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# Exploring expert and patient opinions and recommendations regarding anti-retroviral treatment compliance

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# EXPLORING EXPERT AND PATIENT OPINIONS AND RECOMMENDATIONS REGARDING ANTIRETROVIRAL TREATMENT COMPLIANCE

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**A research report submitted to the Faculty of Humanities, University of the Witwatersrand, Johannesburg, in partial fulfilment of the requirements for the degree of Master of Arts Counselling Psychology**

**Johannesburg, 2006**

**DECLARATION**

I declare that this thesis is my own unaided work. It is submitted for the degree of Master of Arts in Counselling Psychology at the University of Witwatersrand, Johannesburg. It has not been submitted before for any other degree or examination at any other university.

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Janice Meryl Frank

10 April 2006

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The following research report is dedicated to my father, Mervyn Sidney Frank, who passed away suddenly on 2 January 2005. His love, wisdom and humour have made me the person that I am today.

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**ABSTRACT**

The recent introduction of antiretroviral treatment (ART) to the public health sector has meant that for millions of Human Immunodeficiency Virus (HIV)-positive patients this deadly disease has been transformed into a chronic condition. There has been much research done internationally on adherence to ART but in South Africa there has been little investigation in this area. This study aimed to bridge this gap by exploring expert and patient opinions and recommendatio ns regarding adherence to antiretroviral medication. To attain this, four experts and seven patients were interviewed using a semi-structured interview schedule. The experts had worked within the HIV field for at least two years while the patients had been chosen from public antiretroviral roll-out programmes and had been on ART for at least six months. These interviews were audio recorded and transcribed. The transcriptions were then explored for themes using thematic content analysis. These themes were categorised and discussed under four broad categories: patients' perceptions of barriers to adherence, patients' recommendations for improving adherence, experts' perceptions of barriers to adherence and experts' recommendations for improving adherence.

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## CHAPTER 1: INTRODUCTION

The surveyed literature has suggested that stringent adherence is imperative to the success of antiretroviral (ARV) therapy (Buick, Fisher, Horne, & Leake, 2004; Ickovics & Meade, 2002; Kimmerling, Wagner & Ghosh-Dastidar, 2003; Stone & Smith, 2004). Antiretroviral medication has been recently introduced to the public health sector in South Africa. However, there appears to be little existing research on antiretroviral adherence. Hence, this study aimed to explore the opinions and recommendations of HIV/AIDS experts and patients regarding patient adherence to antiretroviral medication.

### RATIONALE

In 2000, AIDS became the largest single cause of death worldwide. The Actuarial Society of South Africa (ASSA) model calculated that in 2002, 6.5 million South Africans were infected with HIV (Human Immunodeficiency Virus). Last year, it was predicted that in Gauteng alone, 1 538 208 people were HIV infected while the cumulative number of AIDS related deaths stood at 139 249 (Dorrington, Bradshaw & Budlender, 2002).

The HIV/AIDS epidemic has had and will continue to have a significant socio-economic impact on the country. The ASSA model predicted that 6.1 million people within the age group 18 to 64 years were infected in 2001 (Dorrington et al., 2002). Among the many consequences of having such a high rate of infection, are the economic implications for the country, as this age group forms the country's labour force (Dorrington et al., 2002; Umeh, 1997). Thousands of children are being orphaned by parents dying from AIDS and HIV related illnesses, thus contributing to an increase in the number of street children, which in turn contributes to the high level of poverty and crime in this country (Umeh, 1997).

Antiretroviral therapy (ART) has been successful in the United States of America (USA) and other developed countries, being associated with a significant reduction of HIV related mortality and morbidity rates (Chung et al., 2002; Kimmerling et al., 2002). The introduction of antiretroviral therapy to South Africa means that for those who are granted access to medication, this disease is transformed into a chronic condition (Buick et al., 2004).

To ensure ART success and that viral levels are suppressed, maximum adherence (i.e. > 90% adherence) is essential. Much research concerning adherence to antiretroviral medication has been done internationally (Becker & Clark, 1998; Berlant & Pruitt, 2003; Buick et al., 2003; Chung et al., 2002; Ickovics & Meade, 2002; Kimmerling et al., 2002; Ockene, 2001). However, in South Africa, due to the introduction of antiretroviral medication to the public health sector being very recent, there appears to be little research regarding adherence to antiretroviral medication. The theoretical aim of this study was to begin to bridge this gap by exploring the opinions of both experts working within the HIV/AIDS field and patients who are currently on antiretroviral medication regarding adherence to medication. The practical aim is for the findings of this research to be used to generate suggestions for antiretroviral adherence intervention.

## STRUCTURE OF THE RESEARCH REPORT

The following is an outline of the structure of this research report. Chapter 2 presents a survey of the literature reviewed related to the issues of adherence and antiretroviral treatment. It begins by introducing a discussion on the human immunodeficiency virus and explaining the structure of the virus and how the virus replicates. This is imperative in understanding the subsequent section, which provides an explanation of antiretroviral medication and how this class of medication functions. This is then followed by a section on adherence, which begins by discussing the construct of adherence and focuses on the complexities of measuring the construct. The literature review then discusses what the surveyed literature has highlighted as potential predictors of adherence

Chapter 3 presents the methodology of the research report. It begins by defining the keywords of the research report and presents the research design. This is followed by a presentation of the rationale and identifying details of the participants. The next section discusses the potential influence of the researcher's subjectivity on the research process. The data collection strategy and analysis of the data is then discussed and the chapter is then concluded by a discussion of the ethical considerations in the research.

Chapter 4 presents the findings of the research. This is presented under four broad themes: experts' perceptions of the barriers to adherence, experts' recommendations for

improving adherence, patients' perceptions of the barriers to adherence and patients' recommendations for improving adherence.

The data analysis revealed some similarities and differences in the accounts given by the experts and patients. Hence, Chapter 5 explores a comparison of the expert and patient reports.

Chapter 6 is the concluding section of the report and examines the limitations of the study. This is followed by a discussion of the areas highlighted for future research and finally some closing comments are presented.

## CHAPTER 2: LITERATURE REVIEW

The following is a literature review of research on adherence and antiretroviral medication. It begins by discussing the structure and replication of the Human Immunodeficiency Virus (HIV) in an effort to understand the functioning of antiretroviral medication. This is followed by a discussion of the construct of adherence, noting its complexities with regards to measurement and prediction. Given the complexities of predicting adherence, some predictors highlighted by the literature are the presented. To understand the functioning of antiretroviral medication, it becomes necessary to have a basic understanding of the structure and replication of the HIV.

The HIV is a retrovirus that slowly destroys the human immune system over time (Jenkins, 2003). The term retrovirus is given because the transcription stage of HIV replication occurs in reverse to that of human cell replication. HIV is classified as part of the retrovirus family and the lentivirus subfamily. There are two types of HIV, namely, Type 1, which is found throughout the world and is common in South Africa and Type 2, which is found particularly in West Africa. There are further groupings within the different types, with Type 2 being further subdivided into groups M, O and N. There are still further sub-groupings within each group. It must be acknowledged that every type of virus is different and that it is this slight difference that contributes to a virus being either easily destructible or resistant (Jenkins, 2003).

### THE STRUCTURE OF THE HIV

The HIV is composed of the proteins and enzymes necessary to replicate the virus. These enzymes, reverse transcriptase and protease, play an integral role in the replication of the virus. The core of the virus is its genetic material, i.e. two strands of RNA embedded in a jelly-like protein. The RNA serves as the blueprint for HIV replication (Jenkins, 2003). The core is enclosed in an outer envelope of protein, fat and sugar. The structure of the envelope is an important feature, as it too guides HIV replication. The viral envelope contains glycoproteins that can only attach to specific receptors on human cells, called CD4 receptors (Jenkins, 2003). Only certain human cells contain these receptors, thereby making these cells susceptible to HIV. Human cells containing CD4 receptors are T

helper cells (cells that have a protective function in the immune system), Monocytes (cells that initiate antibody production), Glial cells (cells of the central nervous system) and Langerhans cells (cells found in the skin and mucous membranes) (Jenkins, 2003).

**HIV REPLICATION**

The process of replication can be seen as having six steps (Jenkins, 2003), a basic summary of which will now be discussed.

Step 1 - Binding: This occurs when the glycoprotein on the viral envelope makes contact with a CD4 receptor of another cell. When the HIV binds to the CD4 receptor, other surface proteins are activated that allow the HIV envelope to fuse to the outside of the cell.

Step 2 - Reverse Transcription: At this point, the viral core containing RNA and the enzymes, Reverse Transcriptase and Protease, is released into the host cell. Reverse transcriptase then synthesizes a DNA copy of the RNA. This is called Proviral DNA.

Step 3 - Integration: The proviral DNA is then transported to the host cell's nucleus. Another enzyme, Intergrase, then incorporates the proviral DNA into the cell's DNA. Thus, when the cell attempts to replicate, it in effect replicates the HIV.

Step 4 - Transcription: Once the proviral DNA is in the cell nucleus, the two strands of DNA separate. Enzymes then create a complementary strand of the DNA called the Messenger RNA (mRNA).

Step 5 - Translation: The mRNA contains the instructions for the synthesis of the new virus. The sequence of proteins on the mRNA strand serves as a code for which proteins from the cell nucleus will be assembled to form the new virus. This stage is thus concerned with the mRNA code being translated.

Step 6 - Viral Assembly: The enzyme Protease breaks down long strings of proteins into smaller proteins. These proteins are then assembled according to the code translated from the mRNA to form the new virus. Once the virus is created, it buds off the host cell and has the potential to infect a new cell. Thus, an infected cell will give rise to many more infected cells.

There are certain points in HIV replication where the process can be stopped. This is the logic governing antiretroviral medication. It is possible to intervene at the points of binding, reverse transcription and viral assembly, to prevent replication.

**DEFINING ANTIRETROVIRAL MEDICATION**

Antiretroviral medication (ARV) acts directly on HIV to prevent HIV replication. ARVs are classified into two main types, depending on which part of HIV replication they intervene at. The two types are Reverse Transcriptase Inhibitors and Protease Inhibitors, which act at the point of HIV replication where these enzymes function (Gallant, 1995; Jenkins, 2003; Maenza, 1998).

Reverse transciptase inhibitors prevent the synthesis of proviral DNA. Reverse transcriptase inhibitors are further categorized into two types, nucleoside inhibitors and non-nucleoside inhibitors. The nucleoside inhibitors insert into the nucleoside chain and serve as a blockage, preventing the completion of nucleoside chain synthesis and thus the replication of the proviral DNA (Gallant, 1995). There are two important considerations regarding the use of reverse transcriptase inhibitors. The first is that the usage of this group of drugs has shown improvements in patients in the asymptomatic, intermediate stage of the disease. Secondly, treatment with this class of drugs alone appears to be inferior to combination therapy and to treatment that excludes this drug (Gallant, 1995; Ickovics & Meade, 2002; Maenza, 1998).

Unlike the reverse transciptase inhibitors, which act early on in the HIV replication cycle, protease inhibitors act later on, preventing the protease enzyme from deconstructing protein and sugar chains into its constituents that are required to produce the new HIV (Gallant, 1995). This class of antiretrovirals appears to have greater potential for decreasing the viral load than the reverse transcriptase inhibitors. However, protease inhibitor treatment alone is associated with the rapid development of resistance and hence these drugs will always be used in conjunction with other treatments (Gallant, 1995).

From the above, it is evident that the most effective treatment lies in a combination of reverse transciptase inhibitors and protease inhibitors. This is supported by Montaner et al. (1998), who established that a combination of nevirapine, zidovudine

and didanosine (i.e. triple ARV therapy) led to a more significant and sustained decrease in viral load and increase in CD4 cells. After one year, only patients who adhered stringently to this regimen sustained maximum viral suppression.

The efficiency of highly active antiretroviral therapy (HAART) means that for those who have access to treatment, HIV/AIDS is transformed from a terminal disease into a chronic condition (Buick et al., 2004; Kimmerling et al., 2003). The introduction of HAART to the USA in 1996, has led to the significant decline of HIV/AIDS related morbidity and mortality in that country (Kimmerling et al., 2003; Stone & Smith, 2004). Though this condition requires consistent, long-term management, it is but a chronic condition nonetheless (Buick et al., 2004). This transformation is marked by significant viral suppression and this can only be realized with high levels of adherence; yet, in the USA, 50% to 60% of patients fail to achieve this (Stone & Smith, 2004). The necessity for strict adherence concerning antiretroviral medication has spurred interest in identifying and understanding the correlates of adherence.

**DEFINING ADHERENCE**

Many chronic medical disorders, such as asthma, diabetes and hypertension can now be managed with medication. For the chronically ill, taking medication means a greater quality of life and, in some instances, a prolonged life (Haynes, 2001). Chronic medication, however, does not cure the disorder and the patient is thus forced to take the medication for as long as the disorder exists, which in most cases is as long as the patient is alive (Haynes, 1991). The chronic medication has to be taken regularly for it to be effective. In many cases, patients who cease taking their medication do not relapse immediately and thus begin to believe that the medication was not necessary to begin with. Some chronic medications may be fat - soluble and remain in the body for a long time, thus allowing the patient to benefit for some time after terminating the treatment regime. This is seen especially in the administration of antipsychotic medication, where patients cease taking their medication once their hallucinations have disappeared. The effects of the medication may still be seen for days afterwards but eventually, the sudden cessation of medication leads to a relapse of psychosis and subsequently psychotic behaviour (Drugweek, 2004). Often, patients cease taking medication because the

symptoms associated with the disorder have disappeared e.g. influenza (World Health Organisation, 1999).

Adherence or compliance is defined as the extent to which the time history corresponds to the drug regimen (Chung et al., 2002). In other words, adherence refers to how closely patients follow their treatment programme (Haynes, 2001). Following from this, non-adherence or non-compliance refers to patients who do not follow their prescribed treatment. This may take many forms, such as not taking their medication, reducing or exceeding their dosages, taking their medication at the incorrect times or not following the dietary specifications associated with the said medication (Chung et al., 2002; Haynes, 2001).

Adherence in the HIV context becomes an issue of great complexity for three main reasons. Firstly, HIV patients may have to take as many as 30 tablets a day. This is the result of the combination of antiretroviral medication, as well as numerous prophylactic medications for pneumonia, tuberculosis and other HIV-related illnesses. Secondly, certain medication may be associated with certain dietary requirements e.g. an empty stomach. This means that HIV-positive patients must remember which medications to take at which times and with which dietary restrictions. The third reason for the complexity of HIV medication regimens is the strong side effects, such as nausea and vomiting that are frequently associated with HIV medication (Chung et al., 2002; Ickovics & Meade, 2002).

In spite of these difficulties, maximal adherence to ARV regimens is crucial for three main reasons. Firstly, adherence to ARV allows a patient to gain the full benefits of Highly Active Antiretroviral Therapy (HAART), including a suppression of viral load, reduced destruction of CD4+ cells, the promotion of immune system repair and a slower progression to AIDS (Chung et al., 2002; Ickovics & Meade, 2002; Kimmerling et al., 2003, Popp & Fisher 2002).

Secondly, sub-optimal adherence can promote the mutation of the HI virus, which could lead to the development of one or more resistant strains (Chung et al., 2002, Ickovics & Meade, 2002, Kalichman & Rompa, 2003; Kimmerling et al., 2003; Lucas, Wu & Cheever, 2004). Once resistance begins, it becomes very difficult to stop mutations resulting in resistant strains, even if maximal treatment is administered. Such resistant

mutations can lead to new strains of a virus developing that will not respond to current treatment regimes (Chung et al., 2002; Ickovics & Meade, 2002).

Thirdly, failed treatment regimes present major expenditure for health-care services. Having to repeatedly treat patients will no doubt be costly, especially in South Africa where antiretrovirals have only recently been released, due to economic and political factors (Chung et al., 2002; Ickovics & Meade, 2002).

**ASSESSING ADHERENCE**

The construct of adherence poses considerable challenges with regards to assessment. The monitoring of adherence-related behaviour is important firstly, in detecting non-adherence and secondly in monitoring adherence as part of effective treatment planning. The surveyed literature offers three broad categories of adherence assessment: subjective measures, objective measures and biochemical measures, with objective measures being the most widely acceptable in first world countries (Berlant & Pruitt, 2003; Kimmerling et al., 2003).

The subjective measures entail patients and health-care providers reporting the former's levels of adherence. This is potentially problematic for two reasons. Firstly, it has been proven that health-care providers often tend to over-estimate their patients' levels of adherence. Secondly, patients' reports often also err on the side of inaccuracy. Those patients who report that they have failed to follow medical recommendations will be generally be more accurate than those who do not report that they have failed to follow medical recommendations. In addition, many patients will not report non-adherence for fear of the termination of their treatment (Berlant & Pruitt, 2003). This study, however was exploratory in nature and hence the use of a subjective measure of adherence (i.e. patient reports) did suffice. In addition, the patient participants had been on ART for at least six months and had had their adherence levels objectively measured via blood tests, hence it was felt that their account of adherence levels would be fairly accurate.

Objective measures of adherence include pill counting and system monitoring. Pill counting involves health-care workers counting patients' pills at predetermined intervals in an effort to assess whether medication has been taken or not. In addition, some hospitals monitor their databases to assess whether patients have successfully

attended their follow-up check ups. Though effective, random errors of measurement contribute to the drawbacks of objective measurement. Medication Event Monitoring Systems (MEMS) have been utilised to record the exact date and time that a medication container was opened, thus providing an indication of the exact nature of consumption. However, the cost of such systems limits their use, especially in the South African setting (Berlant & Pruitt, 2003; Kimmerling et al., 2003).

Some medication contains non-toxic biological markers, which can be detected in the blood or urine, providing evidence that the medication has been ingested. Such biochemical measures have their own drawbacks, as the detection of the substance is influenced by a myriad of factors such as diet, rate of absorption and excretion. The construct of adherence is thus a difficult one to assess and this contributes to the difficulties around research in this area. Though each method offers some estimation of the patient's adherence, there still appears to be the need for an accurate, cost effective assessment of adherence (Berlant & Pruitt, 2003; Kimmerling et al, 2003).

## PREDICTORS OF ADHERENCE

Many factors have been found to influence medication compliance. The following section discusses some of the factors covered by the surveyed literature. When predictors of medication compliance are analysed, there appear to be two broad categories: predictors related to the medical regime and predictors related to the individual.

### Predictors related to the medical regime

As previously mentioned, one of the challenges of adherence to antiretroviral medication is the complexity of the regimen, the strict dietary requirements, as well as the associated side effects (Chung et al, 2002; Ickovics & Meade, 2002). The AIDS Clinical Trial Group 370 found that adverse side effects were the strongest predictor of non-adherence (Ickovics & Meade, 2002). Side effects of the medication include but are not limited to diarrhoea, fatigue, nausea, vomiting, peripheral neuropathy and metabolic changes (Max & Sherer, 2000). In the trial group, these side effects were found to occur in the first to fourth week. Those patients experiencing an adverse effect were 16 times less likely to be compliant (Ickovics & Meade, 2002).

Among the other adherence predictors was the complexity of the drug regimen, in addition to the number of different prescribed medications (Ickovics & Meade, 2002). Even difficulty ingesting large pills has been found to contribute to non-compliance (Mann & Roberts, 2000). It has also been found that the perceived 'fit' of the medical regimen into the patient's lifestyle was a strong predictor of adherence (Gillford, Bormann, Shively, Wright, Richman, & Bozzette, 2000). Patients have reported that the complexity of the drug regimen requires that they structure their daily routine around the medication and that this has contributed to poor adherence (Mann et al., 2000).

**Predictors related to the individual**

*Socio-demographic factors*

Generally, socio-demographic factors have not been found to predict adherence. However, some studies have found an association between adherence and variables such as age, gender, race, economic status, educational level and literacy (Ickovics & Meade, 2002). For example, gay men face considerable challenges to adherence that are associated with their own particular lifestyles (Shernoff, 2001) while women tend to be more concerned than men with the effect that the antiretroviral medication has on their body weight (Mann et al., 2000). Pressure on women to fulfil the role of 'mother' has also affected disclosure of their status, thus impacting on the opportunity to be compliant (Mann et al., 2000).

In pilot studies done by the Gay Men's Health Crisis in 1998, the most frequent reasons for non-compliance by both heterosexual and homosexual men and women were: being away from home without the medication, forgetting to take a dose due to timing, fatigue, conflicts with eating and running out of medication (Shernoff, 2001).

*Psychological factors*

Patients scoring high on the Hostility Scale of the Brief Symptom Inventory have reported higher levels of non-adherence than those who scored lower on this scale (Burke, Dunbar-Jacob, Schlenk & Matthews, 1998). Emotional distress over one's health has also been found to be associated with adherence. In general, high levels of distress were associated with low levels of adherence (Burke et al., 1998, French, Weiss, Waters,

Tesoriero, Finkelstein & Agins, 2005). Emotional distress, in general, has also been found to be a correlate of sexually risky behaviour, serving as an indicator for health compromising behaviour, which includes lower levels of adherence (Kalichman & Rompa, 2003). The occurrence of Post-Traumatic Stress Disorder has also been found to predict poor health outcomes in HIV-positive patients, including poor levels of adherence (Brief et al., 2004).

Personality traits have not been found to be predictors of adherence. However, certain psychological states have been seen to affect patient levels of adherence (Burke et al., 1998). An example of this is avoidant coping strategies, that have been found to be related to low levels of adherence (Halkitus, Kutnick & Slater, 2005). Burke et al. (1998) cite an association between depression and adherence in some but not all studies while Ickovics & Meade (2002) reports a relationship between adherence and depression. The Kalichman and Rompa study (2003) revealed that non-compliant patients scored higher on the Beck Hopelessness Scale, supporting a possible relationship between depression and adherence. Anxiety has also been found to be associated with adherence (Burke et al., 1998). Mental health challenges, especially with regards to depression and anxiety, have been found to pose challenges to adherence among gay men (Shernoff, 2001).

The approximation of the prevalence of depression among HIV-positive patient varies in the literature. However, it appears that depression is found to be common in this population (Malan, 2003; Moosa, Jeenah & Vorster, 2005), with major depressive disorder being the most commonly diagnosed psychiatric disorder (Moosa et al., 2005). The complexities of such a diagnosis among a HIV-positive population must be acknowledged, and are due to the similarities of the somatic and physical symptoms of depression and HIV. Depression affects the HIV-positive individual by decreasing immune deficiency and contributes to poor adherence to ART (Brief et al., 2004; Moosa et al., 2005). In addition, the poor quality of sleep associated with depression has also been found to be associated with poor levels of adherence (Phillips et al., 2005). The National ART Guideline (2004) cites active depression as a psychosocial consideration for administering ART. Though it is not an exclusion criterion, it highlights the impact that depression may have on an individual's level of motivation to adhere to his or her treatment regimen (Department of Health, 2004). Yun, Maravi, Kobayashi, Barton

Phoebe and Davidson (2005), and Turner, Laine, Cosler and Hauk (2003) found that adherence to ART was improved by antidepressant treatment in HIV-positive patients. In addition, the levels of adherence were highest among those patients who adhered to their antidepressant medication (Yun et al., 2005).

*Belief systems*

Patient perceptions of antiretroviral medication have also proven to be predictors of adherence. A study of 109 HIV-positive patients receiving HAART revealed that medication compliance was dependent on how worried a patient was about related side effects balanced against his or her perceived need for the medication. Patients reported low levels of adherence if their concerns regarding side effects were high, relative to their perceived need for the medication (Buick et al., 2004). Belief in the efficacy of antiretroviral treatment, as well as the medication serving as a reminder of their disease status have been cited as being strongly associated with non-compliance (Mann et al., 2000).

Chung et al. (2002) found that higher measures of self efficiacy, i.e. subjects being confident that they would be able to take all or most of their medication, predicted high levels of adherence. In addition, it has also been found that strong beliefs in the creation of resistant strains as a result of non-compliance have served as a positive motivator for adherence (Chung et al., 2002).

*Drug and alcohol abuse*

Drug and alcohol abuse have also been found to be associated with adherence (Ickovics & Meade, 2002; Kalichman & Rompa, 2003; Shernoff, 2001). A study by Kalichman and Rompa (2003) revealed that patients who reported being non-compliant within the past week also reported current use of marijuana. The influence of alcohol and drug abuse can affect an individual's ability to remember to take his or her medication. If people are intoxicated and in a social gathering, they will also feel less inclined to consider their HIV status and hence remember their medication. Such social gatherings will also contribute to a person being non-compliant, especially if they have not disclosed their status (Shernoff, 2001).

Substance abuse is viewed as a correlate of sexual risk practices in HIV-positive individuals, and thus may serve as an indicator of health-compromising behaviours, including treatment adherence (Kalichman & Rompa, 2003). In addition, it is also hypothesized that certain drugs and alcohol may interact with the antiretroviral medication, rendering the medical regime less effective.

Rothlind et al. (2005) stated that the occurrence of alcohol consumption in the face of HIV-infection is associated with an increased risk of neuropsychological impairment and that this would impact a patient's capacity for adherence. Some studies have found that participants using alcohol and/or drug use were associated with worse adherence levels than those who did not use alcohol and/or substances (Berg, Demas, Howard, Schoenbaum, Gourevitch & Arnsten, 2004; Heckman, Catz, Heckman, Miller & Kalichman, 2004). However, Ware et al. (2005) felt that the stereotyping of alcohol and substance users as poor adherers to medication underemphasizes the non-alcohol/drug-related factors affecting adherence, hence contaminating one's assessment of their capacity for adherence. This means that it cannot be assumed that an alcoholic will be unable to adhere to ART. He or she may have an excellent support system or a strong will to live that may contribute to his or her adherence.

*Sexual practices*

The Kalichman and Rompa study (2003) advocates a relationship between adherence and sexual practice. Patients who reported a significantly greater number of sexual partners, greater rates of unprotected vaginal intercourse, sexually risky behaviours, including less protected intercourse with partners who were HIV negative or of unknown status were also patients who had been non-adherent.

**Conclusion**

High levels of adherence thus becomes an issue of complexity due to the varying psychological, treatment related, behavioural, social and demographic variables that intervene. Though perfect adherence becomes unrealistic, due to the multiplicity of variables involved, the literature has proven that it is not impossible (Chung et al. et al., 2003).

Though, internationally, a wealth of information on antiretroviral adherence does exist; there is little, if any, literature available on antiretroviral adherence in the South African context. To generalize the results of international research to the South African population would be naïve, since South Africa comes with its own considerations of poverty, low education opportunities and the poor health-care services offered to many South Africans (May et al., 1998; Seedat et al., 2001).

It has been thought that poverty is synonymous with poor levels of adherence and many may argue that this has been one of the long-standing excuses justifying the delay of large scale antiretroviral implementation. Surveys in Khayelithsa (South Africa), Senegal and Uganda have proven that African patients on antiretroviral medication have been found to have compliance levels equal to their first world counterparts, with extreme poverty being paradoxically responsible for their high adherence levels (Oransky, 2003). Such shattering of beliefs implies that researching antiretroviral adherence in South Africa is essential if one is to plan successful treatment interventions for our unique population.

## CHAPTER 3: METHODOLOGY

The research study aimed to be exploratory in nature and sought to explore what experts and patients perceived to be the barriers to adherence to ARVs and as a consequence generate recommendations for the improvement of adherence levels. The study was directed at understanding the experiences of those currently on ART, as well as those that were deemed to be closely involved with ART intervention in a professional capacity. This understanding was sought through the investigation of patient and expert opinions and recommendations regarding adherence to ART, using semi-structured interviews and the exploration of the themes emerging from these interviews.

### DEFINITION OF KEYWORDS

Before presenting the methodology of the research, it is necessary to clearly define some of the commonly used words in the study.

*HIV/AIDS expert:* For the purpose of this study, an HIV/AIDS expert is defined as someone who has worked in an HIV setting, particularly with antiretroviral medication, for at least two years. It was felt that two years was a sufficient amount of time to have been exposed to this specific setting in order to generate informed opinions and recommendations concerning adherence to ART.

*HIV/AIDS patient:* For the purpose of this study, a HIV/AIDS patient is defined as someone who has been on antiretroviral medication for at least six months. The researcher felt that six months was an adequate amount of time for the patient to have experienced/ not experienced side effects associated with the ART as well as witness/ not witness improvements and hence able to comment on these dynamics.

*Antiretroviral medication:* Antiretroviral (ARV) medication acts directly on HIV to prevent it from replicating. It does not kill the virus and hence does not function as a cure but rather serves to keep the virus at a low level in the body (Gallant, 1995; Jenkins, 2003; Maenza, 1998).

*Adherence/ Compliance:* Though two expert participants highlighted a significant distinction between the two words ‘adherence’ and ‘compliance’, for the purposes of the research, the two words were used synonymously. Adherence or compliance is defined as

the extent to which the time history corresponds to the drug regimen (Chung et al., 2002). Hence, adherence refers to how closely patients follow their treatment programme (Haynes, 2001).

## RESEARCH QUESTIONS

On a broad level, the research initially sought to explore the opinions and recommendations of experts and patients regarding antiretroviral adherence in South Africa. As the research unfolded however, it appeared that the emerging themes were organised around four questions and these are as follows: (a) What are patients' perceptions of the barriers to antiretroviral medication adherence? (b) What are experts' perceptions of the barriers to antiretroviral medication adherence? (c) What are the patients' recommendations regarding the improvement of antiretroviral medication adherence? (d) What are the experts' recommendations regarding the improvement of antiretroviral medication adherence?

## RESEARCH DESIGN

This study employed the semi-structured interview as the data collection strategy and thematic content analysis as its method of data analysis. There was no control group, the independent variable was not manipulated and randomisation was not employed. Thus the proposed study can be classified as a qualitative, exploratory design. No initial hypotheses were proposed, as hypotheses could only develop after the interviews had been analysed.

## PARTICIPANT SELECTION

The original intention of the research was to interview only experts as to their opinions and recommendations regarding antiretroviral medication compliance. However, taking cognisance of the emphasis of local knowledge proposed by the community psychology perspective, it was decided to include patient participants in the sample. The underpinnings of local knowledge is that communities possess systems of knowledge, encompassing their experiences and coping strategies and that this forms the basis of their participation in the research process (Seedat, Duncan & Lazarus, 2003). Following

this, it appeared to be almost 'common sense' that the patient interviews would be integral in understanding the actual experience of taking ART.

Participants were recruited by means of non-probability, purposive sampling. In keeping with the objectives of this study, the sample consisted of seven patients currently on ART and four experts working within the field of HIV/AIDS. The terms expert and patient have been defined under the heading of 'definitions of key words'.

**The experts**

The four experts were chosen from different health-care institutions within the Johannesburg and KwaZulu Natal regions. All participants had worked within the field of HIV/AIDS-healthcare or research for a minimum of two years. A description of their experience in the field of HIV/AIDS healthcare or research is as follows.

Expert 1 was a counsellor and coordinator of an adherence programme at a public hospital - based antiretroviral clinic. She has been trained specifically around issues pertaining to adherence to ARVs. Her interventions are adherence focused and are pitched at both an individual and group level. She has been involved in the HIV/AIDS field for four years.

Expert 2 was a project manager at the Treatment Action Campaign (TAC). The project aims to provide sponsorship and treatment support to HIV-positive individuals that are not receiving ARVs from the government roll-out sites with an end goal of aiding them to achieve long-term access to ARVs. He has also worked as a home-based care worker and has also been involved in providing psycho-education pertaining to ARVs around the country. He has been involved in the HIV/AIDS field for three years.

Expert 3 was a medical doctor who heads an antiretroviral roll-out programme. He liases between international organizations and the Department of Health in an effort to attend to the various needs of the HIV-positive community. He has been involved in HIV/AIDS related work for more than five years.

Expert 4 is a psychologist and social researcher. He is involved in the World Health Organization's (WHO) '3x5 Initiative'. He is also a member of one of the science councils in South Africa. His work focuses specifically on mental health issues pertaining

to HIV/AIDS with one of them being the effects of mental health issues on adherence to medication. He has been involved in the HIV/AIDS field for well over two years.

**The patients**

The seven patients were chosen from two antiretroviral roll-out programmes in South Africa. These patients were already part of established antiretroviral rollout programmes. All patients were above 18 years old and reported to have been on ART for at least six months. The patients all presented as being cognitively able to participate in the interviews. The demographic information of the patients is tabulated below. (See Table 1 and 2)

Table 1. Demographic information

| | AGE | SEX | OCCUPATION |
|---|---|---|---|
| Patient 1 | 28 | Male | Unemployed |
| Patient 2 | 38 | Male | Unemployed |
| Patient 3 | 32 | Female | Counsellor |
| Patient 4 | 35 | Female | Counsellor |
| Patient 5 | 35 | Female | Unemployed |
| Patient 6 | 45 | Female | Unemployed |
| Patient 7<br>Patient 8 | 29 | Male | Educator |

Table 2. Medicine regime

| | DURATION OF TREATMENT | DOSAGE (No. Of Tablets or Fluid/ Day) | LEVEL OF ADHERENCE |
|---|---|---|---|
| Patient 1 | 6 months | 7 | Never forgets. |
| Patient 2 | Not stated | 5 | Never forgets. |
| Patient 3 | 7 months | 12 | Never forgets. |
| Patient 4 | 12 months | 4 | Has forgotten once. |
| Patient 5 | 7 months | 45 ml of fluid | Has forgotten. |
| Patient 6 | 60 months | 6 | Has forgotten. |
| Patient 7 | 6 months | 5 | Never forgets. |

**THE SEMI-STRUCTURED INTERVIEW**

In exploratory research, the research area is one that is generally so unfamiliar that it becomes difficult to schedule a structured interview (Welman & Kruger, 2001). As

previously discussed in the literature review, antiretroviral medication has only been introduced recently to the public health sector. Hence, the field is fairly new and the semi-structured interview seemed to be the best way to formulate research questions and generate hypotheses for further investigation.

The semi-structured interview differs from the structured interview in that the researcher merely suggests a theme of discussion and further questioning is largely determined by what the participant brings to the interview (Welman & Kruger, 2001). Since the research aimed to capture the experiences of patients and experts with regards to ART, it appeared that such a technique would extract the participants' experiences that were significant to them, thus adding to our understanding of their interaction with the medication. This type of interview technique is coupled with a conscious effort on the part of the researcher to explore emotions and convictions about the theme being discussed, thus adding to the richness of the experience being explored (Welman & Kruger, 2001).

This semi-structured interview used was developed based on the existing literature and sought to explore themes relating to adherence to antiretroviral medication. Two separate interviews for the experts and the patients were developed. Each interview was developed in a manner that allowed the researcher to tap into opinions that that specific category of participant could offer. In addition, much consideration was given to language usage in the development of the interview schedule. Patient schedules were comprised of questions that were structured in a simpler manner, to allow for easier translation if necessary. Both interview schedules were piloted to investigate any intrusiveness or inappropriateness (Refer to appendix A and appendix B).

**RESEARCHER REFLEXIVITY**

Another factor that distinguishes the semi-structured interview from the structured interview is the fact that the structured interview requires that researchers distance themselves, adhering strictly to the planned interview schedule whereas in the semi-structured interview, the researcher interacts with the participant (Welman & Kruger, 2001). Such interaction is grounded in the anti-positivistic framework and means that the researcher takes with him or her, his or her own experiences that also influence the

interview process. According to Seedat et al. (2003), the researcher's experiences are no more or less important than the participant's and are acknowledged as a real contributor to the research process.

The researcher has always had an interest in HIV/AIDS and in the scientific attempts that have been made to find a cure. In particular, the researcher has been fascinated with the concept of a virus that is able to manipulate the body's own immune system cells to replicate and though there has been extensive research conducted on the virus, a cure has yet to be found. The above interest in HIV/AIDS spurred my decision to conduct research in this field. With the controversy around access to ART in the public health sector being highlighted in the media for months leading up to the commencement of the research, and the stringent adherence necessary for ART to be effective, I became interested in what factors would affect adherence to ART.

During the researcher's psychology internship, she counselled many HIV-positive patients and after listening to their struggles, her passion for wanting to contribute to helping these patients heightened. In addition, her experience of working in a psychiatric ward exposed her to barriers to adherence within the psychiatric setting. Her desire to contribute in some way in the HIV/AIDS field, and her exposure to HIV-positive patients and issues around adherence continued to fuel her interest in adherence to ART.

The researcher's experience as a Masters' counselling psychology student, meant that she brought to the interview the experience of basic counselling skills, which led to the exploration of the participants' feelings regarding their experiences with ART. It was felt that the researcher's natural interaction with participants was one of unconditional positive regard that facilitated rapport building, thus allowing participants to openly share their experiences with the researcher. Though the research was conducted as part of the fulfilment for a Masters psychology degree, it must also be acknowledged that the research area has a strong medical aspect to it. It was felt that the researcher's previous experience as a medical student also allowed the exploration of these aspects. The experience of interviewing patients on ART and experts was a rich and rewarding experience and it is hoped that this research does help people to understand the barriers to adherence to ART.

## PROCEDURE

### Gaining access to the expert participants

All the experts were contacted directly. Firstly, permission to conduct the interview with the experts was obtained. This was done both telephonically and through a letter that outlined the rationale and aims of the research, assured confidentiality and requested written consent to continue with the research.

### Gaining access to patient participants

Firstly, the relevant facilities at which the patients received their treatment were contacted. Then, permission to interview the patients, from the relevant facility was obtained. This was done both telephonically, and through a letter. This letter outlined the rationale and aims of the research, assured confidentiality and requested written consent to continue with the research.

Once permission from the relevant facility was obtained, the potential participants were approached via the social worker or counsellor at the facility to ascertain whether they wanted to participate in the study. The potential participants were given informed consent forms to ensure that they understood the nature and purpose of the study. At this stage, a translator was utilized where necessary, to ensure that the patients understood the content of the informed consent form. Only once participants agreed to participate, were the interviews conducted with the participants. Upon receiving permission from the participant, the interviews were audio recorded.

## DATA ANALYSIS

The interview tapes were transcribed by an administrative worker. These tapes were transcribed verbatim, with no additions or omissions made to the text. English was not the first language of some participants and even though their narratives comprised poor grammar, this was still captured verbatim. Some emphasis was also placed on the manner in which participants shared their information, hence dramatic pauses were also captured in the transcription. Once the administrative worker had completed transcribing the material, the researcher then checked the transcribed material against the original tapes to ensure the accuracy of the transcription.

The method chosen to analyse the interviews was a thematic content analysis. Thematic content analysis is a technique of analysis that provides an objective and systematic presentation of interview content by identifying themes within the interviews (Titscher, Meyer, Wodak & Vetter, 2000). With antiretrovirals being only currently introduced to South Africa, the issue of adherence to antiretroviral medication is thus a fairly new one and it was the aim of this research to ascertain what experts and patients perceive as possible barriers to adherence to antiretroviral medication as well as their recommendations for improving adherence. Content analysis was thus chosen because it provided an expansive view of the available information. Though this technique was limited in its ability to delve deeper into issues, for the purposes of the proposed, primarily exploratory research, it did suffice.

The data were categorized into themes as a starting point of the research. These categories were initially developed by two separate individuals and then matched to ensure the accuracy of the categorisation. The process of categorising the information began with extracting similar themes that emerged from the interviews. This was done separately for the patients and experts. The themes were then re-analysed and it was found that certain themes could be grouped together. This process of systematically conceptualising the different categories was done several times and resulted in an end product of four broad themes: experts' perceptions of barriers to adherence, patients' perceptions of barriers to adherence and experts' recommendations for improving adherence and patients' recommendations for improving adherence. Numerous sub-themes were then discussed under these broad themes, as will be presented in the next chapter.

## ETHICAL CONSIDERATIONS

The starting point of ensuring the ethical integrity of the research process was to gain ethical clearance from the University's Medical Ethics Committee. The application for ethical clearance was drafted with the assistance of the ethics coordinator of one of the antiretroviral roll-out sites. This ensured that all research procedures were in keeping with the ethical requirements stipulated by the hospital, as well as the university.

Contact with the participants and the associated facilities only commenced once ethical clearance from the university and permission to commence with research at the facilities had been obtained. All the participants were notified both verbally and by means of an informed consent form of the nature of the study. In addition, their permission to conduct the interview, as well as their permission to audio record the interview were requested. Interviews with the participants only commenced once this was achieved.

The informed consent form given to the participants informed them of the following: (a) The decision to participate was entirely voluntary, particularly, for patient participants, who were informed that the decision to not participate would not affect them in any way, especially with regard to their inclusion in the government antiretroviral roll-out programme.

(b) All responses were confidential. The participants were also informed of limited anonymity, due to the face-to-face nature of the interview. However, they were assured that there was no reason for their names or any other identifying particulars to be disclosed.

(c) Due to the sensitivity of HIV/AIDS, the participants were allowed to answer only those questions that they were comfortable with and for any reason were allowed to terminate the interview. This was imperative for two main reasons. Firstly, patients who are on antiretroviral medication often suffer side effects and it was felt that it would be inhumane to expect a patient to endure a 20 minute interview if they were not feeling well. In the interviewing process, two patients did terminate the interview prematurely due to physical ailments. These interviews were not included in the data analysis. Secondly, many participants began to share personal life stories that had either motivated their decision to work in the HIV/AIDS field or had motivated their levels of adherence. These stories were often emotive. It was felt that patients needed to feel that they were in control and did not feel emotionally overwhelmed during their narratives.

(d) Should the interview have initiated any surfacing of unpleasant emotions and should the participants have needed further counselling, the participants would have been referred for further counselling. Again, due to the sensitivity of the content discussed, the researcher only conducted interviews at facilities where there were prompt, counselling referral systems set in place.

(e) No deception of any nature was used in the research process, thus participants were informed of the exact nature of the study.

(f) The interview was recorded only once permission had been obtained from the subject. This considered those participants who felt uncomfortable being audio recorded for whatever reason.

(g) All interview tapes were destroyed upon completion of the research. The original transcripts were retained but all the indices of identification had been removed.

Other ethical measures that were implemented during the research process included the manner in which patients were approached. Patients were approached by the social worker at each roll-out site, for permission to participate, as opposed to being approached by the researcher. It was felt that this would lead to patients feeling less pressurized when deciding whether they wanted to participate or not. The patients were then given appointments for the interviews approximately one week later. This gave the participants time to decide if they still wanted to participate or not. In addition, the researcher's contact details were given to every participant. They were encouraged to contact the researcher should they have had any queries regarding the research or should they have needed any counselling after the interview.

## CHAPTER FOUR: PRESENTATION OF FINDINGS

This chapter presents the analyses of the expert and patient data. These findings have been divided into two main sections, namely expert data and patient data. The analysis of both the expert and patient interviews revealed two major themes, namely barriers to adherence and recommendations for improvement. The expert data are presented first, beginning with the experts' perceptions of barriers to adherence, followed by the experts' recommendations for improving adherence. Secondly, the patient data are presented beginning with the patients' perceptions of barriers to adherence, followed by the patients' recommendations for improving adherence. Finally, a discussion of the differences between the expert and patient accounts is presented.

### EXPERT DATA

This section presents the themes emerging from the expert interviews. The experts' perceptions of the barriers to adherence are discussed first, followed by a presentation of their recommendations for improving adherence.

#### Perceptions of barriers to adherence

Prior to engaging with the sub-themes that emerged, a quote from Expert 3 is considered.

> There have been many studies done. We try to predict who is going to adhere and who is not going to adhere, and what they show is that doctors are the least competent people in the way to decide who will adhere. When I say doctors, I include professional health care providers. We might be tempted to think that the patient, who regularly comes to the clinic here, regularly makes it his prerogative, answers all the questions right, and etc; that he is going to take responsibility at home, but that has not proved true at all (Expert 3).

The above account is in keeping with the literature that demonstrates that clinicians have difficulty predicting a patient's level of adherence (Kimmerling et al., 2003). Clinicians have been found to overestimate patients' levels of adherence and have difficulty detecting poor adherence (Miller et al., 2002). The difficulty of health care-providers to predict levels of adherence emphasizes the complexity of the issue of adherence. One's levels of adherence appear to be influenced by a myriad of factors.

Some sub-themes of barriers to adherence did emerge from the Expert interviews and these are discussed below.

*Human error*

The sub-theme 'human error' was used to classify those attributes of poor adherence that are largely errors of human nature. The experts identified human error as one of the factors affecting poor compliance. Human error encompassed forgetfulness, as well as the tendency to follow others' opinions even though they may not be the most sound.

The experts' reports demonstrate a common problem; the frequency of which probably occurs more than anyone would like to admit.

> And also what I have seen, is that other people they just forget to take their medication you know. They just say, "I forgot to take the medication" (Expert 2).

The above account highlights forgetfulness, pure human error, as an obstacle to compliance. This is supported by pilot studies conducted by the Gay Men's Health Crisis (1997 & 1998) that highlighted forgetting to take a dose as one of the most widely reported reasons for non-adherence among homosexual men, as well as heterosexual men and women (Shernoff, 2001). One needs only to consider how many individuals forget to take their antibiotics to highlight the difficulties of remembering to take medication.

It must be acknowledged that there are probably underlying reasons for forgetfulness. Forgetfulness may be related to having to hide the medication, which stems from a lack of disclosure or, as will be discussed later, forgetfulness may be a means of avoiding the side effects of the medication.

Of consideration though, is the fact that patients vary in their levels of forgetfulness with some patients maintaining a 100% level of adherence. An extension of this idea would lead one to explore whether the concept to be examined is one of forgetfulness or one of wilfulness and it would be interesting to investigate if there exists a relationship between the two.

Even though patients have been educated around issues pertaining to adherence, some are influenced by messages that conflict with the ideas of medical professionals and

sometimes patients relapse as a result. Below follows an attempt to explain this behaviour.

> I am a Christian, I am making an example and I am suppose to know what to do and all those things, but sometimes you are in a situation when you are faced with people that believe so much in cultural things and they tell you about ancestors…Which religion? Should I follow the way I always do, kneel down and pray to somebody I do not know? … But at the end of the day, it is up to you the individual to choose (Expert 1).

Expert 1 felt that it is human nature to reason and that this accounts for why people tend to listen to the advice of other people that are generally less qualified than the medical professionals. She used the analogy of being Christian in a culture that believes in ancestral traditions. Expert 1 verbalized that even though she knows what it means to be a Christian and is fully aware of all the commandments and rituals, there is still a side of her that occasionally is influenced by the ancestral tradition. From this, she inferred that no matter how strong one's belief systems are, it is human nature to question and seek alternatives and that this may explain why patients are persuaded by the ideas of those less knowledgeable than the medical professionals.

*Lack of disclosure*

Disclosure refers to the admission of an individual's positive HIV status to those around him or her. This is problematic, as the disclosure of one's status can often lead to stigma and discrimination (USAids, 2005). The discourses associated with a positive status are generally related to a fear of contamination and being perceived as threatening, especially by those with a poor knowledge of the disease (USAids, 2005). Though fraught with difficulties, disclosure can open up the doors to support from one's family and friends. It is granted that the physical and psychological stressors of HIV could be complicated and accessing emotional support could serve as an important coping mechanism during this time.

The expert participants identified disclosure as a factor that influenced the individual's level of adherence. The fact that all expert participants highlighted the lack of disclosure as an obstacle to adherence emphasises its significance to adherence in the HIV/AIDS context.

> Certainly I think that issues around whether the person has disclosed or not and the reasons why they have disclosed or why they have not disclosed might well be related to who they are and to what kind of approach will they have. And certainly issues of disclosure are going to determine whether a person is going to adhere or not adhere. So I think disclosure is one important issue (Expert 4).

The experts cited that the stigma associated with ART accounted for lower levels of adherence in ART, as opposed to other medications like antibiotics. This is supported by a study conducted in a clinic in KwaZulu-Natal (Karim, Karim, Friedland, Lalloo & El Sadr, 2004). The main reason given for participants not disclosing their status was that they felt that those around them would not react positively. They felt that as long as there was no cure for the disease, there would continue to be stigma associated with it (Karim et al., 2004). Kumarasamy et al., (2005), Rowe et al., (2005) and Weiser et al. (2003) supported this, attributing the fear of stigma as a contributor to poor adherence.

The association of ART with an HIV-positive status means that adherence to the regime is an admission of a patient's status and this may increase his or her vulnerability to stigma and discrimination. This was supported by Expert 2, who likened the act of taking the medication to condom usage, which he perceived as a disclosure of one's status. From a practical point of view, Expert 1 also stated that people are also more likely to forget their medication if they had not disclosed their status. This appears logical as people would be more likely to forget their medication if they were taking their medication secretly.

> If somebody hasn't disclosed to their immediate family or to any person who is close to them, it is very difficult for them to take their medication (Expert 2).

> They are hiding the treatment, and again this thing of, if you are hiding the medication, definitely you are going to forget. The chances are, even if you wont forget, you wont get a chance to take the treatment, because there will be questions asked (Expert 1).

Expert 3 was adamant on meeting a member of the individual's family before including the individual in his clinical trial group, thus insisting on disclosure as a means of ensuring adherence. This is the same line of thought shared by the Department of

Health (DOH), as disclosure is deemed to be an important psychosocial consideration in the patient selection criteria. The DOH recommends that patients need to have disclosed their HIV-status to at least one family member or friend or need to have joined a support group (DOH, 2004). Though the merits of this lie in ensuring that the patient has the support of their family, one could also argue that insisting on disclosure before allowing access to ART could in itself be viewed as discriminatory. One would need to consider the effects of stigma and discrimination associated with a positive status and gauge whether the stressors associated with this weigh against the support that a person may or may not receive upon disclosure.

*Stigma and discrimination*

Very closely related to the above theme is that of stigma and discrimination. Stigma and discrimination around HIV is one of the most probable reasons for the lack of disclosure of one's status. This is probably because of the power of the stigma associated with the disease (Liechty & Bangsberg, 2003). The relevance of stigma and discrimination as an obstacle to adherence is seen in the expert reports that highlight the fear of HIV-related stigma and discrimination as a mediator of adherence. This is supported by the literature that highlights stigma as a mediator of poor adherence (Karim et al., 2004; Kumarasamy et al., 2005; Rowe et al., 2005; Weiser et al., 2003). Two strong sub-themes that emerged from the expert accounts were stigma and discrimination in intimate relationships and a lack of support from the family as a result of stigma and discrimination.

*Fear of stigma in sexually intimate relationships*

The issue of stigma and discrimination related to HIV in intimate relationships is very intense, probably because intimacy means that you are essentially placing yourself at risk of contracting the disease. Hence, it follows that those who are HIV-positive would be discriminated against because of a fear of infection. Expert 4 explained this in his account.

> I am thinking of Australia and in the States where especially where in gay clubs and things, people would comment, on ART. "Those people, I will not make a move on tonight." And you can actually see, you can pick them up, through extended fats in different parts of the body. So, you immediately become

> discriminated against because you are on ART, and the people don't want to get involved with you (Expert 4).

The above account refers to one of the side effects of ART, lipodystrophy, which is the accumulation of fats around certain parts of the body (Corless et al., 2005). This allows one to identify who is on ART, which fundamentally is a disclosure of one's HIV status and can lead to discrimination. Thus, the lipodystrophy serves as a visual cue that someone is on ART and hence is HIV-positive. The associated discrimination arises from a fear of infection. The surveyed literature found that lipodystrophy impacted on one's quality of life and that there was an association between this and adherence levels (Corless et al., 2005).

> With all the work that I have been doing, the whole issue of relationships have come up very, very strongly in interviews with positive people. That getting hold of a person is not easy at all, if you positive. Partly because they don't want to get involved with you but partly they and partly because you don't want to infect other people, and even if you do take protection, obviously your risks are higher and so on. If I like you, especially if I like you, I don't want to infect you. And it creates difficulties in ongoing relationships, and it creates severe problems in getting involved in a relationship (Expert 4).

Expert 4 went on to explain that for the above reasons, some patients opt to be involved only with other HIV-positive people. This, however, is associated with its own difficulties of infecting each other with different strains of the virus etc. Another scenario that was highlighted was that even if one was to be in a relationship, where safe sex precautions were exercised, if the two parties had to spend an entire day together, the positive status of the person in question would be disclosed by virtue of them having to take the ART.

Thus, the act of taking medication is in itself an admission of one's status and could open one up to discrimination. In some cases, the penalties of discrimination can be severe and one can see why someone would fail to take their medication in an effort to conceal their status. Such opinions were supported by the literature that highlighted specific challenges related to the gay community. In particular, Shernoff (2001) explained that if an individual were to be in a social setting with the end goal of sexual

gratification, he may choose not take his medication with him as his HIV-positive status is the last thing that he would want to be reminded of.

In sum, it can be seen that the act of taking medication is an admission of a person's status and if the stigma associated with HIV is considered, especially in sexually intimate relationships, it can be seen that the fear of stigma, particularly with regards to sexually intimate relationships could be considered to be a barrier to adherence to ART.

*Lack of support resulting from stigma and discrimination*

The diagnosis of HIV is associated not only with physical complications, but psychological stressors as well (Malan, 2003). From this it follows that social support would be integral to the effective coping of the HIV patient. The stigma and discrimination associated with HIV affect whether an individual discloses his or her status. The choice to keep his or her status a secret has a direct effect on the level of support that individual is able to access. Hence, the lack of support arising from a fear of stigma and discrimination is discussed as a barrier to adherence.

> Poor social support and emotional support from family members or the lack of having family members are also important things in the adherence. We actually ask our patients to bring with them a family member to the adherence classes, so that we can include the family member as part of the support team and that is one thing that has been proven. That there is better accuracy when he is not doing it alone, but when there is a family member that knows what is happening (Expert 3).

The expert participants demonstrated that the level of adherence is enhanced when a family member is able to render support around ART. The rationale behind this is that the family member could remind the person to take his or her medication as well as listen and provide emotional support should the person raise any concerns regarding the medication. This is supported by the study conducted by Karim et al. (2004). Those patients, in the study, that had disclosed their status to their family, had done so for the primary reason of accessing support.

> If somebody hasn't disclosed to their immediate family or to any person who is close to them, it is very difficult for them to take their medication (Expert 2).

The experts argued that the inability to have a level of family support that allows the person to take his or her medication freely is a factor that could serve to discourage adherence. This is probably because the patient would have to hide his or her medication thus increasing his or her chances of forgetting. This is supported by the Department of Health, (2004) and Malan (2003), who advocate the disclosure of an individual's status to his or her family, in an effort to aid their adherence strategies. The expert participants also suggested that stigma in the communities arises from a lack of knowledge of issues pertaining to the virus.

*Psychological Factors*

The experts verbalized the importance of psychological factors as a mediator of adherence. Expert 4, whose work focuses directly with the relationship between psychology and HIV emphasized this.

> I think that a person's mental health status is quite important to whether they actually do decide to continue with their medication or take the medication or not. And why upon difficulties it is to differentiate between mental health status and personality trait. But, I think if for example, somebody does not really care much about themselves and about their futures and their lives, and whether they live or don't live… I do think that people's will to live is an important one and belief, in the face of adverse circumstances; that they can survive (Expert 4).

> Obviously there are personal issues, which determine whether a person is going to take their medication or not. I don't know if there are personality traits as such…but maybe if one's looking for a personality trait, maybe it is perseverance (Expert 4).

The expert participants highlighted mental health status as being important in determining whether patients would take their medication or not. This is significant, as HIV is associated with various psychological disorders (Ickovics & Meade, 2002; Kalichman & Rompa, 2003; Malan, 2003; Moosa et. al., 2005; Shernoff, 2001; Yun et al., 2005) and it is hypothesized that as these worsen and one's mental health status deteriorates, as in HIV-associated dementia (Malan, 2003), this would make it more difficult for the patient to be adherent. In addition, the depression associated with HIV

was also highlighted as being a mediator of adherence (Phillips et al., 2005; Turner, Laine, Cosler & Hauck, 2003; Yun et al., 2005).

The experts could not associate a certain personality profile with a predisposition to good or poor adherence. This is in keeping with the literature that did not find personality to be a predictor of adherence (Burke et al., 1998). However, they did mention that 'perseverance' was a trait that one may find in those who do adhere to their medicine regimes. This could be interpreted in light of the fact that the patient knows that the ART is not a cure and is a life-long commitment, sometimes fraught with side effects, yet they are still willing to commit to the treatment.

*Specific Communities*

From the analysis, it appears that specific communities may impose their beliefs and ideals upon an individual and that this may impact on the individual's capacity for adherence. Such issues within the gay community have already been discussed (under stigma and discrimination). In addition, the expert participants raised concerns regarding the prison community. Two further categories that emerged under this sub-theme were the struggles within specific communities e.g. prison community; and cultural factors that may influence individuals. Cultural factors were categorised under this broad sub-theme of 'specific communities', as it was perceived as being a community-specific phenomenon.

*The Prison Community*

The experts highlighted that the prison community was a community that had to confront specific barriers with regards to ART adherence. This is supported by the literature that stipulates that the prison environment has specific characteristics that directly impacts adherence levels in HIV-positive patients (Blanco et al., 2005). Expert 2's particular interest in this community could be accounted for by the fact that this is one of the communities that the TAC has specifically focused on with regards to access to ART. Though prisoners have access to ART, it appears that their levels of adherence are dependent on the wardens in charge of them. This scenario raises complex issues, as outlined below.

> Well, a recent case is that there are people who are in the prisons which is a very different scenario. People take their medication but when they have to go back to get their follow up, the prison wardens don't bring them back. Then, a week or two passes without them having their medication, which is a great challenge now... the people who are working on this side, who are part of the TAC's project, those practitioners ensure the distribution of the medication… Their allocation are also taken and given to other people, which is very, very bad. And sometimes, the prisoners, they work shifts, one was working in the morning that and the prison warden gave his medication at 9.00 in the evening, so they don't give the prisoners their medication at the right time. They even forget (Expert 2).

Thus, the lack of adherence in the prison community appears to be linked to powerlessness, as the prisoners are entirely dependent on the prison wardens for their medication. The fact that prisoners are not taken for follow-ups at the correct times creates problems as this means that there is no continuity with regards to their treatment regime. Of specific concern is the allocation of medication to other individuals as generally the medication regime is tailored to the specific needs of that patient and may not be suitable for someone else. Such practices could lead to the development of drug resistant strains of the virus (Chung et al, 2002; Ickovics & Meade, 2002; Kalichman & Rompa, 2003; Kimmerling et al., 2003).

The challenges facing the prison community above, raise the issue of the complexity of concerns specific to the different communities. The literature surveyed and data analysis also highlighted gay communities to have specific issues of stigmatisation that impact on levels of adherence (Shernoff, 2001), as discussed under the theme of stigma and discrimination. Such community-specific concerns require further investigation and consideration in the development of adherence-related interventions targeted at these groups.

*Cultural Factors*

The expert participants made reference to cultural factors that may influence patients' levels of adherence. These cultural practices appear to be specific to particular

communities. These cultural practices are discussed below under the sub-headings of gender and traditional medicine and other practices.

*Gender*

The issue of gender in relation to the HIV/AIDS scenario cannot be denied. The literature surveyed highlighted gender inequalities as a reason for women's vulnerability to infection (Smith, 2002). Even though females have been known to engage in more health-seeking behaviours (Mansfield, Addis & Mahalik, 2003), the literature did not support women as being better at adherence than men. The literature did, however, support differences in the adherence levels of males and females. Berg et al. (2004) found that there were definite social and behavioural factors between the genders that accounted for the different levels of adherence. Women were also found to be more likely to be diagnosed with depression and this was seen to mediate adherence levels (Turner et al., 2003).

The experts felt that in black cultures men took a 'blaming' stance toward women disclosing their HIV-positive status. This is assumed to contribute to a fear of disclosure among women. Expert 1 narrated an instance of a patient who was too ill to fetch her medication and had to get her husband to fetch it without him knowing. This brings attention to the measures that a patient will take in order to avoid disclosure. She had to disguise the ART as a gift to prevent the husband from being suspicious.

> So I think this thing goes back to culture. Zulu, Sotho, all of us blacks, some of us are similar, there's this thing that when a woman discloses something serious to the man, the man will put the blame back to the woman, who brought shame to his family, so they are scared to tell them (Expert 1).

Expert 1 declared that black men, did not support women taking the ART. Her rationale for this was that men were unable to face challenges and battled to confront obstacles that they could not understand.

> You know, as far as I know, males like other people are very scared to face challenges. They are very afraid, they don't like challenges, especially life threatening challenges, you can rather come with a gun or a knife, so they can fight, but battles that are

> not fought, with weapons, they are scared of those things, confrontations and all those things (Expert 1).

Thus, the experts highlighted that there exists a gender dynamic around adherence in black cultures. It was felt that male attitudes may hinder women from adhering to their medicine regimes. However, their reports did not account for which gender would be better at adherence. The surveyed literature suggested that men were better at adhering to medication than women but this was attributed to higher rates of depression among women and depression was conceptualised as being a mediator of adherence (Turner et al., 2003).

*Traditional Medicine And Other Practices*

In South Africa, many individuals lean toward traditional remedies to treat medical ailments and this includes treating their HIV-symptoms (Manci, 2005; Tjoa, 2005). Traditional medicine consultation encompasses two broad categories, those who consult with the ancestral spirits in their diagnosis and those who use their own knowledge of organic resources e.g. herbs to diagnose and treat illness (Cole, 2005). This appears to be a more culturally accepted practice than conventional medicine and for seventy percent of the African population, may be their first attempt to seek help (Homsy, King, Balaba & Kabatesi, 2004). The competition between Western medicine and traditional medicine has been deemed to be a barrier to adherence (Rowe et al, 2005). These opposing health care systems have not been found to foster a collegial relationship, which leads to internal conflict in those patients who subscribe to traditional medicine (Tobias, 2001).

All expert participants raised issues around traditional medicine as a barrier to adherence, thus highlighting the significance of this practice as a consideration in adherence.

> The medication they get from traditional healers are still much more accepted and much more in line with culture when compared to the ARVs that the hospital gives out (Expert 3).

Expert 4 highlighted that the manner in which people perceive health and disease is a key mediator in how they confront their illness and subsequently how they will seek to remedy their illness.

> …. I think that the question of 'Why me?' and 'Why is this happening?' are very different from people who have traditional beliefs about health and illness. And that if you say, it maybe because of such a witchcraft or such a displeasure of the ancestors or whatever then you are going to take a different approach as to why I got ill and therefore probably a different remedy to getting yourself better (Expert 4).

The above account is integral in understanding why individuals from certain cultures may opt to seek traditional cures, as opposed to ARVs that have been scientifically proven to be effective. At the foundation of such a decision lies the instilled cultural belief of what is perceived to have triggered the illness.

Expert 1 discussed the situation of a person visiting his or her rural home and being persuaded to take traditional cures. This ties in with the sub-theme of conflicting messages that is discussed later.

> We've got this person or, we have 'Mr. So and So', who can do wonders, we have this and this and this." And the pressure will be on you. And, if you don't take that because whether you die, don't tell us, because you refused what they tried to give you. Some of the people are so dependent to their husbands or their in-laws that they find really they can't refuse and they have to follow what they say (Expert 1).

It appears that the dependency on these family members puts pressure on the individual to succumb to the pressure of trying alternative cures. This could be because the alternative cures are culturally a more accepted method of treating illness, especially if the illness is perceived to be the product of witchcraft or other spiritual interventions. The decision to listen to family members as opposed to the medical professionals is an area that warrants further research. It is hypothesized that a respect for one's elders, an acknowledgement of the wisdom of one's elders and financial dependence may mediate such decisions.

The experts raised the issue that traditional medicine often conflicts with modern medicine. This does not only refer to the perceptions of illness underpinning these

different interventions but also on a more practical level. The two approaches appear to differ in how they perceive their remedy to work.

> …if you go to traditional healers, some of them will tell you that this is the things that make you so sick. You have to stop taking these things, and they will give you better things to use. Things that are going to get much stronger. And then, you might start diarrhoea, or they can start, this cultural vomiting, especially for a person with TB (Expert 1).

The above text refers to traditional healers that advocate that ARVs are not good for the body. Instead, they administer cultural cures that induce vomiting and diarrhoea. In a patient with tuberculosis, their sputum would be composed of mucous and phlegm, thus serving as 'proof' that the traditional cure is effective. However, the purging of fluids from the body may lead to dehydration and is perhaps not always the best solution for a patient with low immunity, potentially causing further complications.

A similar practice that decreases the efficacy of ARVs is the use of the highly publicised African potato, as raised by the experts.

> A big story was made about the African potato being an immune booster. The African potato has been proved now to interfere with the actual antiretroviral therapy. So, there are many formulations going around, which is like a vitamin supplement, plus all the different goodies. And when you look on it, it says African potato as well, as an ingredient. We cannot use that type of thing with the antiretroviral therapy because you want your antiretroviral therapy to be absorbed and to work properly and you don't want to be under dosing the patient, even though they are taking the full dose, but it is not absorbed and they are getting under dosed (Expert 4).

> Some African shares some African potato and all those stuff like people will say, "Don't take this medication, it might kill you (Expert 2).

The African potato (Hypoxis), a common substance in traditional cures, has been marketed as an immune booster. However, recent evidence proves that it decreases the absorption of ART, thus decreasing its efficiency. One study in particular found that after eight consecutive weeks of using the African Potato, the patients presented with severe bone marrow suppression (Manci, 2005). In spite of this evidence, pro-African potato beliefs are promoted by traditional healers and their opinions are respected by the

community. Thus, interventions aimed at modifying such deeply ingrained beliefs will have to be conducted with utmost sensitivity.

Another practice, raised by the exerts, that has been seen to conflict with ART has been encouraged not by the traditional African belief systems, but rather by the church.

> There are some churches where you find 'forced fasting'. Maybe they say you are praying so we have to have a seven day dry fast, and some of them take their fast in church, you have to go to church and they have keep on praying, so that HIV person will also have to. It is not easy to keep those things when you are sick. …..you have to take your medication, and you can't take your medication on an empty stomach. ……...We find that they went to a church, where they are told, "There is no HIV! You just have to pray, and then it will go away." There was another lady on Monday, she was told to come and test 3 times and on the 3rd time she will be negative. ……..And if you look at their brochures, when they write there, they can do a miracle healing e.g. HIV, diabetes, they know that the people are desperate and they will go (Expert 1).

The above account makes reference to a common church practice of 'fasting', which is the abstinence of food as a sacrifice to God. However, depleting body reserves of nutrients for someone with low immunity may cause more harm than good (Steinman, Conlon, Maki & Foster, 2003). In addition, patients are unable to take some of their medication as they have empty stomachs. There definitely exists a circular relationship with the act of fasting and HIV. Those with HIV may resort to such drastic measures of religious practice in an effort to seek a cure to the disease. However, the practice of such measures may in turn contribute to the maintenance of a low immunity.

*Political issues related to adherence*

One cannot deny the association between the South African political context and HIV (Butler, 2003; Mbali, 2004). There has been much controversy around the access of ART to public health consumers, with the government being less than willing to grant this population access to ART (Mbali, 2004). In addition, recent statements by government officials opposing the use of ART have projected ART in a negative light. Even though the public health sector now has access to ART, the original stance taken by the government could be seen to have affected the public's perception of the efficacy of

ART. An individual's perception of the treatment would affect how well he or she adheres to it (Godin et al., 2005). An extension of this is that the government's negative portrayal of HIV could affect patients' perceptions of the efficiency of the treatment and subsequently their levels of adherence. Hence, the South African political context is hereby discussed as a potential barrier to adherence. Following this, issues that are closely related to the political context are discussed under the headings of poverty, a lack of education and conflicting messages.

The experts viewed adherence as being affected by the political context in the following way.

> And I think that there are probably political issues there, that probably in South Africa people who are poorer are probably greater supporters of the government perhaps and if they are saying that antiretrovirals are more … they're less sceptical towards them than many of the followers (Expert 4).

The above account refers to those individuals emanating from poorer socio-economic circumstances that may be more inclined to support the government's stance on HIV. More specifically, this refers to the opinion that 'HIV does not cause AIDS' (Popp & Fisher, 2002) and the dangers of ART. It then follows that it would be challenging to advocate ART adherence to those who have strong loyalty toward the government and their opinions. The expert participants continued by describing the conflicting messages stemming from AIDS activists that promote their own cures and inherently detract from the importance of ART.

> What is happening is that we have AIDS activists who are promoting their own things against the antiretrovirals. No matter what, at a certain point of time in a HIV positive person's life, they need to start antiretrovirals and they also need to highlight the side effects (Expert 2).

One can understand how such conflicting messages would result in confusion for patients, especially for those who are strong supporters of the government. The challenge for adherence would be in attempting to convince an individual of a treatment that is not supported by his or her government and one can see how that would affect an individual's belief in the efficacy of the treatment.

*Poverty*

There is a clear association between poverty and adherence to ART due to the fact that high levels of adherence to ART is associated with numerous factors such as education, nutrition and the financial costs associated with treatment. This is of special significance in the South African context, where many patients live below the poverty line (May et al., 1998).

The expert participants highlighted that poverty was an important consideration in attempting to understand adherence, particularly given that nutrition is a component of adherence.

> …Also nutrition. Other people say, "How can I drink medication without having food on the table" (Expert 2).

> I think that firstly poverty is linked to nutrition very often, and I think that taking medication on empty stomach's and things like is quite difficult for people and I think once they start feeling the impacts, their motivation becomes decreased. I also think that very often people in poverty have or feel, some people feel that they don't have quite the same reasons to live as people who do have food in their stomach and are able survive in better circumstances. And I think that poverty is also linked to education and as I said earlier, education is a big issue… but when you are living in poverty you have got many other concerns and you are not sick, you are going to be concerned about the things about keeping alive, rather than those things might affect you in the future and they may not. So it looks like an immediacy issue linked to poverty (Expert 4).

The above account describes the various ways in which poverty mediates an individual's level of adherence. Firstly, poverty means that a person may not be able to adhere to the medication regime in terms of dietary requirements, as food may not always be available. Secondly, the experts commented on how poverty may affect one's cognition in terms of motivation level, as well as whether HIV is a prioritised concern in one's life. A person in a situation of poverty may be more concerned with immediate problems like the availability of food and hence may be less inclined to be concerned with an illness that would only manifest in the future.

The issue of poverty is of special concern in a country like South Africa where many live below the poverty line (May et al., 1998). The government roll-out clinics

attempt to assist such patients via a fortified porridge that is given to patients. However, this alone is not sufficient. Thus it appears that the issue of HIV highlights many other social ills and it is thought that HIV and its management have deep roots in political and social circumstances. The surveyed literature has mixed views in respect of the notion that poverty would serve as a barrier to adherence. A study of 289 African patients over 48 weeks revealed that their levels of adherence matched those of their counterparts from the developing world. This study concluded that socio-economic status had no impact on adherence and should not be viewed as a limitation to adherence (Orrell, Bangsberg, Badri & Wood, 2003). Similar findings were found in Khayelitsha (South Africa), Senegal and Uganda (Oransky, 2003). However, Popp and Fisher (2002), felt that adherence was already complex under optimal conditions and that poverty-related obstacles such as a reliable source of medication, an efficient health-care infrastructure, adequate food, water and electricity could impact adherence to such a degree that Africa becomes a hub of treatment resistant viral strains. The author advocated that appropriate levels of adherence could be achieved with the use of adequate adherence intervention (Popp & Fisher, 2002).

*Lack of education*

An individual's understanding of the nature of his disease and how the medication works plays a role in his or her level of adherence. Studies have revealed that patients who do not understand their illness or their treatment are more likely to make mistakes and less likely to adhere to their medication regime (Ockene, 2001). A sturdy education would allow patients the capacity to make sound decisions regarding their treatment and allow them to confront challenges regarding adherence in a more responsible manner.

The experts highlighted that education serves as a mediator of one's level of adherence. Expert 2 originates from a community where people possessed a poor knowledge of HIV/AIDS and he felt that this contributed not only to their poor levels of adherence but also to whether they decided to use ART at all.

> What I have seen, if you are White or Indian or Coloured, they are the people who take the medication better compared to the black community. I am from a black community with people with a total lack of knowledge around AIDS. Not knowing what to do, or how to start the medication or where to go. To take or

> not take their medication, or if they take it, they do not take it properly (Expert 2).
>
> I think that issues like education do come into it, understanding of the medical issues. And possibly in South Africa also there are mixed messages and I would suggest that possibly people who are less educated, less or living in more dire economic circumstances may be able to assess the pros and cons of it less dynamically and therefore might be influenced by different messages as well. (Expert 4).

Expert 4 offered an explanation for the possible relationship between education and adherence levels. He argued that a lack of education could account for an individual not being able to understand the medical issues concerned and hence being unable to assess the pros and cons of the situation holistically. This appears plausible, as one would need to understand the dynamics of HIV and ART in order to have faith in the medication's efficacy. Expert 4 associated the lack of education with a vulnerability to conflicting messages. It is thought that a lack of understanding as to how the medication works would render someone more susceptible to the alternative treatments. This is in keeping with current adherence interventions that have a strong focus on psycho-education around HIV/AIDS as a preliminary intervention to discussing issues around adherence.

*Conflicting messages*

The term 'conflicting messages' is given to opinions that were different to those advocating the use of ART. An alternative to the stringent adherence requirements of ART may appear enticing, especially for patients that do not understand all the dynamics behind HIV and ART.

The experts viewed the impact of conflicting message on levels of adherence as significant. With reference to the discussion under the heading of political issues, the experts referred to information from the government that ultimately opposed the use of ART, especially in relation to the fact that the government initially opposed the idea of granting ART to the public health sector (Mbali, 2004). In addition, the experts raised issues around AIDS activists that were marketing their own remedies. This would appear very contradictory to the public, as these political figures are associated with being pro

ART and now, even they are marketing alternatives. In both instances, one could see how such practices would dampen one's beliefs in the efficacy of the treatment.

The expert participants felt that the pro-ARV community was at a disadvantage to begin with, due to the negative media associated with ART, especially during the time when the government had not yet granted access to ART in the public sector.

> I think we had a big disadvantage. Before ARVs, there was a lot of negative information coming over, talking about side effects, talking about problems with cost, cautions about it not working because of adherence etc, etc. And our community took this up and they heard about it (Expert 3).

This is closely related to the discussion under the heading of political issues, which hypothesized that those from lower socio-economic groups may be more inclined to support the government. In addition, the reluctance of the government to allow access to ART in the public sector as well as the other circulating negative media may be associated with a perceived inefficacy of the medication. It is thought that such cognitions would definitely impact on whether someone opts for ART and how adherent he or she would be.

> You know the main problem we find with our patients is they start perfectly but when they go out, they listen to other people. They had heard somebody saying this thing about the ARVs, that once you start taking this, you will start to feel well but then you are going to be forsaken and terminally ill. You will die. Although they did the adherence and they understand the information correctly, but you know the power of the mind, because now, they are alone… There they are amongst the people that are anti ARV, so they put all those negative things, and then they believe, that this is going to happen to them and they even show them examples, "Look at so and so, look what happened to them"… We ask them, "How long is the person been ill? Was that person taking medication correctly. What happened? Did they go back to the clinic to report that there were the side effects? (Expert 1) "

The above account depicts how some patients may succumb to the negative views of others even though they have had the relevant adherence training. Some have the perception that ART is toxic and can kill you. However, what most fail to understand is

that in those situations, the patient's immunity was probably already low so the ART was not the cause of death.

**Expert recommendations for improving adherence**

The following section highlights recommendations emerging from the expert interviews as well as recommendations inferred from the perceived obstacles to adherence that were highlighted. First, the recommendations arising directly from the expert interviews are discussed and this is followed by a discussion of the recommendations inferred from the perceived obstacles to adherence highlighted above.

*The health care provider – patient relationship*

According to the expert participants, the relationship between the health-care provider and the patient is very significant, as it has a direct influence on how a person perceives conventional medicine, as well as contributes to the person's perception of illness and medication. In some cases, interaction with the health-care worker will be the platform where the patient first confronts issues related to disease, such as psycho-education around infection and finding out one's status. It is felt that this interaction will impact on future decision-making and influence how one understands the illness and how one chooses to treat it.

The experts felt that the relationship between the patient and health-care provider was one of the most important factors that influenced the levels of adherence. This was supported by the literature that cited physicians as the source that most influenced a patient's medication related decision-making (Meredith, Jeffe, Mundy & Fraser, 2001). In addition, satisfaction with the physician-patient relationship was highlighted as being a mediator of adherence (Godin et al., 2005; Heckman et al., 2004; Murphy, Marelich, Hoffman & Steers, 2004).

> I think if you can develop a health care provider patient relationship, where there's an open, warm, understanding and communication between the two groups, and there is an element of trust both ways, and the patient feels well informed, and he feels very much included in the team and has an opportunity to voice his concerns, his problems at home and any barriers that he or she might think that might impact on the adherence; those will be very important things, and one of the most important factors of adherence is that relationship between the health care provider and the patient (Expert 3).

The experts felt that fostering a warm patient-health-care-provider relationship was closely linked to confronting traditional belief systems, as well as social perceptions that conflicted with the belief systems behind ART. Expert 3 felt that the health-care provider-patient relationship should be such that the patient should feel comfortable enough to voice any concerns; including those about controversial issues, such as traditional medicine. An extension of this idea would be that adherence interventions would have to be directed not only at patients, but also at health-care providers. This means that perhaps health care providers will need to be educated on how to foster a relationship that would facilitate an open discussion of issues related to HIV.

*Mental health*

The relationship between HIV and psychological disorders cannot be denied and has been covered extensively by the literature (Brief et al., 2004; Halkitus et al., 2005; Ickovics & Meade, 2002; Kalichman & Rompa, 2003; Malan, 2003; Moosa et. al., 2005; Phillips et al., 2005; Shernoff, 2001; Yun et al., 2005). The literature also stipulated that mental health care was significantly associated with adherence levels (Turner et al., 2003). The experts felt mental health interventions were important in encouraging adherence.

> So I think again that it comes back to the individual. And as a way we know about introverts and extroverts all those people. I prefer extroverts a lot, because they can talk about everything. When they are angry you know they are angry, they can fight with you, but tomorrow they have forgotten about it. They have cleaned their souls of everything (Expert 1).

Expert 1 argued that those who are more aware of their emotions are more likely to voice their concerns and have fewer problems with issues of adherence. This implies that efforts to get patients more in touch with their emotions, i.e. psychotherapy should be implemented, along with the usual adherence counselling.

> What is one thing in particular is the finding and certainly my strong belief that if you are not psychologically well or psychiatrically well, it is going to have quite a bearing on whether you do continue to adhere to your medication or not. And the research seems to suggest that the people that are

> depressed, don't really care all that much about their futures and so die or not die, well, if I have to bounce that against side effects, against disclosure, against all the other negative things about being on ART, I would rather not (Expert 4).

The co-morbidity of psychological illness and HIV has been well documented and it is felt that psychological intervention in an effort to treat these illnesses would need to be in place as part of adherence intervention. Depression associated with HIV was highlighted as being a direct mediator of adherence (Brief et al., 2004; Halkitus et al., 2005; Turner et al., 2003; Yun et al., 2005). Anti-depressant treatment has also proven to improve levels of adherence in depressed patients (Turner et al., 2003, Yun et al., 2005). This means that perhaps a screening for depression needs to be compulsory when administering ART and patients need to be directed toward antidepressant treatment and/or therapy in an effort to ensure maximal adherence levels.

*Accessing support*

The experts verbalised the importance of support in maintaining good levels of adherence. This is supported by the literature. Godin et al. (2005) cited that a positive perception of support affected a patient's perception of the medication and this in turn improved adherence. In a study of 113 patients, it was found that relatively low levels of adherence was observed in patients that did not belong to a support group (Berg et al., 2004). Kumarasamy et al. (2005) found that being able to turn toward family for support was a facilitator of good adherence levels. Three different avenues of support emerged from their interviews: support groups, family support and a treatment supporter.

> That is why the support groups are so helpful to other people. We sit there thinking that they have the worst problem in the world, and then, they listen to other people's problems and they say, "Hey Cindy, I am much better. You see that beautiful lady. Yes, that lady has got so many problems. I am much better than her." Then you see something good happen to that person (Expert 1).

It was felt that support groups were effective as it gave patients the chance to be around individuals who are in similar situations, and as a consequence, the ability to witness stories that are sometimes worse than their own. This serves a motivational

function, as the afflicted individuals can see that there are those that are worse off than themselves, yet still coping, and this inspires them to continue with their struggle.

> They must have a treatment supporter. Someone who is going to weekly monitor that person…Someone who is going to be there for you. Like a daughter supporter. Someone will come around and see that you did take your medication. "Do you feel well? Do you have any side effects?" Someone to give you the support, you know, so you can take your medication. (Expert 2)

The concept of a treatment supporter was presented i.e. an individual who would be able to monitor the patient's treatment and provide support around any difficulties that may emerge. This system is currently used by the TAC and most patients are allocated a treatment supporter.

> I would also see that there is in place a friend or family member or a social contact that can help and I would establish a friendly relationship with the patient if possible, and create that sense of feeling that it is not a once off thing. The patient is going to go home and there are going to be problems and there is an open door for discussion and the patient must feel that, "If I have a problem, I can access help immediately, ask questions and get clarification" (Expert 3).

The importance of developing support in the home environment to facilitate problems being dealt with as soon as they arise was discussed. This may entail the health-care provider making contact with these family members, establishing rapport with them and educating them around the issues of adherence. As a future recommendation, since the family could serve as a support system, perhaps adherence interventions including family members should be developed. This is in keeping with the national guidelines on ART that list disclosure to at least one family member as an important psychosocial consideration in the management of ART (Department of Health, 2004).

*Education*

The experts felt that education played a role in whether someone adhered or not.

> And get the education about taking the medication and the benefit of taking it… It's very important. Should the person start he must be told about adherence, when they started taking the

> treatment, they must continue. They have to be reminded at all times (Expert 2).
>
> In the antiretroviral therapy context, to make sure that the patients understand themselves, everything (Expert 3).

It seems that it is imperative that the patient understands the entirety of what is going on. Such education, would not only allow them to understand their illness but a firm grounding in the HIV and the rationale behind ART could also serve to counter conflicting messages, hence boosting levels of adherence.

Expert 2 stressed that stigma was the product of a lack of understanding of the virus at the level of the community. From this it follows that an increased focus on psycho-education at the level of the community is vital. The aim of such an intervention would be to increase awareness and as a consequence, decrease the stigma associated with the disease, ultimately resulting in better support systems for patients to draw on.

*Human error*

Expert 2 emphasised forgetfulness as an element of human error that served as an obstacle to adherence. The exploration of this sub-theme implies that future studies on adherence levels would need to focus on what is deemed to contribute to forgetfulness and strategies would need to target these contributing factors. This leads one to believe that time-keeping devices in an effort to combat forgetfulness should be a component of adherence strategies.

In addition, future research could also look at the relationship between forgetfulness and wilfulness in an effort to ascertain whether a person's level of motivation affect his or her memory and, by extension possibly intervene at a level of increasing his or her motivation in order to decrease his or her level of forgetfulness.

*Specific communities*

The challenges highlighted by the specific communities such as the prison community and the gay community warrant that adherence needs to be investigated, not only at a global level but also at a level of the specific community concerned. It is thus

recommended that further research be done at the level of the specific community in an effort to further highlight these issues.

*Gender*

It should be noted that the issue of gender though expressed quite passionately had only been highlighted by Expert 1. By the same token, however, it must also be stated that that Expert 1 was the only female expert and perhaps may have been more inclined to highlight issues pertaining to gender inequality. Gender prejudices aside, however, there definitely appears to be complex gender dynamics with regards to taking ART. It is hence recommended that this area be investigated further. Should the research find that gender is an important variable, then perhaps interventions will need to focus on adherence as a 'couples' issue, perhaps employing a couple's therapy component to adherence counselling. This was supported by a study (2005) that employed the use of a couples-based intervention to improve HIV medication adherence. It was found that the couples that participated in the couples-based intervention showed higher levels of adherence than their counterparts who did not participate in the intervention (Remien et al., 2005).

*Traditional medicine and other practices*

The consideration of traditional medicine and other practices is imperative in future adherence education interventions, as one would have to analyse the different cultural discourses around the origin of illness and this may need to be the starting point for any intervention. It is felt that further research along this avenue will also help us to understand why patients may be more prone to listening to opinions that appear to oppose ART. The literature surveyed recommended the involvement of traditional healers (Tobias, 2001) in helping to counsel and using them to advocate adherence strategies.

The decision to listen to family members as opposed to the medical professionals is an area that warrants further research. It is hypothesized that respect for one's elders, an acknowledgement of the wisdom of one's elders and financial dependence may mediate such decisions.

It also appears that the church may be a source of messages that conflict with the ARV roll-out campaign. This is an important consideration in the development of future

adherence interventions, as the churches will then need to be a recipient of education around HIV and adherence to HIV medication.

*Poverty*

The association between poverty and adherence is undeniable, especially since maximal adherence requires adequate nutrition, which is not always achievable. It is thus recommended that the dynamics of adherence to ART are examined in the light of the political and social circumstances affecting the patients concerned. It is hoped that an understanding of these dynamics would lead to an increased understanding of the challenges faced by patients and hence facilitate better intervention. The link between levels of adherence and the socio-political context (Butler, 2003; Mbali, 2004) also suggest that adherence intervention could be guided by a community psychology approach, where communities are empowered to improve their socio-economic circumstances (Seedat et al., 2001) and, as a consequence, their level of health consciousness. May et al. (1998) argue that there is strong link between poverty and unemployment. They suggest a greater focus on education training in an effort to facilitate greater employment to help fight poverty.

## PATIENT DATA

This section presents the themes emerging from the patient interviews. The patients' perceptions of the barriers to adherence are first discussed, followed by a presentation of the recommendations for improving adherence, emerging from the patient interviews.

### Patient perceptions of barriers of adherence

*Failure to adopt a responsible approach to one's life*

Prior to reflecting on the patient excerpts, it is necessary to reflect on what it means to adopt a responsible approach to one's life. It can be assumed that the concept of 'responsibility' is relative and would differ among participants. Considering the other themes that have emerged thus far, it becomes apparent that what one deems to be responsible will depend on various factors such as mental health status and social perceptions of ART. If one goes back to the issue of poverty, taking a responsible approach may mean going to work and if the side effects of the medication hinder your work performance, then one could argue that being responsible could mean terminating your treatment to facilitate maintaining an income as the issue of poverty is probably a more immediate threat. Thus, the discourses around what is responsible are quite complex.

> The thing is that if someone is not responsible for his life, then they just forget to take the medication…He means that here they are taught that they must take the medication, on the time that they have structured and if you don't do that, the sickness will go on. It is important to take the medication and if you don't do that you are not responsible (Patient 1).

The patients felt that not taking the medication was an act of irresponsibility. Patient 1 appeared to rationalize this by stating that if one had received the appropriate psycho-education around ART and adherence, then poor adherence was being irresponsible. As one will see in the data analysis, the issue of poor adherence, even in the face of good education, is not that simplistic. There does appear to be a myriad of factors like conflicting messages, errors of human nature and psychological well-being that would mediate a decision to take ART or not. It would be interesting to examine patients that have failed to maintain the optimal levels of adherence in the face of the

appropriate psycho-educational interventions to establish why they were unable to adhere.

*Substance abuse*

Though only one patient had spoken of the effects of alcohol on one's level of adherence, it warrants discussion, as this was one barrier that had been highlighted by the literature surveyed. Drug and alcohol abuse has been found to mediate levels of adherence (Ickovics & Meade, 2002; Kalichman & Rompa, 2003; Shernoff, 2001). The influence of alcohol could affect an individual's ability to remember to take his or her medication. In addition, when the individual is under the influence, he or she may be less prone to remember his or her status and the medication. Rothlind et al. (2005) stated that the occurrence of alcohol consumption in the face of HIV-infection is associated with an increased risk of neuropsychological impairment and that this would impact a patient's capacity for adherence. Some studies have found that alcohol and/or drug use was associated with worse adherence levels than those who did not use substances (Berg et al., 2004; Heckman et al., 2004). However, Ware et al. (2005) felt that the stereotyping of alcohol and substance users as poor adherers to medication underemphasizes the non-alcohol/drug-related-obstacles to adherence, hence contaminating one's assessment of their capacity for adherence.

> The people maybe….if the people are drunk. They drunk the beer, maybe they smoking, they smoking the dagga and then you forget to take the tablets. Because me, there's no smoking and me don't drink beer and some things like that (Patient 2).

Patient 2 felt that the use of alcohol and drugs could contribute to someone forgetting to take their medication, as in agreement with the literature (Berg, et al., 2004; Ickovics & Meade, 2002; Kalichman & Rompa, 2003; Rothlind et al., 2005; Shernoff, 2001). He implied that the altered state of mind associated with the use of alcohol and drugs could lead to patients forgetting their medication.

*Disappearance of symptoms*

Patients have been seen to terminate their medicine regimen when they perceive that they have been cured. This scenario is not exclusive to ART. Poor levels of adherence to chronic illnesses such as asthma, hypertension (Ockene, 2001) due to patients feeling better have been noted. This is of special concern in the HIV/AIDS setting because the purpose of the ART is to minimize symptoms to facilitate a better quality of life. However, the disappearance of symptoms does not mean that the virus has been destroyed. It merely means that the virus is present at a low level in the body. Rowe et al. (2005) highlighted the absence of symptoms as a barrier to adherence. Accessing the full benefits of ART means a life-long commitment to the medication, a concept that may be difficult to digest for some.

The patients cited the disappearance of symptoms as a reason for poor compliance. This means that poor adherence as a result of the disappearance of symptoms is an avenue that needs to be considered.

> They just look at their body and say it's okay. I can't take the medicine because their life is alright now. But the doctor never give you the results. The doctor must give the results again and then the doctor must check you okay. Now the life is okay now (Patient 2).

> People won't take the medication at first, you feel better maybe because they are not very sick at that times and sometimes they do forget…They think are normal now, they are healthy, it's ok. That's why they stop it (Patient 4).

> They going to take the medication for maybe 2 – 3 months, and after 3 months they think, there is no pain in my body, I'm ok, I'm fine, then they decided they are not taking the medication, and then by the time and when the pains come, then it is worse, then they remember to take the medication. They have never been committed to the medication before, so they have decided they are only taking the medication now (Patient 5).

All three excerpts demonstrate patients who forget to take their medication once their symptoms have been treated. Thus, the presence of symptoms may serve as a reminder for patients to take their medication. Patient 5 referred to a scenario where a patient had forgotten but once the symptoms returned, began to take her medication again. With regards to ART, this poses difficulties, as fragmented compliance as

described above can lead to mutation of the virus and the development of resistant strains, making the disease even more challenging to treat (Chung et al., 2002; Ickovics & Meade, 2002; Kalichman & Rompa, 2003; Kimmerling et al., 2003; Lucas et al., 2004). The issue of poor compliance in relation to the disappearance of symptoms is something that already appears to be confronted in adherence interventions at present (Ockene, 2001).

*Conflicting messages*

Conflicting messages refers to messages that emanate from the media and general public that are anti-ART. The patients felt that conflicting messages constituted a contributing factor to poor adherence. Three different examples of conflicting messages and the associated context are discussed separately.

Some individuals have heard of the death of a patient soon after the patient had begun to take antiretroviral medication. This is not a common occurrence and is generally due to the patient having such a low level of immunity that it is too late for the situation to be remedied. However, to the layperson, the association between ARVs and death is already made. This leads to the medication being viewed as toxic and more damaging to the body than the HI virus. Such perceptions have a negative impact on how one perceives the efficacy of ARVs.

Patient 3 was the only patient to raise this issue. This may be because she also functions as a lay counsellor and may have highlighted circumstances that she has observed during counselling.

> Because, when you counsel someone, you tell him or her about medication, they tell you, "You know, someone was telling me their big brother was taking this medication and now he's dead." And me, I'm advising him that, "You don't know how sick was that guy. You don't know his CD4 count. You don't know how long he's been sick." We can be HIV together but we can't die together and we can't face it like the same (Patient 3).

In the above account, Patient 3 attempts to explain these concerns by stating that one needs to have much more information before we can ascertain whether the cause of death was due to ARVs. However, it is understandable that to an individual who is

ignorant of the intricacies of HIV and ART, it would be easy to make the association between ART and death in such a circumstance, especially since the death has occurred after the commencement of treatment.

In the quest for a cure for HIV, many have claimed to have found the cure to this disease (New Mexico AIDS Education and Training Centre, 2005). This may be grounded on false belief systems, desperation for a cure or mere financial opportunism. The result is that many alternative 'cures' have been publicised and to a desperate public, this may be viewed as convincing.

Patient 4 mentioned one such alternative cure, namely multivitamins.

> Because every time one listens to the radio – you hear different stories…They tell you that, "I was very, very sick, then I went and got multivitamin." You see those things. So people, they don't know if the retrovirals are working…Because they think it could be the multivitamins…And that can just confuses everyone (Patient 4).

The above excerpt refers to a patient that was taking multivitamins in conjunction with his ART. When improvements were noted, it was not clear to him whether this was a result of the ART or the multivitamins. This could cause confusion, as should a patient decide that his or her recovery is due to the multivitamins, then he or she may cease his or her treatment. This is of special significance, as many vitamins and immune boosters have recently been advertised as potential cures. Adherence intervention would need to explain to patients the role of such additional treatment i.e. they serve to boost the body's immune system but do not serve to suppress the virus.

The political controversy around HIV/AIDS policy in South Africa has received wide coverage (Butler, 2005; Mbali, 2004). A government of a country plagued by the virus appeared initially hesitant to provide ART to its citizens (Mbali, 2004). These actions could have influenced patients against ART. Patient 6 shared one such opinion on the government and ART.

> My sister used to say that our Government is very clever. He must first find out what the after effects of the medication, he wants to do proper research. Because the Americans just wants to dump things on us and he first want to find out what other

> long term after side effects and so on, and she thought it was right of him to take time, and to research on it and all that (Patient 6).

In the above extract, Patient 6 refers to her sister who was of the opinion that ART has not been adequately tested for long-term side effects. She believed that the Americans were using the South African population as guinea pigs and that the government's hesitance to roll out ARVs was so that they could run further tests on the medication. The present study does not aim to establish whether this is true or not, neither does it aim to take a political stance toward HIV related issues. Rather, the research aims to highlight that the political context in which perceptions of ART are situated must be considered in adherence intervention. This may mean that adherence intervention may have to nurture attitudes that may not always be in keeping with government opinions, which may prove to also come with its own complications.

*An itinerant lifestyle*

An itinerant lifestyle is the term given to one whose lifestyle involves much travelling. This is of particular significance in South Africa, as many have migrated to the cities for employment and yet still have family back home. It appears that this type of lifestyle may hinder an individual's capacity to adhere to his or her medication regimen. Weiser et al. (2003) highlighted travel and migration as a barrier to adherence. A study of HIV-positive patients' travel patterns and associated behaviour revealed that travel was associated with poor adherence and risky sexual practices (Salit, Sano, Boggild & Kain, 2005).

Disclosure of one's status to the family appears to be one such mediator of poor adherence. Perhaps the pressure of disclosing an individual's status to his or her family is overwhelming or those in more rural areas may not be educated and may not understand when family members disclose their status. The patients highlighted this, leading one to believe that an itinerant lifestyle is an important consideration for adherence.

> Ja. We used to tell them, please disclose your status because when you are in Johannesburg, it's easy for you to take medication but when you go there to your family, your family doesn't know nothing about your status, then, it's going to be tough for you to take your medication and it's true. People take

> their medication when they are here but when they go to their places like Natal or Lesotho, they don't (Patient 3).
>
> Ja. Some of them they don't take the medication at home, but some of them they decided to take the medication now (Patient 5).
>
> Being at home is quite difficult, but it is up to you. Its your life and it is not someone else's life it is your life to know you must take treatment (Patient 7).

The above three accounts demonstrate that patients do find it more difficult to adhere to their medication regimen when they are at home, however none offered any explanations for this. The difficulty of taking medication at home is something that would need to be explored further in order to investigate the dynamics contributing to the difficulties faced.

Patient 6 articulated the difficulties of adherence related to an itinerant lifestyle in a slightly different manner.

> Ja, that maybe at night, maybe after visiting and normally I take my medication 8.00 or 9.00 and remember and 10 or 11 or so, but at a later stage, my sister says put tablets in the car, so where I went, I drink them, but there were times where I forgot (Patient 6).

She refers to forgetting to take her medication when she goes visiting and has admitted that even though her sister did keep tablets in the car for her, she still forgot to take them at times. This could be related to a break in her daily schedule or perhaps a fear of taking the medication in public. Adherence is possibly better achieved if one keeps a routine. However, this is not always possible when an individual is travelling and he or she would need to develop strategies for such circumstances.

*Quantity of medication*

The quantity of medication in the prescribed regimen has been seen to affect the individual's level of adherence. The frustration surrounding large quantities of medication as a barrier to adherence, has been well documented (Figueiredo et al., 1998; Ickovics & Meade, 2002; Mann et al., 2000; Therrien, Mailhot & Gagnon, 1998). In effect, the more medication there is, the more difficult it will appear to be to remember to

take it. In addition, the more medication there is, the more complex the regimen becomes. One would need to consider that the doses, times and dietary requirements of the different medications may not be the same, thus further increasing the complexity of the regimen.

Though this issue was raised by only one patient participant, it's extensive coverage in the literature and its prominence in the interview transcripts justified its discussion.

> People, they say that this medication is too much for them…Like, Stockrin. You take 3, then 3TC 1, D 14, 1, in fact D 14 is twice a day, 3TC is twice a day. Stockrin is 3, once and maybe Bactrim and vitamin B and vitamin C. Sometimes that person got TB. They feel, those people, that the medication is too much and they ignore to take the medication (Patient 3).

Patient 3, above, refers to a typical medication regime and attempts to demonstrate how it's complexity and the quantity of medication may affect patients' levels of adherence. An important factor raised by the above excerpt is the fact that the patient's regimen is not always limited to the ARVs. Patients may present with a range of illnesses due to their susceptibility to infection and may need to take more medication in addition to ARVs (Chung et al., 2002; Ickovics & Meade, 2002). This may also be in conjunction with vitamins, which may be needed to aid the immune system. On the whole, it leads to a complex regimen with different medications, treating different illnesses. Such a difficult regimen would be difficult to adhere to.

*Side effects*

There appears to be an association between levels of adherence and the side effects experienced. This has been documented in the literature (Berg et al., 2004; Godin et al., 2005; Ickovics & Meade, 2002; Lucas, et al., 2004; Mann et al., 2000; Weiser et al., 2003) and it appears that bad side effects of a medication are a common reason for patients not adhering to their treatment. Side effects of ART include but are not limited to diarrhoea, fatigue, nausea, vomiting, peripheral neuropathy, metabolic changes (Max & Sherer, 2000) and lipodystrophy (Corless et al., 2005). The AIDS Clinical Trial Group

370 found that adverse side effects was the strongest predictor of non-adherence (Ickovics & Meade, 2002). Even if one decides to use additional medication to manage the side effects, this further increases the quantity of medication and subsequently the complexity of the regimen, thus hindering adherence (Figueiredo et al., 1998; Ickovics & Meade, 2002; Mann et al., 2000; Therrien et al., 1998).

The patients raised the issue of side effects affecting adherence.

> …So, people, they don't want to take medication because of side effects …(Patient 3).

> I think why people are denying the treatment, actually I cannot say they forget, they are denying the treatment, especially the evening treatment, with the Stockrin, it is because of the side effects. Because of the bad dreams at night, maybe they are afraid, because you dream something that you have never seen in your life. they have never dreamt before. But they should carry on taking it, although the side effects and those bad dreams, because after time, they dream normally. It won't happen anymore (Patient 7).

Patient 7 observed that the vivid nightmares associated with the medication served as a barrier to taking the ART. She felt that experiencing these nightmares were frightening but also explained that this side effect is temporary and that should the person continue to adhere, the nightmares would eventually pass. This is relevant in the consideration of adherence and the temporality of the negative side effects is something that should be focused on in adherence intervention. Patient 3 did not discuss any specific side effects but supported Patient 7's narrative by stating that patients do not adhere to medication due to the side effects of the medication.

*Human error*

Forgetfulness was highlighted as one of the reasons for poor medication compliance. It appears that time-keeping devices such as alarms may serve as a reminder to take medication (Mannheimer, Hirsch & el-Sadr, 1998) but one may forget to set the alarm as can be noted by Patient 4 below. In addition, as noted in the excerpt above, forgetfulness may also be an unconscious effort to avoid the side effects of the medication. The

patients felt that forgetfulness was a reason for poor adherence. This is supported by the literature (Shernoff, 2001).

> Actually I use to set my alarm, and I use my cell phone as a time beeper. So at that time I think I forgot to put my alarm, but I took them. I still took them, because I am taking my medication at 8.00, I remember at about half past ten, but I took them (Patient 4).

> When I wake up in the morning before six, she is not up. And then I get busy working, and doing the washing and then I forget, and then I remember I didn't give her the medication then I go back and give her medication (Patient 5).

> No, weekends ja, maybe Sunday mornings. During the week when I was working, I was taking every day the same time but weekends and I never used to take it at the same time as during the week, because I used to sleep till late. Now I am up, its time to go to church, I bath, I don't eat. I run to church and when I come back, I eat and I take my tablets (Patient 6).

From the above patient accounts, it would appear that a break in one's schedule could lead to forgetfulness. Patient 6, who appears to remember her medication during the week, tends to forget on the weekends because of the break in routine. It seems that time keeping devices are not always effective and hence future considerations of adherence will need to focus on generating more creative methods of time keeping.

*Dietary Requirements*

One of the factors that contributes to the complexity of adherence in ART are the dietary requirements associated with the medication. Certain tablets need to be taken on an empty stomach while others need to be taken with food. This becomes an issue of concern, especially in poorer communities, where the availability of food, let alone nutritious food, cannot always be expected. A balanced diet, high in vitamins and minerals is needed to supplement the ART in boosting the immune system but such a diet is not easily available. Again, even though only one patient highlighted diet as a barrier to adherence, its coverage in the literature warrants its discussion.

> Another thing is, you can have the proper medication, but if you don't have proper food, like I am a single parent, and I used to have the medication here, but at times I would feel that I am

> weak from not eating, and not really sick but I still feel weak, and the minute I eat a piece of pumpkin when I go somewhere or visit someone, I feel better (Patient 5).

Patient 5 shared her experience of feeling weak, due to not having enough food and feeling better after she had eaten something. It is hypothesized that this is a similar experience of those who do not have enough food, and is something that must be considered.

**Patient recommendations for improving adherence**

As with the expert recommendations, the following section is comprised of recommendations that were directly cited in the patient interviews, as well as recommendations that were inferred from the discussion of the patient's perceptions of the obstacles to adherence.

*Witnessed improvements*

Five of the eight patient participants mentioned either themselves or others witnessing the effectiveness of ARVs. This means that viewing improvements after taking ARVs had a significant impact on these patients to the point that they felt that their own experiences and those of others were worth mentioning. The accounts of witnessed improvements were revealed in response to the enquiry of participants' perceptions of ARVs. Thus, it can be said that witnessed improvements have a direct effect on an individual's perception of ARV efficacy. It is felt that there is possibly no other better advocate for ARVs then witnessed efficacy.

The literature surveyed however failed to cover this aspect. However, it can be seen that witnessed improvements could serve as a motivator of ARV adherence. This means that adherence interventions should also focus on sharing success stories. Though this is the rationale behind group intervention, perhaps those who have witnessed improvements should be encouraged and trained to be spokespersons or counsellors around adherence. Their stories could possibly serve to counteract the effects of conflicting messages as identified in the expert interviews.

> I start to be sick. I've got sores all over the body. And I came back to the hospital. Then, I used to come here to Helen Joseph and met another doctor. When I came, I met only one doctor. By that time they tell me, "You are very, very sick. Don't you think you must start taking ARVs?" "ARVs, whats that?" "It is the medication for HIV. You'll be better."… So I took them from October, November, December, January, February, March, April. In April, they sent me to come and collect them here from the hospital because government bring them to the hospital. And, I start to take them from the hospital and up to now, I'm still fine…It works because at that time,I was losing lots of weight. I was wearing size 28. By that time I was having lots of sores but now I'm fine (Patient 3).

> I felt worse, until antiretrovirals was so helpful because I was very, very sick, and then I got the access to the antiretrovirals. I resigned from my previous job. I am an ex-cop, and after I resigned I was very, very sick and after I got the anti-retrovirals, I was well. I was able to work and I was able to do everything, and I applied for a job. I am now a counsellor, so I feel very very good… I was maybe 46kg, then I gained weight and I am eating a lot, and I can feel the difference, when I was sick, and with the antiretroviral. Now I can see the difference (Patient 4).

> I can be in the bed in the hospital. It is hard. I was admitted for about a month, so I think about all these things so that is why I am always taking my treatment (Patient 7).

The above accounts represent patients' accounts of how they have witnessed improvements of their physical health due to ART. These improvements vary from the disappearance of stomach ailments and body sores, weight gain and an overall increase in general functioning. The effect of witnessing these improvements has led to a belief in the efficacy of the treatment. At the time of the interviews, the above patients reported maximum compliancy, which leads one to believe that believing in the treatment plays a role in the individual's levels of adherence. This has implications for further research. Should the belief in efficacy serve as a motivator of adherence levels, then further research would need to investigate the various factors affecting patients' beliefs in efficacy.

*Social support*

One of the main motivators for disclosure, as highlighted by the expert narratives, is the potential acquisition of support to assist one with taking their medication. Three patients highlighted that social support would improve one's level of adherence.

> There must be someone who will be responsible for that particular person, to help him or her with the medication (Patient1).

> Disclosure, its very important, because if you know I am HIV and we are friends, and you come and visit me, and it is time we have to go somewhere, you'll tell me not to forget my tablets, so if you don't know, you wont tell me that (Patient 6).

> You can even have a calendar to just to tick – have your taken the morning treatment / dose or evening dose. You should tick and see when you forgot to take the medication, so you must

> have a calendar and a person to assist him or her, anytime, a sister, wife, husband (Patient 7).

From the above, it appears that having someone to assist you with taking the medication makes it that much easier to adhere. It is thus recommended that adherence intervention continue to focus on generating support for patients. This may take the form of encouraging disclosure or engaging patients in support groups so that they may be exposed to other individuals in similar predicaments to themselves. However, patients must be encouraged to disclose their status only when they feel it is safe to do so. It is not uncommon to hear of HIV-positive individuals that have been victims of discrimination and it would be unfortunate if patients were exposed to this following disclosure.

*Timing mechanisms*

Five patients found that time-keeping mechanisms helped them to remember to take their medication. The use of time-keeping devices to aid adherence was supported by the literature surveyed (Mannheimer et al., 1998).

> Okay, see the nurse make the calendar… They tell me when to take the tablets. Then, we got the paper to make the calendar and it tell me when to come back. So, I know everyday. And then I know not to forget. You see you take the tablet on the calendar. (Patient 2)

> By 8 o'clock I know, when it's "Generations". Sometimes I'm watching news and when it's finished I know it is time to take the medication…Yes. Because sometimes you forgot to set cell phone. Sometimes, you don't have cell phone. So, sometimes you can use soapies or something else to remind yourself. (Patient 6)

> You can even have a calendar to just to tick – have your taken the morning treatment / dose or evening dose. You should tick and see when you forgot to take the medication, so you must have a calendar and a person to assist him or her, anytime, a sister, wife, husband. (Patient 7)

The above excerpts demonstrate the usefulness of cellular phones to set reminders to take medication, as well as calendars to keep track of medication and appointments. A creative reminder appeared to be the association between a television programme that screens at the same time everyday and taking one's medication. Hence, it can be seen that

patients find such time keeping strategies effective in reminding them to take their medication. However, of concern, is the fact that one has to remember to set these alarms. So, even though such strategies may help to improve adherence, they may not be sufficient in ensuring maximal adherence.

*Antiretroviral awareness*

The patients felt that an increase in antiretroviral awareness could aid in improving patients' levels of adherence. The rationale behind this was that if patients were more aware of HV and antiretroviral medication, this would facilitate better adherence.

> I think we have to go to schools, to make lots of adverts and famous people like, for example like, Mandela talking about his son. People were coming ad saying that Mandela was taking about his son. Black people must get tested (Patient 3).

> Ja, if they can make more … If they can use media, or TV or to educate people about HIV about the antiretrovirals. The antiretrovirals are new, about a year now, so people do not know, so they must advertise – we've got this antiretrovirals now so people must know. They must tell people the institutes where the antiretrovirals are available, because people they still sit and they die, because they do not have access to the antiretrovirals… Everywhere. Posters and banners everywhere. Newspapers. (Patient 4).

The patients felt that the media could be used as a medium of increasing awareness. Patient 3 mentioned that it would be beneficial if important figures in the country spoke openly about HIV, as this would impact on patients. Patient 4 felt that because ART has only recently been introduced to the public health sector, one needs to advertise that ART exists because there are those that are ignorant of this option and face death as a consequence.

> We have to make sure ... like sometimes, that person maybe she don't understand you, you must make sure that you book her for another appointment to make her to come back and understand about this medication (Patient 3).

> I think people need to do counsellation more especially. And their families, they need a workshop or something like that, and to take care of the patient or the person who is affected to see that the taking the tablets accordingly (Patient 7).

Patient 3 and Patient 7 felt that counselling around adherence would be beneficial to the patient. Patient 3 highlighted that in certain instances, a patient may still not entirely understand the dynamics around antiretroviral medication, even after counselling. In such a situation, she advised that it was necessary to repeat the psycho-education until the patient grasped the importance of maximal adherence. Patient 7 felt that counselling should include members of the person's family, probably in an effort to increase the individual's support system.

*Alcohol and substance use*

The literature has covered the association between alcohol or substance use and adherence extensively (Heckman et al., 2004; Ickovics & Meade, 2002; Kalichman & Rompa, 2003; Rothlind et al., 2005; Shernoff, 2001; Ware et al., 2005 ). Hence, the negative effects of alcohol and drugs on medication compliance cannot be denied and health care professionals would need to screen for alcohol and substance dependency prior to administering the medication and possibly refer to rehabilitation facilities. Those who are perceived to be either alcohol or substance dependent could then be reviewed after rehabilitation to see if they were candidates for ART. However, a study in Boston (2005) found that such an intervention did not improve adherence levels or decrease alcohol consumption, supporting the idea of supervised medication delivery and simplified medication doses (Samet, Horton, Meli, Dukes, Tripps, Sullivan & Freedberg, 2005).

*Conflicting messages*

Three recommendations emerged from the discussion around conflicting messages. It was felt that one may be able to confront opinions opposing ART, if the following was undertaken. Firstly, it was recommended that the political context in which perceptions of ART are situated must be considered in adherence interventions. This may mean that adherence interventions may have to nurture attitudes that may not always be in keeping with government opinions, which may prove to also come with its own complications.

Secondly, it was acknowledged that to an individual who is ignorant of the intricacies of HIV and ART, it would be easy to make the association between ART and

death, especially since the death may occur after the commencement of treatment. Hence, it was, recommended that adequate psycho-education about HIV, immunity and ARVs be conducted in an effort to challenge such associations.

Thirdly, adherence interventions would need to explain to patients the role of additional treatment such as vitamins in the treatment programme, that is that. they serve to boost the bodies immune system but do not serve to suppress the virus. Hence, there needs to be an emphasis on the additional medication as a supplement rather than a substitute for ART and then, only if the additional medication does not decrease the efficacy of the ART.

## CHAPTER FIVE: DISCUSSION

The following chapter discusses pertinent observations made in relation to the expert and patient interviews that did not fit into the four themes discussed in chapter four, but nonetheless deserved mention in this research report.

### THE USE OF THE WORDS 'ADHERENCE' AND 'COMPLIANCE'

The author had found that the words 'adherence' and 'compliance' were used synonymously in the literature. It was therefore not surprising that the interviews conducted reflected the use of both words. However, Experts 3 and 4 highlighted a significant distinction between the two words, while Experts 1 and 2 failed to use the word 'compliance' at all.

> Compliance, more gives you the idea of the patients following an instruction. It has something to do with obedience, whereas adherence is a more active participation of the patient, where he takes responsibility for himself, and understands as much of the picture as possible, so that he can buy into, and to operate and participate in something that going to be beneficial for his own health (Expert 3).

> And I believe the better word is 'adherent', rather than 'compliant. Compliant is kind of associated to a doctor's instruction rather than a choice (Expert 4).

Of interest was the manner in which Expert 4 responded to the author's incorrect usage of the word 'compliant'. He was quick to correct the author, indicating that the two words are associated with different subtexts.

An analysis of the expert dialogues indicates that the word compliance is associated with an instruction, implying a non-involvement of the patient in decision-making in respect of his or her treatment regime. Adherence, on the other hand is associated with a sense of empowerment on the part of the patient where he or she has a choice whether to follow his or her regime or not.

A further analysis of the literature revealed that the word 'adherence' is used more frequently in psychological journals while the word 'compliance' appears more frequently in medical texts.

## A COMPARISON OF THE EXPERT AND PATIENT INTERVIEWS

Before discussing the similarities and differences of the expert and patient excerpts, it is necessary to comment on the context grounding their responses in the interviews. The expert participants had generated their opinions from at least two years of working within the HIV/AIDS field. Hence, their opinions were based on their specific training, which influenced the manner in which they conceptualised the issues pertaining to adherence, in addition to their exposure to others' experiences. This could explain why Expert 4 offered many psychological explanations to account for patient behaviour, while Experts 1 and 3, who dealt directly with the patients, offered suggestions of more practical, as opposed to theoretical, nature. Expert 2 reported to be currently on ART, hence his opinions were not only from his work experience but from his own personal experience of being on ART as well.

The patient responses were based on their own personal experience of the medication. Hence, they articulated what they felt were the 'real-life' issues that influenced their levels of adherence. This was based on their own perceptions of which aspects of their lifestyle and behaviour prevented them from adhering to their medication regime.

When one combines the inputs of both the experts and patients, it becomes apparent that the barriers to adherence can be conceptualised at a macro-level and at a micro-level. Those concerns that are pitched at the level of the community and that are situated in the political climate, such as a lack of education and poverty, are macro-level or systemic concerns. The concerns surrounding the patient lifestyles, such as dietary requirements and the quantity of medication, are concerns that can be conceptualised at a micro-level because they are situated in the context of the patient themselves. However, the two levels are related. Problems related to poverty at the macro-level will impact on whether a patient, at the micro-level, has food or not and is able to follow the nutritional requirements necessary.

When comparing the expert and patient responses it was seen, firstly, that the experts' perceptions of the barriers to adherence appeared to be focussed on a more systemic level than the patient perceptions of the barriers to adherence that seemed to be focussed on barriers experienced at a more micro-level. An example of this is the experts'

consideration of psychological factors, the challenges in specific communities and political issues. The association between these factors and adherence levels cannot be denied and in most cases were also supported by the surveyed literature. However, it must be noted that these factors are systemic and would require macro-level interventions. The patients on the other hand, spoke of personal barriers that they had experienced and hence, their perceptions of the barriers to adherence, such as side effects, dietary requirements and substance abuse were barriers that would need to be confronted at a more individual level.

The above findings could be explained by the fact that the patients, who are directly affected by the barriers to ART, tend to examine what they have power over, namely their own lives. In comparison, the experts' training equips them with insights to look at factors from a more systemic perspective. Thus, to the patients, HIV/AIDS and ART are personal battles and the presence of HIV/AIDS in their lives is probably so overwhelming that all they can focus on is the direct association with themselves. On the other hand, to the experts, these issues cannot be separated from the political, economical and social contexts of the country.

Secondly, the experts' perceptions of the barriers to adherence were concerned more with 'theoretical' or assumed concerns about political issues and stigma and discrimination, whereas the patients' perceptions of the barriers to adherence were centred around more practical concerns such as concerns about the medicine regimen. This could be because patients discussed those barriers that were of immediate concern to them, whereas experts could use their knowledge and expertise to conceptualise the problem more systemically, yet again. The concerns raised by both the experts and patients, however, were both supported by the literature, hence validating their concerns.

The implications of these differences in the way we think about adherence is that adherence is a concept that has to be confronted on various levels from the individual to the community. The knowledge of the patients help to highlight problems at the level of the individual while the 'academic' knowledge and work expertise of the experts may help us to conceptualise the problem of adherence at a more systemic or global level.

Thus, in sum, the expert and patient interviews have demonstrated that adherence needs to be conceptualised at both a systemic and individual level. This means that

adherence intervention needs focus on implementation at both these levels. Macro-level intervention, however, is generally concerned with nurturing broader social change, which may require more long-term intervention. It must be noted that some of the systemic level barriers such as poverty cannot be seen as barriers exclusive to ART adherence. Rather, poverty probably contributes to many other problems within healthcare as a whole. Thus, we cannot deny the impact of these 'systemic' barriers on health-care as whole and intervention at this level would probably require the mobilisation of resources across all health-care infrastructure in the country to bring about social change.

## STRENGTHS AND WEAKNESSES OF THE RESEARCH

A fundamental strength of the research lies in the profiling of the expert panel. All experts have worked for a long time in the HIV/AIDS field and have worked specifically with adherence to antiretroviral medication. Hence their recommendations were supported by years of experience. In addition, the range of professionals approached was fairly extensive, allowing representatives of all the key role-players concerned with adherence to antiretroviral medication to voice their opinions.

A further strength of the research was the inclusion of the patients. This allowed the researcher to tap into knowledge from patients that were taking the ART. The inclusion of the patient participants emphasised the importance of local knowledge and gave this sector an opportunity to voice their concerns.

Another strength of the research is the research methodology employed. Given the fact that adherence to antiretroviral medication is a fairly new research area in South Africa, the research methodology employed also allowed the researcher to provide an exploratory view of this area. The decision to not stipulate a hypothesis at the outset of the study allowed the researcher to focus on those themes that emanated from the participant excerpts and focus on those as hypotheses. In addition, the use of thematic content analysis allowed the researcher to explore these themes further.

A potential weakness in the study is the small sample size, in spite of the fact that the 11 participants yielded a wealth of information. However, for the purposes of a qualitative study, the number of participants does suffice.

Another potential hindrance to the research process came from the patient responses. It was found that patients were very hesitant to disclose poor adherence. All patient participants were part of antiretroviral programmes and all reported maximal adherence levels. Though it is very possible that all seven patients may have achieved maximal adherence, it is felt that patients may have been hesitant to disclose their true adherence levels as they felt it would affect their inclusion in the antiretroviral roll-out programme. The analysis of the patients' reports demonstrated that even if this was the case, the patients still yielded a wealth of information regarding barriers to adherence and recommendations for improvement, which were the aims of the research.

# CHAPTER SIX: CONCLUSION

The research has thus explored the patients' and experts' perceptions of barriers to adherence and their recommendations for improving adherence. This chapter first looks at a summary of the recommendations generated from the interviews, followed by a presentation of those areas requiring further research. Since, the practical aim of the research was to generate recommendations for improving adherence, it was felt that it was necessary to present a summary of the recommendations generated from the expert and patient interviews.

## SUMMARY OF RECOMMENDATIONS

### Experts' recommendations

From the expert interviews, the following recommendations for improving adherence are made:

A greater focus needs to be placed on the health-care provider-patient relationship, in an effort to nurture a warm open relationship in which all concerns can be confronted (Godin et al., 2005; Heckman et al., 2004; Meredith et al., 2001; Murphy et al., 2004). This allows patients to confront conflicting messages, traditional belief systems and concerns about the medicine regime with their physician if an effort to facilitate a better understanding of HIV/AIDS and ART.

. The co-morbidity of HIV and psychological illness and its impact on adherence to ART (Brief et al., 2004; Halkitus et al., 2005; Ickovics & Meade, 2002; Kalichman & Rompa, 2003; Malan, 2003; Moosa et. al., 2005; Phillips et al., 2005; Shernoff, 2001; Yun et al., 2005) suggests that screening measures for psychological illnesses and appropriate treatment if necessary should be implemented at the outset of the treatment.

Avenues where patients can access support, such as support groups and the use of treatment supporters need to be identified. Patients need to be encouraged to seek family support and support through support groups; as support has been seen to improve adherence levels (Berg et al., 2004; Godin et al., 2005; Kumarasamy et al.; 2005).

There needs to be a greater focus on education, both at the individual and community level, in an effort to allow patients to understand the entirety of their disease and treatment options.

Following more research in the area of traditional medicine, efforts need to made to integrate traditional and western belief systems in an effort to convince more patients to use ART.

The link between levels of adherence and the socio-political context also suggest that adherence intervention could be guided by a community psychology approach, where communities are empowered to improve their socio-economic circumstances and, as a consequence, their level of health consciousness (Seedat et al., 2001).

**Patients' recommendations**

From the patient interviews, the following recommendations emerge:

Given the motivational impact that witnessed improvements has upon adherence, it is recommended that ART-related success stories be given more coverage.

Patients need to be encouraged to access support (Berg et al., 2004; Godin et al., 2005; Kumarasamy et al.; 2005).

Patients need to incorporate time-keeping devices into their lifestyles, to help them remember to take their medication.

There needs to be an increase in antiretroviral awareness, in an effort to increase knowledge and facilitate informed decision making and health behaviour in relations to medication.

Given the association between poor adherence and alcohol and/or substance use, there need to be screening measures for alcohol and/or substance use at the outset of treatment and rehabilitation if necessary in an effort to ensure maximal adherence (Heckman et al., 2004; Ickovics & Meade, 2002; Kalichman & Rompa, 2003; Rothlind et al., 2005; Shernoff, 2001; Ware et al., 2005 ).

## AREAS FOR FUTURE RESEARCH

The following areas were highlighted as areas for further research:

The relationship between forgetfulness and adherence needs to be explored further. One patient participant claimed that forgetfulness was an unconscious effort to avoid the side effects of the medication while an expert participant stated that perhaps it is wilfulness that affects forgetfulness. This perhaps highlights that the mere act of forgetting to take one's medication is a complex issue and for this reason requires further research.

It became evident that certain communities face community-specific challenges, as was seen in the prison community and black communities. This suggests that further research be done at the level of the community so that these challenges can be highlighted.

The experts noted that there are complex gender dynamics that affect adherence levels. The issue of gender and adherence is something that requires further research. Should findings be similar to the experts' opinions, then adherence interventions may need to be addressed as a couples issue (Remien et al., 2005).

More research around the area of traditional medicine is also needed, as this is an area that competes with the philosophy of ART.

Some patients, even in the context of appropriate adherence interventions, have failed to take their medication. The patients labelled this as a failure to take responsibility for one's life. Such patients need to be investigated to examine if there were any other factors that contributed to their poor adherence and what could serve to motivate them in future.

In conclusion, it can be seen that the expert and patient interviews yielded valuable information regarding the perceptions of barriers to adherence and their recommendations for improving adherence. The difference between the expert and patient recommendations have implications on how we conceptualise adherence. The concept of adherence needs to be confronted at both an individual and community level and this must be considered in future adherence interventions.

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## APPENDIX ONE: PATIENT TRANSCRIPTS

### Patient 1

Key: I – Interviewer

R – Respondent

… - Pause

(Please note that a translator was used, hence the dialogue in the second person.)

I: Hi. My name is Janice and I'm from Wits University and I'm trying to find out about how patients take their medication.

R: Okay.

I: How old are you?

R: 28.

I: And, what do you do for a living?

R: (Patient mumbles.) I'm not working.

I: Please can you speak a little bit louder because otherwise your voice won't be taped by this machine.

R: Okay.

I: How long are you taking the antiretroviral medication for?

R: From last year (2004).

I: And, what do you think about the medication?

R: Before he was using the medication, he used to have the stomach problems and the stomach is running. After an hour after taking the medicat ion.

I: Thank you but what I am trying to ask, is what does he think about the medication. Does it help? Is it good for him?

R: Okay, he thinks that the medication is helpful and must be used by other people.

I: Is that everything you said, because it seems that you were speaking for along time.

R: Yes. He was just not understanding, so I am trying to explain.

I: Tell me about your medication, like how many tablets he takes a day?

R: In the morning he takes two and in the afternoon he takes three. He takes medication two times a day. In the morning he takes two and in the afternoon he takes five. (Attempts to name the specific tablets are not successful.)

I: Does he ever forget to take his medication?

R: No. Never.

I: And, why does he think other people forget to take their medication?

R: The thing is that if someone is not responsible for his life, then they just forget to take the medication.

I: What does he mean by "If someone is not responsible for their life"?

R: He means that here they are taught that they must take the medication, on the time that they have structured and if you don't do that, the sickness will go on. It is important to take the medication and if you don't do that you are not responsible.

I: Ask him why do people forget their medication the most?

R: He doesn't know.

I: Ask him what does he think can help people to take their medication properly.

R: There must be someone who will be responsible for that particular person, to help him or her with the medication.

I: Ask him if there's anything else that he feels will be able to help the person?

R: There must be something like a media or radio that can help this particular person. Or he must have a watch so he can be able to set the time so that he will remember to take his medication.

I: Thank you very, very much for agreeing to answer these questions.

**Patient 2**

Key: I – Interviewer

R – Respondent

……. - Pause

I: Your name is?

R: Abozondo.

I: And how old are you?

R: 38 years.

I: And what do you do for a living?

R: Me?

I: Ja.

R: (Patient mumbles.)

I: I beg your pardon.

R: I am taking the tablets for HIV.

I: Okay. Sir, what do you do for a living?

R: For living?

I: Ja.

R: I am coming to the hospital now.

I: Do you work?

R: No.

I: So, you are unemployed?

R: Ja. Now, I go back to unemployed. It starts in January.

I: How many tablets are you taking a day?

R: I take in the morning, two, the afternoon, three.

I: So, you're taking five tablets a day.

R: Yes.

I: Do you ever forget to take your medication?

R: No. No, I don't forget.

I: Why do you think you don't forget?

R: Because, it's my life.

I: Okay. Why do you think other people forget to take their medication?

R: The people maybe….if the people are drunk. They drunk the beer, maybe they smoking, they smoking the dagga and then you forget to take the tablets. Because me, there's no smoking and me don't drink beer and some things like that. See, these tablets are good for life. You see me, I'm sick for now I think one year and then you start taking these tablets and my life is coming back. Until now is fit. All the people, they ask me "You taking this tablets?" and then I tell them "I go to KwaZulu Natal to take these tablets and that they good for life." I think that maybe, if its not eating these tablets, my body is not good. So, now it's the same if you eating the tea or porridge.

I: Tell me about the porridge.

R: You see now, the porridge, the pap.

I: What about the pap?

R: If you eating now, for these tablets, I know every ….only 9 o' clock before you drink the tablets …….you have something slice…..

I: What do you think about the antiretroviral medication?

R: The medication?

I: Yes. What do you think about it?

R: I think…so it is good.

I: And how do you remember to take your medicine?

R: Okay, see the nurse make the calendar.

I: Yes.

R: They tell me when to take the tablets. Then, we got the paper to make the calendar and it tell me when to come back. So, I know everyday. And then I know not to forget. You see you take the tablet on the calendar.

I: Do you mark it when you take the medication?

R: Yes.

I: How many times a day?

R: You mark it every day.

I: When you taking the medication?

R: Yes.

I: For what other reasons, do you think people don't take their medication?

R: I think also that people are not taking the medicine. If maybe, I think it is good now, I am never going to take this medicine. Right now it's okay. But me, I think until the doctor must take the results. Until, it's okay now.

I: So, some people, think that everything is gone and that's why they don't take their medication?

R: Ja. They just look at their body and say it's okay. I can't take the medicine because their life is alright now. But the doctor never give you the results. The doctor must give the results again and then the doctor must check you okay. Now the life is okay now.

I: Why do you think that you take your medication properly but other people don't t take their medication properly?

R: Because me, I am serious. Because me, I'm going in the wheel chair. Can't go. And then you go, I think so, if you've got the good tablets, you can't leave because we don't like to die. Ja. So I speak to doctor. Doctor says, "Okay, take these tablets. Tell me what is going on in your body with these tablets." The sick in the stomach, maybe sick in head. You see, I know what I will win with these tablets. And then I was sick in the stomach too much in the stomach and then I say, okay, I am sick until the body is coming alright. For two months, you eating, you sitting on the hospital. After two months, you see I am okay. So, I know every month I must come to take the tablets.

I: Thank you very much for agreeing to do this interview.

**Patient 3**

Key: I – Interviewer

R – Respondent

……. - Pause

I: First of all, thank you so much for agreeing to do this interview. The information that you are going to give me will really help me with my research.

R: Okay.

I: Please feel free to speak your mind. Your honesty will be appreciated.

R: Okay.

I: How old are you?

R: I am 32 years old.

I: And what is your occupation?

R: I am a counselor.

I: And before counselling, did you do anything else?

R: I was working as a domestic.

I: How long ago were you diagnosed?

R: I was diagnosed by 2002. It was late October.

I: How long have you been on antiretroviral medication?

R: I start taking antiretrovirals by 2003……by September?

I: Tell me, how did you come to take the medication?

R: First of all, I used to have a problem of abdomen. I was having abdomen pain. So, I used to go the clinics and I used to go to the hospitals but nothing would help

me. They give me panados, pain killers, all those medications but my abdomen continued to be painful. Then, one day I go to JHB Gen. They say, maybe I got cancer, womb cancer. And then they take a test for cancer and they say I must come back, and I go there after one week. They say I don't have cancer. They say I must back to find out what is it. I go back and they don't give me anything. Then, after some few days, after the JHB Gen, I used to watch TV. At that time, I was working Monday, Wednesday, Friday as a domestic. And I was having a husband. So, I used to watch TV. I saw that show, the Felicia Show. Then, they were talking about HIV and AIDS. At that time, I don't know nothing about HIV.

I: So, you didn't know you were HIV+?

R: No.

I: What year was this, mam?

R: When they were talking……..2003? So, I was watching, you know, other people, they talk about they were having headaches, this headache, this and that. And there was another lady. She was talking about a womb problem. And then she end up at the clinic where she took an HIV test, they tell her she's got HIV. And me too, I got the same problem as this lady. Then, I told my husband when she came back from work. I tell her about the show, about HIV AIDS. And then, she didn't agree for me to go and take a blood. But no, I suffer a lot. Maybe I should go because I don't know. I feel very sick. I go, cause I want to know. By that time, my daughter was ten. So, I took my daughter the following day. I go to the clinic. I took blood. They say I must come back after two weeks. I go back and they give me my test blood. They ask me how I am feeling. I tell them, "No, fine." They say, "Okay." Then they give me the results. They give me a letter to come here to see the doctors for HIV. I came to Helen Joseph the following day. Then I attend this clinic from that time. Then I used to come here and then my husband start to be sick. He was having asthma. They admit him at Helen Joseph. They say maybe he's got asthma but they are not sure. Maybe its TB. He slept here mainly about two weeks or three weeks. They give him lots of Bactrim and

then he comes back. I am staying with him and my baby. He was sick, sick. And, after some time, he became better. He ignore to come back to the clinic. He go to work, after some time. Maybe late 2002, he start to be sick again, that same asthma again. Then he was admitted. Came back here at Helen Joseph and they admit him. He stay for one month. After one month, they discharge him. Then, he came back to the house. He stay for one week. Then after one week, I took her to his mother. Then, he stay there in Natal for 30 days, one month. After one month, he passed away…..24th June. June….July….August, my mother passed away from a blood disease. After July, August, I start to be sick. Because at that time I was working as a domestic. I earn small money. I can't pay rent. My daughter goes to school. There's no one to help me. I've got a brother. He's useless. So, I was stressed. I start to be sick. I've got sores all over the body. And I came back to the hospital. Then, I used to come here to Helen Joseph and met another doctor. When I came, I met only one doctor. By that time they tell me, "You are very, very sick. Don't you think you must start taking ARVs?"

"ARVs, whats that?" "It is the medication for HIV. You'll be better."

I: The doctors told you that?

R: Yes. Okay, I agree cos' I was sick and used to hear about those medications from the pharmacist but I didn't see them. Then, same time, they make a letter for me and then they sent me to research. Then I went there the following day. They start me on ARVs. I start taking 3TC and (names another medication. So I took them from October, November, December, January, February, March, April. In April, they sent me to come and collect them here from the hospital because government bring them to the hospital. And, I start to take them from the hospital and up to now, I'm still fine. I don't see any problem. But, it's tough to take the medication but before you think ……sometimes you think of leaving to take them. To forget about taking them but we have to. That mind comes back; you are HIV. That you remember about HIV. You remember everything, then you go back and take them. I don't, I don't remember even one day that I didn't take my tablets.

I: How do you think that the medication is working inside of you. How do you think it works?

R: It works because at that time,I was losing lots of weight. I was wearing size 28. By that time I was having lots of sores but now I'm fine.

I: So, you were having lots of sores and now you're okay. That's how you think it worked?

R: Ja. It is working. ARVs are working.

I: Tell me, how many tablets do you take in a day?

R: In a day?

I: Yes. Tell me about your schedule for the whole day?

R: Stockrin, 2, 1, 1, 10.

I: 10. Tell me when do you take them?

R: In the morning, I am taking 3TC, D14 and then at night I am taking 3TC, D14 1, 1 and then Stockrin, 3, Bactrim, 2 and vitamin B, 2, vitamin C, 1. And also I forgot, I've got TB. I developed TB. But next month it's my last month. Six months is over. That means I am taking twelve tablets. (Repeats the medication schedule, including the TB medication.)

I: And, do you ever forget to take the medication?

R: No, I don't think so. Because, I'm staying with my daughter. Before she go to school, she used to take that box of tablets- I put my tablets inside a box, a shoes box. I put al my tablets there and then I put under my table. I've got a small table for TV, for TV. Then I put my box there. In the morning, she wakes u. She took out that box and put it on the table and I don't forget it.

I: That's very good of her to help you like that.

R: By 8 o' clock I know, when it's "Generations". Sometimes I'm watching news and when it's finished I know it is time t o take the medication.

I: So, you think it's quite helpful to associate it with something that you do.

R: Yes. Because sometimes you forgot to set cell phone. Sometimes, you don't have cepp phone. So, sometimes you can use soapies or something else to remind yourself.

I: What happens on weekends, when there's no "Generations"?

R: On weekends, I use my daughter.

I: So, she will take it out?

R: Sometimes because she is used to waking up in the mornings.

I: Do you think the people around you affect how you think about the medication?

R: You know, other people, they can take medication but people, they like advices from other people.

I: Tell me about that.

R: Because, when you counsel someone, you tell him or her about medication, they you, "You know, someone was telling me their big brother was taking this medication and now he's dead." And me, I' advising him that "You don't know how sick was that guy. You don't know his CD4 count. You don't know how long he's been sick." We can be HIV together but we can't die together and we can't face it like the same.

I: Now you say that people are negative like that. Before you became a cousellor, because now you re well educated- When you first started, did people's talk like that worry you?

R: But at that time, people, they were not that much about ARV. They didn't know nothing about ARV because ARVs started last year April and I was already on ARVs.

I: How do you think people around an HIV+ person affects whether the person takes their medication or not?

R: You know, I don't know how to put this. May be you can explain it in another way.

I: Okay. Just say that it's you who is on the medication, you have a lot of people around you. People you work, people at home, people at church, people in you social groups. O those people affect whether you take you medication or not?

R: Ja. Other people, they ignore you but others they support you. Like people who's those, maybe you come from Lesotho, you can take your medication totally but when you go to Lesotho, they going to ignore you. It's like when your eat something, you drop it there. When you use a spoon, they going to reject them. They need education. People need more education about HIV. People, they know nothing about HIV.

I: Are you trying to say that that when people go to their homeland, they might not take their medication?

R: Ja. We used to tell them, please disclose your status because when you are in JHB, it's easy for you to take medication but when you go there to your family, your family doesn't know nothing about your status, then, it's going to be tough for you to take your medication and it's true. People take their medication when they are here but when they go to their places like Natal or Lesotho, they don't.

I: If you look at your lifestyle, what do you think about your life and your lifestyle makes you remember to take your medication?

R: I think I learn a lot of things about HIV. Even now, maybe I'm working this job, because I want to learn more about HIV and I think that HIV is gonna be curable.

I: So, do you think that the fact that you got this job has a big impact o the fact tat you're taking the medication.

R: Yes.

I: Is there anything else in your lifestyle that you think helps you to take your medication?

R: May be, you know to read magazines, to read something. Sometimes I know, here at the hospital we've got pamphlets on HIV and AIDS but when you go to a private doctor, sometimes you get other things on HIV and AIDS. I used o take them and g and read them. I don't ignore them like I don't know nothing about HIV. I'm learning more about HIV, I think every day.

I: What do you think causes people to not take their medication?

R: People, they ……like- People, they say that this medication is too much for them.

I: What do you mean by too much?

R: Like, Stockrin. You take 3, then 3TC 1, D 14, 1, in fact D 14 is twice a day, 3TC is twice a day. Stockrin is 3, once and maybe Bactrim and vitamin B and vitamin C. Sometimes that person got TB. They feel those people that the medication is too much and they ignore to take the medication.

I: Do you think they get confused?

R: Ja.

I: What about it being too much, stops them?

R: People, they give up. People, they just give up.

I: Why do you think they do?

R: In the other side (the on clinical trial group) people, when you talk to them, they can agree here but when they go through the corner they just through those pills away and take other advices, you see.

I: Tell me more about why you think people just give up.

R: They think that HIV, this medication can't work for HIV.

I: But you, know about the medication. Why is it that you feel that the medication is gonna work yet others feel that it's not gonna work? What do you think affects that difference in thinking?

R: Because, sometimes, other people, they start medication when they are fit. And this medication doesn't need a person who is sick. They are forced to take medication while they are sick and this medication has got side effects. Just imagine, this person is sick and then takes ARVs. Arvs got side effects. Where are those side effects? They're going to be to him or her. So, when they think about that someone who died, they think maybe this tablets kill him/her.

I: You spoke about side effects. Tell me, do you think side effects affect whether someone takes their medication.

R: Ja, most of the people, you have to be fair with the patients. You have to explain to them about side effects. That this medication, when you start them, you going to have side effects, maybe something like head ache, rash, stomach cramps, dizziness and dreams. So, people, they are scared. You explain, you can't have these things in one time. You can have headache once, but when it's bad, it's bad. When it's bad, they must come back to the hospital. They will say, "I will come back. I want to think about it." So next time, when that same person is coming in a wheelchair, he is very, very sick. So, people, they don't want to take medication because of side effects, or because someone died of ARVs. And ARVs, doesn't kill people.

I: What does the hospital do to make sure that you take your medication properly?

R: Me? …….. Because my viral load, my CD4 count was low when I started the medication and I was sick. My viral load, I didn't know it but now it's undetectable. That's why I said, this medication is working. I was very, very ill. I was dying.

I: What do you think can be done to help people take their medication properly?

R: I think we have to go to schools, to make lots of adverts and famous people like, for example like, Mandela talking about his son. People were coming ad saying that Mandela was taking about his son. Black people must get tested.

I: That applies to HIV awareness in general. More specifically, about taking medication properly, what do you think we can do?

R: We have to make sure …….. like sometimes, that person maybe she don't understand you, you must make sure that you book her for another appointment to make her to come back and understand you about this medication.

I: How will you know that the person understand?

R: When the person is coming, you ask her some questions to see that she is thinking. Then you can see if this person is understanding, even if she is going to a doctor. Doctor can't just write medication and give to her. She must ask her about medication and they used to do it here. When she doesn't know nothing, they bring her back to the counselors. To teach them about education.

I: Is there anything else that you think can be done to help people take their medication properly?

R: You know what, me I was like the other people that used to when they talk about medication, they ignore you. When they come here, they are crying, so, I used to disclose to them about my family. Then, most of them, they know me. I was attending this clinic.

I: So, you are suggesting personal examples, making it real to the person.

R: Yes, some people will tell you, “I want to see a person who is taking the medication.” They don’t believe when you tell them.

I: Thank you very much for agreeing to this interview. The information you gave me as very valuable and I hope we can use this to help other people.

**Patient 4**

Key: I – Interviewer

R – Respondent

……. - Pause

I: Thank you so much for agreeing to do this interview.
First of all – 'How old are you'

R: 35.

I: How long have you been taking the anti retroviral medication?

R: A year.

I: One year?

R: Yes.

I: What do you think about the medication?

R: I felt worse, until antiretrovirals was so helpful because I was very, very sick, and then I got the access to the antiretrovirals. I resigned from my previous job. I am an ex-cop, and after I resigned I was very, very sick and after I got the anti-retrovirals, I was well. I was able to work and I was able to do everything, and I applied for a job. I am now a counsellor, so I feel very very good.

I: Excellent. So did you resign from your work because of HIV?

R: Yes

I: When were you diagnosed? How many years ago?

R: In 2000.

I: In 2000? Did you manage to get onto the anti-retroviral programme?

R: Actually I took antiretroviral after I was diagnosed.

I: Okay

R: It was the wrong information that I got, because immediately I took my anti-retroviral without any advise. Without anything. At the doctor, he gave me a prescription for the antiretroviral, and when I resigned I stopped taking my medication. And I resigned in 2002.

I: Tell me about that: What made you stop taking your medication?

R: Because I was working at the police. I was working with public, PDP, public Drivers (unclear), so they were paying me money, and I have to pop out R1700.00 every month out of my salary for the tablets. I was taking Combivet, part of the antiretrovirals, and it was the wrong combination because I had to take Triple the medication and pay R1700 for that, so I was actually just distracted. So, I used that money and thought I could replace it with my money later. And one day there was a monitor in the office, and they found out that I took money, and they opened a case against me. Before I could go to disciplinary, and everything, I resigned, because I explained that I was HIV positive, and then I wanted to buy me the kitchen, so I took that money and thinking how I would replace it before they knew, but the found out. So I resigned.

I: So the cost of the medication was an incredible barrier for you?

R: Yes?

I: And I would like you to give me an understanding of how you think the antiretroviral medication works.

R: Actually the antiretroviral are good. If you take them, the first few weeks you get side effects. You get sick, you get drowsy, you got headaches. You've got back pain, all those everything, that painful feet everything, but after some weeks you will see the results.

I: How do you think it is working in your body and why? How do you think it is working in your body?

R: Ok, I would like to say. I was maybe 46kg, then I gained weight and I am eating a lot, and I can feel the difference, when I was sick, and with the antiretroviral. Now I can see the difference.

I: So how old are you again?

R: I am 35.

I: And do you think that the people you are surrounded by affect how you think About the medication?

R: Affect? Ja they do.

I: Tell me how?

R: It's a long story.

I: No, no it's all right

R: Actually, …… I was attending the institute before they moved here. It was IC institute on the other side of the hospital.

I: What is IC control?

R: Infectious control. So, when I was very sick I was diagnosed with pneumonia at first. And it was terrible. After that I had TB. When I was still on TB I was still attending the clinic and there was no antiretroviral available. I asked the doctors when are we going to get the antiretroviral, and they said they don't know, and I was running, I was hopeless, and people were dying. When I was admitted, people were dying in front of me because of HIV. I felt I had to do something, so I wrote a letter to Thabo Mbeki.

Then Thabo Mbeki sent my letter to the Health Minister, Tshabalala Msimang. They came to my house, and asked me why I wrote this letter. I told them that I do not want to die, and I am about to die, so I need antiretrovirals. So she has

commissioned nothing. So after 2 weeks, she announced that the antiretrovirals will be available on the 1st April.

I: That was last year. What about the other people around you like your family, have they impacted how you think about the medication?

R: My family and friends?

I: Yes.

R: Actually at my home, it's a counselling place. Everybody that is infected and everybody comes to me, when they need help. They saw something in me. What are you doing? What are you eating? So I advise them that I am only taking my antiretrovirals.

I: But, what do they think of the antiretrovirals?

R: They felt that maybe the antiretrovirals will kill you. They do not want to hear anything bad about it but I used them before.

I: So you knew. And the first time that you used them? How did the people around you think about that?

R: They didn't know, because I did not disclose it at the time.

I: Ok, so you have disclosed it now?

R: Yes, everybody knows.

I: And tell me about your medication. What is you daily medication like?

R: It's Stockrin.

I: How many times a day.

R: Once a day at night, and then it's (tape unclear)

I: Tell me how.

R: You take Trestity and Veritan in the morning. At night I take them 20.00. I take at night and Stockrin, everyday – morning and night.

I: So all your tablets are at night?

R: No, it is morning and night.

I: Morning and night?

R: Yes – 8 to 8.

I: So you know which one's to take. How many do you take in the morning?

R: I am taking one Zeret in the morning. At night Zeret 1 and Tretisy, and then Stockrin. Stockrin you only take at night.

I: And do you ever forget to take them?

R: Never!

I: Have you ever forgotten?

R: Ja, once.

I: Tell me why you have forgotten.

R: Actually I use to set my alarm, and I use my cell phone as a time beeper. So at that time I think I forgot to put my alarm, but I took them. I still took them, because I am taking my medication at 8.00, I remember at about half past ten, but I took them.

I: Do you feel that a person's lifestyle affects whether you take the medication or not?

R: Ja it does affect.

I: How do you think so?

R: Because when you don't take it, before you take it. Before you take it, you got sick, you think that people can see that you are very sick on this aids thing is a stigma itself. And then after you have taken it people can see, this is the real person.

I: But do you think that maybe where someone lives, that maybe a hectic lifestyle, or what might not be - or you find that you found in police work and you have a very structured lifestyle. Maybe that helps you to take it better?

R: Ja.

I: Do you think that other types of lifestyle might not?

R: It depends on individual. But if you want to live you will take them.

I: What do you think causes people to forget their medication the most.

R: People won't take the medication at first, you feel better maybe because they are not very sick at that times and sometimes they do forget.

I: So you think their symptoms have got better?

R: Ja

I: Now in the initial education that you get when getting the antiretrovirals, do they tell you that you will feel better and that you need to keep taking them?

R: Ja they do.

I: What do they tell you at the beginning?

R: They tell you that they forgot their medication. Others they did not disclose. Disclosure is very, very important. Because when you forget to take your tablet, at least if I knew you were HIV positive, I can still send you an sms – Please take you tablet – or if living in a household, they can still remind you – Have you taken your medication. Have you done this? If you didn't disclose, it's a big problem.

I: And you spoke about the fact that some of the symptoms disappear. Lets just go back to that for a little bit. Because here at the offset, where people – the social workers - explains to you that when they take the medication, the symptoms are going to disappear but you still need to take your medication.

R: Ja

I: So why do think that in spite of the telling you, people still stop taking that, when their symptoms disappear?

R: Why do they have to take it?

I: But why do people stop taking it. When know they feel better. Even though the Social Worker had said to them, you must not do this.

R: They think are normal now, they are healthy, it's ok. That's why they stop it.

I: Tell me about things in your life, because you seem to be a very good example, because you've only forgot to take your medication once.

R: Ja.

I: So, to help other people out there, tell me all the things in your life that you think are making sure that you take your medication.

R: You have to remember every day. You know about taking your antiretrovirals. At the time, when you are diagnosed with my HIV, before I took my medication, before I took my antiretrovirals. It will take some 2 months or 3 weeks or some time – to forget about my HIV. I just forget about HIV positive, but to take your medication it reminds you that you are HIV – everyday.

I: Do you think it's important for someone to remember that they are HIV positive?

R: Ja – they must know that they are HIV positive. They need antiretrovirals, and they need to take medication.

I: So what motivates you?

R: I don't know what's motivating me, but – as I said I've disclosed my status, everybody knew. Even if I forget, somebody will call me. Hi, how are you Cindy. I'm fine thanks. How are the tablets? How are you coping? And the other one will say – everyday –they will ask, even if I forget, someone will remind me. Even if it doesn't remind me direct, but they will ask me – how are the tablets – are they checking out ok, then you remember – oh I have to take my tablets.

I: What advice do you have for people taking antiretrovirals – to help them remember?

R: I just – you know – to be sure, that believe antiretrovirals are helping.

I: You seem like a very positive person. Are you positive by nature?

R: Yes, I am a positive by nature.

I: Because it seems that you are very motivated, and maybe that positive nature is what helps you.

R: I am like that.

I: Do you think there is anything else that maybe the Health Care System can do, to try and help people take their medication?

R: Ja, if they can make more ……If they can use media, or TV or to educate people about HIV about the antiretrovirals.

I: Tell me more about that – about the adverts.

R: How and what is HIV. How can HIV infect you? What are the antiretrovirals? Because every time one listens to the radio – you hear different stories.

I: Tell me about that. Those conflicting messages.

R: They tell you that – I was very very sick, then I went and got multivitamin – you see those things. So people, they don't know if the retrovirals are working.

Because they think it could be the multivitamins. Ja, because this person is talking about multivitamins.

I: So you think that the conflicting messages almost confuses people?

R: Yes. And that can just confuses everyone.

I: Tell me about the side effects that you experience, and how long they last.

R: Actually they last for about 2 weeks, but that doesn't mean they comes everything in 2 weeks. It can come today, tomorrow – it jumps. And there are different side effects. It's like headaches, stomach cramps and bad dreams. Stockrin gives you bad dreams. And tiredness – sometimes.

I: And do they put you off.

R: No.

I: I am referring to the first time, because the second time you knew.

R: The first time they didn't tell you. Its not all severe side effects, but there are severe side effects. The patient has to come to the hospital, if you see a severe side effect.

I: I am very interested in that first time that you took it. It must have been difficult to pay out R1700.

R: At first – I didn't know anything – I knew there was this tablets for HIV, and I wanted them desperately.

I: How did you know about this? The HIV tablets.

R: After some time I was consulting the doctor. At the doctor, I asked, what can I drink for the HIV? He told me that there is this Combifer. Where can I get this combifer? Can I get it from the chemist, can you prescribe it for me.

I: So you really did believe in the medication?

R: Ja. But at first when I started taking the antiretrovirals – like mad. But I didn't want that thing to stop.

I: Why?

R: Because HIV ….. my boyfriend was very sick at that time. I don't want to be like him.

I: So it was the fear.

R: Yes it was the fear that I needed to do that.

I: Is he HIV positive?

R: He died long ago in 2001.

I: I like the idea about increasing public awareness through the media, the increase in the programs. Tell me more about that.

R: They need to give sex education in schools.

I: But specifically towards helping people to take their medication regularly. Not so much about HIV prevention. Getting the people to take their medication properly.

R: The antiretrovirals are new, about a year now, so people do not know, so they must advertise – we've got this antiretrovirals now so people must know. They must tell people the institutes where the antiretrovirals are available, because people they still sit and they die, because they do not have access to the antiretrovirals.

I: Where do you think the best place is to start with advertisement?

R: Everywhere. Posters and banners everywhere. Newspapers.

I: Thank you so much for this interview. It was very very usefull, to see somebody whose is so motivated. Keep on with your motivation. You look extremely happy. How are you feeling now? Any side effects?

R: No. It’s only that sickness. So it is very good that you see somebody who is motivated, because it gives us hope that we can actually motivate other people.

I: Yes. Thank you very, very much.

**Patient 5**

Key: I – Interviewer

R – Respondent

……. - Pause

I: Thank you very much for agreeing to do the interview with me.
How old are you?

R: 35 years old.

I: You're 35. How long have you been taking the medication for?

R: I am not taking the medication. My child is taking the medication. I am not on the antiretroviral drugs.

I: Your child is taking it. How old is your child?

R: Six years old.

I: Is your child here?

R: No – she is not here – she is at home.

I: Ok. And what do you think about the medication?

R: Ok, for the first time when I starting her on the medication, I thought that if I took this medication then I would be there when she gets big so that she can live longer. But the medication is Alot of money so now only she is on the medication.

I: So you are not on any medication?

R: No. I was on it for seven months when I was first diagnosed but I did not know then that I must only start at a certain time. So, I stopped it.

I: How come?

R: Because my immune system is still strong. See, you only start taking it when you get sick at a later stage. But now, it is time for my daughter.

I: What do you think about the medication?

R: The medication?

I: Yes

R: Ok, what I am thinking to myself is this. If I take this medication for my child then it will prolong its life and then thereafter maybe God will think about us and will give us the cure, that why I decided we must take the medication.

I: And how many tablets is your child taking?

R: She is not taking the tablets, she is taking the solution.

I: Ok. Tell me about it.

R: So in the morning she is taking 19 ml and then 11ml and then it is 25ml.

I: And that is every morning?

R: Yes.

I: And in the evening?

R: In the evening, I am giving her……..19 ml, and …….2.5 ml.

I: Do you ever forget to give her medication?

R: Before …….I used to forget, but I now I give it on time, but I give it each and every day in the morning but it was too early. I was giving for her 6.30 in the morning, then sometimes I forgot, when I got busy, then only I give it to her at 8.30.

I: What makes you used to forget?

R: When I wake up in the morning before six, she is not up. And then I get busy working, and doing the washing and then I forget, and then I remember I didn't give her the medication then I go back and give her medication.

I: And how did you come to some sort of way to give her the medication at the same time?

R: Ok. About this medication. At the first time when I started given her the medication, I will give her lots of pap so she can be strong and also feed her in the morning giving lots of vegetables and lots of fruit so she can be strong without the medication then ……boost the immune system.

I: What do you think make you forget to give the medication the most?

R: The most?

I: Yes.

R: Before I never give her the medication before, but what makes me forgot sometimes, is that I wake up early in the morning, then sometimes I going early in the morning. Then I take her and leave her with my sister. Then sometimes I forgot, and then I phone her and ask her – did you give my child her medication? Then she remembers to give the medication.

I: So, it had to do with just not being used to giving her the medication?

R: Yes.

I: Do you think there is anything that can help you to help her take the medication properly?

R: Yes

I: What can help you?

R: If I do, I give her the medication ok, it will help me, so she can live longer and then afterwards her body will be ok.

I: Is there anything that you think will help you to make sure that you give her the medication?

R: Ja, because I used to on my cell phone, so it must cry on 6.00, then I knew at 6.00 I wake her up then I give her the medication at 6.30.

I: You use your cell phone to remind you.

R: Yes. Before I didn't. Then, they gave me a time table to remind me, so that I can give her the medication.

I: And does that help?

R: Yes

I: Where did they give you the timetable?

R: They gave me at the hospital.

I: Is there anything else you want to tell me about? Do you think that other HIV positive people, maybe battle to take their medication on time.

R: Ja. Some of them they don't take the medication at home, but some of them they decided to take the medication now. They talked about it now. They're going to drink it each and every day. They going to take the medication for maybe 2 – 3 months, and after 3 months they think, there is no pain in my body, I'm ok, I'm fine, then they decided they are not taking the medication, and then by the time and when the pains come, then it is worse, then they remember to take the medication. They have never been committed to the medication before, so they have decided they are only taking the medication now.

I: Do you have any advice that you can give to anybody?

R: Ja. I have lots, because I am a comforter and also a HIV person, so I have that and also I am proud of myself because I have experience of it, because my child is taking the medication, so I give them lots of advice about it. And then I also tell

them about the side effects of taking the medication, because I'm worried about my child and they have a responsibility to their child.

I: And do you have any suggestions that you have to help parents on giving the children the medication on time?

R: On time. I'll tell them as a comforter in the morning, I tell them everyday, I tell them about the risk of not giving their medication on time. I tell them what is all about the medication, and why the medication is important for them. So when I tell them I explain a lot of things, everyday, like yesterday I had a patient of mine. I explain to him, he must take the medication right on time and prolong their life and if he is not taking his medication right on time and he might sometimes forgot, because he forgot for almost after 6 hours. You can forget for an hour or 30 mins, but not for 6 hours. You cannot forget it for so long. That is what I am telling them.

I: Thank you so much for this interview

R: Ok.

I: And good luck to you and your daughter.

R: Thank you.

I: Goodbye

**Patient 6**

Key: I – Interviewer

R – Respondent

……. - Pause

I: Hi. Thank you so much for agreeing to this interview.

R: Actually at the moment, they took me off the study, so they are no more giving me medication, because I was been in prison. I was supposed to be there till August, and then I ask how can I get my medication. How do I get to see them, the doctors and all that there? They said no, they will come back to me, and then they phoned me back to tell me and they said that they tell me no, I am taken off the medication.

I: Ok let's start from the beginning. How long have you been taking the antiretroviral medication?

R: Since 1999 November.

I: And how long were you diagnosed with HIV?

R: Since 1994. It has been about 6 years.

I: And have you been on clinical trials?

R: Yes, clinical trials.

I: What do you think about the medication so far?

R: I felt good and nobody actually noticed that this was wrong with me, even like now my heart is very sore, because they took me off, because I preferred the study medication, because when I see people who takes from the normal clinics, but then you can see its like ok, nobody can say that they have AIDS or, but us that knows, that knows who are HIV positive. Yes, they have this rash, they have all these things, and its with this study medication, there was no really bad side effects on my side.

I: So you've quite been lucky with major side effects?

R: Yes. I do not know how this is side effects or what. (Patient points to her neck.)

I: What is?

R: My glands are all swollen, and it is putting pressure on my brain. I do not know now, because I have to get an biopsy done at the JHB hospital, and I need to go to a private doctor, so I went to a local clinic, and they sent me to hospital and the hospital send me for a biopsy, because the Dr needs to check if it is TB, or something else. He mentioned 3 things.

I: How long have you been off the medication?

R: Since round about 19th January this year.

I: The reason that they took you off was because you were in prison.

R: In prison, ja.

I: And you were supposed to be in till September this year.

R: No, August, and they said that with my CD count at 1282 I can still go on without medication, till I come out and when I can come out, I can come and see them. But my family actually thought that they did want me on medication there, especially knowing that I am sick and Christmas Eve, I had this terrible pain in my heart and all that and I was in hospital there in prison for 4 days, and so my family made an appeal for me to come out, so that I can get medication.

I: So now you are out, because you need to get treatment?

R: Treatment, yes.

I: So what happens now if you don't get the medication, do you have to go back in?

R: No.

I: Do you think that the people around you affected what you thought about the medication, like the other people in prison?

R: No.

I: But people around you like your family?

R: They don't know. No, they don't know. Only my sister and my dad knows. I told them form beginning. And my sisters, and my girlfriend. She is an AIDS co-ordinator, but my children does not know.

I: How old are they?

R: The eldest is 27 and the other is 22, and my baby is 18.

I: How old are you mam?

R: I am 45. I will be 46 this year.

I: Do you think the people around you affect how you think about the medication?

R: Ja, they are affected.

I: No, do they affect how you think about the medication?

R: Like my brother.

I: Yes.

R: No, I don't really understand the question.

I: What I am trying to ask is, you know how the people think about the medication, about how it will help you. If people around you, says something in particular about AIDS antiretroviral medication doesn't work, that make you think about the mediation in a certain way?

R: Oh. No, actually my sister that was at one stage, doesn't want us to have it. My sister used to say that our Government is very clever. He must first find out what the after effects of the medication, he wants to do proper research. Because the

Americans just wants to dump things on us and he first want to find out what other long term after side effects and so on, and she thought it was right of him to take time, and to research on it and all that.

I: So, he was worried about side effects?

R: Yes.

I: When you were taking medication, how many tablets were you taking a day?

R: A day. That's morning and evening. In the morning I used to take 2 capsules. I used to take 4 in the morning and at night I used to take 2.

I: It is six all together. Did you have any side effects or anything.

R: No, in the beginning, I was on a different tablet, and I had to drink it on an empty stomach, it was a round tablet that you put in, and it fuzzes, like ENO. I had to drink that, so after some time, it was in 1999, then since then I had stomach problems, then it was bad.

In April 2000, I had to have an emergency operation, I had to go for a hysterectomy, but my appointment was for the Monday for the hysterectomy, then the Saturday night I just got sick at home. I went to the loo, and came back and I could not get off the toilet seat, I could not wipe myself, nothing. I called, and my husband tried to pick me up and he touched me, when I was still married, when he touched me. I was in pain, so I crawled to the bed. We called the ambulance, and took me to the clinic. They could not take me to the Kenridge, where I had my appointment for the hysterectomy. And then the Sunday they took me to the Kenridge. Only to find then that they need to do an emergency op on me. My bowel separated. And that was Prof Rice that did the op, and he could not understand, why / how come a person can get a separated bowel, so I let the people know. The Dr who was in charge of me that time. The Dr was, she was my doctor, Dr Yanks. And then I let them know, and she said I must not take any medication for that time, so I did not take medication. Only after Dr Rice found

out I was infected with HIV. I did not tell him that, and he said it was no wonder he was struggling with my blood pressure and things like that, to get my blood pressure down to normal.

I: So the medication did affect you?

R: Ja, I went back to the clinic, when they took me off and never put me back, ever since I have not been back. I have a thyroid problem as well; I got very thin, before I knew I had a thyroid problem. Eventually I was treated, and then the Dr did tell me I am going to get fat, and now I am actually very fat, and none of my clothes actually fit me. Now this morning when I put this on, I saw no it was slipping in nicely. So it means I lost weight since last week or so.

I: So, the medication has affected whether you pick up weight or not?

R: Yes, the Altroxin , not actually the thyroid. But even this medication, we got this thing that tells you what are the consequences, and inside and outside effects. It says you will get fat like in your neck, or you will get a big stomach, only thing is, I see my stomach is quite big.

I: When you were on the medication, did you ever forget to take the medication?

R: Ja, that maybe at night, maybe after visiting and normally I take my medication 8.00 or 9.00 and remember and 10 or 11 or so, but at a later stage, my sister says put tablets in the car, so where I went, I drink them, but there were times where I forgot.

I: And do you skip in the morning or the evening?

R: In the evening most of the time, especially weekends, because Sunday's we spend with the families.

I: And, why do you think you used to forget?

R: I did not have it with me.

I: So you never used to take it with you?

R: I told my sisters, to start carrying it.

I: And you got better?

R: Ja.

I: In the mornings, do you ever forget?

R: No, weekends ja, maybe Sunday mornings. During the week when I was working, I was taking I every day the same time but weekends and I never used to take it at the same time as during the week, because I used to sleep till late. Now I am up, its time to go to church, I bath, I don't eat. I run to church and when I come back, I eat and I take my tablets.

I: And in terms of taking the medication, to do it as part of a routine seems to be better?

R: Ja that is very important. You have to have that set time for the medication.

I: Do you feel your lifestyle affects whether you remember to take your medication or not?

R: Ja, because it works on my nerves, because I skipped, hey I did not take my medication. It is this time already, and you are like in a panic state and eventually ag I take it when I get home. You say – ag I forgot about it, when you reach home, you just want to get to bed; you completely forget to take it. Or you think for yourself, is it still going to work, because it is now 2 – 3 hours after the time that I normally take it.

I: What do you think used to cause you to forget to take your medication the most?

R: That's a good question. I can't really say.

I: Tell me all the things that you think used to cause it. Anything.

R: Like maybe even when I have visitors at home.

I: Why would you not want to take it in front of them?

R: Because I have to eat first, and then take it. I always believed I have to have something in my stomach before you take it. When I had visitors at home, I used to take it later than the normal time.

I: Did you ever think that maybe that your visitors would see your tablets. Do you show them your tablets?

R: No. I usually kept in on my fridge, and on the fridge next to it, is my sugar bowl, so that why I kept it on there so whether I take my tea or coffee the sugar is there, I touched those tablets. I used to have a small Tupperware holder where I used to put it. At night when I take out the nights tablet, and I took out the morning's tablet as well and I put it in there.

I: Did the hospital help you to take your medication properly?

R: Ja, like in September I was hospitalised with my knee, some sort of arthritis in the knee, and they were quite nice, and I was in a ward where I was not supposed to be, and those sisters loved me. They enjoyed me being there, and they were quite nice, knowing that I was HIV. I did not expect that from them, because it is heart patients in that ward only. This is JHB general, and they always used to remind me about the medication. Don't forget to tell your visitors or whoever is coming to bring your medication with, because I went for my normal thyroid check up and they saw that, and the doctor thought, no, I had to be admitted, and I did not have my medication with me.

I: Do you have any advice for people who are taking medication, because it seems to know the importance of taking it on time. Do you have any advice or any suggestions to improve when people take their medication?

R: One should always carry you know, extra tablets with you, when you are going for a day's visit. Take today and tomorrow's tablets with you because you never know when you have to stay over, because this happened to me many a times. I

used to go to my sister, and where I park, I live in a flat, so I park at my auntie's house and walk to my place and then many a times she used to say, sleep over, she says, sleep, as it is quite a distance for me to walk, then I used to sleep and never used to have my tablets or just tell her I have to go, I don't have my tablets, things like that. That is why I think you should always carry your tablets with you, and always try and have it more or less the same time with a couple of minutes difference, and I always make sure not have it on an empty stomach, don't have it on an empty stomach.

I: Is there anything else you would like to tell me about what you think could be affecting the way people take their medication?

R: What I think, not actually the way they take their medication I think some people think, no I am on medication and maybe I am fortunate to really have a partner right now who support me about the medication. I divorced my husband, but we still used to be like boyfriend and girlfriend, that's since 2003. Now I think why some people while taking the medication they are still careless on themselves. They don't really look after themselves. I think good eating also helps a lot.

I: What do you think cause people to be careless, and others not to be careless?

R: In the beginning, I don't know if it is because I am a Christian but I was very hurt, when I found out that I was like that. And you know that thought comes to mind, I am also going to give the next person this, and fortunately me being a Christian, I thought no, normally say God forgive them because they know not what they do or what they say, and that went away. But then I also found out that if you are HIV positive, it doesn't mean ok – you can use a condom, it doesn't mean you can be like a normal sexual person, having sex like a normal person. Like me that was married was trying to have it like twice a week when you are used to have it like everyday. Try to minimize it, when you are HIV positive, whether you use a condom or not, because I believe the sex does something. May be it's friction but it also contributes to you getting more sick and things like that.

I: If you have to think more about people taking their medication on time, do you have any more suggestions you want to give? Or anything you think it affects the way people take their medication?

R: Can also be if you did not tell people. Like me. I only told my immediate family, but my children don't know, because they was schooling and I didn't want to tell them, and now my eldest son and daughter they are overseas, so also now my sister says, I can not tell them over the phone. So I said, what if something happens to me and they need to be here you know, but then she said, I don't know, we need to work out something. I need to go there and tell them or so. What was the question again?

I: If you have any suggestions, but like you said, disclosure is very important.

R: Disclosure, its very important, because if you know I am HIV and we are friends, and you come and visit me, and it is time we have to go somewhere, you'll tell me not to forget my tablets, so if you don't know, you wont tell me that.

I: So you think the support system is important.

R: Yes it is very important.

I: Anything else your want to tell me, any problems you see with the whole aspect of adherence to the medication?

R: Another thing is, you can have the proper medication, but if you don't have proper food, like I am a single parent, and I used to have the medication here, but at times I would feel that I am weak, and not really sick but I still feel, and the minute I eat a piece of pumpkin, or I go somewhere, visit someone. I used to actually crave, I am wishing for food but veggies, and then I used to have you know things like that – hey, go to my sister - did you cook, and she will say chicken, and I used to get angry, and she said no I made veggies, after eating that, I used to feel the difference in my body, I don't know if it is psychologically or what, I used to feel, I feel how I feel strong, feel have something in my system, something of that sort.

I: Thank you so much for this interview

R: You are welcome

**Patient 7**

Key: I – Interviewer

R – Respondent

……. - Pause

I: The first thing, I want to ask you, is how old are you?

R: I am 29 years old.

I: 29 years. And what do you do for a living?

R: For a living?

I: Yes.

R: I am a teacher.

I: And how long have you been taking antiretroviral medication?

R: Ok, I started last year in August.

I: Last year in August. And how has it been going for you?

R: Very well. Because I was seriously ill by the time I started with the antiretroviral treatment, so after taking it I recovered my life up until now, and I am gaining weight and all of these things. I am quite well. Even in the bone I can feel that I am now good.

I: So you are definitely feeling a difference?

R: Yes.

I: And you are feeling that you are getting better?

R: Yes, I am getting better all the time, because even my weight is going up, I can see. I am gaining weight all the time.

I: And what do you think about the antiretroviral medication?

R: I think everyone who is HIV positive must take these tablets because they are good. They have a strong effect in the body, more especially for a person suffering from HIV, and like to treat other diseases. Actually you have to go for a test and get to see if you can have all those things, and then begin the medication. The antiretroviral treatment.

I: So you seem quite motivated about taking medication and things. What do you think caused that for you?

R: For taking medication?

I: For causing you to be interested in taking the medication.

R: It is because of taking this antiretroviral treatment. Because if I neglect it or desert from it I could have died, but because of taking it, I am feeling very very well, so I encourage everyone who is HIV positive to take this treatment, because this is the most important in South Africa, the world as such. So it is very important to take it.

I: Tell me about your medication. How many tablets do you take in a day?

R: Okay, a day. In the morning I take two tablets and in the eve ning I take 3 tablets. Trestisy as well as S…….., and in the evening I take Trestisy,…….. and Stockrin. So 5 a day, you can say.

I: So you are taking 5 tablets a day? Do you ever forget to take it?

R: No I don't forget to take my tablets. To me it seems like meals, and there's no one who can live without food, so they seem like food and when I take it, it is like the tea in the morning it is like breakfast and at night it is like supper. So I am used to this treatment.

I: Have you ever forgotten to take it?

R: No, I've never ever forgot to take it, because if I forget to take the treatment, it is where I release the virus so if I take, so I have to take it to keep it under suppression.

I: Will you please tell me how you remember to take your medication?

R: Yes.

I: You said that you are using it with your food so that you remember to take it.

R: Yes.

I: Do feel that your lifestyle, how you live, the type of person you are, do you think that affects how you take your medication.

R: No, it doesn't affect me to take medication, and as I said before, that medication to me seem like food, in the morning and in the evening. No, so I don't feel like I am taking medication, and I seem like everyone in the community or in the world, so I don't have a problem taking medication. Certainly, that I know myself, that I am taking this type of medication.

I: Okay. Do you think, that you know the people you live with, or even your family or friends, do you think they affect how you take the medication?

R: No, my friends and family are positive, so they help me. More especially when I started on the medication, there were problems or difficulties that I came across, so in that time I need someone to assist me in taking the medication, especially the one which I took in the evening, as having a strong affect on the body, when you starting to take it especially after a month, so there are no side effects. But there is side effects when you take the medication the first time. You feel like you are drunk, dizzy and bad dreams, all those stuff, so I need a person to be with me so that I can continue to take this medication. But it happens, when I started with the treatment, when you gone and after about 2 months all those things disappeared, it seemed like any tablets you take.

I: So the people around you, are they also HIV positive?

R: I don't know, but there are people who are HIV positive that I know, and we are sharing treatment, but you come to the clinic together to get the treatment.

I: And does it help you, that you also know somebody else who is taking it also?

R: No.

I: No, no, I said, is it a good thing that you know other people who are also taking medication?

R: Yes, yes, we know each other. My friend is also taking treatment, he knows me that I am taking treatment, so they have no problem about that. We also used to remind one another about that. Hey, did you take your medication in the morning. Yes I did, oh I forgot, let me rush and take it, something like that. We share ideas about the treatment. Mostly during the first time of taking it, because there are side effects. So some of the people when they start with the treatment and coming across with the side effects, they just leave the treatment and stop the treatment, because of this side effects, so what we must do is carry on using it although there is side effects.

I: If you have to think about people who don't take the medication. What do you think causes them forget to take their medication the most?

R: The treatment?

I: The antiretrovirals. Why do you think people forget to take the medication?

R: Some of them forget. I do not know what is the problem, because I do not forget. Maybe it is they counsellation and to be told to take treatment every day at a specific time. It is very, very important. I think why people are denying the treatment, actually I cannot say they forget, they are denying the treatment, especially the evening treatment, with the Stockrin, it is because of the side effects. Because of the bad dreams at night, maybe they are afraid, because you dream something that you have never seen in your life.they have never dreamt

before. But they should carry on taking it, although the side effects and those bad dreams, because after time, they dream normally. It wont' happen anymore.

I: Why do you think you were able to take your medication, even though you have side effects, where other people don't take it?

R: It is because I know, actually when my doctor gave me the treatment, he told me everything about the treatment and also emphasized to me, that now is your second chance, and if this treatment was not invented, or if this treatment was not given to patients, they died. So I know if I denied this treatment or forget this treatment, I know where it will end, I will die, definitely, so that is why I take the treatment every time and every day. I do not forget. Because if you forget, as a result I can be in the bad in the hospital. It is hard. I was admitted for about a month, so I think about all these things so that is why I am always taking my treatment.

I: Do you think there is anything that can be done to help people take their medication better?

R: Ok. Something like not to forget the treatment.

I: Yes.

R: I think people need to do counsellation more especially. And their families, they need a workshop or. something like that, and to take care of the patient or the person who is affected to see that the taking the tablets accordingly. You can even have a calendar to just to tick – have your taken the morning treatment / dose or evening dose. You should tick and see when you forgot to take the medication, so you must have a calendar and a person to assist him or her, anytime, a sister, wife, husband.

I: And what about those people who do not have anyone they live with?

R: It is quite difficulty, what to do with a person are living without parents, without a wife or anything or somebody else. It is quite difficult. Even the people in the

hospital are those people who are sick. Being at home is quite difficult, but it is up to you. Its your life and it is not someone else's life it is your life to know you must take treatment even if there is difficulties around, you must take treatment, but you must visit the clinic at least once a week, so you always have people around you.

I: What does this hospital do, to help you take your medication?

R: The hospital. They helped me a lot, from the day I started the treatment, because, they give me tablets for a month, but if you start with the treatment you get tablets for about 2 weeks, and then you come back. So I am taking the tablets for a month, and then after each month, I used to come back here. They helped me a lot. They motivate me, and they weigh me and all of those things and I have to know about the weight, am I gaining or am I losing the weight. So they keep on motivating me, even the doctor. Always ask me wherever, the doctors who knows me – are you still continuing your treatment – yes. So that give me a motivation to my life. Even if I am suffering from a headache, they give me tablets, because they understand me. They know me very very well, that is what I can say.

I: Do you have any advice to help other people take their medication?

R: Yes, I do. They must take this treatment, because this treatment is most important. And you can survive through this treatment for almost 15 years. You can survive even 15 years, if you take this treatment. It is very, very important. Like I said before, I was taking it for a month, months ago so after taking the treatment I wake up and I can run about 20 km after taking this medication. It is very, very important to take the medication. They mustn't deny it; they must take the treatment accordingly.

I: Do you have any advice that could help somebody to take the medication?

R: Yes, if you are suffering from this HIV you must take this treatment. It is very, very important, and get this treatment. You must go for test, and get the

counselling and begin with the treatment. This treatment is the same as any other treatment, for flu or something else, and it helps you a lot. And a person who is suffering from HIV denying or have no treatment like this, and he / she died, but if you have taken the treatment you carry on with life, you can buy your car, buy your house, and all other things and continue with work and get money. This treatment, you can carry on like anybody else who is HIV negative, there is no difference. The only difference is HIV positive. But after having this treatment you carry on with life doing anything you wish to do, but you must abstain from sex. Okay those who are married, you can do sex, but use a condom. That is what I can say.

I: Thank you very very much for this interview

## APPENDIX TWO: EXPERT TRANSCRIPTS

### Expert 1

Key: I – Interviewer

R – Respondent

……. - Pause

I: The first thing I would like you to do is to basically tell me what kind of work it is you do.

R: I am a co-ordinator and a counsellor. When patients come in they get counselling.

I: And you yourself, are you a counsellor by profession?

R: Yes I am.

I: Can you tell me a little bit about your qualifications?

R: My qualifications, unfortunately, the time I was supposed to do my standard 10, that was the time of the unrest, 1976 so I was a teenager by then and I saw it as a chance to skip school, and I got married. But after a while I realized, that really; I need to do more. I joined the field of marketing, and I was doing well, and I was working for a very big marketing company, driving all different types of cars, and enjoying myself. Until such time something happened in my family, that's what's drawn me to the HIV field. Then, I started basic information on HIV and then counselling, as you know afterwards. The organization I belong to took me for adherence training.

I: Whom did you attend the adherence training through?

R: By the Community AIDS response. I think we were the first group to get trained. Dr Venter, Dr Conradie, those are the people who trained us.

I: So how long have you been working in the HIV AIDs field for?

R: Since 2001.

I: And specifically with adherence?

R: Adherence started ……. The roll out started in 1994. We started in December 2003.

I: You know antiretroviral medication, has only recently been introduced to the public sector. If you consider the individual who is taking the medication, do you think there are any individual traits or behaviours that acts as barriers to adherence?

R: Yes, that is what I realized really. Because some of the patients, since 2001, I find them in here attending their clinics regularly, but as soon as they started with ARV's, some of them are doing well, and some of them have some issues that were not there before, and are now coming out and they are making the adherence a problem. Firstly, some of them will discover they haven't disclosed, which is the main issue, so with the antiretroviral therapy it is worse than with the antibiotics and the vitamins. Some of the people now are becoming more educated, and they know what the ARV's are and what they are for. So, it is making them not really adhere to the treatment, and it is drawing them back to stage where we started when they were diagnosed, you know, depression, stress etc.

I: So you are trying to say that because they know that it is ARV's and not antibiotics, that causes them not to adhere?

R: Yes, They are hiding the treatment, and again this thing of time, if you are hiding some, definitely you are going to forget. The chances are – you wont forget, but wont get a chance to take the treatment, because there will be questions asked.

I: Do you think there is any specific types of people e.g. by race, by wealth that you have seen experienced that are good or bad at adherence?

R: You know what I have realised now, I never thought that men would adhere.

I: Why did you not think that?

R: You know men at most times they take things lightly. Men, the ones who are not trusted are the ones that are now serious in taking the treatment, even though you look at him and see that this one is a heavy drinker, but he still tries, and they still take their treatment. And coming to a relationship issue, that's the one who gets the woman to fail to take the treatment correctly, because woman mostly depends on their husbands, so their lives depends on their husbands. So, they are scared to disclose to the partners, or even if they disclosed, they are scared to tell the partners that they are now taking ARVs. That's the case but when the partners are also on ARV's the woman is the one who is helping the partner.

So I think this thing goes back to culture. Zulu, Sotho, all of us blacks, some of us are similar, there's this thing that when a woman discloses something serious to the man, the man will put the blame back to the woman, who brought shame to his family, so they are scared to tell them.

I: To take their antiretroviral medication?

R: Yes. But they are willing to take the antiretroviral drug, just to make a small example. You know why I am here today when it is my day off? One of my patients is from KZN and she is supposed to come and get treatment on the 20th, which is on Monday and requested that she does not have money and is scared to ask the husband for money, because they ask questions. But the husband knows she is HIV positive, but the husband does not want her to take the antiretrovirals. He throws it away. Last month again he came to fetch it. He collected the medication, and we put it in a cooler box, to make it look like a gift, one of her family members left here, and that's how I help her to get the treatment. We packed it so nicely like a present, so this month she wants us to do the same thing again, but unfortunately it is her day to see the doctor.

I: So she has to come?

R: Yes, she has to come and see the doctor.

I: That's the good example of the dynamics in such a relationship. One thing that I am battling to understand is that you would have expected men not to be able to adhere but they do?

R: They do, but with the help of the woman.

I: Then, you spoke specifically more about black females and males, and the males who put the blame on the woman, bringing in the infection.

R: The males do that thing, involving the family to sort out the woman's problem.

I: Why do you think the males do not want the females to take the medication?

R: You know, as far as I know, males like other people are very scared to face challenges. They are very afraid, they don't like challenges, especially life threatening challenges, you can rather come with a gun or a knife, so they can fight, but battles that are not fought, with weapons, they are scared of those things, confrontations and all those things. So, in some cases, we find out that once a woman takes the initiative to say I don't care, they can say whatever they want, I am doing it. When the husband comes in, he will be surprised but husband knew about his status long before the woman knew, but he never told the woman he was infected, and never used a condom, and when you ask the reason why, they were scared to tell the wife. They wanted the wife to find out herself. That's why most of them get so violent in the first place, because – you cant be scared of something you don't know.

I: Do you think there are any factors that influence, how somebody thinks about adherence?

R: Ja. You know the main problem we find with our patients is they start perfectly but when they go out, they listen to other people. They had heard somebody saying this thing about the ARV's, that once you start taking this, you will start to feel well but then you are going to be forsaken and terminally ill you will die.

Although they did the adherence and they understand the information correctly, but you know the power of the mind, because now, they are alone. The counsellor is no longer there, the sister from the clinic is no longer there. There they are amongst the people that are anti ARV, so they put all those negative things, and then they believe, that this is going to happen to them and they even show them examples – look at so and so …… look what happened to them. And now when they come back, those who are brave enough to come back and tell us that this is what is happening. We ask them – how long is the person been ill– was that person taking medication correctly. What happened? Did they go back to the clinic to report that there were the side effects? Anytime you experience side effects, because you do not understand, do come back and so you can get clarity on what is happening with you. Then they realize that that person died not because of the ARVs.

I: Why do you think though that this person would rather listen to those people in their community than to you, when you are the professional, who is trained to do this. Why do you think that is?

R: Just to make a right example of the antiretroviral. I am a Christian, I am making an example and I am suppose to know what to do and all those things, but sometimes you are in a situation when you are faced with people that believe so much in cultural things and they tell you about ancestors and tell you everything and go to the grave, and slaughter goats and everything. So, as I told you the power of the mind really, you will end up being confused. Which religion? Should I follow the way I always do, kneel down and pray to somebody I do not know? Although you see that good things do come your way, because they are slaughtering, they think maybe God is coming. But at the end of the day, it is up to you the individual to choose.

I: So it is human nature to reason?

R: That's the thing. You have to sit down and check yourself. Even your kids, you can have 3 children. Teach them same things but they wont follow exactly the same steps.

I: That is very interesting. If you look at an individual, and their environment – like you spoke a little bit about that just now about people being surrounded by other people who put them off. If you look at someone's, you can almost say physical environment, do you think the environment plays a role in whether they adhere or not?

R: Please can you rephrase that?

I: If you have to look at the relationship of an individual in their environment – where they live – what they are surrounded by. Do you think that that will affect whether they adhere or not

R: Yes, yes it will.

I: Tell me about that

R: I don't know how much you understand about the cultures, as I touched the issue of ancestors, traditions and all those things. You will find out that if you stay in JHB and originally your family, in-laws and friends are down in Cape Town or KZN, or anywhere in the rural areas. Then they know about your status, because you disclosed within the family or they find out anyway, maybe it is TB, even if they don't know the status, they find out anyway, when you are sick. Then you go down there and they ask you. "What kind of treatment are you taking?" You go to the hospital where they give me some medication. Then they say, "It is how you young people are, dying so much. It is because you believe so much in those medications. We've got this person or, we have Mr. so and so, who can do wonders, we have this and this and this." And the pressure will be on you. And, if you don't take that because whether you die, don't tell us, because you refused what they tried to give you. Some of the people are so dependent to their

husbands or their in-laws that they find really they cant refuse and they have to follow what they say.

I: So, western medication which is what ARV's are. That conflicts quite a bit with the traditional black cultures?

R: Yes, because if you go to traditional healers, some of them will tell you that this is the things that make you so sick. You have to stop taking these things, and they will give you better things to use. Things that are going to get much stronger. And then, you might start diarrhea, or they can start, this cultural vomiting, especially for a person with TB. Once you have this, you have the sputum, and you've got these things coming out of you, medicine that just forces that vomit out. And they are going to be there, and they will say, "See, this is what you have in you every day!" And this is how they convince you. "This is the signs." There is a lot of damage when that happens. So we educate them on those things, because we know them. And we know our families, and we just try and tell them exactly what is going on. There are some churches where you find 'forced fasting'. Maybe they say you are praying so we have to have a 7 day dry fast, and some of them take their fast in church, you have to go to church and they have keep on praying, so that HIV person will also have to. It is not easy to keep those things when you are sick.

I: It must be extremely detrimental to your body to be fasting like that?

R: Yes, because you have to take your medication, and you cant take your medication on an empty stomach. And sometimes, you can also laugh, when I say to them "I understand. I don't say, 'It is wrong to fast', but there is nowhere in Bible where I read that the Lord only hears prayers from people that are hungry." I haven't seen it, but it is an individual thing if you feel you have to do it, but with ARV's you must think about what you are doing, because it does not go together.

I: I see quite a reciprocal relationship there. Because do you think people fast, because they are praying for a cure.

R: Yes. They think the prayer is much more effective if you fast.

I: I do understand, but do you think these people are also drawn into the fasting, so that God can heal them?

R: That's the thing, yes. Because now really, as you are getting deeper and deeper with people taking ARV's, looking at the adherence, and those who started with adherence, and we are now doing re-adherence, because people are taking their medication the whole times but now we look at the issues that made them mess up their treatment. We find that they went to a church, where they are told, "There is no HIV! You just have to pray, and then it will go away." There was another lady on Monday, she was told to come and test 3 times and on the 3rd time she will be negative. We had to sit down with her and tell her the truth.

I: Where did she get that information from?

R: From the church. That is why there are so many churches coming up. So many churches. And if you look at their brochures, when they write there, they can do a miracle healing e.g. HIV, diabetes, they know that the people are desperate and they will go.

I: So you think that the church is almost capitalizing on the epidemic to get more followers?

R: Yes, I do really. And I find it so difficult, because first they went to the traditional healers and now the traditional healers are now coming closer to us now. Because some of them even bring their patients to us just for the test, and they ask us, because this person is HIV positive. "Can you please take this person for counselling. Give her the treatment, because HIV is so strong. I might cause more damage." That is what the Traditional healers are doing. Now the churches are standing against us.

I: It is almost as if the traditional healers are coming around a bit?

R: Yes, they are. Because some of them are even here, and they are helping some of our patients too. I asked one of them, "Is it difficult?" What if you are going to attend the ritual where they are suppose to slaughter a cow, and do all those things. And they said, "Cindy look here, it is my life. I will tell the ancestors that I am taking the ARV's, so I wont be able to do some of the things. I do things I would be able to do like the washing."

I: It is amazing. Because I actually haven't heard so much of this before.

R: We help them here.

I: In your opinion, because adherence is what you do, what do you think is the main thing that can be done to improve the patients adherence?

R: If only people can understand to take their lives seriously. Not to leave their lives for somebody else. It is all that I can say. I have seen other people who take that, who say those words, and the next time they come here, their viral load is undetectable. Then you ask, "What's the secret?" Then they say, "You know what Cindy, I have decided that this is my life and nobody else's" and one lady said, "I am not a cat, I do not have 7 lives. I have only 1 life, so I have to make use of this life of mine."

I: That's beautiful.

R: Yes, very. It's up to an individual thing. It's the willpower to live. Just tell yourself, "You are going to do this."

I: There is definitely a point, where people think, a conscious point where people think, "I want to live!" Do you think some people can come to that point, and other people don't?

R: I think it's the way we take things. Lets put aside the AIDS thinking. Even in life in general there are people who hold grudges so much that it ends up affecting them. When you ask a person, "Why hold this grudge?", the person who has the grudge, doesn't even know. You are not angry with that person. You are angry

with yourself. How do you deal with it? And is so painful for us counselors, looking at this person and knowing that this person can do so much better than they are doing, if only they can let go of other things. Those are the things they are worried about. “They do not want to let go.”

So I think again that it comes back to the individual. And as a way we know about introverts and extroverts all those people. I prefer extroverts a lot, because they can talk about everything. When they are angry you know they are angry, they can fight with you, but tomorrow they have forgotten about it. They have cleaned their souls of everything.

I: Do you feel that being aware of your emotions and what you are feeling are important in trying to conquer this?

R: That’s why we always encourage them to do that, “We are there for you guys.” If you got anything, there are people who can’t even talk to their family members, but when they come here, we try to encourage them but, but this is the place where, because I don’t know you, just take out everything. Because at the end of the day, in life, I have realized one thing. You might think that is a mountain when you think about it, but when I ask you what is that thing, you say, “You know Cindy, take a pile of sand and you can take your shovel and just spread it around. You see a big mountain, so by talking to the next person, what you thought was a major problem, it is a minor problem, and it can be solved within minutes.”

I: It is almost a sense of comparing yourself to those in a worse situation, in a positive, outlook on how things are going.

R: That is why the support groups are so helpful to other people. We sit there thinking that they have the worst problem in the world, and then, they listen to other people’s problems and they say, “Hey Cindy, I am much better. You see that beautiful lady. Yes, that lady has got so many problems. I am much better that her.” Then you see something good happen to that person.

I: You know I am listening to you and listening about the adherence programmes here. Tell me a bit more about that, because I know that you guys have an adherence strategy in this part of the clinic. Talk me through that a bit please.

R: With adherence, firstly when a person comes here, we book them with the adherence group. The adherence group talks about things to expect. What is ARVs? What do they do? All those things that are general talk. Then we take them individually, one on one, to go and sit down with them and do adherence counselling now. We look at the lifestyle of the person. We look at the cultural thing, religion. We talk about a lot of things that might be obstacles on his way and the disclosure. The disclosure is the main thing. Others think there is no need to disclose to your family, then we point out this thing that accidents do happen, and accidents can happen any time. What happens when you are unconscious and you have to be admitted to the hospital, somebody in the family should know so they can tell the doctor who is attending to you. And we warn them about believing every medical person, because not all of them know HIV AIDS. This will help them to know the full information, starting from the HIV information, what it is, coming to the city for counselling, what do the ARVs do. They are not a cure. It is just that they suppress the virus, you know. Knowing all that information will help a person when they maybe go to a doctor, only to find out that a doctor does not understand so much about HIV. They will be able to pick up the things that the doctor does not understand what he is talking about, and they could be able to come to the hospital – the best place is the hospital. They are helpful here. No matter how many chairs you change before you see the doctor, but in the end of the day you will get the proper treatment.

I: So you are quite confident in the training?

R: Yes, because they are well trained. You see, usually people with medical aids actually, who come from private doctors and taking ARV's, "I have never been adherent, and not even been counselled." They take the treatment, whenever they feel like taking the treatment. And when they come here they see that the medical

aid has been exhausted, they have been referred to the hospital, and when they come here, they are already resistant to treatment. It means there is so much different, which means we must now start from scratch and person will be dwelling on those things – why did I waste my time, if only I knew. So we are dealing with 2 issues.

I: The resistance and the adherence?

R: Yes.

I: Now if a person comes to this clinic the first point of entry is the adherence group?

R: No. If you haven't tested it is pre-test counselling.

I: No, with specific regards to adherence.

R: Oh, adherence. When the count is below 200 then you start talking about adherence.

I: And they go to the group.

R: Yes they go to the group.

I: And who gets individual counseling? Does everybody from the group eventually get the individual counseling?

R: Yes. Because in the group, we have different groups here. The wellness group, they give them their CD4 results. The CD4 counts below 200, that is when they start talking about adherence, and we invite them for Wednesday's group which are an adherence group. Those who are leaving for the ARVs, we give them about 2 days to go home and to think about it, because they tell you after you gave the talk that, "You know what Cindy, I am not good at taking tablets. I'd rather go and practice first, so give me a doctor's appointment" and they see the doctor on the Thursday. We do not let them go without any counselling and when they are ready, they take the doctor's appointment so they can be seen by the doctor on a

Thursday and when they are ready then they go through the adherence counselling, so they can prepare for the antiretrovirals.

I: Earlier, you mentioned something about 6 months later.

R: 6 months later they come back and we re-do the adherence. We even started a support group on Tuesdays. We sit down and talk about things, the fears, good things that came up. You know they are in a group, they are going to tell us stories. It was easy for them to say they are going for ARVs not realizing all the problems along the way. So it is a good place to talk about such things. Every Tuesday we have the support group.

I: What do you think was their main barrier?

R: The main barriers?

I: That come up, like even practical things.

R: Ja, you know. The first one is disclosure, because right now sometimes a person can collect the medication. But they sit there, take another container, empty all the containers and throw them in the dustbin. That is the problem.

After disclosure, we have this thing in relationships. We find that the husband is very strong when he looks at himself. Then the wives start taking ARVs and there's this thing, that once you take ARVs you are about to die. And they don't take their ARV's and they stop.

Also, a person going to the wrong person and getting the wrong information. Everything affects adherence. When the person missed and appointment, go to the house and make another, to tell the person about the dangers of not adhering.

I: If you have to think about an intervention to help patients – do you think it should be at individual level or community level or both?

R: Both, I think both. They are both important and they need to educate each other. But is doesn't always mean that by helping the community, you help the individual. Sometimes you find that the family are so much supportive and that they were educated, but the patient is still in denial. If an individual is affected, the family is affected. So, even the involvement of the family I think it helps, because right now the thing with the communities. There is this thing, I don't know where they got it from, is that ARVs kill. Don't ever, ever take those tablets. They are going to kill you. And when you ask, how many people were killed by this medicine, they say no we heard they are highly toxic they can kill you. Also, side effects. I would like to refer them back to the doctors to show them that any other treatment, has got that paper which is written with everything about the side effects. Everything we take has side effects, even coffee, even cold drink. I think it is just that the side affects of the ARVs are just so much more visible and just so much more intense but not all people get them. And some of them only get minor side effects, that's all.

I: Where do you think people get these misconceptions from, where do you think people get perceptions of this toxic thing that kills you?

R: Wrong information, especially in medical field is common and I believe that anything that is happening for the first time, people will have a lot to say for obvious reasons. People will say negative things and positive things, until they get used to that thing and something new comes, and they say oh, we can concentrate on the new thing. Because the ARV's are still new to the market. These are still new on the medical side, even the professionals, are still making mistakes. There are people being admitted, and things stopped by the private doctors, and they say that it is because they are like this. Then another patient comes here to this department, and says no you are not suppose to stop. So, we educate our patients, so that once the doctor tells you to stop try to call the clinic. To try and keep contact numbers and everything, so that the doctors can communicate.

I: So you think it basically is new, and has to be tried and tested, and people see it working?

R: Even professionals have to see and learn about ARV's, because now it confuses the patient, if the one doctor say this and the other says that. Some patients don't know who to trust, and then go back to the traditional healers. And those rumours spread faster than anything. That's human nature as well.

I: Thank you so much for doing this interview – it has been so helpful.

**Expert 2**

Key: I – Interviewer

R – Respondent

…..... - Pause

I: The first thing I would like you to do is to basically tell me what kind of work it is you do here.

R: When patients with a count of about 200 come here, we just monitor them and see where are they after every two months. And we also sponsor patients for a certain time and then we refer them to other government roll outs, like the Helen Joseph in Auckland Park. We give them free medication while they are with us. And also in other provinces, where there is a demand for medication and low supply, we supply that.

I: You mentioned a bit earlier that you are involved in other aspects of working in the HIV. You want to tell me about that also.

R: Firstly, I worked as a care-giver in Vosloorus, looking after people living with and dying of HIV. And I did a bit of counselling while I was there. Then, also for the past year and a half I was doing project management, going around the country giving education around HIV antiretrovirals and adherence and just trying to support those people who are living with the virus.

I: And how are you been working in the whole HIV Aids field for?

R: I started in 2002 to presently.

I: So it has been quite a long time?

R: Yes.

I: The antiretroviral medication just been introduced to the public sector for the individual person who is taking the medication. Do you think that there are any specific types of people that will be better at taking the medication or not?

R: Well, firstly it should be the disclosure. If somebody hasn't disclosed to their immediate family or to any person who is close to them, it is very difficult for them to take their medication. And secondly, with the fear of the side effects, they have no information about the side affects and also the stigma around HIV. Those are the major ones that I think also. Also nutrition. Other people say, "How can I drink medication without having food on the table". Some African shares some African potato and all those stuff like people will say, "Don't take this medication, it might kill you. If I can go to a sangoma," and the myths around AIDS.

I: Would you say that there are like certain types of people, like certain categories of people for e.g. white, coloured, black or Indian people. Any types of categories of people that in your opinion will take their medication better?

R: What I have seen, if you are white or Indian or coloured, they are the people who take the medication better compared to the black community. I am from a black community with people with a total lack of knowledge around AIDS. Not knowing what to do, or how to start the medication or where to go. To take or not take their medication, or if they take it, they do not take it properly.

I: And do you have any reasons for why that happens?

R: As I have mentioned before, disclosure, the family not knowing. Also, what the treatment says. The usage of the condom between the two. You keep from infecting yourself, and but you are admitting your status. And also what I have seen, is that other people they just forget to take their medication you know. They just say, "I forgot to take the medication."

I: I would like to get a bit more information from you on that but I will come to that just now. Are there any other sort of categories that you can think of? Have you seen that certain types of people are more apt to take medication?

R: Well, a recent case is that there are people who are in the prisons which is a very different scenario. People take their medication when they have to go back to get

their follow up, the prison wardens don't bring them back. Then, a week or two passes without them having their medication, which is a great challenge now. People who are in prison now, and who are taking medication will have to go and take the from the government clinics outside at other departments.

I: Would you say that, that may have more to do with the fact that the wardens themselves are not being responsible enough for bringing them there?

R: No it is because of the authorities in the prison. But the people who are working on this side, who are part of the TRC's project, those practitioners ensure the distribution of the medication. The prisoners always complain that the prison wardens don't want to take them back to the clinic for their appointment. And on the 15th and the 25th and the 29th when they get their salaries, they say that they do not have time and by then, the medication ends. Their allocation are also taken and given to other people, which is very, very bad. And sometimes, the prisoners, they work shifts, one was working in the morning that and the prison warden gave his medication at 9.00 in the evening, so they don't give the prisoners their medication at the right time. They even forget. You know all those things.

I: Would you like to comment on any of the factors that affect a person's perceptions of the actual antiretroviral medication?

R: Personally, I think firstly that the whole thing with the HIV is disclosure. The first thing is that people need to come out and live with the virus or come out and be an example to the community. There is nothing wrong with being HIV positive. We have to change our lifestyle and try to live positively, and also the stigma and also going back to the thing of the beliefs that people have in terms of politics and those stuff.

I: So you do thing that the political part of it does play a big role?

R: It sure does.

I: Do you want to tell me a little bit more about that?

R: What is happening is that we have AIDS activists who are promoting their own things against the antiretrovirals. No matter what, at a certain point of time in a HIV positive person's life, they need to start antiretrovirals and they also need to highlight the side effects. It does have the side effects but even myself, I am on treatment. So, I know it works very well, even with the side effects. But I do eat good food, but then there are people who are rich, who have good nutrition, but because of this myth which surrounds ARVs, they are afraid to take and eventually they die.

I: Do you think that the way society looks at HIV and antiretroviral medication plays a big role in whether a person decides to take it or not?

R: I would say yes, that is why we have a challenge. As much as we must allow people to make their own choice in terms of the decision if they want to take, but also we must not run away from the fact, that the usage of the antiretrovirals eventually works for someone, especially if you start at an early stage. You do not have to wait until it is very low. There is one thing we should not forget and that is that for someone that has a count that is very, very low in terms of the side effects, it is already happening when you start taking the antiretrovirals. And when it starts working in your body, you may have a low resistance and be prone to infections or maybe your body cannot cope with age. So, the earlier the better. Also with regards to society, I feel we must do lots of education, more teaching the people about using the antiretrovirals. And the people that are using them, then they must come out and tell their stories, so that people can see.

I: Are you saying that a patient should not wait until they have a CD count of say under 200?

R: Well, you can wait until it is below 200, that is what the government has stipulated, before that you can have the antiretrovirals. That's if you go to the government site. But also if your count is below 50, it is a good time where someone must start taking the ARV's or if someone maybe has a count of 666, but still clinically shows stage 4 symptoms, this person is very, very sick. They

should start on the antiretrovirals immediately. It's dangerous because if they look at the levels, and they say you do not qualify for the antiretrovirals, you must wait until the count is below 200 but you may still be able to take them.

I: If you had to look at the relationship between a person and their surroundings, how important do you think the environment is, in influencing whether people take their medication properly or not.

R: Well, looking at someone's environment and whether a person is taking his medication or not, firstly it is the support that he has around him. And also, the behaviour. If you are smoking, or you are drinking; because those factors especially can make someone forget. I used to drink myself too. I thought I needed to but eventually I had to stop because otherwise, I would forget to take the medication. Or you go somewhere and you forget your medication at home, and when the time comes for you to take the medication, you don't have it. And also, to go back to the disclosure. The issue of living freely in the environment, that one must not be scared of taking the medication freely, wherever you go. And also the support and the stigma around HIV, and the lack of understanding the disease amongst the communities.

I: For those patients that have received the medication, what do you think can be done to help them take their medication on time?

R: They must have a treatment supporter. Someone who is going to weekly monitor that person. And someone who can follow up. It is very important, besides, to do a follow up on patients on the medication. To see where and what is happening also. And also people must encourage each other to take the medication and be told what is the importance of taking the medication. And get the education about taking the medication and the benefit of taking it.

I: When you talk about a treatment supporter, what do you mean?

R: Someone who is going to be there for you. Like a daughter supporter. Someone will come around and see that you did take your medic ation. "Do you feel well?

Do you have any side effects?" Someone to give you the support, you know, so you can take your medication.

I: You also spoke about the education around it? Can you please explain?

R: It's very important. Should the person start he must be told about adherence, when they started taking the treatment, they must continue. They have to be reminded at all times. People need to take responsibility for their own lives. That person who is going to remind you all the time sometimes may forget but you must not forget. There are many ways to do adherence, because I remember when you attend the clinic, they told you the ways of how can you remind yourself of not forgetting. And to take it at the right time every day. The thing is if you have a cell phone, you must put in an alert. Reset the alarm. You can keep a chart that you can put in you bedroom or on your fridge or wherever in the house. When you look at it you can remember or when you are watching TV and taking your medication at 8.00. And, that once 'Generations' start, you take the medication. All those methods. Even use your own methods that will just remind you to take your medication.

I: What do you see yourself and the organization that you represent doing to help people to take their medication?

R: As an HIV positive person who is on treatment, I do interviews, I talk about the usage of antiretrovirals in my life. Before I started the treatment, and after taking it and I was also fighting for the better services of people living with HIV at an organization, and also tried to correct the myth around HIV.

I: Presently, what does your organization focus on?

R: We try to train people around everyday issues, that they need to take their medication and not stop. They need to go immediately to their doctors, and also if they have any difficulties they should contact us or call our services in the health districts or service points around the vicinity. They need to report to us and

find out what is happening. They need to inform us if they don't get the treatment. They also need to treat whatever other illnesses they are having.

I: If you have to think of intervention that is going to improve adherence, do you see it working mainly at an individual level or mainly in the community level?

R: I could say both initially, because what we do now is we are also running workshops about adherence to individuals and for groups around the country. I know that even this week we have a workshop to train the patients in adherence, the ones who are taking this medication. The taking of their medication at the right times, and what are the treatments offered is covered. So, we treat individuals and pass information on to the community. We've got our book called Equal Treatment that we take to the train stations, taxi ranks, to everybody. As an organization we can read and listen to the other peoples stories around the country who are taking the medication.

I: Thank you so much for agreeing to this interview with me.

**Expert 3**

Key: I – Interviewer

R – Respondent

**…….** - Pause

I: Thank you so much for agreeing to do this interview with me. The first thing I would like to ask you is, could you please tell me about the work that you've been doing here.

R: I am a medical officer employed at the hospital, and my primary goal is to be a hospital doctor. To work and get help get to the patients here. I have taken interest in the HIV Aids programs and over the years have tried to create programs with the help of another organization and the department of health, to be able to offer our patients the continuing of care in terms of all the different requirements required by HIV patients. We are looking at setting up a mother to child transmission program, voluntary counselling and testing, TB, home based care, a hospice, orphanage and wellness centre. Those are all the types of things that we have set up, and I think the most exiting one is the recent introduction of antiretrovirals, to the community for the very first time after many years of waiting.

I: When did this hospital start?

R: We handed out our first antiretroviral therapy on the 6th October 2003 to a group of 6 patients, and that was sponsored by Yale University with a special study that we are doing. And the Yale study has increased to 75 patients at the moment, but there are 65 or so patients on the Yale project. It gave us confidence understanding Yale, and seeing them in practice and also implementing such a program, in a rural community. We were the first hospital in Kwa Zulu Natal to hand out antiretroviral medication through an international program. The date was 24 March 2004, and we started with that and we are about a year later now and we have about 400 patients on this national program, including 25 children that are on the program.

I: When you first started to give out antiretroviral medication, did adherence become an issue?

R: Even before we started, our mentors and our investigators of the Yale program very, very much highlighted the importance of adherence, as the centre of any antiretroviral program, and we were in a very privileged position of being coached by world class experts in adherence. They very much brought to the front the different issues of adherence, and what we put in place, before we started antiretrovirals, there was very thorough patent for adherence. As I say, we really took a lot of trouble to address the adherence issue and to try and put in all the checks and balances, and when we started with the antiretroviral program the adherence took well.

I: How did you go about doing that? What sort of procedures did you put in place to help patients adhere to their medication?

R: What happens is, that the patients go through a patient preparation program, and this usually involves 4 teaching sessions on different occasions, where the patients interact in groups or can be one on one, where they learn and go through all the steps. Topics that are covered are things like positive living, medication, names of medication, the importance of preventing resistance, the CD4 counts, understanding CD4 counts and viral load because that is very important in the future monitoring of the patients. They need to understand that the CD4 count that is going down is not a good medical result. They need to understand this and they look forward to hearing their next CD4 counts. We made a distinction between adherence and compliance. Compliance more gives you the idea of the patients following an instruction. It has something to do with obedience, whereas adherence is a more active participation of the patient, where he takes responsibility for himself, and understands as much of the picture as possible, so that he can buy into, and to operate and participate in something that going to be beneficial for his own health.

I: I just wanted like to ask you a few things around adherence and not compliance. The first one is, if you have to consider an individual who is taking the medication. Do you think there are any individual traits that affect how a person responds to the medication in respect of how well they take it?

R: There have been many studies done. We try to predict who is going to adhere and who is not going to adhere, and what they show is that doctors are the least competent people in the way to decide who will adhere. When I say doctors, I include professional health care providers. We might be tempted to think that the patient who regularly comes to the clinic here, regularly makes it his perogative, answers all the questions right, and etc; that he is going to take responsibility at home, but that has not proved true at all. There are very, very few factors that you can isolate and say that if the person scores well in this factor the likelihood of adherence is going to be good. So the blue collar worker coming in his Mercedes Benz to work everyday might not be as good with adherence, as the street sweeper who is uneducated who is better with adherence. Obviously somebody who has an alcohol problem, who is having a psychiatric problem, who is depressed, who has got an addiction problem, those are people who you need to do a really, really good assessments and definitely bring in support to help them with adherence. What I do believe is that one of the most important factors in adherence is a good health care provider in a relationship.

I: Do you want to speak a bit more about that?

R: I think if you can develop a health care provider patient relationship, where there's an open, warm, understanding and communication between the two groups, and there is an element of trust both ways, and the patient feels well informed, and he feels very much included in the team and has an opportunity to voice his concerns, his problems at home and any barriers that he / she might think that might impact on the adherence; those will be very important things, and one of the most important factors of adherence is that relationship between the health care provider and the patient.

I: In your experience have you noticed any specific types of people that will be less likely or more likely to adhere to their medication.

R: No. What I have been surprised at is that going through the patient preparation, that we were talking about and establishing the health care provider / patient relationship that all types of people are able to adhere and that includes your illiterates or farmworkers. It includes your school teacher. It includes your school principal. It includes a very sick patient. Right across the board we have seen amazing adherence.

I: Would you like to comment on any factors that you feel influence one's perceptions of ARVs?

R: Yes. There are obviously many factors. I think we had a big disadvantage. Before ARVs, there was a lot of negative information coming over, talking about side effects, talking about problems with cost, cautions about it not working because of adherence etc, etc. And our community took this up and they heard about it. Having said that, our community was also dying because of HIV and AIDS, and every single family either had a person in their family or a close relative or friend that have died in the last two or three years because of HIV AIDS. The reality of the epidemic is that it is very real to the community, and I think in the beginning people started taking ARV and I am talking about sick people with low CD4 counts, and within 3 months they had undetectable viral loads and weight gains of about 6 – 12 kg and feeling much better, and feeling that they are on the road to recovery. This, in the community speaks louder than any words that we could talk as doctors and staff, and so you had this word of mouth advertisement in the community of living people who were improving because of the anti retroviral therapy, who themselves remembered where they came from in terms of how sick they were, in hospital, in and out, losing weight, not being able to look after their children, losing their jobs etc, etc. And I think the fact that the epidemic was allowed to go so far before antiretrovirals came in really had a massive impact on the community, so that when something came that can really turn it around, their very lives depended on it. And you can see it in the

teaching groups. They will sit on the edges of their chairs, listening to every single word that is said about the medication, the right times to take them and what they must do. There's really that understanding that, "This is my life!" and I think that that is a huge factor in adherence.

I: You've already spoken about society's perception via the media, and how the individual conceptualizes the treatment. Can you think of any other ways that society affects whether the individual responds to the medication or not?

R: I think we are just touching on it. We are working here in a rural traditional Zulu community. This type of chronic disease, slow progressing, taking the strength out of a person's body. And our patients go to traditional healers and use traditional medicine, and for many years, us as doctors have been saying, we can help you with the signs and symptoms, but we have no cure. And we were very frank about that. We made very sure that the patients understood that we could not offer a cure. We didn't want anybody to be deceived to think that the medicine they are going to get from the hospital was going to cure them. That's where the traditional healers said, "Well let's try. You give me a cow, and I will see," and they even went further to claim and point out stories about cures. We work with quite a few patients and when things suddenly change we still say that we don't have a cure but we have something good that works, that can turn it around. I think in the community itself, this might have taken some time to set in and for people to believe it. You know people were in a situation for many years, where they were very desperate for any cure. They came to the hospitals, we help them with their TB, the TB got worse, we help them with TB medications, so the TB got a little bit better, they went home, but they were back in hospital with something else. They were in and out, in and out and they could feel themselves deteriorating. And they can see they are getting thinner and thinner. So they started pursuing other things. Magic cures they heard about. You go into people's homes and you find a who le string of medication over there. So, it was driven by desperation in that period, and I think there were so many false promises and so many people making irrational claims, plus that negative media I was talking

about and then suddenly, the information changed. Perhaps they were cautious in the beginning.

I: If you had to comment currently. If someone found out they were infected do you think they would go to the hospital first, or would they try traditional healers.

R: They would first try traditional healers. The medication they get from traditional healers are still much more accepted and much more in line with culture when compared to the ARVs that the hospital gives out. What we frequently saw is kidney failure, liver failure, severe anaemia, and blood function disorders, that came in as side effects or as consequences of intoxication. That was our bread and butter for a long time over here, to see that happening. A good story would be a person who is HIV positive, coming in, they get better on TB medication, going home and feeling quite strong on their legs, and a week later coming in with renal failure. And we do all the tests, confirm renal failure and then find out that it was intoxication. A big story was made about the African Potato being an immune booster. The African potato has been proved now to interfere with the actual antiretroviral therapy. So, there are many formulations going around, which is like a vitamin supplement, plus all the different goodies. And when you look on it, it says African potato as well, as an ingredient. We cannot use that type of thing with the antiretroviral therapy because you want your antiretroviral therapy to be observed and to work properly and you don't want to be under dosing the patient, even though they are taking the full dose, but it is not absorbed and they are getting under dosed. Just to give you an example, I had one of my very first patients was a nurse, who actually had access to antiretroviral therapy through her medical aid. She was very sick when she started and she did quite well, really recovered to the point to come back to work. And she was on ARV therapy for about 4 or 5 months making slow but steady progress and one Saturday morning she was brought in by her family in a semi-coma with renal failure. She was more or less unconscious. I could not understand this, and thought this is some side effect that really hit hard, and I phoned a consultant in Durban who frequently gave advice and I presented him with the picture and the

first thing he said she is that she is using herbal medicine. I said that this is not possible. He said she is using herbal medicine, so I asked the family, do they think it is possible? And they said they don't know, and they don't think so. We admitted her and I got her transferred to ICU and in all this activity, somebody from the family came back home with a packet of things and they said this was in her top drawer next to her bed. And there it was, herbal medication. You know I am not saying that there are not herbs that can't improve the immune system and make an impact, but what I am saying is that antiretroviral therapy has been proved beyond a shadow of a doubt that that alone can afford a huge improvement in patients. That is the only real thing existing today, that gives the best results, so I would like to offer them to my patients as a first priority. And so we actually, we can't prescribe to any patients that he don't use herbal medication. The responsibility to keep them in the picture as to how the herbs work together with the antiretroviral therapy and try and explain rather than saying, "Don't use herbs, and herbs are dangerous." Rather say, "Herbs can do this and that," just have an open discussion and using herbs and try and keep that open door for communication, because I can guarantee that there is a huge amount of pressure to use traditional medicine. And the reality about the use of traditional medicine is that we want to be able to interact and not have created a closed door, where they feel terrified talking to the doctors, when telling they are using herbs. "He is going to blow me out of the door." Tend to be able to feel free to talk about it.

I: Are there any other sort of myths or cultural beliefs systems that seem to interact with the adherence to medication?

R: There might be. Talking about the important ones and to say that what we are doing is working. If it wasn't working, I would be forced to talk to patients to find out what is happening. But with 65 patients in the program there is almost a 100% round the clock brilliant adherence, so it is working, the patients are taking their medication. Just talking to patients in the evening, they tell us all and say "Hey doc, that is my reminder to take my medications at 18.00 now." I have been

on ward rounds and the patients have a clock in front of him watching the hand, and waiting for the hand to touch six o'clock, so that he can take his medications on time, and this is so brilliant. Patients really believe in the medication, and they've got to believe in it. And this has happened. Patients say, "I remember where I come from, and I don't want to go back there. My sister died, my brother died, and I felt that I was on that road and I am off that road, and I do not want to go back there." So those are very important factors. "I saw my neighbour, he started on antiretroviral therapy and he is much better, and he has gone back to work and we saw the living testimonies of keeping people to adhere." (E3)

I: Do you have many follow ups with regards to adherence?

R: No, the home based care is like a treatment supporter in the community, but you can use things like the local clinic, seek and organize small groups to come together in a taxi and small things like that, that can help. Like little organizational things that help.

I: We have spoken a lot about the social environment, and how social perceptions of whether they take the medication or not, but if we look at something a bit more concrete the physical environment. Do you think that the environment affects whether someone takes their medication or not?

R: Well, somebody who doesn't have food on the table, because some of the antiretrovirals. Some of the patients just generate a roaring appetite and that is a sign of the body building up strength to strength and they just need to feel the energy from lots and lots of food. So, there you have a problem of a patient who feels hungry because of the medication, so the health department has provided food supplementation which we give out to and it is readily available. And, we do not have a short of supply or anything that in fact my problem is that there are boxes and boxes of in our offices and it is in the way but we use it when we give it out to our patients. You cannot live eating porridge three times a day but at least it gives them one good meal a day. There is patients that are so sick with such a low CD4 count that it is not actually physically possible for them to come

in a taxi and reach the hospital. We provide for those people by actually admitting them into our hospice and the hospice has turned around from our old traditional idea of looking at terminally patients till they die to being a place where the seriously ill can recover.

Poor social support and emotional support from family members or the lack of having family members are also important things in the adherence. We actually ask our patients to bring with them a family member to the adherence classes, so that we can include the family member as part of the support team and that is one thing that has been proven. That there is better accuracy when he is not doing it alone, but when there is a family member that knows what is happening. And often the guy would say "I don't have anybody," and it is not something that they are not willing to discuss. They really do not have, anyone, they have gogo, but she is sick, and not really able to do anything. The ladies are really on their own, with not much support from anyone. That is also a problem.

I: Is disclosure part of your disclosure admittance criteria?

R: No, but we strongly recommend it. And for the Yale study it is a exclusion criteria. I wont put somebody on the study unless I have actually had the opportunity to meet and speak to members of the family. And like I said we need a 100% compliance there. In the roll out in the national guidelines, it is not insisted on, so we don't have that as an exclusion criteria. It is strongly recommended though.

I: So, what advice would you give to help people to adhere better to their medication?

R: In the antiretroviral therapy context, to make sure that the patients understand themselves, everything. I would also try and make sure that the patient is not depressed. I would also see that there is in place a friend or family member or a social contact that can help and I would establish a friendly relationship with the patient if possible, and create that sense of feeling that it is not a once off thing.

The patient is going to go home and there are going to be problems and there is an open door for discussion and the patient must feel that, "If I have a problem, I can access help immediately, ask questions and get clarification."

I: What role do you see the hospital playing in helping patients to adhere to their medication?

R: We provide the patient with counselling sessions. We provide the patient with interaction. We provide clinics. We have an open door, virtually from 7 in the morning to 7 at night, not including weekends, where patients can come in any time and ask questions and get help. And we have community workers in the community. We try and link every patient with a home based care worker or direct family member. It is also a home based carer who knows about the patient and we visit the patient once a week when they are ill. That is the kind of a support systems we establish. We also encourage the patients to join support groups, and they come to support groups, and that makes a difference.

I: What role do you see with other health care professionals in helping patients with regards to adherence?

R: What you need from the other health care professionals is that we all speak the same language, and we are all are part of a team. That is what we would like to achieve. And for instance, if a patient gets side effects and it is on a Saturday, and they arrive in the out patients department, and are seen by a doctor who is not part of the antiretroviral team, what we would like is that that doctor is sympathetic to the patients problem and has been able to pick up that this is a side effect of the antiretroviral therapy, and know what to do about it, and then that patient are admitted to the ward, and needs bed side care, and taken care by the medical staff and antiretroviral therapy, and they keep on encouraging the patient. The clinic sister out there in the clinic must also be aware of the problems, when a patient presents himself at a clinic and the clinic sister is also sympathetic and understanding so ideally you looking at the whole network being important to the

whole antiretroviral efficiciency. Knowing what is happening and interested in continuing the adherence message to the patient.

I: If you had to conceptualize an adherence intervention, do you think it should be pitched mainly at the individual level or community level?

R: I think what we have done well is the individual patient preparation that every patient goes through here in the hospital and each patient goes through it. What we would like to build up is to put in place a community understanding of antiretroviral therapies, awareness of those that benefited, and to have an informed community that are aware of all those things. And that is going to take a long time, but it is something that should be done and must be done, and people like school teachers, church leaders, indunas, regional authorities; these are all people that need to be involved. It is a huge task but I would definitely want to include that in the adherence programmes.

I: Thank you so much for giving me some time on this.

R: I hope it was helpful.

**Expert 4**

Key: I – Interviewer

R – Respondent

……. - Pause

I: Hi. Thank you so much for agreeing to do this interview. The first thing I would like to ask you is; to briefly describe the work that you do.

R: I have 2 main jobs. The one is with the World Health Organization where I am working with the 3 x 5 initiative, that is to get 3 million people antiretroviral medication by 2005 and I am specifically looking at the mental health issues that are linked to that. One of them being that people's mental health has a bearing on their continuance and adherence on antiretroviral medication and therefore one needs to intervene at a mental health level to try to level the success of the program. So I have been developing materials and so on to do with that internationally. And my other job is on the human sciences research council where I am a researcher in the area of the mental health and HIV AIDS. Looking at various aspects.

I: And how long have you been involved in this type of work?

R: About 2 and a half years.

I: If you had to look at the individual, who is taking the ARV medication, do you think there is any individual traits or behaviours that would influence adherence?

R: I am not quite sure what you mean by traits. Obviously there are personal issues, which determine whether a person is going to take their medication or not. I don't know if there are personality traits as such. Certainly I think that issues around whether the person has disclosed or not and the reasons why they have disclosed or why they have not disclosed might well be related to who they are and to what kind of approach will they have. And certainly issues of disclosure are going to determine whether a person is going to adhere or not adhere. So I think disclosure

is one important issue. I think, I suppose to get to where I'm at, I think that a person's mental health status is quite important to whether they actually do decide to continue with their medication or take the medication or not. And why upon difficulties it is to differentiate between mental health status and personality trait. But, I think if for example, somebody does not really care much about themselves and about their futures and their lives, and whether they live or don't live. It is going to have a bearing on whether they decide to continue with the medication or not. To what extent they are prepared to tolerate the side effects if they are, but certainly I think people who have a greater will to live, and who understands some of the medical issues involved, are more likely to adhere than people who have lesser of an understanding and less of a will to survive.

I: In your experience have you seen any specific types of people or categories of people that are more or less likely to adhere to ARV?

R: You are trying to get me on the personality thing again (laughs). I must say I haven't worked that much directly with ARV programmes, so when I talk it is more from what I've read in the literature and from specifics, but certainly I think that issues like education do come into it, understanding of the medical issues. I think people in poverty are probably less likely to adhere and to have the ability to adhere than the people who are better off.

I: Why do you think so?

R: Why do I think so? I think that firstly poverty is linked to nutrition very often, and I think that taking medication on empty stomach's and things like is quite difficult for people and I think once they start feeling the impacts, their motivation becomes decreased. I also think that very often people in poverty have or feel, some people feel that they don't have quite the same reasons to live as people who do have food in their stomach and are able survive in better circumstances. And I think that poverty is also linked to education and as I said earlier, education is a big issue. And possibly in South Africa also there are mixed messages and I would suggest that possibly people who are less educated, less or living in more

dire economic circumstances may be able to assess the pro's and cons of it less dynamically and therefore might be influenced by different messages as well. And I think that there are probably political issues there that probably in South Africa people who are poorer are probably greater supporters of the government perhaps and if they are saying that antiretrovirals are more ……they're more sceptical towards them than many of the followers. I think that there may also be relations between more traditional beliefs and poverty situations in South Africa . So I think that some traditional force towards saying it is our indigenous remedies and solutions where we can understand why this thing is happening to us. And I think that the question of 'why me?' and 'why is this happening?' are very different from people who have traditional beliefs about health and illness. And that if you say, it maybe because of such a witchcraft or such a displeasure of the ancestors or whatever then you are going to take a different approach as to why I got ill and therefore probably a different remedy to getting yourself better. I think that when I say poverty, you say why? I think you can never separate poverty out from any other issues, especially in a big country like South Africa, although I think that poverty in itself and probably internationally is an issue too.

I: I know you touched on this in your last response, but can you comment on any other factors that can influence someone's perceptions of ARV's?

R: I definitely think that political is an issue. I think that ……again if I can come onto my mental health issues. I do think that people's will to live is an important one and belief, in the face of adverse circumstances; that they can survive. I think that another issue is that sometimes, people are not all that ill at a time when they should start ART and that's obviously a debatable issue. But I think that when you… I think maybe I'm answering the last question rather than this one, but when you are living in poverty you have got many other concerns and you are not sick, you are going to be concerned about the things about keeping alive, rather than those things might affect you in the future and they may not. So it looks like an immediacy issue linked to poverty. This is probably an issue of what I think. There is an immediacy issue, and then of course the side effects issue and the

difficulties with maintaining large regiments of medication. I think also that because people become ill with other diseases and so on, and let me push my mental health issues or psychiatric issues, but I was at a conference recently where someone from America who said that their son was on something like a 110 medications a day, you know because you have to take antiretrovirals 3 times a day, and I don't know many of those there are, but maybe 3 of each and then this person was epileptic and they might have had TB or whatever and then one thing after another, after another. And eventually this person said, "No thanks" and just and one day take 110 and the next day taking nothing. And I think it is very understandable by somebody doesn't want their lives to be dominated by their medication, and I think that when you are on ART life has to stop and becoming dominated by it, and you've got to have a real will to survive in order to do that. I mean most of us are pretty poor in taking medication over a short period, and we've seen the difficulties with things like TB medication and DOTS strategies and all that kind of stuff, which do help but to try and get somebody to take lots of medications with side effects for extended periods of time, is difficult, but maybe if one's looking for a personality trait, maybe it is perseverance. If you basically have to just keep on hanging in there and say "This is keeping me alive, and therefore I have to carry on taking it!" But it does dominate your life and if you travel you have to remember to have sufficient quantities. You got to have good relations with health systems all over the place in order to get your medications that you need and there are quite migrant patterns, where people do move around a lot, and you have to have your medication, or you have to be able to expose yourself also possibly to more than one health person, and if there is stigma, and there is stigma around, perhaps you do not want another person, I am HIV and how they are going to respond to you, and I think that the whole stigma and discrimination actually do make a difference. If you are taking medicines, and you may have disclosed to people at home. You may say that's fine and then you go out, and have lunch somewhere and you got to take your medication, so every time you show your pills, you are saying I am HIV positive. And that's fine if you are out and you do not mind, but most people do mind who knows, and

given the stigma probably, correctly so. So it is a major exposure to take medication. Then there is the whole physical side effects, it is called lipodystrophy, where if you are on ART and you have been for a while, if I see you I'll know. So, do you want me to know? I am thinking of Australia and in the States where especially where in gay clubs and things, people would comment, on ART. Those people, I will not make a move on tonight, and you can actually see, you can pick them up, through extended fats in different parts of the body, so you immediately become discriminated against because you are on ART, and the people don't want to get involved with you and that there might be another reason why you do not get on, because say I get into a relationship with you and I don't necessary want you to know that I am positive at the beginning of the relationship. I do insist that we use a condom because thats the way I handle it, but I am very worried because if you know, I'm going to stop the relationship, but if we spend a day together, you are going to know. So I think there are so many issues, which determine whether people are going to take it properly or not.

I: Do you feel that the way society perceives HIV affects whether individual is compliant or not, and to what extent?

R: All the reasons that I have been talking about. I think if there was no discrimination and no stigma, then it would be much easier for people to be open and to take the medication, but it is not and people do not want everybody to know that they are positive. With all the work that I have been doing, the whole issue of relationships have come up very, very strongly in interviews with positive people. That getting hold of a person is not easy at all, if you positive. Partly because they don't want to get involved with you but partly they and partly because you don't want to infect other people, and even if you do take protection, obviously your risks are higher and so on. If I like you, especially if I like you, I don't want to infect you. And it creates difficulties in ongoing relationships, and it creates severe problems in getting involved in a relationship. So a lot of people that we interviewed said, "I only want to get involved with somebody else who is positive", and it is a very limited thing. And then it also has problems of course.

You still have to take precaution as you can still infect each other etc. Sorry, what was your question?

I: Whether society's perceptions affect whether the individual is compliant?

R: I think it largely linked to openness about it, and to the stigma and discrimination.

I: And, if you have to look at an individual's environment. Do you think their actual environment is going to play a role in compliance?

R: Yes. Environment is also linked to disclosure. In this house, perhaps I can hide my medication somewhere and if I live in a very small little shack somewhere, there is no way I am going to hide it from people. Yes certainly I think it would. But if you are talking about environment, it may be a hospital, maybe you are talking about a boarding school. People live in very different environments and if you don't want other people to know about it, of course you are going to find a way. And I believe the better word is 'adherent' it rather than 'compliant' it. Compliant is kind of associated to a doctor's instruction rather than a choice.

I: What do you think can be done to help patients take their medication properly?

R: I suppose there is the usual things like the cool boxes and things like that. I think they have done very well with chronic medications, and so on, there is things like alarms that people have on their watches and things where at certain time it rings, which reminds them to take their medication. There is of course getting others to help you to remember, remind you at certain times, and that becomes your joint responsibility. Putting a lot of pressure on others, but I suppose if it is your loved one you probably will adhere to that. But I don't want to talk about things you might not get from other people. When that is one thing in particular is the finding and certainly my strong belief that if you are not psychologically well or psychiatrically well, it is going to have quite a bearing on whether you do continue to adhere to your medication or not. And the research seems to suggest that the people that are depressed, don't really care all that much about their futures and so die or not die, well, if I have to bounce that against side effects,

against disclosure, against all the other negative things about being on ART, I would rather not. And part of what we've have been doing at the WHO, is trying to look at programmes to help people not just to go through adherence counselling but rather have mental health counselling, so that you're not just getting your ducks in a row, and I have seen a lot of these things in the WHO manuals, well if you haven't seen it, you should get it, but you properly have seen. There's about 20 other things that people have to know about to be adherent but when it come to get to peoples psychological difficulties, it don't think that may or may not be absolutely directly linked to being HIV positive. And why I say they may or may not be directly linked to, because mental problems are both a risk factor to becoming HIV positive and the consequence of being positive. So, lets say you are depressed to start with, your behaviour would probably be more risky or you got a substance abuse problem. So you don't engage in protective sex, they way you would if you were in a better mental health status. If you are suffering from mania, you are not going to worry about using a condom. You might also be less slightly to be able to say, "no", because you don't have the same social skills. If you have mental health problems, so people are risk at risk, but then also, once you become positive that may well lead to depression, to anxiety, to dementive states and so on. As a consequence, then, one's mental health goes down. You might have been at poor mental health to start or as a consequence. So, you got a high percentage of people who are HIV mental health problems as well. We are doing a study at the moment and that there has been some small studies. It is not unrealistic to say that the probably half people with HIV also have mental health problems. And most of those are not being dealt with, either through medication or counselling or psychotherapy and the research has also shown that those people with poor mental health are less likely to adhere to medication. The research is there, so you have higher numbers more likely to not adhere, so you got to deal with the mental health problems in order to try and help with improving adherence. All the mental health problems, because people need help with the mental health problems. A good secondary outcome of that probably is that you are going to improve adherence if you do that. It is also you know like you have

to treat opportunistic infections impacts, so you also got to treat the mental health impacts, but in doing that what should get better adherence and the research is not yet there to say that treating the mental health problems is going increase the adherence. At the moment I am still trying to raise the money to do that kind of study. There is some evidence from the USA that it would improve adherence, but we've got evidence from developing countries, where your rates are so much higher and where your complications are possibly more linked to some of the stuff we talked about earlier and to what extent these other things will impact on your adherence relative to your poor mental status. It's worth finding out.

I: What role do you see yourself and the organisations that you are working for, how do you see yourself helping people take their medication?

R: Probably at our point of view, we are now, we are adding a mental health section to be training of people in how to deal with positive people and how to give people ART. And we are just testing our materials at the moment. Most of the roll out of ART internationally is taking place through something called the Integrative Management Of Adult And Adolescent Illnesses I don't know if you know that approach. That's what the WHO are using for training people on how to deal with ART. It is quite a comprehensive health approach and it is not just concentrating on the HIV. What are the person's complaints and how does one deal with them. And through that process you pick up the HIV and it links into pre and post test counselling and being integrated into a primary healthcare system. But that is the main way ART is going to be given out internationally. That's the 3 x 5 objective. And we now are including a mental health component in that, so now we are saying what are your problems, and they will give them you, and you will ask about their mental health or their mental well being. And, if they are suffering from depression or anxiety or whatever, you will treat them. Some people will get treated with medication and some people give them individual counselling, other people you put in groups. What we have done is develop materials for the integrated primary care level mental health intervention for basic counselling and then we got to the second level with more

psychotherapeutic interventions, different models and more interpersonal therapy and motivational interviewing, bereavement counselling and things like that. You've got a second level psychiatric module and so we really saying, well, if it is true more that people with HIV have mental health problems and I've got very little doubt if that is true. And I've got no doubt that being positive is a damn difficult thing especially in dealing with relationships. So I think that merely looking at adherence and adherence strategies limiting for a certain proportion of people and where I hope my work would come in is that for those who need something else, health to adhere to that. So from that point of view, I'm hoping that my work would be more than sitting at a computer developing materials. From the HSRC side, I think we still need the evidence that people with HIV are more likely to have mental health problems and that study I hope will help to establish that. But in that study what we are also doing, is looking at the directionality about what comes first – the mental health problem or the HIV. We are also looking at things that people say, support them when dealing with their lives, and what makes things worse for them, so that will also give us some insights into what people need, which we will then have a social environmental level as well as at a personal level. I am also looking as I said for money to do a case control trial where we give some people mental health interventio ns and not others, and see whether that actually improves adherence or not. And then I am also just getting involved in a study where we are looking at HIV status amongst people with severe mental illness because they are in a whole other group. Again, in the USA people with severe mental illness are 20 times more likely to be HIV positive than your general population. If we try to convert to it here we well have a 100%. I don't think it is likely but it is likely that they are a high risk group. They have particular kinds of problems with adherence and so on. Now some people argue that because many people with a serious mental illness are used to taking chronic medication that getting them to take some additional medication will not be that difficult because they understand why, and they have seen the benefits of it and so on. Other people say that people with mental illness are just difficult to keep on chronic medication because of the illness itself and you're

probably going to have low levels of adherence. Now a way of counteracting that is to develop programmes to help them specifically to adhere. And, they might be different counter programs from the general population, far more closely supervised and more focussed training on reasons why and how to do it. So that is a group who probably does have high levels of HIV and they what might be called the sentinal group who you can identify as high risk and you then need both good proficient programmes for them. Prevention primary and secondary prevention and focussed adherence programmes as well. So that is another area where hopefully my work will make some difference.

I: Do you see any other professionals in playing the role in improving adherence?

R: Yes everybody. Doctors, lawyers, business executives and they all live in little boxes. I am not just being facetious. I think certainly all professionals who deal directly with people on ART have to play a role, Doctors, Nurses, Nurse aids, HIV aids, community health workers. I don't know how widely you wanted to define professionals. When I say lawyers, I think that fighting some of the good fights around stigma and discrimination will all make a difference to adherence in the longer term. You pick up a fight of discrimination, people are being discriminated against and the lawyers are not taking up the cases. They need to be taking up the cases, because while such discrimination goes on, it is going to be so much more difficult for people to adhere. And the more cases they pick up, the more it is going to help, with the discrimination, people are going to be more scared. This is going to help to normalise the situation, so lawyers you can't say what do lawyers have to do with it, they have. Business executives, they've got to start normalising the practice of people taking ART in the work places. They got to have resources available, they got to have mechanisms to give people ART's. They've got to get involved and possibly, the more people start taking it, and the more it becomes normalised and a norm, the more adherent people become as well. When you're the exception, it's more difficult where if 20% – 30% of the people in the workplace are doing it, you just do it too and maybe help each other.

It is just, "Lets take our the medication now". I think it really needs a concerted effort. And the politicians.

I: What did you feel about introductions of ARV's to the health care sector?

R: What did I feel about it? I must say, initially, I was somewhat sceptical. At first I think most of us didn't know if it was going to work or not. Whether one would just be giving people difficulties for very little reward. But I think I was also one of the people out of department of health, and I am thinking quite a lot as well, I was sceptical about the ability of health systems to back up a major roll out programme. I think you do need well trained people, you do need good laboratory back up, you do need good monitoring, you need availability of your medication all the time, and so on and so on. And I think without those things, you may well be making things worse. Now I am sure you would have people telling you both that unless you have your 95% adherence you are going to get your resistance strains and you are going to get people who tell you a lot of junk, and I am sure you had both already, but certainly there is a risk that if you don't get your adherence and you can make things worse. That your intervention is not just useless, it becomes worse than useless. And certainly I think that I am and I was worried about those kind of things. I don't think that those are smarties one's playing around with. And I do think that one needs assistance in place. And to know more perhaps about what does help people to adhere, before you start giving them these medication, you've got to have proper good support programmes, and I think that your research is probably quite important in helping to understand that what is it that the health system needs to improve adherence. I mean it might sound like its in terms about what I've said about what makes a difference to what other people saying this is what you need for adherence, but we need to be more systematic about it, and we need our systems to be well functional. I don't know if you ever asked the question, where I can put it in. In to say you need well functioning systems to get better adherence, and one of the dynamics. Do you have a question as such?

I: I asked you what did you think can improve adherence.

R: Well certainly, I would put good health systems into that category. And good training of health workers, good training of family members, and good training of patients. But you certainly need the back up and you need to know what you are doing and telling somebody you are going to be on this sort of life, is not going to keep them on for life. The other things that I am not sure if I should have said it when people feel well, then what keeps them on medication? Very little. My experience with psychiatric patients, I mean that is far longer, it shows that when people are doing well, psychiatrically, they stop their medication, maybe until they relax, and they go on again and then maybe after the 5$^{th}$ time after relaxing, they realise that they've got to stay on. It is just human nature. When I was feeling well, and you really need to have an understanding and conception of this virus, and what the cause of doing to control it. And I think it is quite a highly intellectual conceptualisation especially for people who have very, very different conceptions about what causes the illness. And then you worry because it is going to be there forever. Never heard of that before, the illness is caused by witchcraft.

I: You have spoken about quite a few difference interventions. How do you see the interventions being implemented? Do you think have to be implemented at community level or individual level to be effective?

R: I don't think it is either or. Because I think it is both. I think that changing social attitudes and perceptions and norms has to happen at a social and community level. I think that societies can change what is normal, or normative and they do but it takes a long time, so what is it that makes that change and how long does it take. Well certainly I think that you do need public information, public input, media exposure etc etc. But I also think that changes and it influences how individuals behaved, so that changes through individuals changing, so I never believe that individuals affect society, or society affects individuals. I always think it happens both ways and so I think that when people become personally educated, personally start changing their behaviours, then that becomes part of the

social norm. And then that becomes the social norm. But it is not the only way it becomes a social norm because they might also have needed some external inputs, which might have happened on an individual level or a social level for them to get to the point where they start behaving in a way that helps societies to change and for that thing to become a normative. I don't think it is an either or situation. We need multiple attacks.

I: Thank you very, very much for doing this interview with me.