

**FACTORS THAT INFLUENCE ADHERENCE  
TO  
HIGHLY ACTIVE ANTIRETROVIRAL THERAPY  
(HAART)**

**by**

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**Dissertation submitted in partial fulfilment of the requirements of the  
Degree of Master of Social Science (Social Work)  
in the  
School of Social Work and Community Development,  
University of KwaZulu-Natal, Durban**

**June 2011**

## **DECLARATION OF ORIGINALITY**

I declare that this short dissertation is my original work. All references to the work of others has been appropriately acknowledged and referenced in accordance with university requirements.

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## **ABSTRACT**

HIV/AIDS remains one of the most pressing challenges facing South African society. South Africa has the highest number of people living with HIV as well as the highest number of people on HIV treatment globally, yet only 37% of persons eligible for treatment have access to treatment.

The advent of HAART ushered in a new era in the treatment of HIV infection. HIV infection was no longer a life threatening terminal illness, HIV/AIDS became a chronic manageable disease. The full clinical benefit of HAART can only be achieved with near perfect adherence i.e. > 95%. This means taking the medication exactly as prescribed; on time, no missed doses, every day, lifelong. No other chronic medication requires such stringent adherence rates for optimal therapeutic benefit, which may mean the choice between life and death. Achieving near perfect adherence poses a serious challenge to health service providers and persons on treatment as typical adherence rates for medication prescribed over long periods are in the 50 – 75 % range. Persons on HAART live with the additional burden of drug resistance and limited treatment options if near perfect adherence rates are not achieved.

The purpose of this qualitative study was to explore the factors that influence adherence to HAART. These factors may be related to the person, the health care team and system, the treatment regimen, the social and economic environment or to the effects of HIV disease. Factors may either negatively or positively influence a person's ability to adhere optimally to their prescribed treatment.

A small sample of thirteen participants were purposefully selected for this study. Data was collected using in-depth interviews which were tape recorded and transcribed for thematic analysis. The value of this study is that it may assist health care providers, persons on treatment and the health care system to better comprehend the challenges of lifelong optimal adherence to HAART.

## ACKNOWLEDGEMENTS

There are many people who have helped me on this journey and who have made this study possible.

- My husband Kreesen who gave me the time, space and encouragement to achieve my goals. Thank you for your patience, wisdom, understanding, tolerance and so much more ....
- My Mom and late Dad (Lizette and Dudley Nagan) for instilling in me the value of education.
- My children, Hiranya, Rasen and Thishen for being caring, helpful and never complaining.
- To my furry family, Brandy, Crystal, Zin, Alfie and Lars who were my constant companions during my many hours in front of the computer, and who really knew what to do to make me feel better.
- To the participants who made this study possible. Thank you for allowing me into your world and for being so obliging and willing to share and be a part of something that could be of help to others.
- To all the health care professionals, colleagues and friends and who helped me to find my sample and who provided me with wise counsel, knowledge and information to better understand my field of study.
- To my Supervisor, Professor Vishanthie Sewpaul for her excellent guidance and for being an inspirational role model for me in my quest to better understand the world; I will miss our discussions, especially those that added perspective to my view of the world.

This journey has been humbling as well as enlightening and I am grateful to all the people I have met along the way because I am so much richer and hopefully wiser because of what I have learnt from you.

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## Abbreviations

<b>ABC:</b>	Abstain, Be Faithful, Condomise
<b>AZT + 3TC:</b>	Combivir
<b>AIDS:</b>	Acquired Immune Deficiency Syndrome
<b>ANC:</b>	Antenatal Care
<b>ART:</b>	Antiretroviral Therapy
<b>ATLIS:</b>	AIDS Treatment for Life International Survey
<b>AVERT:</b>	Averting HIV & AIDS. International HIV & AIDS charity
<b>AZT:</b>	Zidovudine
<b>CDC:</b>	Centers for Disease Control and Prevention
<b>ddI:</b>	Didanosine
<b>d4T:</b>	Stavudine
<b>DOH:</b>	Department of Health
<b>EFV:</b>	Efavirenz
<b>FDC:</b>	Fixed dose combination
<b>FHI:</b>	Family Health International
<b>FTC:</b>	Emtricitabine
<b>HAART:</b>	Highly Active Antiretroviral Therapy
<b>HCP:</b>	Health care provider
<b>HCW:</b>	Health Care Worker
<b>HIV:</b>	Human Immunodeficiency Virus
<b>HIV &amp; AIDS &amp; STI NST:</b>	HIV & AIDS and Sexually Transmitted Infections National Strategic Plan (2007-2011)
<b>HPTN:</b>	HIV Prevention Trial Network
<b>HSRC:</b>	Human Sciences Research Council
<b>KZN:</b>	KwaZulu-Natal
<b>LPV/RTV:</b>	Lopinavir and Ritonavir
<b>MDGs:</b>	Millennium Development Goals
<b>NRTI:</b>	Nucleoside Reverse Transcriptase Inhibitors
<b>NNRTI:</b>	Non-nucleoside Reverse Transcriptase Inhibitors

<b>NSP:</b>	National Strategic Plan
<b>NVP:</b>	Nevirapine
<b>OI:</b>	Opportunistic Infection
<b>PEPFAR:</b>	US President's Emergency Plan for AIDS Relief
<b>PI:</b>	Protease Inhibitors
<b>SAHR:</b>	South African Health Review
<b>SANAC:</b>	South African National AIDS Council
<b>STI:</b>	Sexually transmitted infection
<b>TAC:</b>	Treatment Action Campaign
<b>TB:</b>	Tuberculosis
<b>3TC:</b>	Lamivudine
<b>TDF:</b>	Tenofovir disoproxil fumarate
<b>UN:</b>	United Nations
<b>UNAIDS:</b>	Joint United Nations Programme on HIV/AIDS
<b>UNDP:</b>	United Nations Development Programme
<b>UNGASS:</b>	United Nations General Assembly Special Session on HIV/AIDS
<b>USAID:</b>	United States Agency for International Development
<b>VL:</b>	Viral Load
<b>VTC:</b>	Voluntary Testing and Counselling
<b>WHO:</b>	World Health Organisation

## **Chapter 1: Introductory Chapter**

### **1.1 Background and Outline of Research Problem**

South Africa has the largest population of people living with HIV/AIDS, the largest number of people on antiretroviral therapy (ART) and the largest public health ART programme in the world (UNGASS RSA, 2010). In 2008 approximately 5.7 million South Africans were living with HIV or 18 % of the adult population were HIV positive. In the same year an estimated 250 000 lives were lost due to AIDS related diseases (UNAIDS, 2010b).

Estimates of the HIV prevalence rates are obtained from the Antenatal HIV Sero-prevalence Survey which is conducted annually among pregnant women aged 15-49 years. These results are also used to estimate the HIV prevalence in the general population. According to the 2008 Antenatal survey report, the overall national HIV prevalence among antenatal women aged 15 – 49 was 29.3%. In 2006 and 2007 the HIV prevalence was 29% and 29.4% respectively. This indicates that the pandemic appears to have stabilized over the last few years, albeit at alarmingly high levels (UNGASS RSA, 2010).

The HIV/AIDS pandemic not only causes death and suffering on an individual and community level, but also has a substantial impact on a countries overall social and economic progress. Average life expectancy in South Africa is around 54 years, hospitals are struggling to cope with the number of HIV related sick persons they have to care for, children have lost parents, schools have fewer educators (2006 estimate of teachers living with HIV was 21%), not to mention the impact of the HIV pandemic on health care workers. People infected with HIV are more susceptible to TB infection thus fuelling the already alarming TB epidemic.

The year 2008 signalled the end of President Thabo Mbeki's era of HIV/AIDS denialism, and heralded in what appears to be the emergence of a comprehensive and determined response to the HIV/AIDS epidemic in South Africa. After years of HIV/AIDS denialism during the Mbeki era and mixed messages about the efficacy of antiretroviral agents there is evidence of committed leadership and political will to confront the challenges that HIV/AIDS poses to South Africa and its people. 2010 saw South Africa launch one of the most ambitious and

quickest scale-ups of a HIV/AIDS response ever. The South African government, under the leadership of President Jacob Zuma, approved a plan to test one third of the population for HIV by the end of 2011, to halve the rate of new infections and to provide antiretroviral therapy to at least 80% of persons in need of treatment (UNAIDS, 2010b).

Antiretroviral therapy (ART) or highly active antiretroviral therapy (HAART) is the only known treatment that is consistently effective in delaying the progression from HIV to AIDS. HIV anti-retroviral drug treatment has transformed HIV/AIDS from a life-threatening disease to a manageable chronic disease and this means that HIV positive people can maintain their health and lead relatively normal lives. Persons who adhere to their medication are also less infectious and less susceptible to opportunistic infections and cancers, thus supporting the goal of reducing the rate of new infections and lessening the burden of disease on the health system.

The 2010 UNGASS Country Progress Report states that the South African public ART programme had approximately 919,923 people on treatment by the end of November 2009. An additional estimated 51,633 people were accessing ART either using private health care or the non-governmental (NGO) sector.

Critical to treatment success is adhering stringently to a potent combination of highly active antiretroviral drugs that requires near perfect adherence, for life (Orrell, 2004). The term compliance and adherence is often synonymously used to refer to taking medication exactly as prescribed. Adherence is however the preferred term as compliance implies that some prompting is necessary to ensure that the medication is taken whereas adherence is a voluntary action by the person in need of treatment (Orrell, 2004). Horne (2006) asserts that the use of the term compliance has been criticised as it was thought to convey a negative image of the relationship between the person in need of treatment and the prescriber. The prescriber appears to be issuing instructions and the person in need of treatment is expected to follow those instructions. Noncompliance therefore implied incompetence or self-sabotaging behaviour towards medical treatment (Horne, 2006). Adherence according to Horne (2006) was introduced as a way to recognise the person's right to choose treatment and to remove the concept of blame. A range of factors may influence a person's ability to

adhere stringently to their prescribed medication and greater insight into these factors may enable the necessary interventions to ensure near perfect lifelong adherence.

## **1.2 Rationale for the Study**

KwaZulu-Natal province, the epicentre of the South African HIV epidemic has the highest prevalence and incidence rates of HIV in the country. The majority of HIV infected patients will eventually need antiretroviral therapy, and near perfect (>95%), sustained adherence to HIV treatment is critical if a healthy long life is the expected outcome.

Sub-optimal adherence to HIV medication has potentially severe health outcomes which may reduce treatment efficacy, cause drug resistance and increase morbidity and mortality as the individual becomes more susceptible to opportunistic infections such as cryptococcal pneumonia and tuberculosis.

HIV and TB in South Africa are referred to as the tale of two epidemics or the terrible twins that are silent killers (Laloo, 2007). What is equally disturbing is that the HIV epidemic is fuelled by the TB epidemic and the TB epidemic is fuelled by the HIV epidemic. HIV negative persons in South Africa have a life time risk of 10% of developing TB. HIV positive persons have a life time risk of 10% per annum of developing TB (Laloo, 2007). TB is the leading cause of death in South Africa and the main cause of death for those living with HIV/AIDS (Stanwix, 2010). Taking into consideration the high prevalence rates of HIV in South Africa reiterates the importance of accessing early treatment combined with optimal adherence to prevent susceptibility to opportunistic infections.

South Africa, during the Mbeki presidency was ashamedly at the receiving end of mixed messages and incorrect information concerning the existence of HIV and the value of ART as life saving medication. People may therefore question the efficacy of ART, or misunderstand issues of toxicity of ART, which may lead to either sub-optimal adherence or not accessing life-saving medication.

Antiretroviral treatment regimens may be complex and side effects severe, therefore without expertise and resources to evaluate and support adherence, antiretroviral therapy can be

ineffective, wasteful and dangerous. This once again reiterates the importance of understanding factors that influence adherence to inform strategies to promote adherence.

Mills, Nachega, Bangsberg, Singh, Rachlis, Wu, Wilson, Buchan, Gill and Cooper (2006) in their systematic review of developed and developing nation patient-reported barriers and facilitators to HAART adherence found that research to determine patient-important barriers and facilitators for adherence in developing world settings is lacking. Studies on factors affecting adherence have mostly been associated with defined populations in specific settings in developed nations. This limitation means that the findings may not be generalized to dissimilar populations thus suggesting the ongoing need for studies on defined populations to inform strategies to improve adherence.

Research on the topic of adherence is emerging from developing countries worldwide and in Africa, particularly Southern Africa (Amberbir, Woldemichael, Getachew, Girma, & Deribe, 2008; Aspeling & van Wyk, 2008; Dahab, Charalambous, Hamilton, Fielding, Kielman, Churchyard & Grant, 2008; Frank & Duncan, 2009; Gilbert & Walker, 2009; Nachega, Stein, Hlatshwayo, Mothopeng, Chaisson & Karstaedt, 2004 and Naidoo, 2009 are examples of studies). What is apparent from these studies and what justifies this study is recognising the value of the subjective experiences of HIV positive people in need of treatment with regard to the factors that influence their ability to take their medication as prescribed.

Information so gleaned enables a broader and more in-depth understanding of specific issues that may affect a specific community or population of people and the individual in that community. Such information may also shed light on the fact that a one fit for all approach to adherence counselling is not necessarily in the best interests of persons in need of treatment. It is also important to impress upon health care workers the value of the subjective experiences of persons on treatment and to promote a case by case approach to tailoring interventions to meet the needs of the individual and the community. More emphasis on the individual's unique subjective experiences may also enable greater insight into strategies that enhance adherence. The information gathered may assist health-care workers to encourage and engage in open discussion with persons on ART to promote HIV medication adherence

or may inform strategies to improve adherence (Mills, Bangsberg, Nachega, et al., 2006). This type of open relationship is both empowering and person-centred and may lead to a type of partnership in health care between health care providers, health care receivers and the systems that influence health care.

### **1.3 Research Problem and Objectives**

The main objective of this study was to explore the factors that influence adherence to HIV antiretroviral therapy. Therefore the specific objectives were to gather in-depth information about the following factors that influence HIV medication adherence:

- Social and economic factors
- Health care provider and system related factors
- Condition related factors
- Therapy related factors
- Person related factors

The researcher prefers to use the word person rather than patient because the word patient tends to imply illness as well as a dependent or subservient position. The word person or people sends a message of empowerment, which means responsibility for one's own health and being respected as equals in decisions about health care.

### **1.4 Key Questions**

- What specific influences might social and economic factors have on adherence to antiretroviral therapy?
- What roles do health care providers and the health system play in facilitating adherence to ART?
- Does the medical condition of the HIV positive person influence antiretroviral medication adherence?
- Are there specific therapy related factors that might influence adherence?
- What personal factors may influence adherence?

## **1.5 Theoretical Framework**

This study was guided by three theoretical approaches; the ecosystems perspective, the bio-psychosocial model of health and the information-motivation-behavioural theory of health promotion. Adherence behaviour is described as a multidimensional phenomena influenced by the interaction between five sets of factors or dimensions namely; health care system factors, social and economic factors, factors related to the condition, therapy factors and person related factors (WHO, 2003). The ecosystems perspective provides a framework that focuses on the interplay between the person and his or her environment. In order to view a person holistically, it is important to understand and appreciate the environmental context within which this person exists. This context takes into cognisance the fact that the person exists within families; families exist within communities; individuals, families and communities exist within a particular political, economic and cultural environment and this environment impacts upon the actions, beliefs and choices available to the person (Berger, McBreen & Rifkin, 1996; Rengasamy, 2010). In other words the ecosystems perspective focuses on multiple levels of phenomena simultaneously and provides insight into how the interaction between the different levels affects or impacts on behaviour. This perspective therefore enables a more holistic view of human behaviour as such an approach attempts to understand an event or behaviour in its larger context (Berger et al., 1996).

The bio-psychosocial model of health and illness as opposed to the biomedical model of health and illness is based on a systems approach and provides a holistic view of health and illness. This approach posits that health care workers attend to the biological, psychological and social dimensions of health, illness or health behaviour as these dimensions all interact in significant ways to influence human functioning, reminding us that nothing ever exists in isolation. This model encourages the health care worker to assess the influence of multiple systems on health behaviour and illness. This process illuminates the context in which the health behaviour or disease occurs and enables the health care worker to gain a broader understanding of disease and other health related issues or behaviours. Both the ecosystems perspective and the bio-psychosocial model provide a holistic view of health, illness and health behaviour and enables greater insight into the complexities of human nature and behaviour and the significance and influence of context on human situations. Theories in health promotion such as the information-motivation-behavioural change model, has been



articulated as a general model for health behaviour change. According to this model if a HIV positive person is well informed about their antiretroviral therapy, is motivated to act, and has the necessary behavioural skills to act effectively, then he or she is likely to adhere to their medication regimen and to reap the profound health benefits of such behaviour. Conversely, if a person is poorly informed about their antiretroviral therapy, lacks motivation and has not acquired the necessary skills for medication adherence, then this person is more likely to be non-adherent, and will therefore not achieve the health benefits of their treatment (Fisher & Fisher in DiClemente, Crosby & Kegler, 2002). Theories may assist in the design of behaviour change interventions to promote adherence, but it must be emphasized that ensuring long-term treatment adherence presents considerable challenges to healthcare initiatives.

HIV and TB, may be particularly challenging because both are chronic, infectious, involve complex treatment regimens and require near perfect adherence rates for many months for TB and lifelong in the case of HIV infection (Munro, Lewin, Swart & Volmink, 2007; Orrell, 2004; Ware, Wyatt & Bangsberg, 2006).

## **1.6 Presentation of Contents**

### **Chapter 1: Introductory Chapter**

The introductory chapter includes a brief description of the context of the HIV/AIDS epidemic in South Africa, the prevalence of the disease, the impact of the epidemic on communities as well as the era of HIV/AIDS denialism and the consequences of that period. The rationale for this study is explored to enable the reader to see value of this research. The research objectives and research questions are clearly documented as well as the three theoretical approaches, which serves to guide this study.

### **Chapter 2: Literature Review**

A detailed account of the literature to broaden understanding about HIV/AIDS and the factors that influence adherence to antiretroviral medication is presented in Chapter two. The literature review starts off with the global update of the HIV/AIDS epidemic and then goes into detail about the South African epidemic including the factors that may fuel the South

African epidemic. The latest reports on the HIV/AIDS epidemic globally were used to give updated information about the epidemic. The UNAIDS (2010a) global report is significant because for the first time in the history of the HIV pandemic there is evidence that new infections globally and in South Africa have decreased. HIV/AIDS policy and the challenges facing the HIV/AIDS response are presented. This chapter also explains the natural history of HIV/AIDS infection without medication as well as prognosis and staging of this disease. The new ART guidelines are explored as well as the goals of ART. Adherence and the importance of near perfect adherence are discussed in great detail. Lastly the various factors that influence adherence are discussed in detail.

### **Chapter 3: Research Methodology**

The methodology chapter explains the reasons for the qualitative method as the method of choice for this study. The sampling technique, sample size and sampling criteria as well as the justification for the choices are documented in this chapter. The data collection method and data analysis are justified and explained as well as the important ethical considerations that concern this study. The reliability and validity as well as the limitations of the study are also explained in this chapter.

### **Chapter 4: Results**

The entire process of data capturing from the transcripts is explained in this chapter. The data collected for this research study was carefully analysed using colour coding and presented under categories and subcategories. Tables were used when necessary to ensure that all data was accounted for and to ensure that the researcher took every aspect of the findings into account when analyzing the data. The results were then discussed according to the categories or themes that emerged taking into consideration the literature available on the findings.

### **Chapter 5: Major conclusions and Recommendations**

The findings were consolidated in the major conclusions in this final chapter. The conclusion also discusses the value of the research study to the general knowledge on HIV adherence and identifies possible areas for ongoing research. The researcher also takes the opportunity to share her concerns about the HIV epidemic in South Africa.

## **Chapter 2: Literature Review**

### **2.1 Global Update of the HIV/AIDS Pandemic**

“The number of people living with HIV worldwide continued to grow in 2008, reaching an estimated 33.4 million (31.1 million - 35.8 million). The total number of people living with the virus in 2008 was more than 20% higher than the number in 2000, and the prevalence was roughly threefold higher than in 1990” (UNAIDS & WHO, 2009). This Joint United Nations Programme Report on the HIV/AIDS epidemic for 2009 summarises the latest data on the epidemiology of HIV worldwide (UNAIDS & WHO, 2009). The epidemic appears to have stabilized in most regions of the world except in Eastern Europe and parts of Asia, where prevalence rates have increased.

Sub-Saharan Africa remains unequivocally the worst affected region in the world accounting for 71% of all new infections in the year 2008 (UNAIDS & WHO, 2009). Sub-Saharan Africa is home to over two thirds of all people living with HIV and nearly three quarters of AIDS related deaths worldwide (UNGASS RSA, 2010). In most countries in Southern Africa, South Africa included, HIV prevalence has stabilized at alarmingly high levels. Some areas like rural Angola still indicate increased incidence rates (UNAIDS & WHO, 2009).

### **2.2 The South African Epidemic**

South Africa ranks as one of the most severely affected countries in the world with regards to the HIV/AIDS epidemic and is home to the largest number of people infected with the human immunodeficiency virus in the world. In 2009 the estimated number of people living with HIV in South Africa was approximately 5.7 million indicating a prevalence rate of 18.1% (UNAIDS & WHO, 2009). Using a different mathematical model, the 20<sup>th</sup> antenatal survey estimates for 2009 are 5.63 million living with HIV and a prevalence of 17.8% (Department of Health, 2010). More than 3 million of these were women aged 15 and over, and 280,000 were children between the ages of 0-14 years. For this reason, South Africa sadly hosts the world’s largest population of people living with HIV (UNGASS RSA, 2010). The 20<sup>th</sup> antenatal sero-prevalence survey in South Africa provided evidence that the national HIV prevalence has stabilized around 29%. The highest prevalence was recorded in KwaZulu-Natal with an increase from 38.7% in 2008 to 39.5% in 2009. What is disturbing according

to this report is the number of districts in KwaZulu-Natal recording prevalence above 40%. This clearly indicates the need for more research into high risk and low risk areas to determine what the main drivers of HIV infection rates are in high prevalence areas and what keeps prevalence levels at lower levels in low risk areas (Department of Health RSA, 2010).

Extrapolation of HIV infection to the general population indicates that prevalence rates decreased marginally from 17.9% in 2008 to 17.8% in 2009. Provincial HIV prevalence rates reveals that KwaZulu-Natal has the highest prevalence at 25% in 2009 (25.1% in 2008) and the Western Cape the lowest prevalence rate, at 6.2% in 2009 and 2008 (Department of Health RSA, 2010).

South Africa is experiencing a maturing generalized HIV epidemic defined as being hyper-endemic because more than 15 % of the population aged between 15-49 years old are living with HIV (high prevalence rate), and because of the modes and drivers of HIV transmission (Shisana, Rehle, Simbayi, Zuma, Jooste, Pillay-van-Wyk, Mbelle, Van Zyl, Parker, Zungu, Pezi & the SABSSM III Implementation Team, 2009; UNGASS RSA, 2010).

Heterosexual sex is the predominant mode of HIV transmission followed by mother-to-child transmission as well as other modes of transmission, for example, men who have sex with men. Injecting drug use is not common in South Africa at this point in time, blood product safety conforms to international standards, and transfusion associated infections are extremely rare (Shisana et al., 2009). Drivers of the epidemic include socio-structural drivers such as high population mobility, wealth inequalities, culture and gender inequality, human rights violations; contributing drivers, such as, male attitudes and behaviours, intergenerational sex, gender and sexual violence, stigma, lack of openness and untreated STIs; and lastly, the key drivers, which are, multiple and concurrent sex partnerships by men and women with low condom use in the context of low levels of male circumcision (AIDS2031, 2010). The authors of AIDS2031 (2010) conclude that a wide range of factors appear to fuel HIV epidemics in hyper-endemic countries like South Africa and other Southern African countries. The relative contribution of these factors in fueling the HIV epidemic appear to vary from place to place making it difficult to quantify their impact on the HIV epidemic. However, the authors assert that there is evidence to suggest that two factors

converge in the hyper-endemic regions with great potency together with other HIV risk factors (STIs, sharing needles/syringes, blood exposure, needle stick injuries). These two factors, and key drivers, of the Southern African epidemic are a generalized lack of male circumcision and multiple concurrent partnerships.

Male circumcision reduces the risk of heterosexually acquired HIV infection in men by 60% and should be considered an efficacious intervention for HIV prevention in countries with heterosexual epidemics, high HIV prevalence and low male circumcision prevalence (WHO: male circumcision for HIV prevention, undated). Reducing multiple concurrent sexual partnerships must be seen as a priority for reducing new infections (AIDS2031, 2010).

At a UNAIDS (Joint United Nations Programme on HIV/AIDS) meeting in Zambia in December 2006, Peter Piot, former Executive Director of UNAIDS emphasized the need to address the drivers of the epidemic: “It is patently clear that we need to make real headway against fundamental drivers of this epidemic, especially gender inequality, stigma and discrimination, deprivation and the failure to protect and realise human rights. This challenge is perhaps the greatest of all those facing the AIDS response. And there can never be a technological fix for these social issues. We need positive social change – and all of us in the AIDS effort must be willing to back this. I am increasingly convinced that just expanding programmes, doing more, even much more, is not going to stop this epidemic. To reach universal access to HIV prevention, treatment, care and support we need to pay attention to the drivers” (UNAIDS. Drivers of the epidemic, undated). All the United Nations member states (South Africa included) committed to attaining universal access to HIV prevention, care and treatment and stressed that gender inequality, discrimination and the marginalization of vulnerable groups constitute major detractors to universal access (UNAIDS. Drivers of the epidemic, undated).

The UNAIDS (2010a) global report reveals that new infections globally and in South Africa have decreased considerably over the past decade. Increased condom use, abstinence and improved HIV awareness have contributed to a fall in infections; however the report cautions that Sub Saharan Africa, the epicenter of the epidemic, continues to be disproportionately affected, bearing approximately 70% of the global burden of HIV/AIDS. Mark Heywood,

deputy chairperson of South Africa's National AIDS Council said there were still more challenges than successes. "When we have less than 50% of people who need treatment on treatment, when we're still failing on prevention, then I don't think there's anything to crow about at this stage. We can be optimistic, but the hard work still lies ahead" (UN: AIDS epidemic slowing, 24 Nov 2010).

The cost of apartheid South Africa's non-action, plus failure to act effectively during the Mandela presidency, compounded by denial of HIV/AIDS during the Mbeki governance are at the root of the enormity of the HIV/AIDS epidemic that South Africa faces today. Mark Heywood stated that the Zuma administration seems to have the political will to respond effectively but the challenge has grown so large that it is difficult to manage and government simply does not have enough resources to tackle this disease (cited in Aziz, 2010).

Heywood went on to explain that the health care system in South Africa is more unequal now than it was during the apartheid era: ZAR80 million is spent on private health care for 16 % of the population and the same amount of spending is available for the rest of the population. The public health system also does not have the human resources to deal with the health burdens facing the majority of the people of South Africa.

To add to this bleak scenario was the antiretroviral drug pricing debacle which saw South Africa fixed into paying almost double the cost for lifesaving ARVs. Thankfully, South Africa's newly announced tender for ARVs has now halved the price government would pay for these lifesaving drugs. However, fixed dose combinations, which would decrease the pill burden are still largely absent from the deal. The South African Health Minister Aaron Motsoaledi stated that with an estimated saving of about US\$685 million from the end of January 2011, South Africa could now afford to treat twice as many HIV positive persons compared to before the new tender (New ARV tender halves drug prices, 20 Dec 2010). Activists from the TAC and Section 27 have welcomed the new tender however they continue to call for improvements in the tender's terms and for greater transparency with regard to the tender process. Jonathan Berger of Section 27 explained that the tender makes no provision for a reduction in drug prices should the prices of the active ingredients decline. He went on to state that as in past tenders, government has yet to release any documentation

about the selection process or how the tender was allocated. TAC and Section 27 call for continued actions to drive prices of essential medicines down even further (New ARV tender halves drug prices, 20 Dec 2010). The recent global economic crisis has further complicated funding and Heywood emphasized that this is not the time for PEPFAR and the Global Fund to pull back on funding as the result would be rapid reversal of the ground gained in the fight against HIV/AIDS (Aziz, 2010).

### **2.3 HIV/AIDS Policy, Implementation and MDGs**

The HIV & AIDS and STI National Strategic Plan NSP (2007 -2011), which now includes TB heralded the end of a period of confusion, frustration, conflict and anger with regard to the goals of the HIV/AIDS policies and marked the beginning of a new chapter of national consensus for strategies, policies and legislation that would enable the goals of HIV/AIDS prevention and treatment programmes to be achieved (Heywood, 2007). The National strategic plan recognizes HIV/AIDS as one of the most pressing challenges facing South Africa today. It aims to provide a broad framework to coordinate the work of all key stakeholders in response to the challenges of the HIV/AIDS and TB crisis. The document views implementation as the collective responsibility of all citizens of South Africa.

Reducing HIV infection by 50% and increasing uptake of ART to 80% of those in need are the overarching objectives of the NSP (UNGASS RSA, 2010). In addition to this, the ten point plan or national health system priorities (2009-2014) that aims to transform the health care system into a well functioning health system capable of improving the health status of all South Africans, signals governments attempt to honour the 2009 electoral mandate of improving the health care profile of all South Africans. Government has also committed to attaining the Millennium Development Goals by 2015 which include: eradicating extreme poverty; achieving universal access to primary education; promoting gender equality and empowering women, reducing child mortality, improving maternal health, combating HIV/AIDS, malaria and other diseases, ensuring environmental sustainability and developing global partnership for development.

The HIV & AIDS and STI National strategic plan for South Africa 2007-2011, the Tuberculosis Strategic Plan 2007-2011 and the ten point plan have been well received by all

sectors of South African society. The publication of these comprehensive documents demonstrates that South Africa is certainly not deficient in policy. South Africa may describe their health policy as supportive; however, concern has been raised about the capacity of the public health system to implement such policy. Sewankambo and Katamba (2009) assert that despite an increase in investments and improved social and health policy, South Africa has not adequately addressed health disparities which have their roots in the past. The reasons according to Sewankambo and Katamba (2009) are an inadequately prepared health-care system to address the changing burden of disease; poor leadership, stewardship, and management; insufficient human-resource capacity and poor surveillance. South Africa therefore appears to be lagging behind in millennium development goal achievement as well, especially with regard to maternal and child health and HIV/AIDS as maternal and child health is mostly associated with HIV/AIDS. The Zuma administration's commitment to attaining the MDGs signals government's attempts to make inroads into the epidemic and some progress has been made as evident in the latest UNGASS RSA 2010 report. For example, programme implementation include the mass testing campaign that came into effect in April 2010, male circumcision has been adopted as a prevention strategy and the task of shifting ART cases from doctors to nurses are some of the strategies that have been put in place.

Millennium Development Goal (MDG) 6 seeks to achieve universal access to treatment for HIV positive persons who need it, and to halt and begin to reverse the incidence of major diseases such as HIV/AIDS, TB and malaria. The HIV and AIDS, TB and STI (NSP) for South Africa has similar goals which are to achieve a 50% reduction in HIV incidence rates and to achieve 80% treatment coverage for those in need of HIV treatment. The targets for the TB strategic plan are a 70% TB case detection rate 85% cure rate and 85% TB treatment success rate (SAHR, 2010).

The SAHR (2010) gives an explanation on what needs to be done in order to meet the goals of the NSP. According to SAHR (2010), countries need to know their epidemic and they need to customize their responses to the epidemic accordingly. This means gathering information about prevalence rates, incidence rates, most at risk populations and factors



contributing to the spread of HIV/AIDS. Strong health information systems and surveillance are critical for generating this type of information (SAHR, 2010).

With regard to available prevention interventions the ABC remains the foundation of HIV prevention but two additional Cs have been added to the ABC campaign and these are knowledge of HIV status through Counselling and HIV testing and medical Circumcision. Many woman are still not able to negotiate safe sexual practices and the Caprisa tenofovir microbicide trial provides hope for woman-initiated prevention methods.

The SAHR (2010) further states that even though South Africa has the largest ART programme in the world questions remain about whether it is reaching the levels of coverage needed to see population level reversals in morbidity and mortality trends.

The SAHR (2010) also reminds us that a key gateway to prevention and treatment services is knowledge of HIV status and this remains relatively low in South Africa. This is the rationale for the implementation of the South African national HIV counselling and testing programme (SAHR, 2010).

Some of the reasons cited for South Africa's failure to deliver lies with the limited routine surveillance data available to monitor progress on targets and the fact that South Africa appears to have limited ability to identify bottlenecks for service delivery and coverage nationally, provincially or at a clinic level. Also limited discussion occurs at the level of service delivery to set targets and timelines. This disconnect between policy, implementation and evaluation is a major obstacle to achieving the NSP goals (SAHR, 2010). South Africa appears to have the political will to fight HIV/AIDS and TB but South Africa does not appear to have the capacity to carry out its mandate.

South Africa faces enormous challenges with regards to the intertwined HIV/AIDS and TB epidemic. TB is the leading cause of death among people living with HIV and accounts for approximately 13% of AIDS deaths globally. HIV and TB are often referred to as dual epidemics or co-epidemics as these epidemics drive and reinforce one another. HIV activates

dormant TB in a person because of immune suppression and this person becomes infectious and is able to spread the TB bacillus to others (WHO TB/HIV facts, 2009).

In order to fully comprehend the challenge that the HIV/AIDS epidemic poses it is important to acquire a reasonable amount of knowledge and understanding about the human immunodeficiency virus and how this virus infects and affects its host. The natural history explains the disease in the host, gives insight into how the disease progresses and helps in determining when therapy should be initiated. It must be emphasized that ART also contributes to prevention as strict adherence results in a negligible viral load which decreases transmission of the virus.

#### **2.4 The Natural History of HIV Infection (without ART intervention)**

The human immunodeficiency virus (HIV) targets the cell of the human host's immune system, in particular the CD4 (helper) T-lymphocytes and begins the gradual process towards the destruction of the immune system. Over time, usually a period of years, the immune system gradually weakens and eventually the immune suppression is so severe that the person can no longer fight infection and thus becomes vulnerable to opportunistic infections and certain types of cancer (Wilson, Naidoo, Bekker, Cotton & Maartens, 2002).

The way in which individuals respond to HIV infection varies widely. A small proportion of individuals experience severe seroconversion illness associated with high levels of viral replication followed by a steep decline in CD4 cell count leading to rapid immune system destruction and death within a year or two. The majority of HIV infected persons are able to regulate viral replication for years because of an effective immune system response. However, over time they will endure a steady decline of CD4 cells and the eventual destruction of their immune system. A select small percentage of persons infected with HIV infection are able to control viral replication effectively with normal or robust immune system functioning. These individuals do not experience immune system destruction over time, their CD4 cell counts remain at functionally normal levels and they appear to not need ART intervention (Wilson et al., 2002).

Before the advent of antiretroviral therapy, the median time to acquired immune deficiency syndrome (AIDS), from the time of infection as described above was 8 to 10 years in developed countries. Socio-economic conditions like malnutrition and poor access to quality health care may cause the natural history in developing countries to be shorter. Age is a very important demographic factor because older persons tend to progress more rapidly to AIDS than their younger counterparts (Wilson et al., 2002; Natural history of HIV, 2007).

Antiretroviral therapy has without doubt altered the natural history of HIV infection progression in a most efficacious way (Natural history of HIV, 2007). Before the researcher explains how antiretroviral therapy works it is necessary to explain how health care professionals determine the prognosis of HIV/AIDS infection in an individual.

The WHO developed a staging system which is a system of criteria, or list of symptoms which help health care professionals decide which of the four stages of HIV infection the person finds himself or herself in. This is particularly important in resource-limited settings as this enables health care workers to determine the appropriate time to start treatment. Often poor regions do not have the capacity to follow through with the blood tests that are more accurate in determining prognosis and when to initiate treatment.

## **2.5 Prognosis and Staging**

Wilson et al. (2002) explain that individual prognosis is best determined by a combination of a clinical evaluation of the person's immune status with information provided by the CD4 count and viral load (VL). These authors further state that the information can be used to give the person knowledge to make important personal and social decisions to determine when to initiate ART and opportunistic infection prophylaxis, or as a guide to palliative care. Prognostic information gives an overall view of the risk of disease progression in large numbers of people and it is important to remember that individual disease progression may vary (Wilson et al., 2002).

The World Health Organisation's (WHO) staging system for HIV infection uses standard criteria to help clinicians evaluate immune system function and to assess HIV disease progression. The Centers for Disease Control and Prevention's classification system (CDC) is

newer and is widely used in developed countries and is described as the cornerstone of HIV/AIDS diagnosis (Natural history of HIV, 2007). WHO describes four clinical stages which are further elaborated in Appendix 2. Appendix 3 displays the CDC classification system.

## **2.6 Background to Public Antiretroviral Therapy Availability**

South Africa's failure to prevent the rapid growth of the HIV/AIDS epidemic in the 1990s and delays in implementing a treatment programme in the early 2000s can only be described as a gross violation of basic human rights. During the denialist period, thousands of babies were denied lifesaving preventative ARVs and thousands of lives were lost because ARVs were simply not made available for treatment in the public sector. The Treatment Action Campaign (TAC) was founded in 1998 in response to the need for an organisation that would campaign for the rights of people living with HIV and to demand access to HIV treatment in South Africa for all who were in need of it. What is ironic is that the Deputy President at that time, Mr Thabo Mbeki who launched the Partnership against AIDS admitted that 1500 new infections were occurring every day, yet he would during his tenure as president prefer dissident views on HIV rather than sound evidence based scientific views on HIV. President Mbeki rejected the link between HIV and AIDS and blamed the growing HIV/AIDS epidemic on poverty. The most rapid increase in HIV prevalence in South Africa took place between 1993 and 2000 amidst confusion, denialism and major political change (Avert. HIV & AIDS in South Africa, undated).

A milestone in the battle for ART came in 2001 when a high court decision in favour of the TAC forced the South African government to make ART for the prevention of mother to child transmission of HIV available in the public sector. Attention then focussed on providing ART for all those in need of this lifesaving medication. The TAC used mass action to highlight its cause and to force the government to commit to providing ART. The South African government continued to drag its heels with regard to ART provision. Eventually the announcement to provide ART to persons who accessed public health care was made at the end of 2003. The South African Department of Health promised the implementation of the national ART rollout by March 2004. Under global and national pressure especially from the Treatment Action and other civil society organisations treatment guidelines were issued in

September 2004. It took another few months (until March 2005) for suppliers of ARVs to be chosen. The roll-out gathered pace from mid 2005 although the number of people receiving treatment lagged behind the operational plan targets (Avert. History of HIV & AIDS in SA, undated). Zachie Achmat and the TAC were joint nominees for a Nobel prize in 2004 for the organisations steadfast fight for the provision of ART for the people of South Africa.

## **2.7 HIV/AIDS Antiretroviral Therapy (ART)**

The human immune deficiency virus (HIV) can be divided into two types: HIV-1 responsible for the global epidemic and HIV-2 which is less pathogenic than HIV-1 and is largely restricted to West Africa with limited spread to other countries (Wilson et al, 2002). HIV-1 virus is a rapidly evolving virus (mutates rapidly with high replication rate) which means that HIV has the ability to escape detection by the host immune system and HIV can rapidly develop resistance to antiretroviral agents. To minimize the risk of resistance, a potent combination of at least three anti retroviral agents are prescribed to maximally suppress HIV viral replication at different stages of the life cycle of the virus halting the progression of HIV disease to improve clinical outcomes (Satyanarayana & Srivastava, 2010). Suppression of the virus is the only way to prevent the progression of HIV infection to AIDS. This process allows for reconstitution of the CD4 T cell population and restoration of the immune system. This can only be accomplished by taking the treatment regimen exactly as prescribed (Orrell, 2008). Treatment regimen, drug ‘cocktail’, highly active antiretroviral therapy (HAART) are all synonyms for HIV antiretroviral therapy.

The persistence of HIV reservoirs means that ART cannot eradicate HIV. ART may not be able to eradicate HIV but ART can reduce the viral load (VL) to negligible amounts, enable restoration of the immune system and maintain this status for as long as possible as eventually resistance will set in and a regimen change will be necessary (Mahungu, Rodger & Johnson, 2009; Noë, Plum & Verhofstede, 2005).

There are currently over 30 ARVs globally and these include NRTIs, NNRTIs, PIs ( Protease inhibitors), the new Fusion inhibitors, Entry inhibitors-CCR5 co-receptor antagonists and HIV integrase strand inhibitors. These drugs are available as either single drugs or fixed dose combinations (FDCs) (Satyanarayana & Srivastava, 2010). The newer drugs usually have less

adverse side effect profiles, are simpler to take (reduced pill burden, lesser food restrictions, no refrigeration), and generally fit in more easily to a person's lifestyle, in other words treatment is simplified. Antiretroviral combinations available in the South African public sector national programme before the new guidelines made accessible on 1 April 2010 included the first line regimen of stavudine, lamivudine and efavirenz or nevirapine (for pregnant females) and the second line regimen of didanosine, zidovudine and lopinavir/ritonavir. Clinical criteria for treatment before the April 2010 changes was a CD4 – T cell count below 200cells/mm<sup>3</sup>, WHO stage 3 or 4 or both for all persons in need of treatment. The treatment combinations include two nucleoside reverse transcriptase inhibitors (NRTI) and either, a non-nucleoside reverse transcriptase inhibitor (NNRTI) or a protease inhibitor (PI), or other such combinations (Cichochi, 2008).

### **2.7.1 New Antiretroviral Therapy (ART) Guidelines**

The long overdue new treatment (last updated in 2004) for South African finally came into effect on the 1 April 2010. These updated guidelines are available on the SANAC (South African National AIDS Council) website ([www.sanac.org.za](http://www.sanac.org.za)). The new HIV/AIDS treatment guidelines complement existing HIV/AIDS and TB management guidelines, and are the result of extensive consultation through the SANAC Treatment Technical Task Team (Department of Health RSA & SANAC, 2010).

HIV positive pregnant women and person's co-infected with HIV and TB are now eligible for lifesaving treatment much earlier (CD4 T cell count less than or equal to 350). Early treatment is available to all HIV positive infants and improved regimens to prevent mother to child transmission is available to pregnant women. Other notable changes include the phasing out of stavudine (because of the long term adverse side effects namely, lipodystrophy and neuropathy), and replacing it with tenofovir, which has a much lower adverse side effect profile.

TAC Equal June 2010 reports that South Africa faces a major barrier to improving treatment regimens because of low registration of drugs by the Medicines Control Council (MCC). Many essential drugs in the new treatment guidelines have not been approved by the MCC, particularly fixed dose combinations and paediatric formulations. The Southern Africa HIV

Clinicians Society has called on the MCC to fast track the registration of a number of ARV drugs, particularly tenofovir fixed dose combinations as well as abacavir/lamivudine combinations and lopinavir/ritonavir paediatric formulations. Fixed dosed combinations are recommended by most health care professionals and the Southern African HIV Clinicians Society because the lower pill burden is associated with improved adherence (TAC Equal, June 2010).

Poor treatment adherence leads to increased drug resistance, meaning a switch to the more expensive second line and third line treatment (TAC Equal, June 2010). The public sector rollout currently offers first and second line treatment options, therefore it is most important that the first line treatment regimen be preserved for as long as possible (Orrell, 2008). The first line options are potent drug combinations which are easier to take as they have a much lesser side effect profile than second line options (Soul City, Jacana Media, Health & Development Africa, 2005). Orrell and Wilson (2003) further emphasise that the first line options are the ones most likely to have success because once exposed to antiretroviral therapy subsequent regimens may have poorer clinical benefits. A person's best chance of combating HIV and living a healthy life is with the first line treatment. Stringent adherence to the prescribed treatment regimen is a prerequisite for optimal health outcomes. The public health sector aims to provide a standard of health care in keeping with the principles of Batho Pela that is cost effective, efficacious and of good quality.

### **2.7.2 Comments on the New Antiretroviral Therapy (ART) Roll-out**

The new treatment guidelines are a step in the right direction but they still lag and fall short of the latest WHO ART guidelines which clearly states that all HIV positive people should be starting ART at a CD4 count of about 350cells/mm<sup>3</sup>. A CD4 count of 350cells/mm<sup>3</sup> should be considered a 'minimum standard of care' for commencing ART, a statement supported by the WHO and the European and British AIDS societies. The USA recommend higher levels for treatment initiation at a CD4 count of 500cells/mm<sup>3</sup> (Rossouw, Richter, Martin, Avenant & Spencer, 2011). According to the new South African guidelines, only pregnant mothers and person's co-infected with TB are eligible for ART at a CD4 cell count of about 350cells/mm<sup>3</sup>, other adults get ART at a CD4 count of 200cells/mm<sup>3</sup> or if they present with opportunistic infections or clinical staging that can motivate for ART earlier.

It must be stated that there is a discrepancy as to when ART is made available in the public sector and the private sector in South Africa. The private sector practitioners may use their own discretion based on the latest available data on when best to initiate ART. The public sector appears to compromise to provide reasonable and affordable health care for the majority of people in need of health care.

Another comment on the new guidelines was that tenofovir needs to replace stavudine for all people on Regimen 1, not only new people who are accessing treatment. WHO recommends that stavudine be phased out due to concerns over “long-term, irreversible” side effects that include lipodystrophy and peripheral neuropathy, and other serious side effects such as lactic acidosis (WHO Press release, 30 Nov 2009).

In April 2010 the TAC, Southern African HIV Clinicians society and other civil society groups lobbied for the new first line treatment to be updated to include tenofovir based three-in-one once daily pills because this is affordable, has a lesser side effect profile and is easier to take, enhancing treatment adherence (TAC, Equal. April 2010). The activists also called on the health department to commit to procuring FDCs where available and for the MCC to fast track the registration of all ARVs and combinations of ARVs so as to ensure a competitive tender. The MCC refused to fast track critical fixed dose combinations (FDC) for inclusion in the country’s massive antiretroviral tender announced in December 2010. There were no FDCs included when the tender outcome was announced and this fact went virtually unnoticed as people applauded the massive price reductions announced by health minister Dr Aaron Motsoaledi (Thom, 2 Feb 2011).

South Africa has the largest ARV programme in the world and FDCs could have made a massive difference especially in settings with few doctors, nurses and pharmacists. FDCs improve the likelihood for good adherence and maintenance of viral suppression which leads to better treatment outcomes. FDCs also just make the process of dispensing and recording so much easier especially in resource constraint settings which is in abundance in South Africa (Thom, 2 Feb 2011).

The advent of HAART ushered in a new era in the lives of people infected with the human



immune deficiency virus. HIV infection was no longer a life-threatening illness, it transformed into a manageable chronic condition. Millions of people worldwide were given hope of fulfilling their life goals as a relatively normal life became a distinct possibility.

### **2.7.3 Goals of Antiretroviral Therapy (ART)**

Machtinger and Bangsberg (2006) state that in countries with broad access to antiretroviral therapy the clinical benefits of treatment have been dramatic. Far fewer people were progressing to AIDS and hospitalisation for AIDS related illnesses decreased dramatically.

Benefits or goals of ART are:

- Maximal and durable suppression of HIV viral replication to undetectable levels.
- Restoration and preservation of the immune system, eliminating the risk of opportunistic infections and preventing opportunistic infections (Moosa, 2007).
- Reduction of HIV related morbidity and mortality - halting the disease progression, improvement in the quality of life and the conversion of HIV/AIDS to a chronic disease.
- Preventing the emergence of drug resistant strains of HIV thus protecting the available antiretroviral treatment agents and not compromising the available treatment options (Public sector ART treatment options are limited to two regimens).
- Potentially reducing the transmission of HIV: reducing transmission in serodiscordant couples, reducing mother to child transmissions and impacting positively on the incidence of HIV infection (Dawood, 2007, The Art of HAART).

The results of the HPTN 052 study released in May 2011 proved conclusively that ART use in serodiscordant couples reduced infection rates by 96% confirming that treatment is prevention (Sax, May 12, 2011).

### **2.7.4 Benefits and Risks of Early and Deferred Treatment**

ART should preferably not be started as a matter of urgency. Persons in need of treatment should have enough time to gain sufficient knowledge about HIV so that they can make informed choices about managing their condition. Some people choose to delay the start of therapy for as long as they can safely do so whereas other people appear eager to start therapy

earlier in the course of HIV disease. Unfortunately most South Africans seem to get to know their status and access treatment at a late stage in disease progression (CD4 well below 200 or when they present with an opportunistic infection) (SANAC, Midterm Review, 2010). In these cases there is clearly no time to contest the matter as their health is already severely compromised and fast track access to ART is their only salvation (Dawood, The Art of HAART, 2007).

#### 2.7.4.1 Benefits and Risks of Early ART

<b>Benefits</b>	<b>Risks</b>
Early suppression of viral replication.	Drug related reduction of quality of life because of drug side effects.
Preservation of immune system function.	Earlier development of drug resistance if complete HIV suppression is not achieved.
Lowers risk of drug resistance if HIV reproduction is sufficiently suppressed.	Fewer future treatment options if HIV develops resistance to drugs used early.
Decreased risk of HIV transmission.	

#### 2.7.4.2 Risks and Benefits of Deferred ART

<b>Benefits</b>	<b>Risks</b>
Avoids negative effects of ART on quality of life.	Possible irreversible immune system depletion.
Avoids drug-related adverse effects.	Possibly greater difficulty in suppressing viral replication.
Delays development of drug resistance.	Possible increased risk of HIV transmission.
Preserves future treatment options.	More drug related adverse effects and health problems.

(Dawood, 2007, The Art of HAART).

## **2.8 Antiretroviral Therapy (ART) Adherence**

Medication adherence may be defined as the extent to which a person takes a medication in the way intended by a health care provider (Machtinger & Bangsberg, 2006). Persons on HAART require adherence rates of greater than 95% to obtain the full clinical benefit of their medication as near perfect adherence is a critical determinant of treatment success (Orrell, 2008; WHO, 2003). This means taking medication exactly as directed: on time, all the pills, no missed doses, everyday, for the rest of their lives (Orell, 2004). No other chronic medication requires such stringent adherence for optimal therapeutic benefit, which may mean the choice between life and death. The extremely rapid replication and mutation rate of HIV means that very high levels of adherence are required to achieve durable suppression of the viral load to undetectable levels (WHO, 2003; Moosa, 2007). WHO (2003:95) further asserts that “these multidrug regimens although highly efficacious, results in HIV treatment having the most complicated regimens that have ever been prescribed for conditions requiring continuous open-ended treatment”.

According to Catherine Orrell (2008) in her discussion on the importance of HAART adherence, achieving adherence rates of 95 – 100% poses a very real challenge. From information about adherence rates for other chronic diseases such as diabetes and asthma it is known that persons on treatment seldom manage to achieve a 95% adherence rate. Typical adherence rates for medications prescribed over long periods are in the range of 50 – 75% (Machtinger & Bangsberg, 2006). HAART adherence has therefore emerged as both a major determinant and the “Achilles Heel” of treatment success as HAART adherence is the second strongest predictor of progression to AIDS and death after CD4 count (Machtinger & Bangsberg, 2006:2).

Adherence to HAART is not the only determinant of treatment success or failure: genetic differences in drug metabolism, severe baseline immune system suppression, prior drug resistance, eventual/acquired drug resistance and concurrent episodes of opportunistic infections may all be contributing factors. However HAART adherence remains an important potentially alterable factor in determining treatment outcomes of HIV infected people (Machtinger & Bangsberg, 2006).

Orrell and Wilson (2003) explain that successful therapy is critically dependent on the HIV clinician and the person in need of treatment establishing a robust therapeutic relationship. The doctor must take responsibility for prescribing medicine that will suit the person's lifestyle and must provide support for the person. The person must accept the need for lifelong adherence to therapy and must understand both the risks and benefits offered by ART (Orrell & Wilson, 2003).

The National HIV roll-out programme guidelines expresses the need for a more holistic approach to health care management, namely the Team Centred Approach, a shift from doctor led care. Each member of the health care team is crucial to the success of the person in need of care and decisions should be made about the person as a team. Regular meetings with all team members enable input from all the disciplines and in this way the team views the problem in a more holistic way and gets a better understanding of the context in which the problem occurs. The team should be multidisciplinary comprising of, for example, medical officers, nursing staff, lay counsellors, pharmacists, social workers, psychologists, dieticians and administration workers (Dawood, National roll-out programme guidelines, 2007).

### **2.8.1 Adherence Rates in Southern Africa**

The high rates of adherence observed in Soweto, South Africa, compare favourably with adherence rates in developed countries. This may be due to greater motivation of South Africans in need of antiretroviral therapy because of the history of scarce access to antiretroviral therapy and because the disastrous effects of AIDS are seen everywhere in their everyday lives (Mills, Nachega, Bangsberg et al., 2006; Nachega, Stein, Hlatshwayo, Mothopeng, Chaisson & Karstaedt, 2004).

Mills, Nachega and Buchan et al., (2006) in their analysis of developed and developing world HIV adherence, found that there are people in both settings that have sub-optimal adherence, and that factors beyond poverty play a role. This analysis of adherence to antiretroviral therapy in Sub-Saharan Africa and North America revealed that expectations of poor adherence in Africa is not an evidence based rationale for delaying expansion of ARV treatment programmes in resource poor settings. The Mills, Nachega and Buchan et al., (2006) study found relatively high levels of adherence in resource poor setting therefore

effort should be directed towards interventions that will aid maintenance of these adherence rates. Understanding culturally specific barriers to adherence may be important in developing evidence based strategies targeted at individuals who are poor adherers to their HIV medication (Mills, Nachega, Buchan et al., 2006).

## **2.9 HIV as a Chronic Disease**

Diseases are usually classified as either acute, chronic or terminal. An acute illness lasts for a short period of time and may go away without any intervention, medication or surgery, a chronic disease recurs or persists for a long period of time or may last for a person's entire lifetime and terminal means that death or nearing the end of life is approaching. Chronic diseases can only be controlled; they cannot at present, be cured. These diseases are among the most common, costly and preventable of all health problems and examples include diabetes, heart disease and now HIV/AIDS (Department of Health UK, 2004).

“There is no doubt that HAART is one of the most celebrated treatment advances in recent medical history” WHO (2003:95). Highly active antiretroviral therapy (HAART) is not a cure for HIV infection but can be hailed as responsible for the transition of HIV/AIDS from a life threatening terminal illness to a chronic manageable disease (Gifford & Groessl, 2002; Meyer & Ogunbanjo, 2006; Nishal, Khopkar & Saple, 2005; Lucas, 2005). HIV as a chronic disease means that HIV infected persons may now look forward to living a long and relatively healthy life provided their medical condition is optimally managed or controlled.

Gifford and Groessl (2002) assert that the care of chronic diseases such as diabetes, asthma and now HIV infection is profoundly different from caring for an acute illness. Chronic disease management usually implies lifelong treatment, and the treatment must be sustainable if the therapeutic goals of the treatment are to be achieved. The management of chronic disease can be described as much more than prescribing medication and giving advice. Effective health care providers have the additional tasks of providing the person in need of chronic care with the necessary tools, knowledge, skills and motivation to sustain life-long treatment (Mahungu et al., 2009). Treatment with HAART has brought along with it other challenges and these include amongst others the unknown long-term history of treated HIV infection, the development of toxicity and drug resistance and the ageing HIV infected person

(Mahungu et al., 2009). The British HIV Association (BHIVA) together with the Royal College of Physicians, British Association for Sexual Health and Infection and HIV Infection Society recently published Standards for HIV clinical care. According to this report, people with HIV infection are best managed within chronic care disease models. The report also makes recommendations on the level of service provision expected from centres providing HIV care and the level of professional expertise required from health care providers. Chronic disease management is a challenge and a model for managing chronic disease enables the health system to respond to the challenge in an appropriate, systematic and cost effective way. Some of the key components of chronic disease management includes early detection, prevention and optimising treatment response (Mahungu et al., 2009).

Almost all HIV positive persons will eventually need antiretroviral therapy. Near perfect ART adherence is required for optimal health outcomes. It is therefore necessary to explore the factors that influence adherence to HIV medication. Information so gleaned may help health care providers and persons on ART to better understand how various factors influence adherence and so inform strategies that will positively influence adherence behaviour.

## **2.10 Factors that Influence Adherence to HIV Medication**

Gray and McIntyre (in Van Dyk, 2005) propose that adherence is a complex issue determined by factors related to the person, the disease process and stage, the treatment regimen, the interaction between the person and the health care worker and the environment in which the person resides. As stringent adherence to ART is crucial to treatment success, Van Dyk (2005) gives some examples of the kind of questions that should be asked in order to gain greater insight into the factors that may influence adherence. This may give the health care worker an indication of the person's ability to adhere to ART as well as inform strategies that need to be developed in order to help the person maximise their chances of successful treatment (Van Dyk, 2005).

### **The Person**

- Is the person motivated to take ART?
- Does this person have adequate social support?
- What are his/her beliefs about sickness and health?

- How did this person take other prescribed medication, like antibiotics or TB treatment?
- Does this person have adequate coping skills?
- What is the cognitive level of this person?
- Will this person be able to follow a stringent adherence schedule?

### **The Treatment Regimen**

- How many pills and how often will these pills have to be taken?
- How does the medication taste and are they easy to swallow?
- What about the dietary requirements for taking the pills?
- What side effects might be experienced and how will the person deal with them?
- What about medication the person is taking for other conditions and possible drug interactions?

### **The Relationship between the Person and the Health Care Worker/s**

- Has a relationship of trust developed between the health-care worker and the person?
- Will the person receive adequate support from the health care worker/s?
- Does the care worker take time to give adequate explanation about the adverse side effects that may be experienced?
- Is the health care system providing a satisfactory level of service?

### **Environment**

- Are the health care services adequate and accessible to the person?
- Is transport to these services satisfactory and easy to access?
- Does this person have access to a reasonable supply of medication?
- Does this person have access to the necessary dietary requirements for taking medication?

(Van Dyk, 2005).

Pratt (2003) explains that for most people on ART, patterns of adherence vary with the circumstances of their lives. He further states that few people claim to be 100% adherent;

most people are adherent 70-99 percent of the time, and about 30 percent are poor adherers, taking less than 60 percent of their medication. Adherence or non-adherence is therefore dynamic, changing or varying according to circumstances in their lives at particular points in time. Pratt (2003) points out that there are a number of factors that need to be considered by healthcare personnel and persons on ART in order to promote adherence and give persons on ART the best possible benefit of their medication sustained viral suppression. Factors relating to the regimen, the person's lifestyle, available social support and the person's knowledge and understanding of treatment may positively or negatively influence adherence behaviour. Pratt (2003) also explains the influence of the health care providers, with particular emphasis on the nursing role in supporting adherence.

The factors that Robert Pratt (2003) explain are included in the World Health Organisation discussion on adherence and are therefore incorporated into the discussion below in order to avoid repetition. The World Health Organisation (2003) argues for a systems approach to studying adherence thus adherence is viewed as a multidimensional phenomenon determined by the interplay of five sets of factors or dimensions: social and economic factors; therapy related factors; condition related factors; person related factors and health care team and system related factors. A systems approach encourages a holistic view and this involves a conscious effort to understand how the various factors impact upon adherence behaviour.

### **2.10.1 Socio-economic Factors**

Socioeconomic factors such as socio-economic status, education level, literacy, income and housing status are generally not predictive of adherence (Meyer & Ogunbanjo, 2006; WHO, 2003). However, low socioeconomic status may put persons on medication in a position where they may have to choose between competing priorities, for example, they may have to direct limited resources to meet the needs of other family members such as children or parents for whom they care (WHO, 2003).

Socioeconomic factors that are reported to have a significant effect on adherence in certain circumstances are poor socioeconomic status, low levels of education, unstable living conditions, inadequate social support networks, long travelling distance to and from the treatment centre, transport costs, dysfunctional family systems, culture and lay beliefs about



the disease and treatment, high cost of medication and the changing environment (WHO, 2003). Heyer and Ogunbunjo (2006) contend that educational level, literacy, income and housing status are not consistently predictive of adherence because in the twenty two studies evaluated by Fogarty, Roter, Larson, Burke, Gillespie and Levy (2002) only five demonstrated a correlation between socio-economic factors and adherence. Heyer and Ogunbanjo (2006) report that a South African study by Orell, Bangsberg, Badri and Wood (2003) found no association between adherence and socio-economic circumstances, asserting that adherence rates in developing countries are comparable with adherence rates in developed countries, and therefore should not be used as an excuse for limiting antiretroviral therapy access to persons in developing countries.

WHO (2003) suggests that race is often reported as a predictor of adherence but it is rather cultural beliefs that may lead to poor adherence confounded by social inequalities. War has also been reported to affect adherence to therapy because of the resulting economic hardship, lack of medical control, fatalism and anarchy that it brings (WHO, 2003). More insight into the influence of social factors is detailed in the paragraph on person factors that influence adherence because of category overlap and to avoid repetition.

### **2.10.2 Health Care Provider Factors**

The qualities of the health care provider are an important factor in helping persons on ART adhere as prescribed (Pratt, 2003). Qualities such as active listening, being sensitive to the persons needs, empathizing, developing an understanding of the persons situation and good communication skills are most necessary for recognising the person as a partner in treatment decisions and for translating complex medical information in a manner that is clear and understandable to persons on treatment (Pratt, 2003). Pratt further states that a health care provider-person relationship of mutual trust and respect is likely to positively influence adherence behaviour because persons will feel free to be open and honest about problems they may experience with regard to ART adherence.

It is interesting to note that organisational factors may be more related to adherence than socio- demographic factors. Albaz, (in WHO, 2003) concluded that time spent with the health care provider, continuity of care by the health care provider and the communication

and interpersonal style of the health care provider may be more important for adherence to therapy than socio-demographic variables such as gender, status, age, educational level and health status.

### **2.10.3 Health Care System Related Factors**

Factors such as poorly developed health services, inadequate or non-existent health insurance, poor medication distribution, lack of knowledge and training of health care providers in chronic disease management, overworked health care providers, lack of incentive and feedback on performance, short consultations, weak capacity to educate both person in need of treatment and health care provider, inadequate community support and health care provider support, lack of knowledge on adherence and interventions to improve adherence cover some of factors that may contribute to poor medication adherence (WHO, 2003). Long waiting times for clinic services were reported as important barriers to a person's ability to return to the clinic for service and to pick up medication. This may be stigmatising as additional time off work may be required. Communication barriers may also be a cause for concern especially when persons in need of treatment spoke different languages to their providers (Dahab et al., 2008).

### **2.10.4 Condition Related Factors**

These factors refer to the illness related demands faced by the person with HIV infection determined by the stage and duration of HIV infection, the physiological markers of HIV disease progression such as CD4 cell and viral load count, associated opportunistic infections and cancers and HIV related symptoms (Machtiger & Bangsberg, 2006; Vervoort, Borleffs, Hoepelman, & Gryndonck, 2007; WHO, 2003).

The stage of HIV disease, severity of opportunistic infections and symptoms present at the onset of treatment are factors that may influence adherence either negatively or positively. WHO (2003) states that when symptomatic HIV positive persons understand the relationship between adherence and viral load, then they are more likely to be adherent. Orrell (2008) states that late or symptomatic HIV disease presentation may promote adherence because people experience the beneficial effects of ART as they begin their recovery and regain their strength and health.

TB and HIV/AIDS are epidemic in South Africa. HIV positive persons are more susceptible to TB infection because of their compromised immune system. Persons who access HIV treatment when they are co-infected with TB and/or other opportunistic infections make taking ART even more complicated because of the pill burden, increased drug interaction, increased adverse side effect profile, and they are immune-compromised, which makes them feel weak, tired and ill.

The latest WHO treatment guidelines recommend initiating ART at a CD4T cell count of greater than or equal to 350cells/mm<sup>3</sup>. In most cases, at a CD4 of 350-500cell/mm<sup>3</sup>, the person is immune-compromised but not necessarily susceptible to opportunistic infections. Taking ART will therefore restore and strengthen the immune system and the HIV positive person is likely to become less susceptible to opportunistic infections such as TB.

#### **2.10.5 Therapy Related Factors**

Treatment related factors that influence adherence are usually associated with the complexity of the regimen, previous treatment failures, the immediacy of beneficial results, adverse side effects and the support the person receives, both medical and social. Complexity refers to, for example, the treatment routine, duration of treatment, the dosing frequency, number of pills per dose (pill burden) and special instructions, for example, with or without food or fluid (WHO, 2003). The factors mentioned above all have the potential to have a negative effect on antiretroviral treatment adherence. Regarding treatment routine, changes in daily routine or being away from home may cause sub-optimal adherence (Aspeling & van Wyk, 2008).

Antiretroviral therapy can cause side effects just like most other drugs that are prescribed. The way in which persons on antiretroviral therapy react to their medication varies considerably between individuals. Individuals who start antiretroviral therapy at lower CD4 T cell counts may be more affected by side effects than those who start therapy at higher CD4T cell counts (Soul City, Jacana Media, Health and Development Africa, 2005). WHO (2003) asserts that the literature on side effects shows that optimal adherence occurs with therapy that removes symptoms whereas adherence is reduced by therapy that causes side effects. HAART may greatly increase the quality of life in persons who are symptomatic but may have a negative effect on the quality of life in asymptomatic persons. Individuals who

were symptomatic when put on treatment usually feel and appreciate the benefits of therapy, and are more aware of the implications of non-adherence than individuals who were asymptomatic when treatment began (WHO, 2003).

Naidoo (2009) found an association between adherence and difficulties swallowing ART. Persons in this study cited difficulty in swallowing as a reason for not being able to take their medication. Participants reported that the protease inhibitor regimen appears to be the most problematic because of their side effect profile, drug interactions and the food restrictions that persons have to contend with when taking this ARV (Naidoo, 2009). HAART regimens are associated with both short-term and long-term side effects.

**Short-Term Side Effects:** Most of the short-term side effects occur in the first two to six weeks after starting medication. Symptoms like headaches, difficulty sleeping, tiredness, nausea, diarrhoea, dizziness, bad dreams or nightmares, mild confusion and rash are common and most will settle and disappear once the body has adjusted to the new drugs (Soul City, Jacana Media, Health and Development Africa, 2005).

**Long Term Side Effects:** The long-term side effects are those that become evident after a few years on treatment. They are also the effects of long-term therapy that health care providers are learning about as persons stay on therapy for longer and longer periods. The common long term side effects to date include peripheral neuropathy, lipodystrophy, liver damage, pancreatitis, lactic acidosis, increased triglycerides and cholesterol, increased glucose levels, and anaemia. Lipodystrophy is not life threatening but is aesthetically difficult to cope with whereas lactic acidosis may be life threatening. Lactic acidosis indicates increased levels of lactic acid in the blood which is harmful to cells of the body. This may be due to ineffective functioning of the mitochondria (the power house of the cell) and interfere with the energy requirements of body cells. Therefore careful monitoring of persons receiving antiretroviral therapy is crucial. Lipodystrophy means disturbance in body fat metabolism and involves changes in the way body fat is distributed in the body. Persons who are affected by this side effect show signs of wasting or decrease in fatty tissue on the face, arms, buttocks and legs and increase in fatty tissue around the waist, in the breasts and the buffalo hump (a lump of fat on the back, just below the neck (Soul City, Jacana Media,

Health and Development Africa, 2005). It is important to note that physiologically these physical deformities are usually preceded by insulin resistance, hyperglycaemia (sugar metabolism abnormalities) and hypercholesterolaemia and hypertriglyceridaemia (lipid abnormalities). The exact relationship between these physiological changes to lipodystrophy is unclear but these physiological abnormalities are side effects that are potentially harmful and need to be treated accordingly (WHO, 2003; Moosa, 2007). Peripheral neuropathy refers to nerve ending damage at extremities such as feet and hands and persons may experience tingling and numbness in the hands and feet as well as a burning sensation, shooting pains, throbbing, aching or “pins and needles” (Soul City, Jacana Media, Health and Development Africa, 2005).

Persons on therapy may decide to discontinue therapy or request and sometimes insist on medication changes if they experience side effects that they deem are too problematic to accommodate (WHO, 2003). Distressing side effects such as fatigue, diarrhoea, stomach pain and nausea can be treated successfully. However there is no available treatment for lipodystrophy and a drug swap may be necessary accompanied by dietary advice and exercise to lessen the impact of this side effect (Heyer and Ogunbanjo, 2006).

Persons on antiretroviral treatment must be educated about the potential adverse side effects they may experience and be advised on how to handle them (Moosa, 2007; Vervoort et al., 2007). It must be emphasised that antiretroviral therapy works, is well tolerated by the vast majority of persons in need, and most side effects are manageable (Moosa, 2007). WHO (2003) reiterates the importance of simplified regimens for optimal adherence. Regimens with fewer pills, fewer doses and a minimal side effect profile are most desirable for achieving maximum adherence.

#### **2.10.6 Person Related Factors**

Person-related factors reported to affect adherence may include, amongst others: forgetfulness; psychosocial and/or psychological stress; anxieties about adverse side effects of ART; low motivation; inadequate knowledge and skill in symptom and side effect management and treatment; lack of perceived need for treatment; misunderstanding and non-acceptance of HIV disease; disbelief in the diagnosis; negative beliefs in the efficacy of

treatment; inadequate monitoring; misunderstanding of treatment instructions; low attendance for follow-up counselling and support sessions; hopelessness and negative feelings; frustration with the health care providers; fear of dependence on the health care system; anxiety over the complexity of treatment regimens and fear of stigmatisation and discrimination associated with HIV disease (WHO, 2003). Psychosocial factors may include mental health, substance abuse and social support as well as socio-demographic factors such as age, gender, income, race/ethnicity, education, literacy, housing status and medical insurance status.

WHO (2003) gives insight into the complexity of adherence behaviour when explaining that the persons knowledge and beliefs about HIV disease, motivation to manage it, confidence in their ability to elicit the necessary behaviour, knowledge and understanding of treatment outcomes, and the consequences of non-adherence, interact in ways that are truly complex, and not always clearly understood. The statement becomes more apparent as it becomes clear that a factor or factors that may be a stumbling block to one person on treatment may not necessarily be one for another person and vice versa.

Williams and Friedland (1997) and Meyer and Ogunbanjo (2006) state that characteristics such as age, sex, race/ethnic group, gender, education, occupation and socioeconomic status appear consistently non-predictive of a person's ability to adhere optimally to antiretroviral therapy. Machtinger and Bangsberg (2006) found that most studies on factors that influence adherence report conflicting evidence about the association between socio-demographic factors and adherence behaviour. However when an association is found, the direction is consistent: younger age, non-white race/ethnicity, lower income, lower literacy and unstable housing are usually associated with non-adherence in developed countries (Meyer & Ogunbanjo, 2006; Machtinger & Bangsberg, 2006). Heyer and Ogunbanjo (2006) found adherence among older persons to be better.

#### **2.10.6.1 Attitude and Beliefs**

A person's knowledge and beliefs about HIV and ART can influence adherence. People who understand the relationship between adherence and viral load, and between viral load and HIV disease progression, are more likely to be adherent than people who do not

understand this relationship. Adherence is likely to be enhanced in people who strongly believe in the efficacy of ART (WHO, 2003). Beliefs about ART such as issues of toxicity and adverse side effects may negatively affect adherence (WHO, 2003). Friedland and Williams (1997) report that studies in reference to AZT revealed that non adherence was influenced by the lack of belief in the efficacy of AZT and fear of its side effects.

Pratt (2003) asserts that a most important factor in adherence to HAART is the person's health beliefs and experiences in relation to medication and HIV disease. Pratt further states that there is good quality evidence to demonstrate that many HIV infected people understand the seriousness of their illness, recognise the importance of adherence and are aware of the virological consequences of poor adherence and that these factors increase the likelihood of optimal adherence. A positive outlook or optimistic approach to life combined with perceived control over personal health also appears to benefit adherence to HAART (Pratt, 2003). In general, persons who understand the goals of antiretroviral therapy are more likely to adhere as required (Friedland & Williams, 1997; Pratt, 2003).

A new and significant finding from a qualitative South African workplace study which examined barriers to and facilitators of adherence by Dahab et al. (2008) was denial about the existence of HIV disease and denial about a HIV positive diagnosis. According to this study persons with this belief will not take their treatment because they do not believe that HIV is the cause of their illness; they believe they were bewitched and that the HIV virus has nothing to do with their illness. A health care provider explained that a person who did not think that HIV existed or that he was infected reported that he stopped taking prescribed ART because he did not feel that this medication was necessary.

The Dahab et al. (2008) study purposively sampled a small group of individuals and was designed to identify potential barriers to and facilitators of adherence in a workplace setting and may not be generalisable. However, complementing person in need of treatment information, with health care provider information using in-depth interviews enabled greater insight into the complexities of adherence behaviour. There appeared to be greater congruency between factors explained by HIV positive persons and health care providers

(Dahab et al., 2008). This study clearly demonstrates the depth of information that can emerge when listening to the individuals experiences of adherence.

#### **2.10.6.2 Motivation**

A person's motivation to adhere as prescribed is influenced by the value the person places on treatment and the confidence he or she has to follow instructions as indicated. A person on treatment may choose to adhere or not to adhere based on his or her understanding of the risks and benefits of the prescribed treatment regimen (cost-benefit ratio), (Friedland & Williams, 1997; WHO, 2003). When a person on treatment shows a decrease in viral load and an increase in CD4 count their trust in the efficacy of treatment increases. As trust and belief can change over time, it is important to discuss this theme during every follow-up visit. When the value of treatment for a person's daily functioning is pointed out during routine check-ups, motivation is enhanced (Vervoort et al., 2007).

#### **2.10.6.3 Knowledge and Understanding**

Pratt (2003) asserts that the person on treatments ability to make decisions and participate in discussions concerning treatment is central to achieving good patterns of adherence. This happens because persons who are well-informed are more likely to be adherent because they understand the reasoning behind treatment and the consequences of poor adherence. Vervoort et al. (2007) state that persons on treatment should receive information about their medication that is appropriate to their level of understanding. In this way individuals will receive information that will guide them towards behaviours that constitute good adherence practice. In order to negate the possibility of faulty personal interpretations of adherence it is important to ask a person on treatment to describe their understanding of good adherence behaviour (Vervoort et al., 2007). Pratt (2003) states that even the most knowledgeable and well-informed person may forget to take a particular dose or make an informed decision to miss a particular dose.

#### **2.10.6.4 Social Support**

Social support for adherence is defined as encouragement from family and friends for the person on ART to take their medication exactly as prescribed by their health care professional (DiMatteo, in Kajee 2008). Social support in HIV infection may also be described as the



assistance offered to HIV positive persons by their social network as opposed to a professional, and is often associated with better health outcomes (Ncama et al., 2008). Williams and Friedland (1997) state that adherence rates are increased by significant others who understand the need to follow the regimen as they may help to organise the pill taking thus ensuring stringent adherence. Persons who enjoy the privilege of supportive friends and families appear to adhere more stringently to their regimen than those without support. Persons on treatment are encouraged to involve family and friends in their care and are also encouraged to join support groups (Friedland & Williams, 1997; WHO, 2003). Social support also acts as a buffer to many psychological problems and therefore positively influences adherence behaviour. The presence of stable relationships and having access to social and emotional support increases the likelihood of optimal adherence. People who live alone and who have poor social networks are less likely to be adherent (Pratt, 2003). The absence of a supportive social environment and fear of stigmatisation are generally associated with non-adherence (Heyer & Ogunbanjo, 2006). The fear of stigma and being seen taking ART by those outside of the persons close social networks present a significant barrier to normalizing adherence behaviour (Pratt, 2003).

Social support is a critical aspect of living with chronic conditions such as HIV/AIDS because social support may improve the quality of life of persons affected by chronic diseases (Dahab et al., 2008; Gilbert & Walker, 2009 and Ncama et al., 2008).

#### **2.10.6.5 HIV Stigma, Discrimination and Disclosure**

HIV/AIDS related stigma and discrimination refers to the prejudice, negative attitudes, abuse and ill-treatment that HIV positive people are subjected to just because of their HIV status. HIV positive people may be shunned by their family, friends and the wider community and they may experience poor treatment by the health care providers. These negative experiences may prevent people from accessing testing and treatment. The UN Secretary General Ban Ki-Moon asserts: “Stigma remains the single most important barrier to public action. It is a main reason why too many people are afraid to see a doctor to determine whether they have the disease, or to seek treatment if so. It helps make AIDS the silent killer, because people fear the social disgrace of speaking about it, or taking easily available precautions. Stigma is a chief reason why the AIDS epidemic continues to devastate societies around the world.”

(Ki-Moon, 6 August 2008).

The most important reported factors to negatively influence adherence in Sub-Saharan Africa are cost, not disclosing HIV status to a loved one, fear of being stigmatised, followed by alcohol abuse and difficulty with complex regimens (Mills, Nachega, Buchan et al., 2006). Mills, Nachega, Buchan et al. (2006) further state that their findings are supported by studies that have shown that the majority of persons on treatment have disclosed their HIV status to close family or friends and this has positively influenced adherence to ART. Individuals who have not disclosed are more prone to treatment interruptions because their medication must be hidden and not taken in the presence of others (Mills, Nachega, Buchan et al., 2006; Naidoo, 2009). Disclosure may lead to negative comments from others and this may have an adverse effect on adherence. Persons prescribed ART are encouraged to bring along a treatment partner for support while they are adjusting to taking ART. A treatment partner is a requirement for ART access in the public sector ART programme. Openness about HIV status is encouraged as openness appears to positively influence medication adherence (Vervoort et al., 2007).

Inungu and Karl (2006) assert that stigma is of utmost concern because it is both the cause and effect of secrecy and denial. Secrecy and denial may cause people with symptoms of HIV infection to claim that they suffer from less stigmatised diseases such as cancer, thus preventing them from accessing life saving ART (Inungu & Karl, 2006). Aspeling and van Wyk (2008) also found that HIV stigma and fear of discrimination prevents persons from seeking treatment and admitting their status as they are terrified of being ostracised, ridiculed, or treated differently if their status is known. They may also have to deal with fear, rejection, shame, isolation, and disgrace, (Avert. HIV & AIDS Stigma and discrimination, undated). Women with HIV infection feel that HIV stigmatises them as unworthy and immoral and this may prevent them from seeking medical intervention (Aspeling & van Wyk, 2008).

#### **2.10.6.6 Self Efficacy**

Heyer and Ogunbanjo (2006) explain self-efficacy as a person's belief in his or her ability to take their medication as prescribed. WHO (2003) adds to the explanation and describes self efficacy as the confidence an individual has in their ability to manage their condition. Self

efficacy is therefore most likely to be positively associated with medication adherence and people who view taking medication as a process that requires much effort are more likely to be non-adherent (Heyer & Ogunbanjo, 2006).

#### **2.10.6.7 Psychological issues**

Untreated depression and stress are strong predictors of non-adherence because feelings of hopelessness are associated with the loss of will to care for the self (Amberbir et al., 2008; Heyer & Ogunbanjo, 2006; Mills, Nachega, Buchan et al., 2006; WHO, 2003). Depressed mood and mental health problems have consistently been associated with poor adherence to HAART as symptoms of depression such as lack of motivation, poor organisation and difficulty in remembering and concentrating make adherence an extremely difficult task (Pratt, 2003). WHO (2003) and Pratt (2003) could find no conclusive evidence to link substance abuse to non-adherence. Substance abuse or alcohol misuse are associated with non-adherence because indulging in this kind of behaviour may interfere with a person's ability to cope with taking the complex HAART regimens as optimal lifelong adherence requires a certain high level of organisation. Pratt (2003) asserts that difficulties with adherence may be associated with the chaotic lifestyle of people who abuse drugs and alcohol rather than the substance abuse. Frank and Duncan (2009) state that alcohol and drug abuse are more likely to affect a person's ability to remember to take their medication and so negatively influence adherence. Substance abuse may lead to sexually risky practices and health compromising behaviour which may include poor adherence (Frank & Duncan, 2009). Co-morbidities such as depression, drug and alcohol abuse and certain cancers, for example, may contribute significantly to poor adherence behaviour (Pratt, 2003; WHO, 2003; Machtiger & Bangsberg, 2006).

The person's views on illness and health and his or her level of belief in the effectiveness of the medication are predictive of adherence and therefore a person may choose adherence or non adherence based on his or her understanding of the risks and benefits of the recommended treatment (Williams & Friedland, 1997; Frank & Duncan, 2009).

#### **2.10.6.8 Parenthood and Responsibility**

Aspeling and van Wyk (2008) found that the responsibility of parenthood and the desire to raise one's own children were huge motivating factors. This study found that children have a positive influence on adherence because parents were determined to raise their children and taking ART meant that they could achieve their goal. Adherence behaviour was reinforced because children often reminded their parents to take their medication (Aspeling & van Wyk, 2008). According to Aspeling and van Wyk (2008) this finding differs from the literature which identifies caretaking responsibilities as interfering with adherence or negatively influencing adherence.

#### **2.10.6.9 Religion and Spirituality**

Aspeling and van Wyk (2008) also found that religion indirectly facilitated acceptance of HIV. Studies support the role of religion and spirituality in achieving hope and physical well-being among person living with HIV. Hope contributes to the necessary lifestyle adjustment essential for good adherence (Aspeling & van Wyk, 2008).

The Konkle-Parker, Erlen and Dubbert's (2008) study on barriers and facilitators to adherence found that prayer and spirituality were considered important support for adherence. Participants in this study described prayer as the ability to trust God to help them through difficulties they may experience. Prayer and spirituality were considered to be a source of internal support during times of distress (Konkle-Parker et al., 2008).

#### **2.10.6.10 Culture and Traditional Medicine**

Traditional medicine claims to cure HIV whereas ART halts the progression of HIV disease. Aspeling and van Wyk (2008) found that even though no participant reported taking traditional medicine, some believed that traditional medicine can cure HIV disease. The consequence of this belief is that some people may combine traditional medicine with ART thereby causing sub optimal drug levels of lifesaving medication (Aspeling & van Wyk, 2008). The Dahab et al. (2008) workplace study reported that both persons and health care providers agreed that ART and traditional medicine should not be taken at the same time. The consequences of this belief was that some persons reported that they stopped ARV treatment while they were on traditional medicine (Dahab et al., 2008).

The belief that persons on treatment are solely responsible for taking their treatment reflects a misunderstanding of how the various factors impact upon a person and so affect a person's behaviour and capacity to adhere to their treatment as prescribed.

## **2.11 Conclusion**

Conway (2007) asserts that success with any pharmacological intervention depends not only on the intrinsic properties of the prescribed medication but on the individual's ability to take the medication reliably. ART requires therapeutic adherence rates of greater than 95% for optimal clinical benefit. An individual's ability to take medication may be influenced by many factors that may impede or facilitate medication adherence. Interventions that address barriers to adherence in a specific way, and those that support facilitators of adherence, may be key to the long-term success of ART, in a given person (Conway, 2007). In doing so the potentially dangerous situation of drug resistance which may compromise ART programmes and future options as well as the life threatening consequences of non-adherence may be avoided. Optimal adherence also ensures less susceptibility to opportunistic infections such as TB and pneumococcal infections because of a functional immune system characterised by high CD4 cell counts and negligible viral load. Undetectable viral load or negligible viral load has an added benefit of making such a person less infectious thus a positive factor in HIV prevention.

Studies such as Dahab et al. (2008), Aspeling & Van Wyk (2008) and Konkle-Parker et al. (2008) demonstrate how culturally relevant and novel findings may emerge when using qualitative methods to better understand factors that influence adherence to antiretroviral medication. These findings may be significant to specific populations as the necessary interventions to improve adherence will take into consideration the issues experienced by this population of people.

Van Dyk (2005) asserts that strategies to improve adherence to antiretroviral medication and the development of effective but person friendly regimens are much needed. In developed countries, resources are readily available to HIV health care providers and their clients, and resources include printed material, electronic media, websites, SMS messages, support

groups, electronic pill counters and alarm beepers, amongst others. Resources may not be easily accessible everywhere in Africa and it might be important for people in developing and underdeveloped countries to find their own unique ways of positively influencing adherence to antiretroviral therapy. When developing adherence programmes, it is important to take into account factors that are specific to the developing or underdeveloped country. Cultural perceptions of what causes HIV; attitudes to health and sickness; a culture of non-disclosure that means no community support for the person; stigmatisation; illiteracy; differing concepts of time; practical and financial constraints involved in getting to clinics and lack of health care providers in the public service to discuss treatment issues are examples of some factors that might influence the ability of a person to adhere optimally (Van Dyk, 2005).

All of the above-mentioned factors may interact and affect a person's capacity to adhere to treatment. Non-adherence should therefore not be viewed as an isolated single factor problem, but rather as a multi-dimensional problem. The ability of persons on ART to adhere optimally is likely to be compromised by more than one factor, and health care providers need to work with persons to assess all potential factors systematically. All five dimensions need exploration that will lead to a deeper understanding of the factors that influence adherence.

Mills, Nachega, Bangsberg et al. (2006) state that there is a paucity of qualitative research in developing countries. This is paradoxical as most developing countries are experiencing HIV/AIDS epidemics with South Africa recording the highest number of HIV positive people in the world. This study hopes to demonstrate the value of the qualitative approach in order to better understand the factors that influence HAART adherence.

Improving adherence is arguably the single most important potentially alterable means of optimising therapeutic outcomes for individuals on ART (Machinger & Bangsberg, 2006; Naidoo, 2009).

## **Chapter 3: Research Methodology**

### **3.1 Rationale for choosing the Qualitative Approach**

According to Reid and Smith (in De Vos, Strydom, Fouche & Delpont, 2005) the qualitative approach enables a researcher to gain first-hand, holistic understanding of phenomena of interest by means of a flexible strategy of problem formulation and data collection. Understanding phenomena involves aims that generally seek answers to questions about the 'what', 'how', or 'why' of phenomena and this is characteristic of the qualitative approach, rather than 'how many', or 'how much' (Green & Thorogood, 2004).

Persons in need of treatment are unique, and it is these unique, subjective experiences of what influences adherence that is of vital importance for our understanding of adherence. In order to better comprehend these experiences it was important that the researcher make sense of the participant's world in order to see how they perceive their situation, to understand what their situation means to them and to relate this to life-saving decisions that will always be an integral part of their daily existence (Green & Thorogood, 2004; Neuman, 1997).

This study may provide insight and justification that there is no one fit for all; but that each population of people are unique and that their subjective experiences is crucial in order to understand adherence behaviour and the factors that influence adherence behaviour.

This research is therefore a qualitative descriptive study to explore the factors that influence HAART adherence among persons who access treatment in the greater Durban area. This qualitative study attempts to better understand phenomena, the 'what', 'how' or 'why' questions that relate to factors that influence adherence to life-saving medication (Green & Thorogood, 2004).

### **3.2 Sampling Technique**

Glass and Strauss, (in Green & Thorogood, 2004) argue that the strength of the grounded theory approach lies in the cyclical process of collecting data, analysing it, developing a provisional coding scheme and using this to influence further sampling until saturation is reached. The non-probability theoretical sampling technique was therefore a method of

choice for this study. This technique afforded the emergence of a rich dense account of the factors that influence adherence from the data collected (Green & Thorogood, 2004). This sampling technique may also be described as a particular kind of purposive sampling as the sample was selected on the basis of their ability to contribute to the development of theoretical constructs (Ritchie & Lewis, 2003).

### **3.3 Sample, Sample Size and Sampling Criteria**

The researcher must emphasize that despite the fact that KZN has the most people on ART in the country, it was no easy task to find people on ART willing and eager to share their knowledge of what influences adherence with the researcher. It was challenging and frustrating at times even though the researcher networked with many people who interacted with persons on ART during her post graduate studies in HIV/AIDS Clinical Management at the University of KwaZulu-Natal in 2007 and 2008. The researcher realised that an approach that demonstrated an understanding of confidentiality and trust issues in HIV/AIDS research was most necessary for colleagues to commit to identifying potential participants who would fit the sample criteria. Patience and perseverance eventually paid off as colleagues identified and helped recruit the small sample of thirteen people.

HIV infection is still highly stigmatised and persons infected and affected can be described as a vulnerable population. Because of the stigma and discrimination associated with a HIV positive status, eligible participants recruited for this study were only those who were willing and eager to share their experiences with the researcher. The researcher anticipated difficulty in the recruitment of the sample but felt that finding a small sample would be achievable.

The sample was identified by social workers and health care professionals working in the HIV/AIDS field. Potential participants were referred to the researcher with the consent of the participants. Eligible participants recruited were persons older than twenty one years of age who have been on HAART for at least two years, and who appear to be adhering successfully to therapy. Language criteria specified the need for participants to be able to communicate with reasonable proficiency in English. A small sample of thirteen participants, were eager and willing to share their experiences for the purposes of this study. The sample was selected on the basis of their ability to contribute meaningfully to understanding the factors that



influence adherence to antiretroviral medication. This small sample size proved to be sufficient to elicit the kind of data necessary for a meaningful short dissertation.

Eight participants were female and five were male. The male participants accessed antiretroviral therapy from their workplace wellness programme and the female participants accessed treatment either using private, semi private or public health care. Three female participants accessed private health care, one semi- private health care, and four accessed public health care in the greater Durban metropolis.

### **3.4 Data Collection Method**

DeVos et al. (2005) state that interviewing is the predominant mode of data collection in qualitative research. Kwale (in De Vos et al., 2005:292) defines the qualitative interview as “attempts to understand the world from the participants point of view, to unfold the meaning of peoples experiences and to uncover their lived world prior to scientific explanations”.

The in-depth interview was the data collection method of choice for this study. This was appropriate because in-depth interviews combine structure with flexibility, is interactive in nature and allows the researcher to use a range of questions to further explore and clarify responses. In this way the researcher listens to the subjective experiences of participants and is able to gain a deeper understanding and insight into the factors that influence adherence to antiretroviral therapy (Green & Thorogood, 2004; Ritchie & Lewis, 2003).

### **3.5 Data Collection**

Interviews were conducted from August 2009 to February 2010. In-depth interviews of one to one and a half hours were conducted in English with each participant. The preferred method of data collection was tape-recording combined with detailed handwritten note taking. Regarding note taking, the researcher was particularly vigilant and careful to ensure that the written word was what the participant intended to state. The researcher would rephrase a response or repeat a question in order to ensure that the written record was the participants response to the question asked. This measure helped to verify the note-taking process. Of the thirteen interviews, one participant preferred not to be recorded and the researcher experienced tape recording problems during the workplace interview sessions

which resulted in two clear recordings, one half recording and two interviews relied only on detailed note taking.

The researcher used an interview guide. Below are the questions that were formulated to guide the process of interaction between researcher and participant:

- I would like to hear your story about being HIV positive and being on treatment. I am particularly interested in what helps you to remain on treatment.
- What was it like, how did you react on learning about being HIV positive?
- What was it like when you first started taking your medication? [detailed exploration, for example, at what point was the decision taken to take medication, what hopes, fears, concern did you experience, who was around to support you, what was the initial reactions of health personnel like towards you?]
- “What makes it harder for you to take your HIV medication regularly?” (Konkle-Parker et al., 2008) [In-depth exploration of factors identified in the key questions].
- “What makes it easier for you to take your HIV medication regularly?” Konkle-Parker et al., 2008) [in-depth exploration of factors identified in the key questions]
- What is it like now that you are on medication for quite some time?
- If there is anything else that would help you to take your medication as required what would this be?
- What do you think will help other persons on ART to take their medication as required?
- What do you think makes it difficult for people on ART to take their medication as required?

Two female participants were eager to share their stories and expressed their feelings of relief and comfort for the opportunity to talk about their experiences of living with HIV. The interview sessions appeared to be cathartic for these participants and the researcher gave these participants the opportunity to talk as it was important for the researcher to meet the needs of the participants.

The other participants were allocated time off from their work schedules but were assured by their employers that it would be alright if the interviews went on for slightly longer than expected. The researcher found that all the participants had enough time to answer the questions that was used to guide the interview. The tape recording was transcribed verbatim in preparation for analysis of data. The detailed hand written account of what transpired during the interview was also available for analysis. The process of sampling and interviewing continued until the researcher was satisfied that data saturation took place, in other words, no new insights emerged (Denzin & Lincoln, 2000; Ritchie & Lewis, 2003).

### **3.6 Data Analysis**

Data was analysed using a thematic content analysis approach. This involves analysis of the data to identify recurrent or common themes and to categorize information under identified themes that emerged from the data. Transcripts were perused on a line by line basis to identify phrases that could be assigned to categories or themes and a 'scissors and paste' method was used to place the identified themes into their categories (Dahab et al., 2008; Green & Thorogood, 2004). Phrases were colour coded to ensure that they were placed under the correct categories. Overlap of themes was expected as definitions of constructs may differ slightly according to different authors. For example, social support may be categorised under socioeconomic factors or person factors. When overlap occurred the researcher made the reader aware of where that particular theme would be discussed in order to avoid repetition. The categories or themes that emerged from the data are identified and explored in Chapter 4. The factors that emerged were compared to what was found in the literature to ascertain commonalities and differences and to see if any novel factors emerged that could be of significance to the individual, this community of participants, their health care providers and the systems that influence their health outcomes.

### **3.7 Ethical Considerations**

Social research in many instances involves an intrusion into people's lives and may depend on building a relationship of trust with the participants so that information that they might not ordinarily wish to make public is revealed under certain conditions only. Ethical responsibility is therefore essential at all stages of the research process and must be seen as an integral part of the whole process (Miller & Brewer, 2003). The sensitivity of this research

must be appreciated; therefore the researcher exercised great caution in ensuring that informed voluntary consent and confidentiality was fully discussed with each participant. Ethical clearance for this study was granted by the University of KwaZulu-Natal ethics committee.

### **3.7.1 No Harm To Participants**

It was important to ensure that the research posed no potential harm to the participants and plans for further counselling were put in place for participants to access if they felt the need for support after the interviewing process.

### **3.7.2 Informed Consent**

Informed consent ensured that the purpose of the research, potential benefits and risks, and any additional information that the participants and researcher deemed necessary was made available to each participant to enable the process of informed decision making about their participation in this study. The researcher made sure that each participant was given the opportunity to listen to her request for their participation in this study and to ask any questions that they may have concerning the research project. All participants were fully informed of the rationale behind the research and the rationale for their inclusion in the project. Participants were given an informed consent document to sign; to verify that all aspects of the research were clearly discussed with each participant. Participants were assured that they could withdraw at any stage of the process if they felt uncomfortable or experienced any doubt or discomfort.

### **3.7.3 Confidentiality**

Due to the stigma and associated discrimination often experienced by HIV positive people it was important to conceal the identities of the participants. Participant's names were therefore changed in order to protect their identities. What was meant by confidentiality was discussed with each participant and participants were made aware of the supervision process and about what would be revealed during this process. The research report was also discussed and participants were assured of their anonymity in any written documents. Pseudonyms are used in the reporting of data. The researcher worked sincerely on developing a relationship of trust with each participant so that they could feel safe enough to share their experiences with

the researcher. This relationship may have added depth to the quality of responses that the researcher elicited from the participants.

### **3.8 Issues Concerning Reliability and Validity in Qualitative Research**

Bashir, Afzal and Azeem (2008) state that reliability and validity are conceptualised as trustworthiness, rigor and quality in the qualitative approach and may be achieved by eliminating bias and increasing the researchers truthfulness of their assertions about some phenomena, by using, for example, triangulation. McMillan and Schumacher, (in Bashir, Afzal and Azeem, 2008) suggest that researchers use a combination of strategies from a list of strategies they recommend, to increase validity in the qualitative research paradigm. The list of strategies include: prolonged and persistent fieldwork; multi-method strategies; participant language verbatim accounts; low-inference descriptors; multiple researchers; mechanically coded data; participant researcher; member checking; participant review; negative or discrepant data.

The researcher used a tape recorder as well as detailed hand written notes of the interviews. During the process the participants were often asked to rephrase or clarify in order to ensure that the intended message was recorded, both mechanically and by hand. The researcher often reflected her understanding of what was said to the participants, for their input, in order to ensure that the intended message was recorded for purposes of analysis. Transcripts of interviews were done immediately after the interviews as most of what transpired during the interview was still fresh in the mind of the researcher. The recordings were listened to more than once to ensure that the verbatim transcripts were accurate and of a high quality. Verbatim recording ensured that participant's perceptions were recorded. When recording failed, the researcher would read her recording of participant responses to the participant, to ensure that the participants perceptions were correctly recorded.

The researcher also made notes on her feelings regarding the research, her interaction with the participants and anything personal that may influence her ability to commit fully to the process of interviewing or collecting data. Being self aware possibly enhanced the quality of the data captured. All these measures were put into place to increase the validity of the research.

### **3.9 Limitations of this Study**

The intention of this study was to listen to the individual's experience of their treatment and to gather rich and in-depth information about their experiences of treatment adherence rather than to generalise the findings to the larger ART population. The sampling method and small sample size means that the results of this study may not be applicable to all persons who access ART.

HIV/AIDS is still a highly stigmatised potentially life threatening disease. For this reason the researcher sought only good adherers who were willing and eager to share their stories about their treatment adherence with her. This may be limiting as barriers to adherence would emerge from the frame of reference of individuals who appear to be adhering optimally. In order to minimize possible respondent bias the researcher put extra effort into explaining the importance of honest answers to questions posed taking into consideration the seriousness of the HIV/AIDS pandemic in South Africa. Participants were made aware of the importance of their answers and of the contribution they were making to improve strategies for optimal adherence to prescribed medication. Possible research bias was minimized by ensuring that no leading questions were posed and by assessing and evaluating what went on during each interview and making the necessary changes to improve the quality of the data that emerged. This self awareness and constructive criticism of the process made the researcher feel confident that everything possible was put in place to ensure that bias was minimized. The researcher therefore felt that the research findings were valid and reliable in this setting.

The findings of this study are analysed and discussed in Chapter 4.

## Chapter 4: Results

Green and Thorogood (2004) explain that the most basic type of qualitative analysis is an analysis of the content of the data to identify the recurrent or common themes. The interview transcripts were analysed and colour coded according to the themes that emerged from the data. Green and Thorogood (2004) explain that the easiest way to do this kind of analysis is using the ‘scissors and paste’ method. The researcher preferred to colour code transcripts and then place them under identified themes or categories for analysis.

Data was tabulated in order ensure that all the information gathered was accounted for and to make analysis of the data more user friendly. The tape recorded interviews allowed the researcher to produce direct quotes as well as record data in the third person and when the researcher relied only on hand written notes then the data was recorded in the third person only. A wide range of factors that may influence adherence emerged from the responses. In certain instances main categories were better explained according to subcategories.

Participant information in presented in the tables below. The researcher refers to these tables in the discussion of results.

**Table 4A: Participant Demographics**

**Participant Information Collected from August 2009 to Jan 2010**

	Name	Gender	Age	Occupation	Marital Status	No. Children	Tx access	Year diagn	Tx start
1	Mel	female	45	Motivational speaker	single	0	public	1999	2006
2	Sharon	female	33	Personal Assistant	divorced	1	private	2007	2007
3	Joyce	female	35	Housekeeper	married	3	public	2006	2006
4	Futi	female	45	Admin worker	single	1	public	2004	2004

5	Trace	female	35	Receptionist	single	3	public	2005	2005
6	Wini	female	35	Home executive	married	2	private	2006	2007
7	Thoks	female	42	PRO	single	3	semi-private	2006	2007
8	Nosi	female	31	Receptionist	single	1	private	1999	2002
9	Kay	male	36	Artisan	married	1	workplace	2006	2006
10	Bob	male	43	Artisan	married	2	workplace	1997	2005
11	Andy	male	35	Artisan	married	2	workplace	2003	2003
12	Frank	male	55	Maintenance Worker	married	5	workplace	2004	2004
13	Kamy	male	39	Senior Artisan	married	4	workplace	2003	2003

**Table 4B: ART regimen, years on treatment, CD4 count at diagnosis and current and HIV testing information**

	Name	Years on Tx	Current Tx	CD4 diagn	CD4 Tx	Last CD4	HIV Testing
1	Mel	3	3TC+AZT+NVP	400	196	600	private doctor
2	Sharon	2	(TNF+FTC) + EFV	78	78	279	hospital
3	Joyce	3	3TC+d4T+EFV	<200	<200	>350	PMTCT
4	Futi	5	3TC+d4T+EFV	100	100	>400	staff programme
	Trace	4	3TC+d4T+EFV	98	17	>350	PMTCT



5							
6	Wini	2	3TC+AZT+EFV	400	20	300	VCT
7	Thoks	2	3TC+AZT+EFV	>200	110	>350	VCT
8	Nosi	7	(3TC+AZT)+EFV	552	265	1500	private doctor
9	Kay	3	(3TC+AZT)+EFV	<100	<100	>400	Wellness
10	Bob	4	ABC+ddI+LPV/RTV	<100	<100	897	Wellness
11	Andy	6	(3TC+AZT)+EFV	<100	<100	>400	Wellness
12	Frank	5	(3TC+AZT)+EFV	<100	<100	>400	Wellness
13	Kamy	6	ABC+ddI+LPV/RTV	133	133	>400	Wellness

#### 4.1 Social Support

All the participants reported having access to social and emotional support from family, friends or colleagues for adherence to their medication and all the participants shared that having such support contributed significantly to their adherence behaviour. The married participants expressed the value of supportive spousal relationships that encouraged adherence, especially if their spouses were HIV positive and on treatment. The single participants also benefited from close relationships with people they could trust to support them to maintain their adherence behaviours. One participant shared about the value of support groups in making her see how well people on ARVs do and that she is not alone. Two participants shared that they would like to be part a support group because sharing experiences and being with other HIV positive people is likely to be empowering. Most of the participants shared that their health care providers were very supportive, providing social as well as treatment support. Participants on the wellness programme and those who accessed private and semi-private health care were particularly expressive about the wonderfully

supportive relationship they shared with their health care providers. These findings are consistent with the literature on social support which states that the presence of stable relationships and having access to social and emotional support will positively influence adherence behaviour (Amberbir et al., 2008; Dahab et al., 2008; Heyer & Ogunbanjo, 2006; Pratt, 2003; WHO, 2003).

Below are extracted quotes and responses that demonstrate the value of social support in the lives of persons living with HIV/AIDS.

<b>Particip- pant</b>	
Mel	<i>“You don’t have to tell the world but you need to tell at least one person, everyone I know is my support, Mom Dad, friends, cousins”</i>
Sharon	<i>“I know I need support ... talking to people does help ... I can talk to my attorney friend, my human resources manager at work and my doctors, and discovery (her medical aid), has a direct line to counsellors I can talk to”. “It’s good to have a support group ... if you see me there and see how good I am doing and you can’t believe that I am HIV positive unless I tell you ... this is empowering because I will want to take my medicine just like her to look so good”.</i>
Joyce	Joyce shared that she receives wonderful support from her employers and their family; her husband, mother, daughter, a friend and she has her own counsellor who comes to visit every month. Joyce also shared that she found group counselling particularly helpful because she realised that she is not alone and she could see how well people get when they are on ARVs.
Futhi	Futhi received support from her sister and her employer.
Trace	Trace shared that she received wonderful support from the HIV counsellor at her workplace.
Wini	<i>“I have a lot of family support, that is why I don’t forget to take my treatment, when I was sick last year my mom came to stay with us, just to support me because she was worried about me”.</i> Wini felt that support from family especially the people who live with you is most important to people on ARVs. She has the support of her husband and her family, especially her mother who

	came to nurse her back to health when she took ill. She also has supportive health care providers.
Thoks	Thoks expressed that she receives lots of care and support from her family and this includes her mom, four brothers and two sisters. Her employer and the HIV counsellor at work are also very supportive. <i>“My family, my kids make me take my meds ...when it is time to take my meds ...they help me ...make a joke to make me take my meds ... say ... it’s tablet time ....if I am tired my mom will sit next to me to make me take it”</i> .
Nosi	Nosi shared that everyone she surrounds herself with is very supportive of her status. She gets lots of support from her family, health care provider and employer. <i>“You need a support system ...you can’t be on your own; you need people”</i> . <i>“Everyone who supports you gives you hope”</i> .
Kay	Kay has the support of his wife and the support of the wellness clinic staff which includes the nurses and the doctor. <i>“I can open up to him ...talk man to man ...if doctor is not there I can go and sit down and talk to her (occupational health nurse)”</i> .
Bob	Bob and his wife are HIV positive and they provide support for each other. They remind each other to take their meds.
Andy	Andy and his wife are HIV positive and they support each other. His brother and sister know his status and are supportive. He felt that it is important to be honest with family, <i>“family must know then they know how to live with me”</i> He also receives <i>“good close support”</i> from the doctor and nurses at the wellness clinic at work.
Frank	Frank and his wife are on ART and they support each other, <i>“me and wife take tablets at same time”</i> . Frank’s sister and his older children are aware of their HIV positive status and they are fine with it, <i>“wife and children told me to take it”</i> . He has the support of his family and his sister who is a nurse, and the staff at the wellness clinic at work.
Kamy	Kamy said that his wife keeps an eye on him and makes sure that he takes his pills. She will phone him to remind him to take his pills. They support each other. Kamy would like to be part of a support group for he feels he has a lot of knowledge of HIV/AIDS that he could share. He wants to help others who

are HIV positive.
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## **4.2 Socio-economic Factors**

Within the broad rubric of socio-economic factors three subthemes emerged: the impact of poverty, transport costs and lack of child care.

### **4.2.1 Poverty**

Two participants reported that some people default on treatment in order to keep their CD4 count below 200 cells/mm<sup>3</sup> in order to continue receiving the social grant for persons with a CD4 count less than 200 cells/mm<sup>3</sup>. One participant shared that she was aware of people selling their stocrin (efavirenz) because of financial constraints because they needed money for their families. Another participant explained how unemployment may lead to depression, hopelessness and non adherence. These findings are supported in the literature as Kajee (2008) states that when social grants are associated with AIDS-related indicators such as CD4 counts or viral load, then non-adherence may become an attractive option for persons who fear losing their grant because this is often the families only source of income.

### **4.2.2 Transport Cost**

One participant shared that financial constraints may impact negatively on adherence behaviour because of the cost of transport to and from a clinic. This finding is supported by Ware et al. (2006). The researchers explained that the cost of transport appears rather complex as it combines at least four factors such as long distances to and from the clinic; actual cost, such as high rates of taxi fares; payment in cash and the cost of incurring these costs indefinitely because of regular clinic visits. Kajee (2008) also found that funds to travel to and from a ART clinic may not be available for many people who need to attend clinics. Tuller, Bangsberg, Senkungu, Ware, Emenyonu and Weiser (2009) found that transportation costs forced persons into having to make serious sacrifices in other essential areas just so that they could adhere to their treatment and this may not be sustainable, leading to suboptimal adherence behaviour. Kajee (2008) further states that competing demands of many responsibilities such as work and family as well as the stresses associated with poverty and unemployment may impact negatively on adherence behaviours.

### 4.2.3 Lack of Child Care

One participant highlighted the fact that needing someone to look after your child may pose as a barrier to adherence. This finding is supported by studies such as Kajee (2008) who found that persons on treatment need to attend clinics on a regular basis for routine checkups and to collect medication. Persons on treatment may therefore need childcare support while they attend the clinic. Child care is often not easily accessible for persons on treatment or child care may not be affordable, and this may lead to persons missing clinic appointments for checkups or to collect medication. Lack of child care may therefore negatively influence adherence to ART. The El-Khatib, Ekstrom, Coovadia, Abrams, Petzold, Katzenstein, Morris and Kuhn (2011) study supports this finding as they found that providing care for children with an uncertain partner is often associated with reduced adherence and an increased need for social support.

Selected participant responses that shed light on socio-economic hardships that may impact negatively on adherence behaviour are tabulated below.

Participant	
Mel	<i>“People also don’t adhere because they get the grant ... don’t adhere so their CD4 count goes down” ... also can make money, R500 for a bottle of stocrin”. “Financial constraints can make adherence difficult because you need ‘combi’ fare and someone to look after your child”.</i>
Nosi	Nosi knows of cases where people go to collect their ARVs but then they stop taking their ARVs because they do not want to lose their social grant. Nosi expressed that eating healthy is expensive and most people can only afford potatoes and onions.
Kamy	Kamy explained that some people on ART <i>“are unemployed and they get depressed because they have no work and they feel hopeless and this makes them forget to take their tablets”.</i>

### 4.3 Health Care Provider Factors

Most of the participants shared positive experiences about their relationship with their health care providers because they received social, emotional and treatment support for adherence from their health care providers. Joyce was full of praise for the ART programme at St

Mary's hospital which included information sessions, ART readiness sessions, counselling sessions, support groups as well as counsellors who did home visits on a monthly basis. The 'personal' counsellor was always available to answer questions and to attend to any concerns regarding treatment and care during the home visits or telephonically. Thoks explained that her interaction with the public health care system at Wentworth was not good as the staff were unpleasant towards persons in need of treatment. She was not happy with the treatment she received and now attends McCords semi private hospital for her ART. She was full of praise about the healthcare at McCords which was affordable and supportive. The staff were friendly, pleasant and easy to talk to.

The public health care attendees were generally satisfied but were not very expressive about the relationship between the health care provider and HIV positive persons, except for the St Mary's attendee Joyce, and Mel who accessed treatment at Addington hospital. Mel shared that there are a few passionate doctors in the public sector as she experienced a passionate doctor when she first found out her status in hospital. Mel explained that "*the passionate doctor takes longer and shows he is concerned*". She went on to explain that it is the attitude of the health care professionals that is important, "*if I didn't have people who were receptive to me I don't know what I would have done*".

The wellness clinic attendees and the participants who accessed private and semi private health care were full of praise, and spoke very highly of the encouragement and support, and the open and trusting relationship they shared with their health care providers. Kay, a wellness programme attendee shared, "*I can open up with him, talk man- to- man with him and he has an open door policy so his patients feel that there is always someone they can talk to if they need to*". Health care providers at the wellness clinic took time to counsel attendees about anything that was troubling them regarding their treatment and their lives, "*he explains things to me ... doctor counselled me and told me that drinking is bad with HIV meds*". The doctor at the wellness clinic appeared to empathise with the persons on ART. He let the employees know that he acknowledged the difficulties associated with giving up, for example, alcohol. He took time to listen and to counsel employees accordingly and to plan a way forward with the employees so that adherence would improve. In this study most of the participants experienced healthcare workers as caring, trustworthy, open, friendly and easy

to talk to. Health care service providers were also described as good listeners who involved persons in treatment decisions. This finding was similar to the literature which states that health care providers who are sensitive to the persons needs and who develop an understanding of the persons situation were likely to facilitate adherence behaviour. The literature further states that persons who perceive their healthcare provider-person relationship as one of mutual respect and trust are more likely to be adherent because they are able to be open and honest about problems with adherence (Pratt, 2003; WHO, 2003; Williams & Friedland, 1998). A supportive person- health care provider relationship is likely to enhance adherence and the qualities of the health care worker are an important factor in facilitating adherence (Williams and Friedland, 1998; Pratt, 2003; WHO, 2003).

An area of grave concern mentioned by most of the participants was the lack of confidentiality with regard to HIV/AIDS treatment at most public clinics and hospitals. Futhi and Thoks explained how confidentiality is compromised in the public health programme because everyone knows that if you are in “that queue” then you are waiting for ART. Futhi stated that confidentiality for her is fine because she accesses her ART from the staff clinic and staff get special treatment. She will never access her ART at the clinic near her home because then everyone would know her HIV status. Bob explained that he lives in Tongaat but his wife attends the ART programme in Pietermaritzburg because if she goes to the clinic in Tongaat, then everyone will know her HIV status. Frank shared a similar experience where his wife attends the HIV/AIDS clinic in Greytown because she is afraid that everyone will know her HIV status if she accesses ART in Tongaat, and the community will treat her differently if they know her HIV status. The participants who accessed semi-private, private, and wellness programme healthcare appear to have little concern about the confidentiality of their HIV status. The wellness clinic participants were grateful for the fact that all employees attend the wellness clinic for a range of health related problems and collecting HIV medication was just one of the services offered. There was no separate queue for HIV positive persons. The wellness clinic participants were therefore full of praise for the care they received at their workplace wellness clinic.

Issues about compromising confidentiality with regard to HIV status was not abundant in the

literature. Sanjoba, Frich and Fretheim (2008) found that confidentiality at treatment centres, especially pharmacies was a concern because the pharmacy for dispensing ART was separate from the general pharmacy which made persons feel labelled by their health care facility. This is similar to what was experienced by persons collecting ART at public clinics or hospitals in Durban because of the separate queue for the collection of ART. Sanjobo et al. (2008) assert that this finding illustrates the importance of taking confidentiality and stigma issues into consideration when provision of ART is being scaled up. Stigma and HIV is explained further under 4.6.2.

Below are selected responses and quotes to give an idea of the participants experiences with regard to their health care service providers.

Participant	
Mel	<p><i>“Passionate doctor takes longer and shows he or she is concerned”. “Attitude of health care professionals ...if I didn’t have people receptive to me I don’t know what I would have done”.</i></p> <p><i>“A problem because we sign for our meds ... People are seen going there ... you are in that queue then you have AIDS”.</i></p>
Sharon	<p><i>“My doctor says you are such a beautiful girl, you can get on with your life with HIV”.</i> Sharon has a trusting and good relationship with her doctors. She can phone them at any time if she if something is bothering her. Her medical aid, Discovery also provide good service for their HIV patients; her medication is delivered to her home as an enclosed parcel so no one will know that it is HIV medication. The Discovery counsellor phones her to provide support for her with her medication and she receives literature on HIV from her medical aid.</p>
Joyce	<p>Joyce stated that when she saw so many HIV positive people at St Mary’s looking so well she realised that she is not alone ... <i>“not only me with HIV”.</i> The group counselling sessions were very supportive for Joyce because she did not feel so alone. Joyce shared that her doctors, nurses and counsellors explain everything to her very nicely and her hospital is the number one hospital to go to for ARVs.</p> <p><i>“St Mary’s ... good counselling ...you also get your own counsellor ...he</i></p>



	<i>comes once a month to visit at home...(Cowies Hill) St Mary's is number 1 hospital".</i>
Futhi	<p>Futhi is happy with the treatment she receives on the staff programme at her workplace in a public hospital (Prince Mshiyeni). She is happy not to have to access treatment in the area where she lives (Umlazi) as then her status would be made public. At her workplace everything is very discrete, <i>"ARVs from staff programme...separate at Prince Mshiyeni ...no queues ....just get from staff sister, not fair that others have to sit in queues with others staring"</i>.</p> <p>Futhi will not attend the clinic in the area where she lives because she will have to sit in the <i>"HIV queue"</i> to collect her ARVs and everyone will know her HIV status. She is happy with the treatment she receives on the staff programme at her workplace as she does not have to sit in the <i>"HIV queue"</i> to collect her ARVs.</p>
Trace	Trace received wonderful support and counselling from the hospice she was referred to when she was severely ill. She was encouraged and supported at the hospice to take ART. Since her recovery she is full of praise for the HIV counsellor and doctor at her place of work for the emotional and treatment support they provide for her. She gets her ARVs from Thembalabantu Clinic and has no complaints about the clinic.
Wini	Wini sees a HIV physician for her HIV treatment and a gynaecologist for her pregnancy. She is confident about the care she is receiving in the private health care sector.
Thoks	Thoks was not impressed with the treatment she received at Wentworth hospital. She experienced the medical personnel as unpleasant in their attitude towards the 'patients' (health-care provider relationship). Thoks is however full of praise about the treatment at McCords hospital (semi-private). Medical personnel were friendly and easy to talk to and they provide emotional and treatment support for her. Thoks explains that people are not eager to go to public hospitals for ARVs as they have to sit in the <i>"ARV queue"</i> and everyone comes to look to see who is in the HIV queue.
Nosi	Nosi spoke highly of her family doctor as he provides her with much support and encouragement and he spends time counselling her.

Kay	<p>Kay spoke very highly of the wellness clinic and explained that the wellness clinic provides very good medication for the workers. He spoke highly of the doctor, “ <i>I can open up with him ...talk man-to-man with him and he has an open door policy so his patients feel that there is always someone they can talk to if they need to</i>”. Kay felt that the wellness clinic is great because no-one knows why you have come as people go there for all kinds of treatment. Kay trusts his health-care team to keep his HIV status confidential.</p>
Bob	<p>Bob trusts that the nurses and doctors at the wellness clinic can keep his HIV status confidential. Bob explained that his doctor told him about a judge who is living for twenty years with HIV and he felt that this story gave him confidence that he too could take his medication and live a long and healthy life. Bob’s wife accesses her treatment in Pietermaritzburg as people don’t know her in that area. She is unwilling to access ART where she lives because of the “<i>ARV queue</i>” and because fellow community members will treat her differently if they know her HIV status.</p>
Andy	<p>Andy has developed a close relationship with the doctor and nursing sisters at the wellness clinic at his workplace. He further stated that “<i>doctor talks to me .... he explains things to me ...doctor counselled me and told me that drinking is bad with HIV meds</i>”. He is happy that co- workers come to the clinic for all their medical needs.</p>
Frank	<p>Frank expressed how the doctor and nurse at the wellness clinic explained to him about taking pills. His sister who is a nurse also explained. His doctor took time to explain about his drinking and how he must cut down and then eventually stop drinking because he is on ART. Frank also mentioned that the clinic is for anyone who is sick. Frank’s wife accesses treatment in Greytown because of confidentiality issues. If she accesses treatment at a clinic near her home, everyone will know her status. Frank’s sister works at the hospital in Greytown and arranged for her to go there for treatment. Frank also mentioned that the workplace clinic was for everyone.</p>
Kamy	<p>His doctor told him that if he takes his medication then everything will be fine. He listened to his doctor and everything is going well. Kamy stated that all people in need of healthcare attend the same clinic.</p>

#### 4.4 HIV Disease Related Factors

HIV disease related factors refer to those symptoms or infections that an individual may acquire or experience because of a weakening immune system response caused by HIV on the body's defence cells. Most of the participants stated that they began to feel sick, tired, feverish or weak more often than not, or they experienced weight loss, or had a rash which could not be explained. Seven of the thirteen participants were diagnosed with opportunistic infections. The list of opportunistic infections and symptoms experienced by participants are presented in Table 4.4.A. Becoming susceptible to opportunistic infections, and unexplained illness, may be indicative of HIV infection and some degree of immune function deterioration. Most of the participants discovered their HIV status when they were already immune-compromised at a CD4 cell count well below 200 cells/mm<sup>3</sup>. Refer to Table 4B for CD4 cell counts when diagnosed and current CD4 cell counts. The above is in accordance with the literature which states that HIV infection in South Africa is often diagnosed late; when the CD4 cell count is well below 200 cells/mm<sup>3</sup> and individuals with a compromised immune system are more likely to have advanced disease, present with opportunistic infections and have poorer health outcomes (AIDS2031, 2010; FHI & USAID, 2007 and Mahungu, Rodger & Johnson, 2009).

Participant responses to indicate HIV disease related factors are presented below.

Participant	
Mel	Mel started getting sick almost every week for about two months. Eventually her doctor requested an HIV test which came back positive.
Sharon	<i>"I was very sick, my chest was heavy and they knew I suffered pneumonia but they didn't know what was wrong with me"</i> , Sharon was very ill with pneumonia. She was in ICU because of the severe pneumonia (OI). In hospital she discovered that the reason for her susceptibility to pneumonia was because she had untreated HIV infection which had severely depressed her immune response to infections.
Futhi	<i>" I was very thin, was very sick ... then got TB"</i> , Futhi got very sick with TB and then found out that she had HIV (OI).
Trace	Trace shared that she was in denial of the HIV test result she received. During her pregnancy, she often got sick and her CD4 count dropped to very

	low levels. She became very ill; so ill that her mother-in-law took her to the hospice.
Wini	Even though Wini was diagnosed early, she experienced a very sudden drop in CD4 count this caused her to develop shingles (OI).
Thoks	<i>“... got so sick ...Wentworth said I must come back for my appointment in Jan ...was too sick ... went to McCords ... admitted to hospital ...put onto TB meds, ...even got crypto”</i> (cryptococcal meningitis). Thoks shared that she battled to take her ARVs when she was sick.
Nosi	Nosi had a rash and fever for some time that wouldn't get better with treatment. Nosi felt strongly that the stress she was going through made her susceptible to TB while she was on ARVs (OI).
Kay	<i>“...actually, I was sick every day, I was feeling sick and weak all the time”.</i>
Bob	Bob got very sick and had to be hospitalised. He found out his status in hospital as his illness was due to HIV infection. <i>“In 97, I was very sick ...had to go to hospital”.</i>
Andy	<i>“ish...got very sick ... with shingles ... doc explained to me ...said I must go for a HIV test ... get shingles ... worry about HIV!”</i>
Frank	<i>“started to feel sick all the time ...got thin, weak, losing too much weight, tired ... came to clinic...got tested”.</i> Frank went to a traditional healer when he first started to feel ill all the time.
Kamy	<i>“ ...was getting sick all the time ... coughing, flu, feeling hot and sweating ... worried because was getting thin, very thin ... came to see Doc”</i>

**Table 4.4A: Symptoms and opportunistic infections experienced by the participants  
Participant No. 1 to 13**

	1	2	3	4	5	6	7	8	9	10	11	12	13
<b>OI/Symptoms</b>													
Sick often, (weak, tired, fever, cough)	x	x		x	x		x	x	x	x	x	x	x
Unexplained Rash								x					
Weight loss									x	x		x	x
TB				x			x	x					
Cryptococcal Meningitis							x						
Pneumonia		x											
Shingles						x					x		

#### 4.5 Treatment Factors

These include the complexity of the regimen, duration of treatment, immediacy of beneficial effects, adverse side effects and the availability of medical care providers to deal with problems related to treatment (WHO, 2003).

The results tabulated in Table 4.5A indicate the wide range of side effects experienced by the participants. The researcher is of the opinion that a checklist approach to listing side effects may have yielded more responses to the side effects experienced. However responses elicited through an interview may indicate more realistically the felt experiences of taking the medication. All participants experienced side effects to some extent when treatment was initiated. The responses to the side effects were varied; from experiencing very little side effects for a few days or a week to really struggling with adverse side effects for a few weeks

or even months. Three participants experienced very little side effects; the side effects were hardly of any concern to them. One participant suffered from the side effects of all her prescribed medication which included ART, TB medication and medication for opportunistic infections (bactrim and fluconazole). After nine months, upon completion of her TB medication, taking medication become much easier as her pill burden reduced considerably. After some time on ART she was very concerned about lipodystrophy and so d4T was changed to AZT which she is more comfortable with. Two participants described really bad side effects initially that lasted for about a month after which taking medication was like “eating sweets every day”. The other seven experienced side effects to some extent, which may be described as moderate and very manageable. Most importantly, all the participants expressed that the side effects became tolerable as they persevered with their treatment regimens. No life threatening side effects were experienced by any participant upon initiation of therapy. One participant experienced lactic acidosis as a consequence of being on treatment for a few years; emphasizing the importance of careful and regular monitoring when taking ART.

All the participants experienced side effects, but their reaction to the side effects and how they experienced the side effects varied quite considerably. This demonstrates that people react very differently to similarly prescribed medication, indicating the importance of individual monitoring and information and education for persons on treatment. Moosa (2007) asserts that it is vital to educate persons on ART about potential adverse medication side effects and to ensure that they know what to do or who to contact if they experience such events.

Table 4.5B gives an indication of the spread of regimen factors that were of concern to the participants. Most of the participants found the regimens relatively easy to take with only one participant complaining about the pill burden, two having swallowing difficulties and two sharing that initially they found taking ART difficult. ART involves three or more tablets and if medication for opportunistic infections are indicated as well then the increased pill burden and increased side effect profile is a concern, once again emphasizing the importance of initiating treatment before the person becomes susceptible to opportunistic infections.

One participant shared that she refused treatment initially because she was in denial about being infected with HIV. She was counselled into taking ART because she became extremely ill. ART was for this participant life-saving medication considering her CD4 count of 17cells/mm<sup>3</sup> (dangerously low) and the two opportunistic infections she acquired (cryptococcal meningitis and TB).

Most of the participants (9 out of 13) were really ill or symptomatic, and presented with opportunistic infections when they first started ART. Despite the difficulties they may have experienced because of adverse side effects and pill burden, all the participants appear to be adhering optimally to their prescribed treatment.

Below are participant quotes and responses to illustrate the range of side effects and regimen factors experienced by participants in this study.

<b>Partici- pant</b>	<b>Responses</b>
Mel	<i>“I can’t say it’s awful ...Side effects irritating at times, lactate problem and severe lipodystrophy, insomnia (with stocrin), cramps and nausea (comes and goes ... doesn’t go away after two weeks) ... didn’t stop me from taking medicine but could affect them taking ARVs.</i>
Sharon	<i>“They are quite big ... and have to take all your tablets ... got stuck and I could feel it in my throat ... coughing and trying to swallow .... felt like bringing up ... didn’t feel like eating ... Thank goodness those nightmare tablets have stopped (on newer treatment regimen ... less tablets and easier to take”(difficulty swallowing). “Soon there will be only one, take at eight in the morning and eight at night”.</i>
Joyce	Joyce shared that taking ARVs is no problem at all. She shared that before she started treatment she had headaches and a rash but once she started treatment everything went away (immediacy of beneficial effects). She also said that all side effects were explained to her during the counselling (information sessions).
Futhi	Futhi experienced very little adverse side effects. Futhi stated that people often go for treatment when it is too late.

Trace	Trace shared that she initially refused treatment and then became very ill. Only then did she take treatment and she is pleased to say that her recovery can only be described as remarkable (immediacy of beneficial effects). Lipodystrophy is not a problem for her, but Trace does believe that this side effect can contribute to non-adherence (adverse side effects of ARVs).
Wini	Wini explained that she is suffering with pins and needles that does not seem go away. She does however assert that this is not a problem as she is convinced that the discomfort will subside once her pregnancy is over (medication side effect). Wini expressed that she doesn't forget anymore as something in her head reminds her at 9 o'clock and her son knows that 9o'clock is medicine time (treatment routine). Wini then went on to explain that taking the medication is not that difficult (complexity of treatment regimen).
Thoks	Thoks shared that she suffered for nine months with nausea, vomiting and stocrin made her go crazy and she had funny dreams (adverse side effects). She found it very hard to swallow the tablets as she was prescribed TB medication, ARVs bactrim and flucondazole (difficulty swallowing; pill burden). She also shared that she had to switch drugs because d4T gave her lipodystrophy (adverse side effect). The TB medication made her skin go black (adverse side effect). She was full of praise about the support she received from the doctor and the HIV counsellor at her workplace (availability of medical support for problems associated with treatment). Thoks shared that it was difficult in the beginning to take her medication as prescribed. She doesn't have a problem now and takes her medication as prescribed. She uses a cell-phone reminder and is adamant that she does not forget to take her medication. She takes her medication at six in the morning and at night (treatment routine). She is on lifelong treatment for opportunistic infections. Thoks also suffered the consequences of accessing treatment late as she succumbed to cryptococcal meningitis and TB (opportunistic infections). Thoks shared that she has personally experienced people she knows accessing treatment much too late (accessing treatment late). They are very weak when they eventually decide to take ARVs and just cannot tolerate the medication,



	so they die.
Nosi	Nosi found the side effects to be tolerable although stocrin kept her awake at night and she felt nauseous and couldn't eat when she first started treatment (adverse side effects). Nosi shared that she takes her tablets religiously at 7:30 every morning and every night but she did confess that taking tablets can be hard at times especially if your are at a bus stop or in a taxi (treatment routine).
Kay	Kay decided to seek treatment only when he started feeling sick often (accessing treatment late). Kay was badly affected by the side effects of his medication especially the stocrin. He felt like vomiting, lost his appetite, felt stressed as he had nightmares and often felt like he was seeing things (adverse side effects). All of this went on for about a month. Kay also felt very hot and had to shower to feel better. Kay explained that after a few weeks the side effects settled and now taking medication is like eating sweets every day. If he has to go out at night he takes his medication with him and he keeps medication at work as well because he is a shift worker (treatment routine, organised)
Bob	In the beginning Bob found taking medication confusing. Bob would forget to take his medication initially when he started treatment and now uses a cell phone to remind him to take his medication. He felt giddy when he initially started taking ART and explained that the giddiness lasted for about a week and then settled. He is however convinced that the medication caused him to have body shape changes (lipodystrophy) and insisted that his doctor change his medication to the next line treatment option. Bob's doctor explained that he would have liked Bob to remain on the first line for as long as possible because that is a patient's best chance of effective treatment. Regimen 2 has a much larger side effect profile and is more difficult to take and also treatment options after Regimen 2 are not readily available as yet.
Andy	Andy was diagnosed with HIV when he became very ill with shingles (opportunistic infection) and was advised to take ART almost immediately. He experienced very little side effects with his ART. He felt much better when on ART and he recovered from shingles quickly (immediacy of

	beneficial results).
Frank	<p>Frank first thought that the medication won't help. He first went to the traditional healer and only when that did not work did he go to his workplace clinic. In the beginning it was difficult for Frank to take his pills as he was drinking alcohol as well... <i>"everything comes out"</i> but things got better after a while. His doctor explained about drinking and taking medication. He also uses a cell phone reminder to take his pills on time. He has a routine; taking tablets at 6am and 7 pm and he has his wife and older children who also remind him. Frank's wife gets her medication from Greytown because Frank's sister is nurse at the hospital in Greytown even though the family live in Tongaat. Frank explained that his wife goes to Greytown because no one knows her there so she feels safe to access her ART there ... <i>"can see that people sitting in that queue are waiting for ART" ... that is what happens in public clinics and hospitals and if she goes to the clinic in Tongaat everyone will know her HIV status"</i>.</p>
Kamy	<p>Kamy experienced about three weeks of bad side effects. He experienced bad dreams and his body started shaking. His doctor had to change his tablets and since the change he is feeling much better. He said that after about three weeks <i>"things came right"</i>. He has established a routine for taking his tablets; just after his morning shower and at night after supper. He also uses the news on TV as a reminder to take his medication. He keeps extra pills in a bag just in case he forgets and is at work. He is clear that it is important to follow the procedure <i>"if you want to make your life better, follow the procedure"</i> (he means take the tablets as you are suppose to take them). He also is clear that you must be organised. He says there is nothing difficult about taking his medication. His wife will also remind him to take his medication.</p>

**Table 4.5A: ART Side Effects**

<b>ART factors</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>	<b>7</b>	<b>8</b>	<b>9</b>	<b>10</b>	<b>11</b>	<b>12</b>	<b>13</b>
nausea	x	x			x		x	x					
vomiting		x					x		x			x	
cramps	x												
headache			x										
rash			x										
skin black							x						
body shaking													x
loss of appetite		x						x	x				
pins and needles						x							
lactate problem	x												
lipodystrophy	x				x*		x			x			
fever									x				
giddy/dizzy										x			
insomnia	x							x					
Going crazy /seeing things							x		x				
nightmares							x		x				x
very little s/e		x		x							x		
s/e tolerable	x	x	x	x	x	x	x	x	x	x	x	x	x
s/e bad (initially)							x		x				x

x = indicates side effect experienced by participant

x\*= indicates that the participant has knowledge from his/her own experience about this side effect.

**Table 4.5B: Regimen factors**

Regimen factors	1	2	3	4	5	6	7	8	9	10	11	12	13
difficulty swallowing /coughing		x					x						
pill burden							x						
immediacy of beneficial effects		x	x		x				x	x	x	x	x
access Tx late		x		xy	x		x		x	xy	x	x	x
refuse Tx					z								
newer Tx easier to take		x											
ART confusing /difficult							x			x			
ART no problem	x	x	x	x	x	x	x	x	x	x	x	x	x

z = refused treatment initially

y = knows from own personal experience someone who accessed treatment too late

x = participant experienced this

ART are responsible for a broad range of side effects or toxicities ranging from low-grade intolerances that may be self-limiting to life threatening events. It is essential for ART adherence, and for the person on treatments safety, that health care providers and person's on treatment are informed and educated about the potential toxicities that may be associated with ART so that the appropriate measures are taken to alleviate or eliminate the potential harmful effects of treatment (WHO HIV/AIDS Programme, 2006). ART related side effects may occur early (within the first few weeks or months of therapy) and late (after six or more months of therapy) and these adverse events may range from mild and tolerable to severe and life-threatening (WHO HIV/AIDS Programme, 2006). Adverse ART related side effects are common and may result in discontinuation of treatment or erratic adherence. Mild to

moderate side effects are managed symptomatically and serious side effects may necessitate discontinuing the causative agent (Moosa, 2007). It must be emphasised that the benefits of ART far outweigh the risks; ART is well tolerated by the vast majority of persons in need of this life-saving treatment, and most side effects are manageable (Moosa, 2007).

All the participants in this study experienced side effects to some greater or lesser degree as well as regimen factors that made taking medication difficult. However all appear to be adhering optimally which means that all the participants are able to tolerate ART as life saving medication, a finding supported and explained by Moosa (2007).

#### 4.6 Personal Factors that may Influence Adherence

A wide range of personal factors emerged from the responses. Below are the participant responses. The responses were then sub-categorised according to themes for analysis and presented.

Participant	Responses
Mel	<p><i>“I think that intrinsically I know I have to be on this medication to get by day to day...” “I know I have to take this to be alive”. “I believe that ARVs are lifesaving medicine ... I believe your mind is stronger than that ...” (attitude and belief)...“HIV to me is like a walk in the park when I compare it to cancer”. “Have to worry about stigma when you have to fetch from the clinic in your community because the clinic sister knows my neighbour and this one and that one”.“HIV is the loneliest disease in the world. You see at Christmas how they hug and kiss you ... since I am HIV+ it is hard for them to hug and kiss me.” “Can’t get a work visa” (stigma and discrimination)</i></p> <p>Mel is completely open about her status but regrets going public about her status (disclosure). <i>“Most motivational speakers do not tell you the truth about being positive ... I will tell you ...I fall apart sometimes when I feel the hurt ... you smile ... but when you sleep in your bed alone at night there is no way that you are not feeling the pain of what people say in front and behind your back”. “You are treated like a dirty leper when you are HIV positive and to really get back your self esteem and self confidence is very difficult ... so often people become quiet and withdrawn or very angry and</i></p>

	<p>venomous”(stigma and discrimination). <i>“Make sure myths about HIV are dismissed before the process starts ...lots of myths about libido ... many things ... white person’s means of controlling you ... mustn’t let that white doctor see you, it is like a conspiracy theory because it can’t be because of the sex”</i> (denial of behaviour as a cause of HIV, myths, culture and lay beliefs about illness and treatment). <i>“Secrecy thing ... hide and have to take later then you forget”</i>. (secrecy and non-disclosure). <i>“Also trust issues, who started making this medication and selling it ... the white people”</i>. <i>“Some ‘black’ people prefer traditional medication and even if some died of HIV they will say no, it is muti”</i> (attitude and belief; knowledge and understanding; culture and traditional medicine)</p>
Sharon	<p><i>“lots of people are not telling about their status, it’s secretive, you just have to eat properly and take your medication and that’s it ... you will live, I don’t look at myself as being sick ... I just have something that I have to fight , “ living for my daughter”</i>. (secrecy and normalisation) <i>“Some people find it difficult because they can’t drink and smoke”</i>. (forgetting to take medication).<i>“Discovery sends me updated stuff to educate me ... they show you pictures of what will happen if you don’t take your medication ...look like a scarecrow”</i>. <i>“If people don’t know your status and they compliment you ... this boosts you up, it makes you feel good, I won’t stop taking my medication, I have too much to live for”</i>.</p>
Joyce	<p>Joyce is keen to keep her status private and to disclose only to a select few people. She has disclosed to her employers, a friend and her husband and daughter. She will not tell her in-laws as she says that they talk badly about HIV and ARVs (judicious disclosure). Joyce is determined to stay on her treatment because she has young children including a baby who is only two years old, <i>“want to live for my family, for my children”</i> (parenthood and responsibility). Joyce shared that she is healthy now and she is determined to stay healthy. She went on to explain that once on ARVs there are lots of rules but the rules make you take your medication. She was scared of all the rules but she realised that she needs the rules in order to take the medication properly, <i>“if it’s hard then I will destroy my life. In my mind I have to take</i></p>

	<p>...” (self-efficacy). Joyce shared that she knows of lots of people who are scared to let their employers know as they fear they will be fired (secrecy, fear of disclosure, hiding to take medication may negatively affect adherence)</p>
Futhi	<p>Futhi believes that alcohol and drug use may cause some people on ARVs to forget to take their medication (forgetting). She has witnessed this first hand with the father of her child. He is educated, a teacher but he drinks and forgets to take his medication and is often sick. Futhi also shared that to her knowledge some people still don’t believe that ARVs work and they prefer to take traditional medicine. She uses a cell phone reminder but says that taking the medication is a habit and she just can’t forget (treatment routine). Futhi emphasised that her son is her motivating factor as she must live for him to look after him and she wants to see her grandchildren (motivating factors, parenthood and responsibility).When questioned about stigma, Futhi shared that stigma attached to being HIV positive is not as bad as before as she has disclosed to close friends and family and they didn’t “isolate” her (stigma). Futhi explained that HIV is just like TB, or sugar diabetes (normalisation).</p>
Trace	<p>Trace felt strongly that her faith in God helped her cope with her illness; she is sure that God spoke to her (spirituality and religion).Trace believes in ARVs (attitude and beliefs about treatment), and she concurred that stigma is not so bad now (stigma).</p>
Wini	<p>Wini described having HIV as just like a normal sickness like heart disease or sugar diabetes (normalisation). Wini explained that she used to forget but her husband would remind her to take her medication (forgetting). This lady explained that drinking, smoking and a hectic lifestyle will not help adherence to medication. She felt strongly that plain irresponsibility was also a reason for non-adherence (responsibility).</p>
Thoks	<p>Thoks believes strongly that faith and God helped her to cope with HIV infection. She prays for God’s help with the medication (spirituality, religion, self efficacy). Thoks shared that she wants to live for her children; she needs to be there for them and her children are her motivation (parenthood and responsibility, motivation). Thoks went on to emphasise that being HIV</p>

	<p>positive is really not the end of the world. She stated that it is important to be strong and to have faith in the ARVs (attitude and belief). She also stressed that education about HIV infection is very important (knowledge and understanding). Thoks believes strongly that denial about HIV infection will prevent people from accessing treatment for HIV infection (denial; disbelief in diagnosis). Thoks is aware that traditional medicine is the preferred medication for some people in need of ARVs or people mix their ARVs with traditional medication (culture and traditional medicine).</p>
Nosi	<p>Nosi is completely open about her HIV status; she told everyone at work because rather than have them talk behind her back. She wanted her HIV status to be out in the open (disclosure). Nosi revealed that when she found out her HIV status she went to her pastor and they fasted and prayed and this gave her the strength to deal with being HIV positive (religion and spirituality). Nosi also explained that she was terrified about how she was going to take medication for the rest of her life but the fear of dying; just the thought of dying was enough to make her take her medication (fear of dying). Nosi went onto share that it is “<i>your attitude</i>” that gives you strength to deal with HIV and she learnt that ARVs will keep her alive and well (attitude and belief). Nosi said that some people take their medication when they are ill and then stop when they feel better. Nosi explained about how she developed TB while on ARVs. She felt that a lot of stress in her life and not being able to eat made her susceptible to TB even though she was taking her ARVs. Nosi felt strongly that denial was big in her community; people just deny that they may have HIV (denial). Nosi also felt that pressure from friends who live like there is no tomorrow may negatively impact on adherence behaviour (peer pressure). Nosi also felt that education is important and she accesses lots of information from her doctor so that she gains knowledge about HIV infection (knowledge and understanding).</p>
Kay	<p>Kay was initially shocked to learn that he was HIV positive. Kay has accepted his status and views his medical condition as a normal part of his life that he has to deal with. He believes he must be positive and that he mustn’t be scared and that he must face this disease. He stated that one must</p>



	<p>be aware of one's status, take medication and live a healthy lifestyle; Kay exercises (plays golf), and he does not smoke or drink (attitude, belief and healthy lifestyle). Kay firmly believes that education and sport are important for living healthily with HIV. Kay has also realised the importance of accessing treatment early, not waiting to get sick and stated that if people come early for treatment they will be helping themselves. Kay does not believe in traditional medicine and only seeks medical advice from his doctor. He is religious and his father is a pastor. He believes that prayer does help one to cope with living with HIV. Kay has only disclosed to his wife and will not let his parents know of his status. He believes that one has to be careful about who one discloses to as he often hears people say "not nice things" about those who are HIV positive.</p>
Andy	<p>Andy stated that his doctor explained three very important things to him – no drinking, sex with condom and taking medication on time. Andy believes in healthy living and having a good night's sleep. He tries to get eight hours of sleep each night; he eats healthily and exercises (his work is physical and he does lots of walking and housework). He believes that if he does what he is expected to do then he will live long. He stated "<i>you have to be organised ...sleeping times can change ...then have to change my meds times ... just have to remember</i>". He sets his alarm (cell phone alarm) as a reminder to take medication. Andy stated that some people feel that it is better not to know your status than to know your status (fear of stigma and discrimination).</p>
Bob	<p>Bob has confidence in ART. He also stated that he has self-belief and went on to state "<i>I believe that I will live to 100 years if I take my medication on time, eat healthy and condomise</i>". He went on to state that he believes in the health care he receives and he is responsible for his own life. He is the boss of his life. Bob clearly believes that ART decreases his viral load and will "extend his time of living". He is stated that "<i>if I'm living the virus is living and if I am dead the virus is dead, I am the boss, Take medication and kill the virus</i>". Bob also believes that he must read and gain more knowledge and understanding, "<i>must know the rules and follow the rules to kill the virus</i>".</p>

	<p>He believes in traditional medication, but not for HIV/AIDS. Bob shared that ART has helped him regain his health and strength. He believes that if he takes his medication he will <i>“come right”</i>. He believes that he must listen to his doctor, take his medication and live healthy as he needs to live for his girls and his wife. Bob and his wife believe that their HIV status is a private matter. He stated that even the church did not talk much about HIV except to tell young people to be careful about getting infected. Bob shared that some people did not believe that ART works. These people believe that traditional medication can cure HIV. Bob felt strongly that the government must stop these rumours.</p>
Frank	<p>Frank first went to a traditional healer with his symptoms and only accessed ART when traditional medicine did not help him (culture and traditional medicine). Frank knows from his own experience that taking alcohol with his ART is not the correct thing to do. Frank says that he must be healthy and strong for his job. His job is very physical so he is exercising while working. He gave up drinking and smoking to be healthy. He believes that sometimes people don't understand about the pills that is why they don't take them. <i>“must teach them to take their pills”</i> ... <i>“just take pills and you will get better”</i> (demonstrates his belief in his medication and importance of knowledge and understanding).</p>
Kamy	<p>Kamy was shocked to hear of his HIV status ... as he thought his life was finished because he had HIV. Kamy runs, exercises and eats healthy ...no smoking or drinking ... <i>“My life is my life ...and I must listen to my doctor ... doctor says it's up to you to take the treatment right, I do what the doctor tells me ....even now</i> (meaning after being on ART for so long) <i>No problem”</i>, (no problem taking medication). Kamy is even interested in additional supplements that can make him healthier, and he is willing to buy these supplements himself. He shared that alcohol and smoking will make you forget to take your medication and said <i>“tobacco is not good on the blood”</i>. Kamy stated that being HIV positive and taking medication should be treated just like other any other chronic condition for example diabetes, <i>“forget you are HIV ...think positive ...just like any other sickness ....like sugar diabetes”</i></p>

	(wants HIV to be treated just like any other chronic disease, normalisation of HIV/AIDS). Kamy stated that <i>“I know I have to take my medication ... nothing can stop me ...treatment make my life perform ... I work better”</i> . He is interested in a support group because he feels that sharing his story may help others. Kamy does not believe in traditional medication. He believes in ART. Kamy is willing to share his knowledge and experience of taking ART with other HIV positive people. He knows that the treatment works and he can explain this to others. Kamy explained what happens if one forgets to take ARVs and he understands how important taking his medication as prescribed is (attitude, belief, knowledge and understanding).
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## Result Analysis

Below is the discussion relating to the themes extracted from the data.

### 4.6.1 Positive Attitude and Strong Beliefs about the value of ART

All participants in this study believed in the value of ART as life-saving medication. All the participants in this study were determined to adhere optimally because they believed in their treatment and because they wanted to stay strong, healthy and alive. These findings were supported in the literature as adherence is likely to be enhanced in people who strongly believe in the efficacy of HAART (WHO, 2003). Key facilitators in the Dahab et al. (2008) study include amongst others a strong belief in the value of treatment which is in accordance with the findings of this study.

Below are a few quotes and responses that were selected to give an idea of the participant’s attitudes and beliefs to ART.

Mel	<i>“I think that intrinsically I know I have to be on this medication to get by day to day, I believe that ARVs are lifesaving”</i> .
Sharon	<i>“ I won’t stop taking my medication; I have too much to live for”</i> .
Bob	<i>“I am the boss; take the medication to kill the virus”</i> .
Kamy	<i>“I know I have to take my medication ... nothing can stop me, my treatment make my life perform, I work better”</i> .
Thoks	They believe it is important to be strong and have faith in ART.

and Frank	
Nosi	She shared that it is your attitude to HIV/AIDS that gives you strength and it is your belief in ART that makes you keep taking your medication.
Kay	He believes he has a positive attitude that allows him to face this disease and he is not afraid of fighting this disease.

#### 4.6.2 Stigma, Secrecy, Discrimination, Disclosure and Denial

Only one participant, Mel was completely open about her status. The other participants except for Sharon, disclosed their status albeit discretely, only to close family, or to close family and friends. Sharon was adamant that her close family not know her status. She disclosed to a work colleague and a close friend she could trust. Mills, Nachega, Buchan et al. (2006) and Naidoo (2009) found that individuals who disclosed their HIV status to close family or friends are more likely to be adherent than those who had not disclosed. Gilbert and Walker (2009) found that disclosure was the biggest challenge in getting persons to adhere to their prescribed treatment. All the participants disclosed to at least one or more persons, therefore disclosure is likely to influence adherence behaviour positively. Most of the participants felt that when people have to hide and take their medication then they may not always be in a position to take their medication as prescribed. This finding was supported by the Dahab et al.'s (2008) study which found that both health care providers and persons on treatment reported that fear of stigmatisation caused persons who had not disclosed their HIV status to hide their HAART or skip doses when in the presence of others. Inungu and Karl (2006) assert that stigma is of utmost concern because it is both the cause and effect of secrecy and denial. Secrecy and denial cause people with symptoms of HIV infection to claim that they suffer from less stigmatised diseases such as cancer, thus preventing them from accessing life saving ART (Inungu & Karl, 2006). Two participants felt that the stigma associated with HIV was not as bad as before.

Participant responses and quotes about their experiences with regard to stigma, secrecy, discrimination, disclosure and denial.

Mel	She is open about her status but shared that if you “ <i>hide and have to take medicine later, then you forget</i> ”. She also shared that some people are in “ <i>denial of behaviour that can cause HIV</i> ”.
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Joyce	She explained that some people feared being fired if they disclose their status to their employers and hiding and secrecy can lead to problems with taking medication.
Sharon	She said, <i>“lots of people are not telling about their status ... it’s secretive”</i> . (Sharon has only disclosed to a select few; her human resources manager and lawyer friend).
Joyce, Futhi, Trace and Nosi	These participants disclosed to a few select people; their immediate family, employers and a friend. Futhi stated that she was not <i>“isolated”</i> when she disclosed her status and she stated that <i>“stigma about HIV is not that bad anymore; not like before”</i> . Thoks and Nosi stated that they were aware that denial about HIV infection will prevent people from accessing ART and Nosi added that denial is big in her community.
Trace	She stated that when she disclosed her status she realised that the stigma around HIV is not so bad now.
Frank	He is aware that <i>“some people just don’t believe they have HIV ...give them pills and they don’t take it”</i> (denial).
Kay and Bob	They shared that you must be careful who you disclose to and they only disclosed to their wives.
Andy	He shared that some people felt that they would rather not know their status because if you know then you have to deal with it (denial).

#### 4.6.3 Education and Knowledge about HIV/AIDS

Five of the participants stressed that knowledge and understanding was important for medication adherence. One participant shared from his own experience that some people may be non- adherent because they do not understand the importance of taking ART as prescribed. This finding was supported by Vervoort et al. (2008). According to Vervoort et al. (2008) people on treatment should receive information about their medication that is appropriate to their level of understanding because, in this way, individuals receive information that will guide them toward behaviours that will enhance adherence.

Participant quotes and responses with regard to knowledge and education about HIV/AIDS are tabled below.

Thoks, Nosi, Kay, Bob, Frank and Kamy	These participants stated that knowledge and understanding is important for taking medication properly.
Frank	He shared that “ <i>sometimes people don’t understand about the pills, that is why they don’t take them ...must teach them to take their pills</i> ”, emphasising the importance of knowledge and understanding of prescribed ART for adherence.

#### 4.6.4 Traditional Medicine

Three participants stated that they were aware of people in need of ART who may not access ART but opt for traditional medicine only. One participant was aware of people mixing traditional medicine and ART. One participant made it clear that he believed in traditional medicine but not for HIV/AIDS, and one participant accessed ART as a last option after realising that traditional medicine did not help his HIV infection. All participants in this study were careful about not using traditional medicine with ART because of the information, knowledge and counselling they received about taking ART.

The fact that participants reported knowing that some people still prefer traditional medicine for treating HIV infection was disconcerting because people with those beliefs are being denied life-saving medication. As reported, people who mix traditional medicine with ART, and people who stop ART while they are taking traditional medicine risk suboptimal levels of ART which has serious implications ( Aspeling and van Wyk, 2008; Dahab et al., 2008).

Below are participant quotes and responses with regard to traditional medicine and ART.

Mel, Futhi and Thoks	These participants stated that “ <i>some people prefer traditional medicine to western medicine</i> ” and Thoks added that some people “ <i>mix traditional medicine with ART</i> ”.
Bob	Bob believes in traditional medicine but not for HIV/AIDS. He shared that some people did not believe that ARVs work and he felt strongly that the government must stop such rumours.
Frank	He went to a traditional healer first and only when this did not work did he access ARVs.

#### 4.6.5 Normalisation of HIV/AIDS

Most of the participants shared that they have accepted HIV/AIDS just like any other illness or disease that is affecting people in the world today. Most of the participants expressed that they do not see themselves as different; they have an illness, just like any other chronic illness and they can live a normal life if they take their medication as prescribed. This finding was supported by Gilbert and Walker (2009) who found that a process of normalisation was taking place regarding HIV/AIDS being viewed as a chronic condition such as diabetes or hypertension. Even though most of the participants expressed that they accepted HIV disease, just like any other chronic condition they were not open about being HIV positive, only disclosing their status to close family or friends whom they could trust.

Cameron (2005) asserts that talking about HIV/AIDS and accepting HIV as just a virus; just a disease may help with the realisation that there is nothing shameful about having HIV or AIDS. If people can talk about it, then they can normalise it and the sooner HIV is seen as a normal disease, the sooner people will be able to deal with it unemotionally, effectively and efficaciously (Cameron, 2005). According to Gilbert and Walker (2009) if the process of normalisation continues and gathers momentum it has the potential to reduce the stigma associated with HIV/AIDS and its negative effects. Castro and Farmer, (in Gilbert and Walker, 2009) state that access to ART triggers a ‘virtuous social cycle’ by alleviating the visible signs of HIV disease, facilitating a return to a normal productive social life (Mahajan et al., in Gilbert and Walker, 2009), thus further normalising the experience of living with HIV/AIDS.

Below are some participant responses that shed light on normalisation of HIV/AIDS.

Mel	<i>“I don’t look at myself as being sick ... I just have something to fight”.</i>
Futhi, Wini and Kamy	They explained that HIV is just like TB or sugar diabetes, <i>“forget you are HIV positive ...you are sick just like other sicknesses, like sugar diabetes ....no one can see that you are HIV positive ... just keep healthy”.</i>
Thoks	She said <i>“HIV is not the end of the world”.</i>
Kay	He accepts HIV as a normal part of his life.
Sharon	Sharon shared <i>“you have it, admit you have it ...eat healthy, take meds and live a normal life ... I don’t look at myself as being sick, I just have something</i>

	<i>that I have to fight”.</i>
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#### 4.6.6 Motivating Factors – Parenthood and Responsibility

Most of the participants with young children and families shared that their motivation for adhering and staying healthy was because of their responsibility as a parent, a provider and a spouse. These participants spoke passionately about their responsibilities and they were determined to stay healthy. This finding was supported by Aspeling and van Wyk (2008) who found that the responsibility of parenthood and the desire to raise one’s own children were huge motivating factors for optimal adherence to ART. Gilbert and Walker (2009) found that children were a strong motivating factor for adherence and Kajee (2008) stated that for many persons, concern for the well-being of their children brought into focus the need for good adherence in order to remain healthy and thus continue caring for their families, which is in accordance with the findings of this study.

Participant responses about parenthood and the responsibility that goes with this role.

Sharon	Her main concern and reason for living is her child, <i>“living for my young daughter, my child”.</i>
Joyce	She is determined to stay healthy because she has young children, including a baby.
Futhi	She shared that her son and living to see her grandchildren is what keeps her taking her medication. She wants to be around when her son gives her grandchildren.
Thoks, Bob	She lives for her children and her children are her motivation. Bob shared that his wife and children motivate him and he needs to live for them.

#### 4.6.7 Lifestyle Factors

Most of the participants were intent on a healthy lifestyle because they felt that eating healthily, exercising and making choices to be organised and responsible helped with adherence. Most of the participants lived a quiet life with their families and one participant mentioned that staying in one place makes it much easier to take ones medication as compared to moving around a lot.



Three participants stated that alcohol and drugs may lead to forgetting to take medication. This finding was supported in the literature by Frank and Duncan (2009) who reported that alcohol and drug abuse may affect a person’s ability to remember to take their medication. Pratt (2003) stated that difficulties with adherence may be associated with the chaotic lifestyle of people who abuse alcohol or drugs. Wini’s statement about a hectic lifestyle alludes to this.

One participant reported that stress made her vulnerable to opportunistic infections and she was adamant that she was not non-adherent. This finding was not in accordance with the literature which states that untreated stress and depression are strong predictors of non-adherence, which may then render a person susceptible to opportunistic infections.

Participant responses with regard to Life Style factors tabled according to themes.

<p><b>Healthy Living, Be organised</b></p>	<p>Kay, Andy, Frank and Kamy shared that they try to live a healthy lifestyle; they exercise, eat healthily and they do not indulge in alcohol or smoking. Frank gave up alcohol and smoking to be healthy. This helps them to adhere to their medication. Kay, Andy and Kamy shared that it is important to be organised when you have to take ART, “<i>you have to be organised...sleeping times can change... then you have to change medication times ...you just have to remember</i>”. Mel and Bob felt that people who struggle with routine may not be adherent. Mel, Thoks and Nosi shared that taking ART is habit and this helps them to adhere.</p>
<p><b>Responsible Living</b></p>	<p>Wini felt that plain irresponsible behaviour and living a hectic lifestyle will cause problems with adherence, and people on ART must be responsible. Nosi shared that living like there is no tomorrow will impact negatively on adherence. Frank and his family live a quiet life. After work Frank goes home to his family. Frank occasionally takes his family to their farm on weekends, “<i>no partying ... only work and family and church</i>”. Kamy shared that it is better to stay in one place as it makes it easier to take tablets.</p>
<p><b>Alcohol and</b></p>	<p>Futhi and Wini shared that alcohol use and/or abuse may cause some</p>

<b>Drug Use /Abuse</b>	people to forget to take their ARVs. Futhi, Wini and Kay shared that taking alcohol may cause adherence problems because you then forget to take your medication.
<b>Stress:</b>	Nosi felt that stress in her life made her susceptible to TB while she was on ART.

#### 4.6.8 Religion and Spirituality

For three of the participants God was a very important part of coping with HIV/AIDS and adherence. Their religious beliefs were strong and they were very expressive about how God helped them to cope with living with HIV infection. This finding was supported by Konkle-Parker et al. (2008) and Sanjobo et al. (2008) as these studies found that prayer and spirituality were important factors that facilitated adherence to ART.

#### Participant responses about Religion and Spirituality

Trace	She felt strongly that God spoke to her when she was very ill and this helped her to come to terms with her HIV status.
Trace, Thoks and Nosi	They firmly believe that prayer and their faith in God helps them to cope with living with HIV/AIDS and to take their medication as prescribed.
Nosi	Nosi added that prayer and fasting gave her the strength to cope with HIV/AIDS.

#### 4.6.9 Forgetfulness

All the participants shared that at some point in their lives they may have forgotten to take their medication. This finding is supported in the literature and is the most commonly cited reason for non-adherence (Amberbir et al., 2008; Naidoo, 2009; Tuldrà & Wu, 2002; WHO, 2003). Tuldrà and Wu (2002) state that persons on ART may really benefit from the use of adherence reminders.

It must be stated that all the participants shared that they knew exactly what they must do if they forgot to take their ART because they understood the consequences of forgetting. Responses such as taking the medication as soon as they remembered, to the use of adherence

aids to minimise forgetting were mentioned. Table 4.6.9A below illustrates the findings of this study regarding adherence aids. Most of the participants made use of adherence aids so that they would not forget thus enhancing their ability to adhere as prescribed.

Below are participant responses and quotes about their experiences of Forgetfulness.

Wini , Thoks, Andy, Frank and Kamy	Wini and Thoks explained that initially they use to forget, but not anymore. Wini shared that something in her head reminds her at 9 o'clock and her husband and son know that 9 o'clock is medicine time (treatment routine). Andy, Frank and Kamy stated that they use to forget but not anymore as they are committed to taking ART and not forgetting. Kamy also said <i>"if I forget ...just take ...just open my bag and take my pills"</i> .
Mel and Bob	Mel shared that from her experience, people who struggled with routine might forget to take their meds. Bob struggled with routine initially and this made him forget to take his meds, but not anymore.
Nosi ,Sharon and Mel	Nosi and Mel said, <i>"I just know I must take my ARVs ... if I forget ... then I take it as soon as I remember ....can't skip medication"</i> . Sharon shared that she used a pocket alarm clock and her mom and daughter would remind her about her medication when she came out of hospital (they did not know that she was on ARVs).
Joyce	<i>Joyce said ... if you forget just take as soon as you remember and try to make sure you don't forget again"</i> .

**Table 4.6.9A: Adherence Aids (Tools) used by participants**

Numbers 1-13 represent the participants in this study

	1	2	3	4	5	6	7	8	9	10	11	12	13
Cell phone reminder	x						x			x		x	
Pocket alarm		x											
TV reminder													x
Family reminders		x				x						x	x
Tx routine	x	x	x	x	x	x	x	x	x	x	x	x	x

Table 4.6.9A displays the range of adherence tools used by participants to help them remember to take their medication as prescribed. Amberbir et al. (2008) found that persons who claimed to use memory aids were three times more likely to be adherent than those who did not. The Amberbir et al. (2008) study showed that adherence interventions should include memory aids and other reminders to help persons take their medication. All the participants had a routine that positively influenced their ability to adhere. Most of the participants used some strategy or aid to help them to remember to take their medication and this is likely to maintain and enhance their positive adherence behaviour.

#### 4.6.10 Self-Efficacy

Bob’s “ self-belief” and being in charge of his own life; Kamy’s statement about following the procedure to make life better; Mel’s intrinsic belief and Nosi’s strength all allude to the confidence most of the participants have regarding fighting this disease with all that is available to them. This finding was in accordance with Heyer and Ogunbanjo’s (2006) explanation of self-efficacy as a person’s belief in his or her ability to take their medication as prescribed; an attitude positively associated with medication adherence.

Below are the participant responses that allude to Self Efficacy.

Bob	Bob shared that he has “ <i>self-belief</i> ” that he will live to 100 because he takes his medication as is required. Bob also said, “ <i>I am in charge of my life ...I am the boss of my own life</i> ”. Kamy said, “ <i>...if you want to make your life better follow the procedure</i> ”. Nosi “ <i>I have accepted it, it’s part of my life now ... I take it as part of my life now ...I believe I am the strongest person</i> ”.
Mel	Mel shared “ <i>I don’t have any factors that will prevent me from taking my medication</i> ”...” <i>you have got to have that intrinsic thing ... I need to take this medication every day for the rest of my life because I want to live ... you have got to own your illness</i> ”.
Joyce	Joyce said ... “ <i>very easy ... I know it is my life ... if its hard then I will destroy my life ... in my mind I have to take...</i> ”

#### **4.6.11 Health Improvement: Ambiguous**

One participant stated that some people on ART take their treatment only when they are very ill and then stop taking treatment when they feel well. This finding was supported by Kip, Ehlers and Van der Wal, (2009); Mills, Nachega, Bangsberg et al., (2006) and Sanjobo et al. (2008) who found that improved health could be a barrier as well as a facilitator to adherence. This study reported that some persons stopped taking their medication when they felt better while other persons were motivated to continue taking their medication when they experienced the benefits of treatment. This finding indicates that the stage of treatment when persons start to feel better may be a critical turning point for interventions to maintain optimal adherence behaviour (Sanjobo et al., 2008). This reflects the need for ongoing counselling and education throughout the different periods to better understand the challenges of lifelong treatment so that the necessary strategies may be introduced to ensure the maintenance of optimal adherence behaviour.

One participant shared that fear of dying was enough to make her take her medication because she wanted to live. This finding is supported by the Gilbert and Walker (2009) study which showed that adherence to ARVs represent survival, health, and a future and non-adherence meant death.

The major conclusions and recommendations are reported in Chapter 5.

## **Chapter 5: Major Conclusions and Recommendations**

### **5.1 Major Conclusions**

“AIDS is above all a remediable adversity. Our living and our life forces are stronger, our capacity for wholeness as humans is larger, than the individual effects on the virus. Africa seeks healing. That healing lies within the power of our own actions. In inviting us to deal with the losses it has already inflicted, and, more importantly, in enjoining us to avoid future losses that our own capacity to action make unnecessary, AIDS beckons us to the fullness and power of our own humanity. It is not an invitation that we should avoid or refuse” (Cameron, 2005 p215).

This qualitative study was designed to explore the factors that influence adherence to HAART. In-depth interviews conducted with thirteen participants as reflected in the analysis of data offered a rich description of the many factors that influence adherence. The results of this study supported prior research findings with regards to the factors that influence adherence. The value of this study is that it may contribute to a deeper understanding of the complexities associated with lifelong adherence to HAART as well as inform strategies that may improve adherence behaviour. The major conclusions based on the major findings are summarised in this chapter and appropriate recommendations are suggested.

Social support emerged a great motivator of adherence behaviour amongst all the participants. All the participants emphasised the value of close family, friends, colleagues or just someone, as instrumental in enhancing their adherence behaviour. All the participants felt strongly about social support as a factor that positively contributes to adherence.

Health care provider factors appear particularly significant because most of the participants shared their opinions about their interactions with their health care providers in great detail. All the workplace programme attendees were full of praise about the kind of care they received at their wellness clinic. They felt privileged to be part of a programme where all people in need of healthcare attended the same facility. No separate queue or clinic for persons in need of HIV antiretroviral therapy. All employees in need of health services attended the same wellness clinic and saw the doctors or nurses regarding their health

concerns. Issues concerning confidentiality about their HIV status was not a concern. The wellness programme attendees were aware of the high standard of care that was made available to them by their employer. They were full of praise for the caring and supportive health care providers they interacted with. This is an important finding that contrasts starkly with the South African public sector HIV programme where people have to attend the HIV clinic or stand in the HIV queue if in need of ART. Issues about confidentiality in the public sector were a real concern for some of the participants because this was the reason why their spouses travelled long distances to access ART. Because of the stigma and discrimination still associated with HIV and having to deal with the additional stress of the HIV clinic may keep many HIV positive people from accessing treatment.

Most of the participants accepted HIV disease as a chronic condition such as hypertension or diabetes. Most participants were not ready to be completely open about their HIV status and only disclosed a few trusted family and/or friends. They alluded to normalisation of HIV because this helped them to accept their status and to cope with HIV disease.

Regarding confidentiality, the “Patient Rights Charter” documents the rights and responsibilities of health care users and health care providers. The charter states that all health care users have the right to be treated by a named health care worker; the right to confidentiality and privacy; the right to a second opinion and the right to refuse treatment. Lack of confidentiality emerged as a grave concern to participants and spouses who accessed ART in the public sector and none of the participants appeared to be aware of the fact that their health care rights were being violated.

An interesting finding with regard to the employee wellness clinic was that even though this user friendly facility was in place with very understanding and supportive staff on hand to attend to the health needs of the employees, all the workplace attendees reported accessing treatment only when they experienced symptoms that were impacting on their daily functioning or when they presented with an opportunistic infection.

With regard to socio-economic factors, although only a few participants reported their experiences of how they think poverty, transport, and child care costs may affect adherence

behaviour their input brings into awareness the daily challenges that South Africans endure and the effect these circumstances may have on adherence behaviour. For optimal adherence to become achievable the underlying socio-economic factors that impact so heavily on the lives of the poor must be addressed.

A wide range of side effects were reported by the participants but how the participants experienced side effects were varied and different. Some participants reported that side effects were hardly a concern, others experienced some side effects when they started treatment that were manageable while a small number experienced very bad side effects initially. However, the side effects were generally well tolerated by all the participants in this study and side effects did not appear to be high on the list of factors that negatively influenced adherence because in most cases the side effects were short lived and manageable, or the desire to live outweighed any negative influences. In other words the value placed on treatment far outweighed any discomfort they may have experienced and persons on treatment found ways to ensure optimal adherence.

Personal factors were many and varied which once again emphasised the importance of the subjective influences of the individual in assessing how these factors may influence adherence. The responsibility that goes with being a parent, provider and spouse and caring for one's family was a strong motivating factor for ART adherence. Lifestyle factors were also reported as very important facilitators of adherence and all the participants appeared to be particular about their lifestyle choices. All lived relatively quiet lives; they ate healthily, exercised, were organised and responsible, and avoided alcohol. All the participants in this study believed in the value of ART as life saving medication, therefore this factor also came out positively as a motivator for adherence behaviour.

The personal experiences of how people cope or are affected by these factors differed considerably, even amongst a small sample of people. This highlights the importance of listening to the unique experiences of people and the value of working with small groups of people in order to find out about their experiences of the challenges they may encounter so that strategies can be tailored to meet their particular needs. The value of this study appears to be in the subjective experiences of the individual in a particular group of people and to



demonstrate the importance of the individual in a group when trying to understand the factors that influence adherence to ART and in tailoring interventions to support lifelong medication adherence.

## **5.2 Recommendations**

The Health Minister, Dr Aaron Motsoaledi revealed in his May 2011 budget speech the four pandemics the country is burdened with. The HIV/AIDS and TB pandemic is by far the most severe, and costly, of the four. The other three are; unacceptable high maternal and child mortality (which is linked to HIV/AIDS), increasing incidence of non-communicable diseases and the pandemic of violence and injury.

HIV/AIDS and TB is the greatest public health challenge facing SA. It is therefore important for South Africans to lend support to civil society organisations such as the Treatment Action Campaign (TAC), Section 27, Médecins Sans Frontières / Doctors without borders (MSF) in their call for the South African government to commit to certain targets in the fight against HIV/AIDS and TB. The above mentioned groups have asked the South African government to commit to:

- Place a minimum of 3 million people on ART by 2015;
- Ensure that at least 80% of public sector health facilities provide integrated HIV/AIDS and TB services;
- Immediately and fully implement WHO treatment guidelines for ART initiation at CD4 count of 350;
- Put in place a policy framework that will enable SA to increase access to affordable effective medicine; and
- Actively support innovative financing mechanisms on both a national and international scale that provide robust funding for HIV/AIDS and other health programmes

HIV/AIDS has been described as an absolute public health emergency which means decisive action should be prioritized in order to reverse the epidemic. But HIV/AIDS is also not a disease that we are comfortable to talk about. Judge Edwin Cameron speaks about the inexpressible relief he felt when he finally broke his silence on being HIV positive. His act

of speaking out made him realise the simple truth, “There is nothing shameful about having HIV or AIDS. If we can talk about it, we normalise it. And the sooner we will be able to deal with it unemotionally and effectively. Normally” (Cameron, 2005:63). Normalising HIV/AIDS as just a disease, like any other chronic disease may be the key to ending the stigma, denial and shame associated with HIV/AIDS. If people can talk freely about HIV disease then they may be encouraged and empowered to deal with the disease more proactively, efficaciously and effectively. Further research with regard to normalisation of HIV/AIDS is highly recommended as this may lead to a better understanding of how this factor influences adherence as well as other aspects of HIV/AIDS.

Many HIV positive people are accessing ART both privately and in the public health sector. Health care providers and health care users must be educated about their rights and responsibilities as documented in the “Patient Rights Charter”. It is equally important that health care users know when their health care rights have been breached and about the action that should be taken if they find themselves in such a situation (TAC. Equal. Issue 35, September 2010).

Studies to explore the link between HIV medication non adherence and the social grant must be encouraged because the consequences of such behaviour has serious implications for the person on treatment as well as ART programmes. South Africa is one of the most unequal societies in the world and the impact of a person’s socioeconomic circumstances on their daily lives may influence their ability to adhere as prescribed.

As persons live longer because of ART ongoing research will be necessary to explore the effects of treatment over time, the effects of treatment at different life stages, as well as the ability to sustain high levels of adherence behaviour over long periods of time.

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## **Appendix 1**

**New HIV Antiretroviral Treatment Guidelines released on the 1 April 2010**

**Standardised National Eligibility Criteria for Starting ART Regimens for Adults and Adolescents in South Africa**

### **Eligibility Criteria**

#### **Eligible to Start ART**

CD4 count <200cells/mm<sup>3</sup> irrespective of clinical stage

**or**

CD4 count <350cells/mm<sup>3</sup>

In people with TB/HIV

Pregnant women

**or**

WHO stage IV irrespective of CD4 count

**or**

MDR/XDR-TB irrespective of CD4

#### **Require Fast-Track\* (i.e. ART initiation within 2 weeks of being eligible)**

Pregnant women eligible for lifelong ART

**or**

People with very low CD4 (<100 - 200cells/mm<sup>3</sup>)

**or**

Stage 4, CD4 count not yet available

**or**

MDR/XDR-TB

#### **Persons Not Yet Eligible for ART**

Persons are transferred to a wellness programme for regular follow up and repeat clinical assessment and CD4 testing 6-monthly.

Persons receive advice on how to avoid HIV transmission to sexual partners and children

INH prophylaxis is initiated if asymptomatic for TB.

Persons receive contraceptive advice and for women a pap smear is recommended.

*\*All other people should receive ART within 2 months of a clinical staging event or qualifying CD4 count*

## **Standardised National ART Regimens for Adults and Adolescents in South Africa**

### **National ART Regimens**

**1st Line:** All new persons needing treatment:

TDF + 3TC/FTC + EFV/NVP

For People with TB co-infection, EFV is preferred. For pregnant women or women of child bearing age, not on reliable contraception, NVP is preferred.

Persons currently on d4T-based regimen with no side effects:

d4T + 3TC + EFV/NVP

Persons to remain on d4T if well tolerated. Early switch with any toxicity to d4T recommended. Substitute TDF if at high risk of toxicity (high BMI, older, female, TB treatment)

Contraindication to TDF: renal disease

AZT+ 3TC +EFV/NVP

**2nd Line:** Failing on a d4T or AZT-based 1st line regimen:

TDF + 3TC/FTC + LPV/r

Virological failure must be followed by intensive adherence management, as re-suppression is often possible. If repeat VL remains >1000 in 3 months despite adherence intervention, switch.

Failing on a TDF-based 1st line regimen:

AZT + 3TC + LPV/r

Virological failure must be followed by intensive adherence management, as re-suppression is often possible. If repeat VL remains >1000 in 3 months despite adherence intervention, switch.

**Salvage Therapy:** Failing any 2nd line regimen:

Refer such persons to a specialist for assessment. Virological failure on protease inhibitors is almost always due to *non-adherence*. Therefore intensively exploring and addressing issues relating to causes of non-adherence will most often lead to re-suppression. If the VL remains high, refer where possible, but maintain on failing regimen.

(Department of Health RSA & SANAC, 2010).

## Appendix 2

### World Health Organisation Clinical Staging of HIV/AIDS for Adults and Adolescents with confirmed HIV infection

The clinical staging and case definition of HIV for resource-constrained settings were developed by the WHO in 1990 and revised in 2007. Staging is based on clinical findings that guide the diagnosis, evaluation, and management of HIV/AIDS, and it does not require a CD4 cell count. This staging system is used in many countries to determine eligibility for antiretroviral therapy, particularly in settings in which CD4 testing is not available. Clinical stages are categorized as 1 through 4, progressing from primary HIV infection to advanced HIV/AIDS. These stages are defined by specific clinical conditions or symptoms. For the purpose of the WHO staging system, adolescents and adults are defined as individuals aged  $\geq 15$  years.

<b>Clinical Stage 1</b>	Asymptomatic infection Seroconversion illness Persistent generalised lymphadenopathy Performance status 1 (fully active and asymptomatic)
<b>Clinical Stage 2</b>	Mild symptoms Moderate unexplained weight loss (<10% of presumed or measured body weight) Recurrent respiratory tract infections: sinusitis, tonsillitis, otitis media and pharyngitis Herpes Zoster Angular cheilitis Recurrent oral ulceration Papular pruritic eruptions Seborrhoeic dermatitis Fungal nail infections Minor mucocutaneous manifestations Performance status 2 (symptomatic but near fully active)
<b>Clinical Stage 3</b>	Advanced symptoms Unexplained severe weight loss (>10% of presumed or measured body weight) Unexplained chronic diarrhoea for > 1 month Unexplained persistent fever (above 37.6°C intermittent or constant > 1 month) Persistent oral candida, chronic vaginal candidiasis

	<p>Oral hairy leukoplakia</p> <p>Severe bacterial infections (such as pneumonia, empyema, pyomyositis, bone or joint infection, meningitis or bacteraemia)</p> <p>Pulmonary tuberculosis (TB) (current)</p> <p>Acute necrotising ulcerative stomatitis, gingivitis or periodontitis</p> <p>Unexplained anaemia (&gt;8g/dl), neutropaemia (&lt;0.5 x 10<sup>9</sup> per litre) or chronic thrombocytopaenia (&lt;50 x 10<sup>9</sup> per litre) Performance status 3 (in bed &lt;50% of past month)</p>
<p><b>Clinical Stage 4</b></p>	<p>Severe symptoms</p> <p>HIV wasting syndrome</p> <p>Extrapulmonary tuberculosis (TB)</p> <p>Pneumocystis carinii pneumonia (PCP)</p> <p>Recurrent severe bacterial pneumonia</p> <p>Chronic herpes simplex infection (orolabial, genital or anorectal of more than one month's duration or visceral at any site)</p> <p>Oesophageal candidiasis (or candidiasis of trachea, bronchi or lungs)</p> <p>Extrapulmonary tuberculosis</p> <p>Kaposi's sarcoma</p> <p>Central nervous system toxoplasmosis</p> <p>HIV encephalopathy</p> <p>Extrapulmonary cryptococcal (including meningitis)</p> <p>Disseminated non-tuberculous mycobacterial infection</p> <p>Cytomegalovirus (CMV) infection (retinitis or infection of other organs)</p> <p>Progressive multifocal leukoencephalopathy</p> <p>Chronic cryptosporidiosis (with diarrhoea)</p> <p>Chronic isosporiasis</p> <p>Herpes simplex virus ulcer &gt; 1 month</p> <p>Oesophageal or</p> <p>Disseminated mycosis (coccidiomycosis or histoplasmosis)</p> <p>Atypical mycobacteriosis</p> <p>Recurrent non-typhoid Salmonella bacteraemia</p> <p>Lymphoma (cerebral or B-cell non-Hodgkin) or other solid HIV- associated tumours</p> <p>Invasive cervical carcinoma</p> <p>Invasive cervical carcinoma leishmaniasis</p>

	symptomatic HIV- associated nephropathy or symptomatic HIV-associated cardiomyopathy Toxoplasmosis Performance status 4 (confined to bed > 50% of past month)
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Unexplained refers to where the condition is not explained by other causes

(WHO, 2007).

## Appendix 3

### CDC Classification System for HIV Infection

The CDC categorization of HIV/AIDS is based on the lowest documented CD4 cell count and on previously diagnosed HIV-related conditions (see below). For example, if a patient had a condition that once met the criteria for category B but now is asymptomatic, the patient would remain in category B. Additionally, categorization is based on specific conditions, as indicated below. Patients in categories A3, B3, and C1-C3 are considered to have AIDS.

#### CDC Classification System for HIV-Infected Adults and Adolescents

CD4 Cell Categories	Clinical Categories		
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Abbreviations: PGL = persistent generalized lymphadenopathy

	<b>A</b> Asymptomatic, Acute HIV, or PGL	<b>B*</b> Symptomatic Conditions, not A or C	<b>C<sup>#</sup></b> AIDS-Indicator Conditions
<b>(1) ≥500 cells/μL</b>	A1	B1	C1
<b>(2) 200-499 cells/μL</b>	A2	B2	C2
<b>(3) &lt;200 cells/μL</b>	A3	B3	C3

#### \* Category B Symptomatic Conditions

Category B symptomatic conditions are defined as symptomatic conditions occurring in an HIV-infected adolescent or adult that meet at least one of the following criteria:

- They are attributed to HIV infection or indicate a defect in cell-mediated immunity.
- They are considered to have a clinical course or management that is complicated by HIV infection.

Examples include, but are not limited to, the following:

- Bacillary angiomatosis
- Oropharyngeal candidiasis (thrush)
- Vulvovaginal candidiasis, persistent or resistant
- Pelvic inflammatory disease (PID)



- Cervical dysplasia (moderate or severe)/cervical carcinoma in situ
- Hairy leukoplakia, oral
- Herpes zoster (shingles), involving two or more episodes or at least one dermatome
- Idiopathic thrombocytopenic purpura
- Constitutional symptoms, such as fever (>38.5°C) or diarrhoea lasting >1 month
- Peripheral neuropathy

#### # Category C AIDS-Indicator Conditions

- Bacterial pneumonia, recurrent (two or more episodes in 12 months)
- Candidiasis of the bronchi, trachea, or lungs
- Candidiasis, oesophageal
- Cervical carcinoma, invasive, confirmed by biopsy
- Coccidioidomycosis, disseminated or extrapulmonary
- Cryptococcosis, extrapulmonary
- Cryptosporidiosis, chronic intestinal (>1 month in duration)
- Cytomegalovirus disease (other than liver, spleen, or nodes)
- Encephalopathy, HIV-related
- Herpes simplex: chronic ulcers (>1 month in duration), or bronchitis, pneumonitis, or oesophagitis
- Histoplasmosis, disseminated or extrapulmonary
- Isosporiasis, chronic intestinal (>1-month duration)
- Kaposi sarcoma
- Lymphoma, Burkitt, immunoblastic, or primary central nervous system
- *Mycobacterium avium* complex (MAC) or *Mycobacterium kansasii*, disseminated or extrapulmonary
- *Mycobacterium tuberculosis*, pulmonary or extrapulmonary
- *Mycobacterium*, other species or unidentified species, disseminated or extrapulmonary
- *Pneumocystis jiroveci* (formerly *carinii*) pneumonia (PCP)
- Progressive multifocal leukoencephalopathy (PML)
- *Salmonella* septicaemia, recurrent (non-typhoid)
- Toxoplasmosis of brain
- Wasting syndrome caused by HIV (involuntary weight loss >10% of baseline body weight) associated with either chronic diarrhoea (two or more loose stools per day for ≥1 month) or chronic weakness and documented fever for ≥1 month

(CDC Classification system for HIV/AIDS

[http://hab.hrsa.gov/deliverhivaidsare/clinicalguide11/cg-205\\_hiv\\_classification.html](http://hab.hrsa.gov/deliverhivaidsare/clinicalguide11/cg-205_hiv_classification.html))

## Appendix 4

### The Patients' Rights Charter

For many decades the vast majority of the South African population has experienced either a denial or violation of fundamental human rights, including rights to health care services. To ensure the realisation of the right of access to health care services as guaranteed in the Constitution of the Republic of South Africa (Act No 108 of 1996), the Department of Health is committed to upholding, promoting and protecting this right and therefore proclaims this **PATIENTS' RIGHTS CHARTER** as a common standard for achieving the realisation of this right.

This Charter is subject to the provisions of any law operating within the Republic of South Africa and to the financial means of the country.

#### A healthy and safe environment

Everyone has the right to a healthy and safe environment that will ensure their physical and mental health or well-being, including adequate water supply, sanitation and waste disposal as well as protection from all forms of environmental danger, such as pollution, ecological degradation or infection.



#### Participation in decision-making

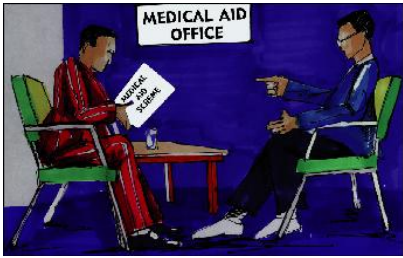
Every citizen has the right to participate in the development of health policies and everyone has the right to participate in decision-making on matters affecting one's health

#### Access to healthcare

Everyone has the right of access to health care services that include:

- i. receiving timely emergency care at any health care facility that is open regardless of one's ability to pay;
- ii. treatment and rehabilitation that must be made known to the patient to enable the patient to understand such treatment or rehabilitation and the consequences thereof;
- iii. provision for special needs in the case of newborn infants, children, pregnant women, the aged, disabled persons, patients in pain, person living with HIV or AIDS patients;
- iv. counselling without discrimination, coercion or violence on matters such as reproductive health, cancer or HIV/AIDS;
- v. palliative care that is affordable and effective in cases of incurable or terminal illness;
- vi. a positive disposition displayed by health care providers that demonstrate courtesy, human dignity, patience, empathy and tolerance; and
- vii. health information that includes the availability of health services and how best to use such services and such information shall be in the language understood by the patient.





### Knowledge of one's health insurance/medical aid scheme

A member of a health insurance or medical aid scheme is entitled to information about that insurance or medical aid scheme and to challenge, where necessary, the decisions of such health insurance or medical aid scheme relating to the member.

### Choice of health services

Everyone has the right to choose a particular health care provider for services or a particular health facility for treatment provided that such choice shall not be contrary to the ethical standards applicable to such health care providers or facilities, and the choice of facilities in line with prescribed service delivery guide lines.

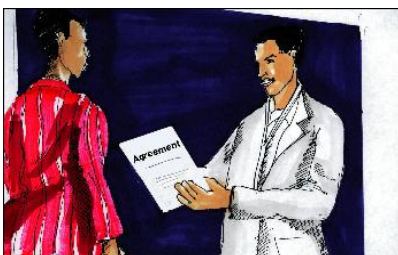


### Be treated by a named health care provider

Everyone has the right to know the person that is providing health care and therefore must be attended to by clearly identified health care providers.

### Confidentiality and privacy

Information concerning one's health, including information concerning treatment may only be disclosed with informed consent, except when required in terms of any law or an order of the court.



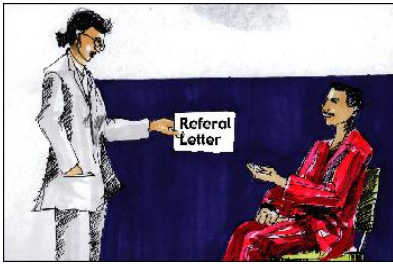
### Informed consent

Everyone has the right to be given full and accurate information about the nature of one's illnesses, diagnostic procedures, the proposed treatment and the costs involved, for one to make a decision that affects any one of these elements.

### Refusal of treatment

A person may refuse treatment and such refusal shall be verbal or in writing provided that such refusal does not endanger the health of others.



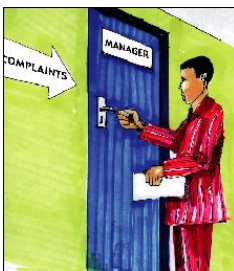


### **Be referred for a second opinion**

Everyone has the right to be referred for a second opinion on request to a health provider of one's choice.

### **Continuity of care**

No one shall be abandoned by a health care professional worker or a health facility which initially took responsibility for one's health.



### **Complain about health services**

Everyone has the right to complain about health care services and to have such complaints investigated and to receive a full response on such investigation.

## **Responsibilities of the Patient**

**Every patient or client has the following responsibilities:**

- to advise the health care providers on his or her wishes with regard to his or her death.
- to comply with the prescribed treatment or rehabilitation procedures.
- to enquire about the related costs of treatment and/or rehabilitation and to arrange for payment.
- to take care of health records in his or her possession.
- to take care of his or her health.
- to care for and protect the environment.
- to respect the rights of other patients and health providers.
- to utilise the health care system properly and not abuse it.
- to know his or her local health services and what they offer.
- to provide health care providers with the relevant and accurate information for diagnostic, treatment, rehabilitation or counselling purposes.

(<http://www.doh.gov.za/docs/pamphlets/patientsright/chartere.html>)

## Appendix 5

### LETTER OF INFORMED CONSENT

#### **TITLE OF RESEARCH: FACTORS THAT FACILITATE ADHERENCE TO HIGHLY ACTIVE ANTIRETROVIRAL THERAPY (HAART)**

Dear Participant

I, Michaela Helene Naicker, student no. 981084140, am a Masters student undertaking research University of KwaZulu-Natal.

The main objective of the study is to explore the factors that facilitate adherence to HIV antiretroviral therapy. The specific objectives are to gather information on the following factors that facilitate HIV medication adherence:

- Social and economic factors
- Health care team and system related factors
- Condition related factors
- Therapy related factors
- 'Patient' /Person related factors

This study will be supervised by Professor Vishanthie Sewpaul of the School of Social Work and Community Development at the University of Kwazulu-Natal.

Your participation in this research is completely voluntary and you may withdraw from this study at any time if you so wish.

I, ..... acknowledge that I have been informed of the objectives of the study. I acknowledge that all information regarding the study namely risks, benefits, confidentiality and participation has been explained to me. I acknowledge that all my questions regarding the study, was clearly explained to me. I understand that any information provided in the interview will remain strictly confidential and that I will remain anonymous in any published research findings.

.....  
NAME OF PARTICIPANT

.....  
SIGNATURE OF PARTICIPANT

.....  
DATE

.....  
SIGNATURE OF RESEARCHER

.....  
DATE

.....  
SIGNATURE OF SUPERVISOR

.....  
DATE

## Appendix 6

UNIVERSITY OF KWAZULU-NATAL

### ETHICAL CLEARANCE APPLICATION FORM (HUMAN AND SOCIAL SCIENCES)

2009

**PLEASE NOTE THAT THE FORM MUST BE COMPLETED IN TYPED SCRIPT.  
HANDWRITTEN APPLICATIONS WILL NOT BE CONSIDERED**

#### **SECTION 1: PERSONAL DETAILS**

- 1.1 Full Name & Surname of Applicant** Michaela Helene Naicker  
**1.2 Title (Ms/ Mr/ Mrs/ Dr/ Professor etc)** Ms  
**1.3 Student Number (where applicable)** 981084140  
**Staff Number (where applicable)** N/A  
**1.4 School** Social Work  
**1.5 Faculty** Humanities, Developmental studies and  
Social Science  
**1.6 Campus** Howard College  
**1.7 Existing Qualifications** Bachelor of Arts in Social Science;  
Post Graduate Certificate in Education;  
Post Graduate Diploma in Clinical  
HIV/Aids Management  
**1.8 Proposed Qualification for Project** Masters in Social Work  
( In the case of research of degree purposes)
- 2. Contact Details**  
Tel. No. 031266 7738  
Cell. No. 0837855046  
e-mail michaela@medis.co.za  
Postal address (in the case of students and external applicants) 4 Heather Road, Westville, Durban, 3630  
South Africa

#### Supervisor's details

NAME	TEL NO.	EMAIL	DEPARTMENT / INSTITUTION	QUALIFICATIONS
3.1 Vishanthie Sewpaul	031260124 1	Sewpaul@ukzn.ac.za	Social Work UKZN	PhD

## **SECTION 2: PROJECT DESCRIPTION**

**Please do *not* provide your full research proposal here: what is required is a short project description of not more than two pages that gives, under the following headings, a brief overview spelling out the background to the study, the key questions to be addressed, the participants (or subjects) and research site, including a full description of the sample, and the research approach/ methods**

### **2.1 Project title**

Factors that influence adherence to highly active antiretroviral therapy (HAART)

### **2.2 Location of the study (where will the study be conducted)**

Durban Metropolis

### **2.3 Objectives of and need for the study**

(Set out the major objectives and the theoretical approach of the research, indicating briefly, why you believe the study is needed.)

The main aim is to explore the factors that influence adherence to HIV antiretroviral therapy. The specific objectives are to gather information on the following factors that influence HIV medication adherence:

- Social and economic factors
- Health care team and system related factors
- Condition related factors
- Therapy related factors
- ‘Patient’ /Person related factors

Adherence behaviour can be described as a multidimensional phenomenon influenced by the interaction of five sets of factors as described above. The ecosystems theory helps to provide an understanding of behaviour in context. The Information-Motivation-Behaviour model provides a useful framework to explain the influence of different variables on an individual’s health related behaviour. This study seeks to explore the factors that influence adherence which may help health care providers and persons on HAART to engage in open discussion to promote near perfect adherence behaviour.

### **2.4 Questions to be answered in the research**

(Set out the critical questions which you intend to answer by undertaking this research.)

- What specific influences might social and economic factors have on adherence to antiretroviral therapy?
- What roles do health care providers and the health system play in facilitating adherence to ART?



- Does the medical condition of the HIV+ person influence antiretroviral medication adherence?
- Are there specific therapy related factors that might influence adherence?
- What personal factors may influence adherence?

## 2.5 Research approach/ methods

(This section should explain how you will go about answering the critical questions which you have identified under 2.4 above. Set out the approach within which you will work, and indicate in step-by-step point form the methods you will use in this research in order to answer the critical questions).

This research is a qualitative descriptive study to explore the factors that influence ART adherence amongst persons who access health care in Durban. Eligible participants are persons over 21 years of age, on treatment for at least 2 years, who are willing to share stories with the researcher. Participants must be able to communicate in English.

The theoretical sampling technique is the technique of choice as this will provide me with the opportunity to obtain a deeper understanding of the factors that influence adherence. The sample size will be determined by how the research questions are answered. I anticipate doing at least ten interviews but will be guided by the data generated by the interviews. Interviews will discontinue once data saturation occurs.

In-depth interviews will be conducted and participants will be identified by health care providers. The interviews will be approximately one and a half hours long. Interviews will be tape recorded and transcribed verbatim for thematic analysis of data.

*For a study that involves surveys, please append a provisional copy of the questionnaire to be used. The questionnaire should show how informed consent is to be achieved as well as indicate to respondents that they may withdraw their participation at any time, should they so wish.*

## 2.6 Proposed work plan

Set out your intended plan of work for the research, indicating important target dates necessary to meet your proposed deadline.

STEPS	DATES
Chapter 2 – literature study ongoing – to complete	November
Chapter 3 – Research methodology/theoretical framework	August
Identification of Participants – explanation of research study, documentation	When approval is granted (mid August or beginning September)
Conducting interviews – can start in Aug is approval granted or else will start in September.	September
Transcription immediately after interviews	September
Interviews – 2 per week. Transcription immediately after interviews	1 <sup>st</sup> and 2 <sup>nd</sup> weeks October – to complete
Transcribing	3 <sup>rd</sup> week October
Analyzing data	4 <sup>th</sup> weeks October
Results – presentation	1 <sup>st</sup> week of November and 2 <sup>nd</sup> weeks of

Conclusion and recommendations Editing & submission	November 3 <sup>rd</sup> week of November
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### SECTION 3: ETHICAL ISSUES

The UKZN Research Ethics Policy applies to all members of staff, graduate and undergraduate students who are involved in research on or off the campuses of University of KwaZulu-Natal. In addition, any person not affiliated with UKZN who wishes to conduct research with UKZN students and / or staff is bound by the same ethics framework. Each member of the University community is responsible for implementing this Policy in relation to scholarly work with which she or he is associated and to avoid any activity which might be considered to be in violation of this Policy.

All students and members of staff must familiarize themselves with AND sign an undertaking to comply with the University's "Code of Conduct for Research".

#### QUESTION 3.1

Does your study cover research involving:	YES	NO
Children		√
Persons who are intellectually or mentally impaired		√
Persons who have experienced traumatic or stressful life circumstances	√	
Persons who are HIV positive	√	
Persons highly dependent on medical care	√	
Persons in dependent or unequal relationships		√
Persons in captivity		√
Persons living in particularly vulnerable life circumstances		√

If "Yes", indicate what measures you will take to protect the autonomy of respondents and (where indicated) to prevent social stigmatisation and/or secondary victimisation of respondents. If you are unsure about any of these concepts, please consult your supervisor/project leader.

Participants' identities will be concealed. Only respondents willing to share their stories will be interviewed. All participants will be fully informed about the nature of the study and will be granted the option to withdraw at any time if they so choose. Should the interview generate emotional trauma the researcher will use her skills as a social worker to provide for a containing environment and to handle this with empathy and sensitivity. Appropriate referrals will be, where necessary.

#### QUESTION 3.2

Will data collection involve any of the following:	YES	NO
Access to confidential information without prior consent of participants		√

Participants being required to commit an act which might diminish self-respect or cause them to experience shame, embarrassment, or regret		√
Participants being exposed to questions which may be experienced as stressful or upsetting, or to procedures which may have unpleasant or harmful side effects		√
The use of stimuli, tasks or procedures which may be experienced as stressful, noxious, or unpleasant		√
Any form of deception		√

If “Yes”, explain and justify. Explain, too, what steps you will take to minimise the potential stress/harm.

### QUESTION 3.3

<b>Will any of the following instruments be used for purposes of data collection:</b>	<b>YES</b>	<b>NO</b>
Questionnaire		
Survey schedule		
Interview schedule: An interview guide will be used with broad areas of exploration as per the main aim and objectives of the study.	√	
Psychometric test		
Other/ equivalent assessment instrument		

If “Yes”, attach copy of research instrument. If data collection involves the use of a psychometric test or equivalent assessment instrument, you are required to provide evidence here that the measure is likely to provide a valid, reliable, and unbiased estimate of the construct being measured. If data collection involves interviews and/or focus groups, please provide a list of the topics to be covered/ kinds of questions to be asked.

### QUESTION 3.4

<b>Will the autonomy of participants be protected through the use of an informed consent form, which specifies (in language that respondents will understand):</b>	<b>YES</b>	<b>NO</b>
The nature and purpose/s of the research	√	
The identity and institutional association of the researcher and supervisor/project leader and their contact details	√	
The fact that participation is voluntary That responses will be treated in a confidential manner	√	
Any limits on confidentiality which may apply	√	
That anonymity will be ensured where appropriate (e.g. coded/ disguised names of participants/ respondents/ institutions)	√	

The fact that participants are free to withdraw from the research at any time without any negative or undesirable consequences to themselves	√	
The nature and limits of any benefits participants may receive as a result of their participation in the research	√	

If not, this needs to be explained and justified, also the measures to be adopted to ensure that the respondents fully understand the nature of the research and the consent that they are giving.

### QUESTION 3.5

**Specify what efforts been made or will be made to obtain informed permission for the research from appropriate authorities and gate-keepers (including caretakers or legal guardians in the case of minor children)?**

No minors are involved in this research. Participation is voluntary. Only persons over 21 years who are willing and eager to share their information with me are eligible.

### QUESTION 3.6

**STORAGE AND DISPOSAL OF RESEARCH DATA:**

**Please note that the research data should be kept for a period of at least five years in a secure location by arrangement with your supervisor.**

**How will the research data be disposed of? Please provide specific information, eg shredding of documents incineration of videos, cassettes, etc.**

Recorded data - cassettes will be incinerated  
Verbatim transcripts will be shredded

### QUESTION 3.7

**In the subsequent dissemination of your research findings – in the form of the finished thesis, oral presentations, publication etc. – how will anonymity/ confidentiality be protected?**

Identities of participants will be concealed.

### QUESTION 3.8

**Is this research supported by funding that is likely to inform or impact in any way on the design, outcome and dissemination of the research?**

YES

NO

√

**If yes, this needs to be explained and justified.**

N/A

### QUESTION 3.9

**Has any organization/company participating in the research or funding the project, imposed any conditions to the research?**

NO

If yes, please indicate what the conditions are.

N/A

**SECTION 4: FORMALISATION OF THE APPLICATION**

**APPLICANT**

I have familiarised myself with the University's Code of Conduct for Research and undertake to comply with it. The information supplied above is correct to the best of my knowledge.

**NB: PLEASE ENSURE THAT THE ATTACHED CHECK SHEET IS COMPLETED**

.....  
31 July 2009

**SIGNATURE OF APPLICANT**

**DATE**

**SUPERVISOR/HEAD OF SCHOOL**

**NB: PLEASE ENSURE THAT THE APPLICANT HAS COMPLETED THE ATTACHED CHECK SHEET AND THAT THE FORM IS FORWARDED TO YOUR FACULTY RESEARCH COMMITTEE FOR FURTHER ATTENTION.**

**DATE:** .....

**SIGNATURE OF SUPERVISOR/ PROJECT LEADER**

: \_\_\_\_\_

**RECOMMENDATION OF FACULTY RESEARCH COMMITTEE/HIGHER DEGREES COMMITTEE**

The application is (please tick):

<input type="checkbox"/>	Approved *
<input type="checkbox"/>	Recommended and referred to the Human and Social Sciences Ethics Committee for further consideration
<input type="checkbox"/>	Not Approved, referred back for revision and resubmission

- \* Senate has delegated powers to Faculty Committee to:
  - Approve Undergraduate and Honours projects
  - Approve Masters projects (if the required capacity exists within the faculty)

**NAME OF CHAIRPERSON:**

<b>SIGNATURE:</b> _____
<b>DATE</b> .....

<b>RECOMMENDATION OF UNIVERSITY RESEARCH ETHICS COMMITTEE (HUMAN AND SOCIAL SCIENCES)</b>	
<b>NAME OF CHAIRPERSON:</b> _____	<b>SIGNATURE</b> _____
<b>DATE</b> .....	

**UNIVERSITY OF KWAZULU-NATAL  
RESEARCH OFFICE**

**HUMAN AND SOCIAL SCIENCES ETHICAL CLEARANCE APPLICATION  
FORM**

**CHECK SHEET FOR APPLICATION**

**PLEASE TICK**

1. Form has been fully completed and all questions have been answered	
2. Questionnaire attached (where applicable)	
3. Informed consent document attached (where applicable)	
4. Approval from relevant authorities obtained (and attached) where research involves the utilization of space, data and/or facilities at other institutions/ organisations	
5. Signature of Supervisor / project leader	
6. Application forwarded to Faculty Research Committee for recommendation and transmission to the Research Office	