

Adherence to ARV treatment requires long-term commitment and maintaining adequate adherence is essential to achieve the potential benefits thereof. Further, optimal adherence and viral suppression are achievable for a significant percentage of patients in places with limited resources such as Crossroads, in Cape Town. The results indicate that strategies to maximise adherence to medication at the site should include easy access to medication, together with HIV/AIDS education programmes to minimize the stigma of the disease.

Furthermore, an important implication of the study is that programmes that identify and address adherence and the clinical, psychosocial, and behavioral impediments to adherence should be closely aligned with healthcare professionals who provide HIV clinical care for people taking antiretroviral medication. Furthermore, regular communication between providers from a variety of disciplines may help ensure that the multiple and complex needs of HIV-infected people taking antiretroviral medication are thoroughly addressed.

Without satisfactory adherence support, ART programmes will be confronted with a huge proportion of treatment failure and the development of drug resistance. Thus, the need to emphasize the significance of treatment effectiveness and adherence to ensure the sustainability of existing attempts to scale up access to antiretroviral medication. Such efforts would include the provision of resources for regular use of simple methods to

monitor adherence and to evaluate new adherence support methods, and to scale up adherence support measures that have proved effective. The proportion of patients on ART continuing with treatment after a year and the proportion of those achieving optimal adherence should be the key indicator to assess adherence programme efforts. Presently, the key achievement indicator is the number of patients who initiated the ART programme, an insufficient method of programme performance, as it only defines success of the programme in terms of access rather than adherence that is prerequisite for sustained health promotion and to protect public health.

Key categories of perceptions of challenges and experiences among the patients in the study include: self-efficacy to take all doses as prescribed, beliefs about taking medication, knowledge about HIV, counselling and education, denial, lack of food and hunger, stigma, perceived social support, side-effects, patient satisfaction, privacy and confidentiality, the challenge of alcohol, depression, and relation to health providers.

Finally, in the process of identifying characteristics extrapolative of adherence to ART and developing programmes that enhance patients' probability to adhere to medical treatment and follow advice, further studies should be conducted. The results of those studies would further contribute to adherence literature to better explain and understand the complexities surrounding the question of adherence to antiretroviral medication.

6.5 Recommendations

The present study recommends that a longitudinal study that tracks adherence for some time is necessary to more accurately assess the adherence-related behaviors among HIV-infected people. Thus, multiple, intermittent evaluation of adherence should be performed among people taking antiretroviral medications to identify lapses in adherence that may lead to treatment failure, poor health outcomes, and reduced quality of life for HIV-infected people.

Furthermore, such continuing evaluations of potential barriers to adherence, for example, homelessness, stress, drug and alcohol use also seem important as the research findings indicate. For some people, it may be the instability in these factors, rather than simply their presence or absence that contributes to adherence or non-adherence. If this is true, more detailed investigation into the factors affecting or producing instability in adherence barriers is needed; as the pathway to increasing people adherence may ultimately be an indirect one, requiring interventions aimed at increasing stability in the life factors that are linked with adherence. For example, it is possible that in some cases, efforts aimed at helping patients cope with and manage their use their medication may be an effective way to achieve and maintain high levels of adherence to HIV medications over time.

Among strategies that should be investigated as means of improving adherence, with induction-maintenance regimens, for example, a more demanding regimen is used during the first few months and is later followed by a simpler regimen. Further, in structured

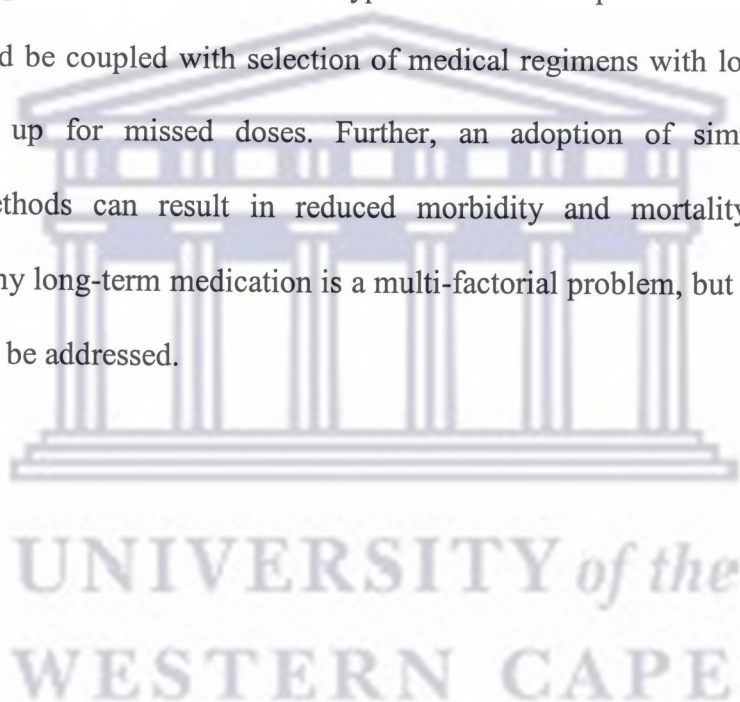
treatment interruption, or intermittent dosing schedules, short cycles of treatment are punctuated by days when the patient takes no medications. With drug switching, for instance, one drug is substituted for another while viral suppression is maintained, together with drug formulations and regimens that are less sensitive to missed doses and the resultant emergence of resistance are under investigation and may more desirable to combat non-adherence.

The major factors associated with non-adherence are related to patient behaviour and a variety of strategies by healthcare providers are beginning to yield improved adherence. Some of the interventions include treatment plan, education and social support. Of particular importance is tailoring of medications to patient's lifestyle. This can be illustrated by consideration of dosing requirements and the need for special instructions that take into account the life patterns of patients. Furthermore, if a patient's treatment fails, the patient should be approached to review adherence before the regimen is substituted. This should help ensure that patients begin with a new regimen with optimal adherence.

Much has been learnt about treating HIV infection in sub-Saharan Africa and in other developing countries. However, because of the demanding and unforgiving nature of the disease and the dependence of taking antiretroviral medication on human behaviour, it is essential that HIV-positive people both truly understand the local complexities of adherence behaviour and respond to it effectively. It is thus important that the scope of programmes funded by large multinational programmes like PEPFAR and GFATM

support exploration of these issues within the context of existing and future programmes in Southern Africa.

Finally, important lessons can be drawn from other studies of adherence among patients with other chronic diseases, where there is a larger body of published literature. Both the factors related to adherence and many other interventions to improve adherence to other medications may largely overlap with those important to antiretrovirals. Chesney (2000) provides an example of a recent review of hypertension which postulated that once-daily medication should be coupled with selection of medical regimens with long duration of action to make up for missed doses. Further, an adoption of simple adherence enhancement methods can result in reduced morbidity and mortality. Thus, non-adherence with any long-term medication is a multi-factorial problem, but it is a problem that can and must be addressed.



References

Airhihenbuwa, C. O. & DeWitt Webster, J. (2004) Culture and African contexts of HIV/AIDS prevention, care and support. *Journal of social aspects of HIV/AIDS research alliance*, 1 (1) : 4-13.

Bandura, A. (1991) Self-efficacy mechanism in physiological activation and health-promoting behaviour. In Madden, J. (ed) *Neurobiology of learning, emotion and affect*. New York: Rave.

Bandura, A.(1977) Self-efficacy: toward unifying theory of behaviour change. *Psychological review*, 84: 191-215.

Bender, B.G. (2006) Screening Patients for Nonadherence. Unpublished paper.
http://www.femalepatient.com/html/arc/sig/screening/articles/030_02_028.asp

Bruhn, J.G. (1988) Lifestyle and health behaviour. In Gochman, D.S. (ed) *Health behaviour: Emerging research perspectives*. New York: Plenum.

Carter M (2005). Adherence. Information series for HIV-positive people. NAM.
<http://www.aidmap.com>

Castro, A. (2005) Adherence to antiretroviral therapy: merging the clinical and social course of AIDS. *PLoS Medicine*, 2 (12): 338.

Chamberlain, K. (1999) Using grounded theory in health psychology: practices, premises and potential. In Murray, M. & Chamberlain, K. (eds) *Qualitative health psychology: theories and methods*. London: Sage.

Charmaz, K. (2003) Grounded theory: objectivist and constructivist methods. In Denzin, N.K. & YS Lincoln (Eds), *Strategies of qualitative inquiry*, Thousand Oaks: Sage.

Chesney, M.A. (2003) Review: adherence to regimens. *AIDS patient care and STDs*, 17(4): 167-177.

Chesney, M.A. (2000) Factors affecting adherence to antiretroviral therapy. *Clinical infectious diseases*, 2 : 171-176.

Chesney, M. A., M. Morin, T. & Sherr, C. (2000). "Adherence to HIV combination therapy." *Social Science & Medicine* 50(11): 1599-1605.

Chesney, M. (1999) The challenge of adherence. *Bulletin of Experimental Treatments for AIDS*
www.aegis.com/pubs/beta/1999/BE990105.html

Clark, L.F., Aaron, L., Littleton, M., Pappas-Deluca, K., Avery, J.B. & McKleroy, V.S. (1994) Stress, coping, social support and illness. In Raczynski, J.M. & DiClemente, R.J. (eds) *Handbook of health promotion and disease prevention*, London: Plenum

Coetzee, D., Boule, A., Hildebrand, Asselman, V., van Cutsem, G. & Goedmaere, E.
(2004) Promoting adherence to antiretroviral therapy: the experience from a
primary care setting in Khayelitsha, South Africa. *AIDS*, 18 (3): 27-31.

Cournos, F. & Wainsberg, M.L. (2001) Promoting adherence to antiretroviral treatment.
American psychiatric association.

www.columbia.edu/~fc15/adherence.pdf

Crossley, M.L. (2000) *Rethinking health psychology*. Buckingham: Open University

Denzin, N. K. & Lincoln, Y. S. (2003), Introduction: The discipline and practice of
qualitative research. In Denzin, N.K. & YS Lincoln (Eds), *Strategies of
qualitative inquiry*, Thousand Oaks: Sage.

Denzin, N. K. & Lincoln, Y. S. (1994), Introduction: entering the field of qualitative
research. In Denzin, N.K. & YS Lincoln (Eds), *Handbook of qualitative
research*, Thousand Oaks: Sage.

DeSimone, J.A., Pomenrantz, R.J. & Babinchak, J.T. (2000) Inflammatory reactions in
HIV-1 infected persons after initiation of highly active antiretroviral therapy.
Annals of internal medicine.133 (6): 447-54.

Dey, I. (2004) Grounded theory. In Seale, C. Gobo, G., Gubrium, J.F. & Silverman, D.
Qualitative research practice London: Sage.

Eiser, C. & Twamley S. (1999) Talking to children about health and illness. In Murray,
M. & Chamberlain, K. (eds) *Qualitative health psychology*, London: Sage.

Elder, J.P., Ayala, G. X. & Harris, S. (1999) Theories and intervention approaches to
health behavior change in primary care. *American Journal of Preventive
Medicine*, 17 (4): 275-284

Ferguson, T.F., Stewart, K.E. Funkhouser, E., Tolson, J., Westfall, A.O. & Saag, M.S.
(2002) Patient-perceived barriers to antiretroviral adherence: associations with
race, *AIDS care*, 14 (5): 607-517.

Fisher, Jr., E.B. Arfken, C.L., Heins, C.A., Jeffe, D.B. & Sykes, R.K. (1997) Acceptance
of diabetes regimens in adults In Gochman, D.S. (Ed) *Handbook of health
behaviour research: provider determinants, II*. London: Plenum.

Fortenberry, J.D., McFarlane, M., Bleaky, A., Bull, S., Fishbein, M., Grimley, D.M.,
Malotte, C.K., & Stoner, B.P. (2002) Relationships of stigma and shame to
gonorrhoea and HIV screening. *American journal of public health*, 92, (3):
378-380.

Furtado, M.R., Callaway, D.S., Phair, J.P., Kunstman, K.J., Stanton, J.L., Macken, C.A., Perelson, A.S. & Wolinsky, S.M. (1999) Persistence of HIV-1 transcription in peripheral blood mononuclear cells in patients receiving potent HAART therapy. *The new England journal of medicine*, 340 (21): 1614-1622

Gaede, B.M., Majeke, S.J., Modeste, R.R.M., Naidoo, J.R., Titus, M.J. & Uys, L.R. (2004) Social support and health behaviour in women living with HIV in KwaZulu-Natal. *Journal of social aspects of HIV/AIDS*, 3 (1): 362-368.

Garcia, R., Ponde, M., Lima, M., de Souza, A.R., de O. Stolze, S.M. & Badaro, R.(2005) Lack of effect of motivation on adherence of HIV-positive/AIDS patients to Antiretroviral treatment. *Brazilian journal of infectious diseases*, 9 (6): 494-499.

Garcia, R., Schooley, R.T. & Badaro, R.(2003) An adherence trilogy is essential for long-term HAART success. *The Brazilian journal of infectious diseases*, 7 (5): 307-314

Gebo, K.A., Keruly, J & Moore, R.D. (2003) Association of social stress, illicit drug use, And health beliefs with nonadherence to antiretroviral therapy. *Journal of general internal medicine*, 18: 104-111

Giesecke, J., Ramstedt, K., Granath, F., Ripa, T., Rado, G. & Westrell, M. (1991) Efficacy of partner notification for HIV infection, *Lancet*, 338: 1096-1100.

Gill, C.J., Hamer, D.H., Simon, J.L., Thea, D.M. & Sabin, L.L. (2005) No room for complacency about adherence to antiretroviral therapy in sub-Saharan Africa.

AIDS. 19(12): 1243-49.

Godin, G., Cote, J., Naccache, H., Lambert, L.D. & Trottier, S. (2005) Prediction of adherence to antiretroviral therapy: a one-year longitudinal study. *AIDS care*

17(4): 493-504.

Greene, J.A. (2004) An ethnography of nonadherence: culture, poverty, and tuberculosis in urban Bolivia. *Culture, medicine and psychiatry*, 28: 401-425.

Greenly, J.R. & Davidson, R.E. (1988) Organisational influence on patient health behaviours. In *Health behaviour: Emerging research perspectives*. New York: Plenum

Hirani, S.P. & Newman, S.P. (2005) Patients' beliefs about their cardiovascular disease. *Heart*, 9: 1235-1239

Howes, K. (2005) Medical compliance. *Update*, 71 (4): 76-79

Hubbard, H. (2006) Dealing with the obstacles in adhering to highly active therapy.

Journal of the association of nurses in AIDS care, 17 (1): 18-25.

- Hutchinson, S. (1988). Education and grounded theory. In Sherman R. & Webb R (eds) *Qualitative research in education: Forms and methods*, New York: Falmer.
- Ickovics, J.R. & Meisler, A.W. (1997) Adherence in AIDS clinical trials: A framework for clinical research and clinical care. *Journal of clinical epidemiology*, 50: 385-391
- Inungu, J., Beach, E.M. & Skeel, R. (2003) Challenges facing health professionals caring for HIV-infected drug users. *AIDS patient care and STDs*, 17 (7):333-343
- Jani, A.A. (2002) Adherence to HIV treatment: Recommendations for best practices. www.apha.org/ppp.hiv
- Johnson, M.O., Cazt, S.L., Remien, R.H., Rotheram-Borus, M.J., Morin, S.F., Charlebois, E., Gore-Felton, C., Goldstein, R.B., Wolfe, H., Lightfoot, M., Chesney, M.A., & the NIMH healthy living project team (2003) Theory-guided, empirically supported avenues for intervention on HIV medication nonadherence: findings from healthy living project, *AIDS patient care and STDs*, 17 (12): 645-656.
- Kagee, A. (2004) Treatment adherence in South African primary care. *South African family practice*, 46 (10): 26-30.

Kennedy IV, S.B. (2002) Developing a self-administered tool to predict adherence to Antiretroviral therapy: Design, method, and objectives. *AIDS patient care*, (14)6: 309-316.

Koenig, S. P., Ferneta, L. & Farmer, P. E (2004) Scaling-up HIV treatment programmes in resource-limited settings: the rural Haiti experience. *AIDS*, 18 (3): 21-25

Le Marcis, E. (2005) People living with HIV and AIDS in everyday conditions of township life in South Africa: between structural constraint and individual tactics. *Journal of aspects of HIV/AIDS*, 2 (1): 217-235.

Maddux, J.E. & DuCharme, K.A. Behavioral intentions in theories of health behavior. In Gochman, D.S. (Ed) *Handbook of health behaviour research: provider determinants, II*. London: Plenum.

Magura, S., Loudet, A.B., Mahmood, D., Rosenblum, A. & Knight, E. (2002) Adherence to medication regimens and participation in dual-focus self-help groups. *Psychiatric services* 53 (3): 310-316.

Mallow, R.M., McPherson, S., Klimas, N., Antoni, M. H., Schneiderman, N., Penedo, Ziskind, D., Page, B. & McMahon, R. (1998) Alcohol & Drug Abuse: Adherence to Complex Combination Antiretroviral Therapies by HIV-Positive Drug Abusers *Psychiatric Services* 49: 1021-1024,

Mark, R. (1996) *Research made simple: A handbook for social workers*. New York: Sage

Madden, J.M., Quick, J.D., Ross-Degnan, D. & Kafie, K.K. (1997) Undercover careseeker: simulated clients in the study of health provider behaviour in developing countries. *Social science and medicine*, 45 (10): 1465-1482.

Mcauley, C. (2003) Ethics. In Miller, R.L. & Brewer, J.D. (eds) *The A-Z of social research*. London: Sage

Meystre-Agustoni, G., Dubois-Arber, F., Cochand, P. & Telenti, A. (2000) Antiretroviral therapies from the patient's perspective. *AIDS care*, 12 (6): 717-721.

Mills, E.J., Nachega, J.B., Buchan, I., Orbinski, J., Attaran, A., Singh, S., Rachlis, B., Wu, P., Cooper, Thabane, L., Wilson, K., Guyatt G.H., & Bangsberg, D.R. (2006) Adherence to antiretroviral therapy in sub-Sahara Africa and North America, A meta-analysis. *Journal of American medical association*, 299 (6): 679-690.

Moses, S., Ngugi, E.N., Bradley, J.E., Njeru, E.K., Eldridge, G., Muia, E., Olenja, J. & Plummer, F.A. (1994) Health care-seeking behavior related to the transmission of sexually transmitted diseases in Kenya. *American journal of public health*, 84 (12): 1947-1951.

- Moreno, M.I.C., Garcia, M.I.D. & Pareja, M.A.V. (1999) Cognitive factors in chronic pain. *Psychology in Spain*, 3 (1): 75-87.
- Murphy, S. & Bennett, P. (1994) Psychological perspectives on young adults' health behaviour: some implications for health promotion. In Penny, G.N., Bennett, P. & Herbert, M (eds) *Health psychology: A lifespan perspective*, Camberwell: Harwood Academic Press.
- Murray, M.D. & Callahan, C.M. (2003) Improving medication use for older adults: An integrated research agenda. *The American journal of geriatric pharmacotherapy*, 139: 425-429.
- Nachal, K.C., Khopkar, U & Saple, D.G. (2005) Improving adherence to antiretroviral therapy. *Indian journal of dermatology, venereology and leprology*, 71 (5): 316 -320.
- Nachega, J.B., Lehman, D.A. Hlatshwayo, D., Mothopeng, R., Chaisson, R.E. & Karstaedt, R. (2005) HIV/AIDS and antiretroviral knowledge, attitudes, beliefs, and practices in HIV-infected adults in Soweto, South Africa. *Journal of acquired immune deficiency syndrome* 38 (2): 196-201.
- Nachega, J.B., Stein, D.M., Lehman, D.A. Hlatshwayo, D., Mothopeng, R., Chaisson, R.E. & Karstaedt, R. (2004) Adherence to antiretroviral therapy in HIV-infected adults in Soweto, South Africa,. *AIDS research and human retroviruses*, 20 (10): 1053-1056.

- Natrass, N. (2006) South Africa's 'rollout' of highly active antiretroviral therapy: a critical assessment. *CSSR working paper*, 158.
- Page, J.B. (2005) The concept of culture: a core issue in health disparities. *Journal of urban health: bulletin of the New York academy of medicine*, 82 (2): 35-43.
- Palella, F.J, Delaney, K. M & Moorman AC, (1999). Declining morbidity and mortality among patients with advanced human immunodeficiency virus infection. *New English Journal of Medicine*. 338: 853-860.
- Parsons, J.T., Rosof, E. & Mustanski, B. (2007) Patient-related factors predicting HIV Medication adherence among men and women with alcohol problems. *Journal of health psychology* 12 (2): 357-370.
- Patel A.K & Patel KK (2006) Future implications: Compliance and failure with antiretroviral treatment. *Journal of Postgraduate Medicine*, 52: 197-200
- Polio, H., Henly, T. & Thompson, C. (1997) *The phenomenology of everyday life..*
Cambridge: Cambridge University Press

- Poppa, A., Davidson, O., Deutshe, J., Godfrey, A. Fisher, M., Head, S., Horne, R., & Sher, L. (2004) British HIV association (BHIVA)/British association for Sexual health and HIV (BASHH) guidelines on provision of adherence Support to individuals receiving antiretroviral therapy. *HIV medicine*, 5(2): 46-60.
- Rapley, T. (2004) Interviews. In Seale, C. Gobo, G., Gubrium, J.F. & Silverman, D (eds) *Qualitative research practice* London: Sage.
- Reynolds, N.R. (2004) Adherence to antiretroviral therapies: state of the science. *Current HIV research*, 2: 207-214.
- Rintamaki, L.S., Davis, T.C., Skripkauskas, S., Bennett & Wolf, M.S., (2006). Social stigma and HIV medication adherence. *AIDS patient care STDs*. 20 (5): 359-368
- Roberts, K.J. (2002) Physician-patient relationships, patient satisfaction, and antiretroviral medication adherence among HIV-infected adults attending a public health clinic. *AIDS patient care and STDs*, 16: 43-50.
- Roberts, Towell, T. & Golding, J.F. (2001) *Foundations of health psychology*. Basingstoke: Palgrave. .

- Rosnow, R & Rosenthal, R. (2002), *Beginning behavioral research: A conceptual primer*, New Jersey: Prentice Hall.
- Ross, E. & Devereil, A. (1994) *Psychosocial approaches to health, illness and disability: A reader for health professionals*. Pretoria: van Schaik.
- Sarafino, E.P. (2002) *Health psychology: biological interactions*. New York: John Wiley & Sons.
- Schonnesson, N. L., Diamond, P.M., Ross, M.W., Williams, M. & Bratt, G. (2006)
Baseline predictors of three types of antiretroviral (ART) adherence: A 2-
year follow-up. *AIDS care*, 18 (3): 246-253
- Schneider, H. and Stein, J. (2001) Implementing AIDS policy in post-apartheid South
Africa. *Social Science and Medicine* 2001, 52(5): 723-731.
- Seidman, I.E. (1991). Interviewing as qualitative research. California: Teacher's
College.
- Simoni, J.M., Frick, P.A., Lockhart, D. & Liebovitz, D. (2002) Mediators of social
support and antiretroviral adherence among indigent population in New York
City. *AIDS patient care*, 16 (9): 431-439.

- Starace, F., Massa, A., Amico, K.R. & Fisher, J.D. (2006) Adherence to antiretroviral therapy: An empirical test of the information-motivation-behavioural skills model. *Health psychology*, 25 (2): 153-162.
- Stetson, A.L., Charalambous, S., Dwaadwa, T., Pemba, L., Du Toit, D. , Baggaley, R., Grant, A.D., & Churchyard, G.J. (2005) Evaluation of antiretroviral therapy (ART) –related counselling in the workplace-based implementation programme, South Africa. *AIDS care*, 17 (8): 949-957.
- Stout, B.D., Leon, M.P. & Niccolai, L.M. (2004) Non-adherence to antiretroviral therapy in HIV-positive patients in Costa Rica. *AIDS patient care*, 5: 297-304
- Straub, R.O. (2002) *Health Psychology*. New York: Worth publishers.
- Strauss, A. (1991). *Qualitative analysis for social sciences*, Cambridge: Cambridge University Press
- Strauss, A. & Corbin, J. (1990). *Basics of qualitative research: Techniques and procedures for developing grounded theory*. California: Sage
- Stretcher, V.J., Champion, V.L. & Rosenstock, I.M. (1997) The health belief model and health behavior. In Gochman, D.S. (Ed) *Handbook of health behaviour research: provider determinants, I*. London: Plenum.

Stroebe, W. (2000) *Social psychology and health*. Buckingham: Open University press.

Thomason, B.T. & Campos, P.E. (1997) Health behavior in persons with HIV and AIDS.

In Gochman, D.S. (Ed) *Handbook of health behaviour research: provider determinants, II*. London: Plenum.

Tladi, L.S. (2004) Poverty and HIV/AIDS in South Africa: an empirical contribution.

Journal of social aspects of HIV/AIDS research alliance, 3 (1): 369-381.

Trehanne, G.T., Lyons, A.C. & Kitas, G.D. (2004) Medication adherence in rheumatoid arthritis: effects of psychosocial factors. *Psychology, health & medicine*, 9 (3): 337-349.

Tsasis, P. (2001) Adherence assessment to highly active antiretroviral therapy. *AIDS patient care and STDs*, 15 (3): 109 – 116.

Tucker, J. S., Orlando, M., Burman, M.A., Sherbourne, & King, F. (2004) Psychosocial mediators of antiretroviral nonadherence in HIV-positive adults with substance use and Mental health problems, *Health psychology*, 23 (4): 363-379.

UNAIDS (2006) *Report on the global AIDS epidemic*. Geneva, Joint United Nations Programme on HIV/AIDS. A UNAIDS 10th anniversary special edition.

UNAIDS (2003) *AIDS epidemic update*. Geneva, Joint United Nations Programme on HIV/AIDS.

UNESCO (1999) A cultural approach to HIV/AIDS prevention and care: South Africa's experience. *Studies and reports, special series*, 3. cultural policies for development unit.

van Damme, W., Kober, K. & Laga, M. (2006) The real challenges for scaling up ART in sub-Saharan Africa, *AIDS* (20): 653-656.

van Servellen, G. & Lombardi, E. (2005) Supportive relationships and medication adherence in HIV-infected, low-income Latinos. *Western journal of nursing research*, 27 (5): 1023-1039.

Wahl, C., Gregoire, J. Teo, K., Beaulieu, M., Laben, S., Leduc, B., Cochrane, B. Lapointe, L. & Montague, T. (2004) Concordance, compliance and adherence in health care: closing gaps and improving outcomes.
An unpublished paper

http://www.terrymontague.ca/e/pdf/concordance_compliance.pdf

Walsh J. C., Pozniak, A.L. Nelson, M.R., Mandalia, S. & Gazzard, B.G. (2002) Virologic rebound on HAART in the context of low treatment adherence is associated with a low prevalence of antiretroviral drug resistance. *Journal of Acquired Immune Deficiency Syndromes* 30(3): 278-287.

Weinman, J. & Petrie, K.J. (1997) Illness perceptions: a new paradigm for psychosomatics? *Journal of psychosomatic research*, 42 (2): 113-116.

Weiser, S., Wolfe, W., Thior, I., Gilgert, F., Makheman, J., Keeabetswe, P., Dickenson, D., Mompati, K., Essex, M., & Marlink, R. (2003) (2003) Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana, *Journal of acquired immune deficiency syndromes*, 34 (3): 281-288

Williams, G. H. (2000). "The determinants of health: structure, context and agency." *Social Health & Illness* 25(3): 131-154.

Wroth, T. H. & Pathman, D. E. (2006) Primary medication adherence in rural population: The role of patient-physician relationship and satisfaction with care. *Journal of the American board of family medicine*, 19 (5): 478-486.

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Appendix A

Interview Guide



This research tool is meant to describe the process by which individuals respond to a perceived health threat. The research tool proposes that situational stimuli (such as symptoms) generate both cognitive and emotional representations of the illness or health threat (HIV/AIDS).

A. Demographic Information

Gender _____

Age _____

Education level _____

Race _____

Employment status _____

B. Background Information

1. When were you diagnosed as HIV positive?
2. When did you get your treatment?
3. How long have you been on treatment?
4. Are you taking a single-drug or multiple regimens?

5. Do you feel sick?
6. Are you presently hospitalised?
7. What is your current knowledge about ART and adherence? (Probe)
8. How frequently do you miss your doses and why?

C. Challenges

9. Some people have problems with taking their medication as prescribed. Do you experience any problems with your medication?
10. Do you experience any problems with regard to the ARV provider, treatment regimen, or social support?
11. Because your medication requires you to eat specific foodstuffs, what do you do when there is no food?

Ask probing questions about their relationship (communication) with the health care providers

Adherence assessment: intrusive or accurate? (e.g. do you take your medication at the specific times?) and then probe.

D. Solutions

With regard to the above challenges (e.g. the ARV provider, treatment regimen and social support), what are the ways of overcoming them? (The interviewer will go through all the perceived challenges in search for perceived solutions.

Appendix B

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Invitation and informed consent to participate in a research project

Dear Sir or Madam

My name is Lungelo Sali, a Master of Arts student at the University of the Western Cape in Cape Town. Presently I am engaged in a research project entitled: Adherence to antiretroviral treatment: perceptions of challenges and solutions among people living with AIDS". The study will be conducted under the guidance of Professor Kelvin Mwaba

The purpose of the study is to determine the perceptions and solutions to challenges of adherence to ARV treatment among people living with AIDS.

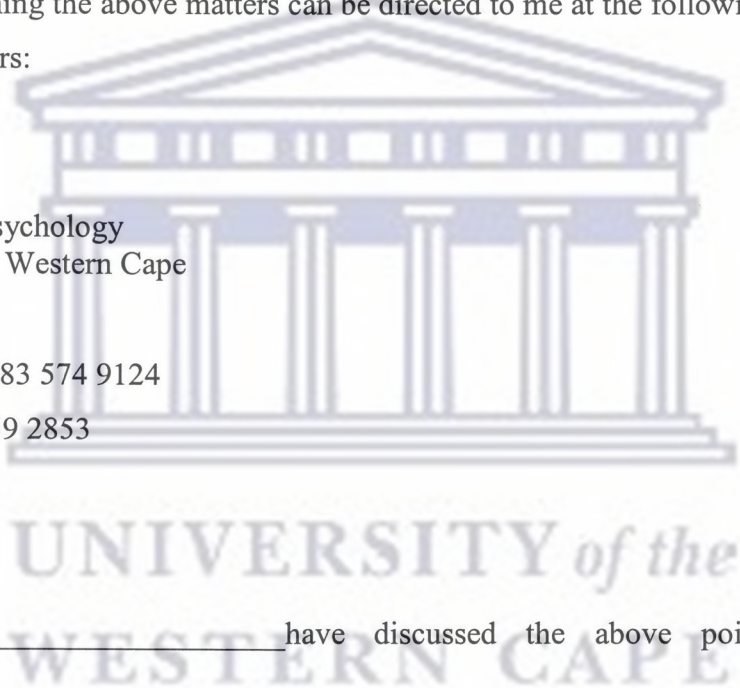
You are invited to participate in this research project because of your HIV positive status. Your participation will mean that I visit you on an agreed date, time and location, for a semi-structured interview that will last for no more than 30 to 60 minutes. During the interview I will be taking notes to keep track with of what has been covered. To get every word on paper I will record (audio-tape) the interview. The audio-tape will be analysed by me, as the researcher.

I undertake to ensure anonymity by omitting the use of your name or any other information that might identify you. The transcription of the taped interview will only be accessible to the supervisor, the person who will be assisting me in the analysis.

Your participation in this research project is totally voluntary. You are therefore under no obligation to participate. You will give your consent but still reserve the right to withdraw from the study at any stage without repercussion or penalty. If you are interested in the findings of the study, they will be communicated to you as soon as they are available.

Inquiries concerning the above matters can be directed to me at the following address and telephone numbers:

Lungelo Sali
Department of Psychology
University of the Western Cape
Private bag X17
Bellville 7535
Cell phone No: 083 574 9124
Tel. No. (021) 959 2853



I _____ have discussed the above points with the participant. It is my opinion that the participant understands the risks, benefits and obligations involved in participating in this research project.

Signature of the interviewer

Date

I _____ understand that participation is voluntary and that I may refuse to participate or withdraw my consent and stop taking part in this research project at any time without penalty or repercussions.

Signature of participant

Date



