

**PSYCHOSOCIAL FACTORS THAT AFFECT ADHERENCE TO
ANTI RETROVIRAL THERAPY AMONGST HIV/AIDS PATIENTS
AT KALAFONG HOSPITAL**

BY

G UGULETHU MORATIOA

**MINI-DISSERTATION SUBMITTED IN PARTIAL FULFILMENT OF
THE REQUIREMENTS FOR THE DEGREE OF**

MA (CLINICAL PSYCHOLOGY)

IN THE FACULTY OF HUMANITIES

UNIVERSITY OF PRETORIA

SUPERVISOR: ANNALIE PAUW

SUBMITTED: SEPTEMBER 2007

**This dissertation is dedicated to my husband Morolong for believing
in me**

ACKNOWLEDGEMENTS

I would like to express my gratitude and thanks first and foremost to God the Almighty, without whom none of this would have been possible. Secondly, thank you to my mother, for loving her children and teaching them the value of education. I would also like to thank my family for their unwavering support and belief in me.

I am indebted to a great number of people who have contributed to this research project. I wish to express my thanks to the following people and institutions for making this research project possible:

- Annalie Pauw, my supervisor, for her patience, assistance, continuous guidance and support throughout the whole process.
- The Department of Humanities for offering me the opportunity to pursue a degree in clinical psychology.
- My son Njabulo for his unconditional love, which has made me want to be a better person.
- My brother Solwazi Majola for his support and motivation.
- My niece Mandisa for her support and patience through the difficult times.
- The Immunology clinic staff at Kalafong Hospital, especially Dr L.M. Phalatsi and Sister Siwela for their assistance with data collection.
- The Immunology clinic patients for their patience and participation in the research project.

SUMMARY

This research focuses on the psychosocial factors that affect adherence to highly active antiretroviral therapy (HAART) amongst HIV/AIDS patients at Kalafong Hospital. Even though the development of such regimens has helped turn HIV infection in the United States into a relatively manageable, though still serious chronic disease, compliance remains one of the major challenges in managing medication for those patients living with HIV/AIDS. This is particularly relevant given the high adherence rate (95%) required to obtain a successful long-lasting effect. In South Africa non-compliance to HAART is an under-explored phenomenon. Consequently, an understanding of factors influencing compliance is still incomplete.

A qualitative study that investigates non-adherence to medication in HIV/AIDS patients was undertaken at Kalafong Hospital. This study aimed to understand patients' psychosocial difficulties resulting in non-adherence. The study was approached in terms of the health belief model (HBM), which addresses individual characteristics pertaining to change, the transtheoretical change model (TTM) and the motivational interviewing model (MI), which address both individual and social contexts pertaining to change. The findings are designed for use by healthcare professionals as a proactive compliance enhancement tool. Participants were recruited through referrals by the medical staff to the researcher. The criteria included that participants had relapsed due to non-compliance with drug therapy. Participants that were currently experiencing difficulties with adherence were also included in the study. Males and females aged between 20 and 40 were included in the study. Fifteen participants between the ages of 20 and 40 participated in the study (13 females and two males).

The data were collected by means of semi-structured interviews and follow-up unstructured questions. The interviews were audio recorded and field notes were taken. . Data were analysed qualitatively. Sixteen themes emerged and were further classified into two categories: individual and social context. The themes were then compared and integrated with the literature. The study concludes that psychosocial factors such as support from family, friends and healthcare workers was found to be of utmost importance in encouraging adherence. Medication can only prolong a patient's life if the psychosocial context in which the patient is embedded is considered in the treatment plan.

KEY WORDS

HIV, readiness, compliance, non-compliance, adherence, HAART

TABLE OF CONTENTS

CHAPTER 1: INTRODUCTION

1	Background	1
2	Motivation for the study	3
3	Objectives of the study	5
4	Overview of the study	5

CHAPTER 2: BARRIERS TO ADHERENCE

1	Definition of terms	7
2	Barriers to treatment	9
2.1	Individual barriers	
2.1.1	Emotional responses	9
2.1.2	Active mental illness	10
2.1.3	Drug and alcohol abuse	11
2.2	Health literacy, level of education and decision making	11
2.3	Belief systems	15
2.3.1	Traditional cultural beliefs	15
2.3.2	The traditional role of women	16
2.3.3	Religious/spiritual beliefs	17
2.3.4	Medication efficacy	17
2.4	Side effects	18
2.5	Self-efficacy	19
2.6	Current symptomatology	19
2.7	Condom use and HIV/AIDS	20
3	Social barriers	
3.1	Social support	22
3.2	Education, employment and social class	26
3.3	Domestic violence	26

3.4	Disclosure, stigma and rejection	27
3.4.1	Social rejection	30
3.4.2	Financial insecurity	30
3.4.3	Internalised shame	30
4	CONCLUSION	32

CHAPTER 3: MODELS OF ADHERENCE

1	Health belief model (HBM)	34
2	Transtheoretical model of change	36
2.1	Stages of change	37
2.2	Process of change	39
2.2.1	Cognitive processes	40
2.2.2	Behavioural processes	40
2.3	Levels of change	42
3	Motivational interviewing approach	43
3.1	Social support and motivational interviewing	44
3.2	Motivational interviewing techniques	45
4	Conclusion	47

CHAPTER 4: METHODOLOGY

1	Research design	49
2	Participant selection	49
3	Research process	50
3.1	Research site	50
3.2	Criteria for HAART medication	52
3.3	Multidisciplinary team	52
4	Data collection	54
4.1	Interviews	54
4.2	The interview process	55
4.3	Data analysis	56
5	Bias	58

6	Seeking sensitive information	58
7	Establishing credibility	59
8	Transferability of the study	60
9	Ethical considerations	61
10	Conclusion	61

CHAPTER 5: RESULTS

1	Participants	62
1.1	Participant 1	62
1.2	Participant 2	63
1.3	Participant 3	63
1.4	Participant 4	64
1.5	Participant 5	64
1.6	Participant 6	65
1.7	Participant 7	65
1.8	Participant 8	66
1.9	Participant 9	66
1.10	Participant 10	67
1.11	Participant 11	67
1.12	Participant 12	68
1.13	Participant 13	68
1.14	Participant 14	69
1.15	Participant 15	69
2	Identified themes	70
2.1	Emotional reactions	70
2.2	Domestic violence	75
2.3	Social withdrawal and disclosure	75
2.4	Condom use	77
2.5	Side effects	78
2.6	Access to information on HIV/AIDS	79
2.7	Belief systems	81

2.8	Support systems	83
2.9	Unemployment and social class	85
2.10	Rejection and stigma	86
3	Conclusion	87

CHAPTER 6: DISCUSSION

1	Barriers to adherence	88
2.1	Individual barriers	88
2.2	Social context	95
3	Conclusion	97
4	Limitations of the study	100
5	Recommendations	100
5.1	Healthcare authorities	100
5.2	Healthcare professionals	101
5.3	Family and friends (support system)	105
6	Future research	105

REFERENCES	107
------------	-----

APPENDIX A: INFORMED CONSENT FORM	117
-----------------------------------	-----

APPENDIX B: INTERVIEW SCHEDULE	118
--------------------------------	-----

CHAPTER 1

INTRODUCTION

1 BACKGROUND

Non-compliance with medication for HIV/AIDS has been cited as one of the major problems in the South African primary health care, (Kagee, 2004) resulting in high rates of relapse, rehospitalisation, morbidity and mortality. Non-adherence studies are still in the exploratory phase, especially in South Africa; and as a result, explanations for this phenomenon are not yet fully developed. The advancement in the medical field has given more hope to those living with the condition for long-term survival and a better quality of life (Ellis, Naar-King, Cunningham & Second, 2006). According to Thrasher, Golin, Earp, Tien, Porter and Howie (2006), the development of highly active antiretroviral therapy (HAART) regimens has helped turn HIV infection in the United States into a relatively manageable, though still serious, chronic disease. HAART may be seen as a basis for hope of a longer and healthier life for those living with HIV. Although it is serious and life-reducing, the future hope is for HIV to be a manageable illness (Kelly, 1998).

Achieving and maintaining the health benefits of this regimen requires near perfect adherence which most patients do not achieve. According to Abah, Addo, Adjei, Arhin, Barami and Byarugaba (2004), twenty antiretroviral products are available in South Africa. High levels of adherence are necessary for the medication to be effective and to minimise the viral load and prevent drug resistance. Achieving this elevated level of compliance remains the concern. When contrasted with treatment for most chronic conditions, highly

active antiretroviral therapy (HAART) requires an adherence rate as high as 95% in order to obtain a successful, long-lasting effect (Patterson, Swindells, Mohr, Brester, Vergis, & Squier, et al., 2000). Adherence that is suboptimal results in replication of the virus, which promotes the development of drug-resistance HIV-variants, leading to treatment failure as well as limited options for future therapy (Louie & Markowitz in Nordqvist, Sodergard, Tully, Sonnerborg & Lindblad, 2006).

South Africa also faces other major problems like unemployment, which leads to poverty that is further compounded by the negative impact of HIV/AIDS. Within the 15-24 year age group, the country accounts for roughly 14 percent of the global HIV infection (Onyejekwe, 2004). Onyejekwe's study (2004) particularly indicated that women are more affected than men. The study further indicates that this difference might be aggravated by gender-based violence such as rape and domestic violence.

The South African National ART guidelines recommend that the following psychosocial considerations (although not exclusion criteria) be taken into account before HAART is initiated:

- Demonstrated reliability, that is, the patient has attended three or more scheduled visits to an HIV clinic.
- No active alcohol or other substance abuse.
- No untreated active depression.
- Disclosure to friend or family member or member of a support group.
- Acceptance of HIV status and insight into consequences of HIV infection and the role of HAART.
- Ability to attend the antiretroviral centre on a regular basis.

- An expression of willingness and readiness to adhere to the HAART medication regime.

The treatment readiness assessment is performed over three clinic visits. The South African guidelines stress that it is not possible for healthcare providers to predict which individual will adhere based on gender, cultural background, socioeconomic status or educational level (National Department of Health, South Africa, 2004).

It has become clear that medication non-compliance, especially in cases of HIV/AIDS patients, warrants more attention by the Health Department as a whole in order to assist the health caregivers so that they can modify their approach where necessary.

This study aims to investigate psychosocial factors that affect adherence to antiretroviral therapy. It is hoped that the results, combined with other studies, might provide a better understanding for the obstacles to treatment that this disease presents.

2 MOTIVATION FOR THE STUDY

The researcher observed the high rate of non-compliance to HAART therapy at Phidisa clinic in 2006, in the course of her internship as a clinical psychologist. A high percentage of patients were struggling with compliance, and were referred as a result to the psychologist for intervention. The topic of this study was therefore motivated by the experience of counselling these patients, together with the fact that the physicians at Phidisa clinic felt discouraged by their failure to predict the high-risk patients so as to prevent non-compliance.

Most of the studies that have been conducted on adherence derive from the United States. In South Africa, studies on adherence are still in the exploratory phase. The American studies have produced consistent results that need to be explored for their relevance and transferability to local priorities and settings, given that South Africa is still a developing country. As such, unemployment, poverty (nutrition), illiteracy, and traditional belief systems are still among the factors that people living with HIV/AIDS (PLWHA) deal with on a daily basis, and which further result in non-compliance (Abah et al., 2004).

The myths that the researcher encountered in the community and at Phidisa clinic also seem to compound the problem of compliance. Among the myths she encountered, especially amongst some of the Zulu tribal men, was the belief that the West wants to reduce their productive numbers by indoctrinating them with the belief that there is something called AIDS, which does not exist. In addition to the belief that AIDS does not exist is a rejection of the use of contraceptives, especially condoms.

Another situation that the researcher encountered in her internship work was that some people living with HIV/AIDS in poverty-stricken circumstances sabotaged the treatment regimen in order to reduce their levels of the CD4 count to below 200. By so doing, they were entitled to the social grant for HIV awarded in such instances.

Knowledge gained from the results of this study, combined with existing studies, may be able to assist healthcare workers in predicting adherence. The rationale behind this is that if healthcare workers can predict non-compliance, then this may be prevented through relevant multi-component cognitive intervention measures that include behavioural or other psychological strategies. These strategies should be designed to ascertain readiness before the patient commences the treatment. They may also be used to improve self-

efficacy, provide stress management and support therapy or motivational interviewing, especially to known previously non-compliant patients.

3 OBJECTIVES OF THE STUDY

- To determine psychological and social factors involved in non-compliance with antiretroviral therapy amongst people infected with HIV/AIDS at Kalafong Hospital.
- To gain a better understanding of the client's perspective on their non-compliance.
- To summarise existing information on adherence, which may serve as a basis for further research.
- To produce results that may enable the medical staff to design suitable interventions to address the specific problems of non-compliance and to generate information for further research.

4 OVERVIEW OF THE STUDY

In order for the researcher to fulfil the above objectives, a group of English, Zulu, Tswana and Southern Sotho men and women between the ages of 20 and 40 were included in the study. These participants were recruited from Kalafong Hospital's Immunology Clinic. Patients struggling with adherence were referred to the researcher for the study. These patients were asked to participate in a voluntary interview with the researcher.

The outline of the thesis is as follows: chapter two entails the literature review, which looks at problems of adherence in terms of predictors of adherence, barriers to treatment and the social context. Chapter three deals

with the theoretical models of compliance. They are the Health Behavioural Model (HBM), which addresses individual characteristics pertaining to change, the Transtheoretical Change Model (TTM), and the Motivational Interviewing Model (MI), which addresses both the individual and the social context pertaining to change. This is followed by a discussion of the research method in chapter four with an emphasis on the method of data collection and analysis. The analyses of the results (themes) are discussed in chapter five. In conclusion, chapter six integrates the results with the literature, explores limitations to the study and makes recommendations for future research.

CHAPTER 2

BARRIERS TO ADHERENCE

This chapter discusses available research on the barriers to antiretroviral medication resulting in poor adherence and compliance. These barriers are approached from an individual as well as a social perspective. Irrespective of various countries and settings, compliance with medication is probably the biggest factor that needs to be addressed when planning HAART services (Heyer & Ogunbanjo, 2006). Compliance is a complex phenomenon that may be associated with patient factors, illness factors and medication factors. According to Thrasher, et al. (2006), HAART has helped turn HIV infection in the United States into a relatively manageable, though still serious, chronic disease. However, achieving and maintaining the health benefits of this regimen requires near perfect adherence, which most patients do not achieve.

Before exploring the research on these barriers, the terms used in the study are defined. In delineating the appropriate definitions, care has been taken to focus on the meanings within the context of studies on adherence to and compliance with chronic conditions in the social science literature. The terms *patient compliance* and *patient adherence* are generally used interchangeably in the behavioural and health sciences (Burke & Ockene, 2001) and this review assumes the same approach.

1 DEFINITION OF TERMS

The definitions for the purposes of this study are as follows.

Adherence. According to The World Health Organisation (WHO) (2001), adherence focuses on both medication and health-related behaviours, in

particular seeking medical attention, filling prescriptions, taking medication appropriately, obtaining immunisations, attending follow-up appointments, executing behavioural modifications that address personal hygiene, risky sexual behaviours, unhealthy diet and insufficient levels of physical activity.

Compliance. This is defined as the extent to which a person's behaviour (in terms of taking medication, following diets or existing lifestyle changes) coincides with medical or health advice (Haynes, Taylor & Sackett, 1979).

Non-compliance. This refers to any patient who, on taking a history, admits to having not taken medication as prescribed and/or did not attend follow-up visits as recorded in the patient file. Compliance is important because following the health professional's advice is deemed essential to recovery (Haynes et al., 1979).

Readiness. For the purposes of this study, this will be defined as:

A conscious awareness on the part of the individuals that they, of their own will, have considered and determined that a particular change will be beneficial. In addition, the individual has identified barriers that may prevent this behaviour from occurring and has accepted responsibility for initiation of the behaviour. Finally, a sense of control; and impending action on the part of the individual must be present. (Fowler, 1998)

Antiretroviral medication. More than ever before, people infected with HIV have a multitude of treatment options. Antiretroviral medication target HIV at a multitude of points in the replication cycle, including reverse transcription of viral RNA, the assembly of new viral particles and the binding of HIV to cell membranes. Combinations of antiretroviral medications are commonly referred to as Highly Active Antiretroviral Therapy (HAART). Advances in antiretroviral therapy have brought more simplified dosing schedules, multi-drug pills that combine two or three medications in one pill, and lower

toxicities (Kalichman & Malow cited in Uldall, Palmer, Whetten, & Mellins, 2004).

2 BARRIERS TO TREATMENT

According to Abah et al., (2004), twenty antiretroviral products are available in South Africa. At least 95% adherence is of vital importance for the medication to be effective and not induce resistance. Achieving this high level of adherence remains the concern. Another concern in South Africa has been the delays in the ARV rollout and also the limited drug supply, which has resulted in delays in treatment initiation in other sites (Aids Bulletin, 2005).

The World Health Organisation (2003) states that interventions that target adherence should be tailored to the demands experienced by the patients with that specific illness. As a result, it is important for healthcare providers to assess those factors that impact negatively on adherence. In order to improve adherence, the healthcare providers should first ascertain treatment readiness, otherwise treatment may be given to patients who are not ready to follow the regime. In addition, patients should be advised on how to take their treatment. Patients who show less than 80% compliance require increased adherence support.

2.1 Individual Barriers

2.1.1 Emotional responses

Nordqvist et al. (2006) note that in an Australian sample of 270 HIV-infected patients who were not on antiretroviral therapy treatment, the most common reason for refusing to start treatment was fear of side effects. They further emphasise that the emotional responses emerging from the diagnoses have to

be dealt with and overcome in order for HIV patients to consider themselves ready to initiate and adhere to treatment.

Fear of possible rejection is another fear that some patients mentioned, as well as subsequent discrimination. Kylma, Vehvilainen, and Lahdevirta, (2003) report that most of the patients in their study indicated fear of being discriminated against as a reason for poor adherence. One of the participants in the this study indicated that his fear of being found out that he is HIV positive kept him from finding information and help from his local healthcare facility. Causes of fear stem from disclosure and rejection; losing a child; death; transmitting HIV to a partner; change in quality of medical care; changes in the manner of obtaining HIV medication; and the HIV progression (Kylma et al., 2003).

2.1.2 Active mental illness

Active mental illness (particularly depression) is strongly associated with poor adherence. Patients exhibiting symptoms of some psychological disorder such as depression are less likely to assert themselves in adhering to medication regimens that in some cases require a stringent ability to follow complex instructions from a medical professional (Kagee, 2004). Patients who are blunting the emotional impact of being HIV positive through substance abuse, depression and suicidal ideation are also less likely to be ready (Nordqvist et al., 2006). Depressed patients also usually harbour feelings of hopelessness towards their future. Therefore adhering to complex HAART with the hope of future health is unlikely (Simoni, Frick, Lockhart & Leibovitz, 2002).

The emotional and the cognitive sequelae of depression may inhibit the patient's ability to concentrate and remember important details such as the time recommended for the medication. Depressed individuals may also lack the physical and mental energy necessary to maintain high levels of adherence, thus requiring the help and support of others. Appetite changes are

usually associated with depression; consequently patients may find it difficult to adhere to special dietary instructions related to antiretroviral regimens (Simoni et al., 2002).

2.1.3 Drug and alcohol abuse

Another group of barriers relates to patients' current lifestyle, for example, active substance lifestyle abuse, imprisonment, financial problems, limited knowledge about HIV treatment and negative attitudes towards healthcare professionals (Nordqvist et al., 2006). Studies done by Chesney, Morin and Sherr (2000) indicate that HIV positive people who live marginal lifestyles, use drugs and have a lower socioeconomic status are at higher risk for future non-compliance. The study further states that drug users are often unable or unwilling to comply with long and complex regimens. They are also known to access medical help at a later phase of the disease and receive less preventative treatment. Power, Koopman, Volk, Israelski, Stone, Chesney, et al., (2003) state that injecting drug users use an avoidance-coping style more frequently than those without a history of drug abuse. The literature on adherence to antiretroviral therapy has repeatedly cited the use of alcohol and illicit substances as a factor predicting lower rates of adherence.

2.2 Health Literacy, Level of Education and Decision Making

Knowledge regarding the effect of antiretroviral medication on viral load is a better predictor of adherence than the patient's level of education (Durante et al., 2003). Therefore it is the duty of all healthcare professionals to provide the necessary information and support at a level or standard that their patients can understand. This should be done in a caring and empathic manner. Professionals should try to answer patients' questions to the best of their knowledge and make referrals where necessary. Healthcare providers should also regularly assess a patient's level of knowledge and information needs.

Determining this aspect will better enable the healthcare worker to accurately assess the patient's adherence.

Since a lack of understanding promotes non-compliance (Ley cited in Ogden, 2000), healthcare workers should take special pains to educate patients and help them understand the cause of their illness, the location of the relevant organs or the process involved in the treatment plan. However, it is important not to overload the patient with all the information at once. To increase effective learning and to enable the patient to remember the information, it should be disseminated gradually, on a need-to-know basis. Olley, Seedat and Stein (2004) conducted a study on individuals that did not disclose their status, engaged in the non-use of condoms, had multiple partners and generally tended to engage in high sexual risky behaviours. The results were worrying. Of the participants, 44% remembered having gone through counselling. This number is low considering that it is during counselling that individuals are informed about safe sexual practices and lifestyle changes necessary for one to be considered as compliant. This confirms studies carried out by Veinot, Flicker, Skinner, McClelland, Saulnier, Read and Goldberg (2006) with youth and adults on timing the sharing of information, and not overloading the patient. These findings suggest that bad timing and information overload result in patients not remembering important information. Patients' understanding of their medical conditions and treatment recommendations is a strong predictor of treatment adherence. From this we may conclude that if doctors recommend that patients follow a particular regimen without the patients being well-informed about various aspects of their condition, adherence may be significantly reduced.

Major themes that emerged from Veinot et al. (2006) were that many of the youths interviewed were sceptical about the treatment due to a lack of knowledge. They did not understand why they should take medication that could not cure them; and as a result they viewed treatment as pointless.

Providing youth with developmentally appropriate answers to their treatment questions may be a first step in overcoming knowledge-based barriers.

According to Veinot et al. (2006), youths' perceptions of their health may be a stronger predictor of whether they access treatment than biological markers such as CD4 count or viral load. Treatment decision making, lack of choice, and feeling emotionally unprepared were identified as being some of the main barriers to initiating treatment.

Veinot et al. (2006, p. 264) found that some youth felt unprepared to deal with treatment decisions. Many were reeling from their diagnosis:

I just told him, like; this is too much for me. Just give me a week or two and I'll come back and we will talk more gradually. Just let me take it all in...after I was told...everything that was said to me, I just did not even hear a word.

Durante et al. (2003) confirm the above in their study with adults. They found that many adults are rushed to make a decision regarding commencing antiretroviral medication without being given enough time to process the news. Healthcare workers must be cautious not to rush the patients, especially since some, such as those tested as a matter of course during pregnancy, may not be prepared for a positive result. Enough time should be allowed for the patient to get accustomed to the idea of being HIV positive, and to consider the lifelong implications of taking the medication. If a patient is rushed through the process, they are more likely to default because they feel that they were not allowed to make the decision on their own but were coerced into it.

Durante et al. (2003) found that the manner in which the information is given to patients plays an important role in ensuring adherence. Education in general as well as treatment-related literacy promotes adherence. Durante et al.'s study concluded that level of education has no bearing on poor adherence; rather it is the knowledge the patient has regarding the effect of antiretroviral

therapy on viral load that is the predictor of adherence. Lack of health literacy may constitute a threat to adherence. The study compared adherence between patients who received education given at the clinic, and those who were educated by a primary physician. The results show that the group attending the clinic showed better adherence, with 100% virus suppression compared to the 70.6% in the group who received information from the primary physician. This confirms that level of education is not a good predictor of adherence; rather it is the level of health literacy as well as the manner in which the information is shared with patients that predicts adherence.

A study by Kagee (2004) indicated that individuals struggle to listen and commit to medical instructions given by healthcare workers on issues such as the lifestyle changes that are necessary to control the symptoms of HIV/AIDS. The study further states that patients often only consider taking medication after the onset of symptoms, rather than as a prophylactic measure. Adherence may not be viewed as important for many people in the preventative stages, like the use of condoms to prevent HIV. Even for individuals who are already HIV positive but who do not show symptoms, measures such as using condoms, eating healthily and exercising will delay the appearance of symptoms. This is an indication that knowledge of illness and health literacy are closely linked.

According to Booysen and Summerton (2002), a straight comparison across the wealth quintiles reveals that poor women are less likely than their wealthier counterparts to be knowledgeable about HIV/AIDS or the sexual transmission routes of the virus, and are more likely to engage in risky sexual behaviour. Kagee (2004) further states that the level of poverty in poor communities and limited educational opportunities result in low health literacy, which accounts in part for the poor adherence in these communities. Women in more affluent households have more appropriate knowledge about HIV/AIDS, and also access to the means to protect themselves from the

spread of the virus (Booyesen & Summerton, 2002). These authors add, however, that telling people to abstain, use condoms and be faithful is not been realistic for many women who are subjected to rape and sexual abuse within their relationship. In these cases being informed does not translate to the partners being faithful and agreeing to condom use (Onyejekwe, 2004).

Knowledge, attitudes, practice and belief studies on HIV/AIDS agree that most South Africans, regardless of socioeconomic status, are aware of HIV/AIDS; yet this knowledge is not being translated into behavioural change. This is confirmed by Onyejekwe (2004), who states that the mass media, as a platform to educate the public about HIV/AIDS, has not succeeded in changing people's behaviour. Other reasons for the lack of action despite awareness highlighted by Nordqvist et al. (2006) are inadequate knowledge and negative attitudes towards the treatment, fear of side effects, complexity of regimens and conflict between treatment recommendations and daily life. These are all considered significant barriers that prevent patients from undertaking treatment.

2.3 Belief Systems

2.3.1 Traditional cultural beliefs

Traditional cultural beliefs play a major role in people's explanations of the aetiology of HIV. How individuals perceive the nature and cause of their illness may act as a barrier to compliance. In seeking the cause of their illness, some patients, especially black South Africans, have turned to traditional medicine for answers and for a cure (Van Dyk, 2001). It is not unusual for patients who hold traditional cultural beliefs to consult traditional healers in seeking to understand and treat the illness.

Traditional and spiritual healers function as psychologists, physicians, priests, tribal historians, legal advisers, marriage and family counsellors in their

communities (Van Dyk, 2001). They are the guardians of traditional codes of morality and values; they are legitimate interpreters of customary rules of conduct, and as a result they have influence in translating HIV/AIDS knowledge into behavioural change. They usually have more credibility with their community than healthcare workers. Consequently, it seems advisable to include them in HIV task teams to help bring about behavioural change.

A study that was carried out by Rowe, Makhubela, Hargreaves, Porter, Hausler, and Pronyk (2005) found that some patients put more trust in traditional healers because they are said to heal HIV, while Western medicine only slows the process down. Even though these patients were on antiretroviral treatment, they expressed doubts about it and showed preference for traditional medicine. The belief that traditional medicine can cure HIV can influence adherence mainly in two ways.

Firstly, according to Hoffman, Rockstroh and Kamps (2005), there may be an interaction between traditional medicine and antiretroviral drugs, leading to high toxicity levels or virus resistance. Secondly, patients may prefer traditional medicine over Western medicine. The combination of traditional and Western medicines can lead to interruption in the use of antiretroviral medication (Rowe et al., 2005). This kind of interference with adherence emphasises the importance of disease and treatment literacy.

2.3.2 The traditional role of women

Buve, Bishikwabo-Nsarhaza and Mutangadura (2002) report that women are still subordinate to men in many parts of sub-Saharan Africa. Women are expected to have little or no sexual knowledge before marriage and are expected to stay faithful to their husbands. Men, on the other hand, are expected to have premarital sex and extramarital affairs are condoned. In such situations, women are not educated, do not work outside their homes or own

property. As a result, women are financially dependent on their husbands and have little relational or sexual power or influence. This impacts negatively on the spread of HIV.

2.3.3 Religious/spiritual beliefs

Religion plays an important role for some patients in helping them come into terms with their HIV status, in giving them hope and reaching a state of acceptance. Clarke (2003) describes hope as giving inspiration and vitality to people. Faith in a higher power may help patients to make sense of their world and acts as a foundation for daily decision making. Parsons, Cruise, Davenport and Jones (2006) state that church attendance, religious practices and spiritual beliefs contribute to the individual's health in general and may benefit the patient. They also suggest, however, that strong religious beliefs concerning sin and morality may also affect the individual negatively by playing into the stigma attached to HIV. This may impact negatively on treatment adherence.

Some patients report that their strong belief in God helps them feel positive about the future. According to a study carried out by Ehman, Ott, Short, Ciampa, and Hansen-Flaschen (1999), many Americans draw on their religious and spiritual beliefs when confronted by a serious illness. These findings have led some medical educators to recommend that physicians routinely enquire about the patient's religion and spirituality when conducting the medical examination.

2.3.4 Medication efficacy

Pill burden and regimen complexity are important contributors to poor adherence (Simoni, Frick, Pantalone & Turner, 2003). A belief in the efficacy of the medication is associated with adherence. This stresses the importance of

assessing patients' medication beliefs before they commence ARVs. This is even more relevant in the African context where Western medical beliefs may conflict with traditional beliefs (Heyer & Ogunbanjo, 2006). Fear, scepticism, mistrust and myths regarding the drug regimens are all negatively associated with adherence (Fogarty, Roter, Larson, Burke, Gillespie, & Levy, 2002).

2.4 Side Effects

Adverse drug events influence the willingness of other patients to take medication, and is therefore associated with poor adherence. In one study, patients with adverse events such as dermatological and gastrointestinal symptoms were less likely to be 95-100% adherent (Heyer & Ogunbanjo, 2006). Patients usually discontinue HAART medication due to the true or perceived side effects. Side effects that can be treated effectively include fatigue, nausea and stomach pains. Side effects like lipodystrophy cannot be treated successfully; in such instances a change in the regimen of medication should be considered (Chesney, Ickovics et al., 2000). Women are more prone than men to severe side effects like hepatomegaly, lipodystrophy and lactic acidosis (Squires, 2003).

Youths have described their treatment options as being limited due to unbearable side effects. Some youths describe difficult personal experiences with side effects, such as a young woman with lipodystrophy: "I was given a medication and I wasn't told that it would shift the body fat in my body, and I was mortified when I saw these really repulsive changes." (Veinot et al., 2006, p. 264). Collaboration between the patient and the healthcare worker can result in the selection of a lifestyle-tailored regimen characterised by low pill burden and tolerable side effects. Side effects should be actively attended to as soon as possible to prevent treatment discontinuation (Heyer & Ogunbanjo, 2006).

2.5 Self-Efficacy

Self-efficacy can be defined as the patient's belief that he or she is capable of organising and executing the course of action required to perform a particular activity (Bandura, 1994). Bandura also stresses that self-efficacy is a prerequisite for behavioural change, because it affects how much an individual invests in a given task. Dilorio, Resnicow, McDonnell, Soet, McCarty and Yeager (2003) found that individuals who regard themselves as highly self-efficacious in their ability to adhere to medication tend to set high goals, be more firmly committed to them and exercise behaviour that fosters adherence.

Several factors have been identified as having a significant negative impact on self-efficacy. High amongst these factors are patients' level of comfort in interacting with the healthcare workers, the complexity of the treatment regimen, and the demands of daily living and poverty (Kagee, 2004). In addition, while self-efficacy is associated with good adherence, the need for increased effort in taking medication may moderate this variable to decrease adherence (Chesney, 2003).

2.6 Current Symptomatology

Wagner (2002) found that current symptomatology, both in terms of the number of symptoms and the severity of symptoms, was consistently associated with lower adherence regardless of the method used to measure adherence. This is consistent with findings that suggest that adherence is particularly challenging for patients when they are struggling with physical or mental symptoms and are not feeling well (Holzemer, Henry, Portillo & Miramontes, 2000). The extent to which the patient's quality of life is compromised by the drug regimen, through high toxicity levels or intolerance, may affect adherence. Factors such as discomfort associated with side effects

and dissatisfaction at having to make lifestyle changes like increasing exercise, condom use and diet changes, play an important role in the quality of patient's life and adherence (Park, Scalera, Tseng & Rourke, 2002). According to Tsasis (2001), disease-related factors such as disease severity, and the acute or chronic nature of the disease, should be taken into account.

2.7 Condom Use

The use of condoms is currently the only globally accepted method to curb the transmission of the HI virus and thus halt the spread of AIDS. The use of condoms to prevent the transmission of the virus is probably the most recognised campaign in South Africa, and is championed by both the private and public sectors. Despite the high profile nature and intensity of the HIV/AIDS (condomise) campaigns; the continually rising statistics of HIV infection rates indicates that this information has not been translated into the appropriate lifestyle changes (Worth, 1989).

Worth's (1989) study further found that for individuals who are socialised to believe that sex should be "natural", condom use implies a decision to have "unnatural" or "undesirable" sex. The same study further notes that the perception that condoms are unattractive and uncomfortable for men makes women reticent to suggest or insist on their use, particularly when they feel the need to protect their men. In some cases women have reported that suggesting condom use means that they are sexually active, that she is "available" for sex, and that she is "seeking" sex. Worth (1989) further states that in many communities such associations violate traditional normative behaviour, which dictates that women should play a passive sexual role.

Among groups in which gender or sex-role confusion exists (for instance, in groups undergoing rapid acculturation or migration), a woman's fertility or potential fertility often has great significance, defining her social role and

therefore her self-esteem (Worth, 1989). Kasiram, Dano and Partab (2006) confirm the above by stating that in African communities, bearing children is viewed as an essential part of being a woman and of being successful. Hence women who are HIV positive and who decide against having children are viewed as unsuccessful, unfulfilled and incomplete. Since condoms prevent conception in addition to protecting against sexually transmitted diseases, including HIV infection, their use can be seen to negatively affect women's self-esteem. By the same token, if a man insists on using condoms, his behaviour can be construed as an attempt to use the woman by removing the possibility for her to fulfil her culturally sanctioned role of motherhood. The introduction of condoms into long-term relationships where they have not previously been used threatens the trust that is implied.

Public health professionals may mistakenly assume that people engage in a rational decision-making process based on middle-class values when considering condom use; they do not look at the social costs to women of negotiating condom use, costs that vary across socioeconomic and ethnic groups. Many of the most vulnerable women have been sexually or physically abused in their lifetime, and may currently be in abusive relationships. Asking them to introduce condoms into their relationships can mean asking them to risk further abuse. Worth (1989) found that decisions to use or not use condoms tend not only to be present-oriented, but they are usually made on a relationship-by-relationship basis based on the women's perception of the cost or benefit to that particular relationship.

Condom use has to be negotiated with every sexual contact. Gender inequality is no longer just costly but fatal, especially where HIV/AIDS is concerned. The issue of control over sexual decision making must be addressed (Kasiram et al., 2006). Women are becoming more educated and securing important positions in the work place compared to the past; and as a result, their place within the family structure is beginning to change. It is these changes that may

allow women a voice in their relationships, to be able to determine their sexual encounters and be able to negotiate condom use.

Unequal power in sexual relationships also finds expression in revenge infecting (Kasiram et al., 2006). This is based on the myth that one may cure oneself of the HIV/AIDS by having sexual relations with children, especially virgins. Kasiram et al. (2006) report that the misconception is that children and virgins have good immunity because of a dry vaginal tract, and as a result the infected person's blood will be purified by the encounter.

Intimacy and sexuality are integral to the human experience. However, intimacy is elusive if it is prefaced by hopelessness, pessimism, suspicion and fear of HIV/AIDS. It is thus important that programmes that promote condom use for AIDS prevention examine power dimensions of sexual decision making, as well as the social and cultural contexts that support such exchanges (Worth, 1989).

3 SOCIAL BARRIERS

3.1 Social Support

The Freirian approach to medication adherence (Williams, Burgess, Danvers, Malone, Winfield & Saunders, 2005) asserts that adherence is influenced by the patients' social context. Patients are encouraged to act to change their social environments to support their desire to achieve high levels of medication adherence. Social support is defined as the attachment among individuals or between individuals and groups which improves adaptive competence in dealing with short-term crises and life transitions as well as long-term challenges, provisions and stresses (Caplan & Killilea, cited in Santelli, Turnbull, Lerner & Marquis, 1993).

A social approach towards medication adherence states that the degree of adherence is not solely the result of psychological processes, but is also the product of interactions with family, friends and healthcare providers (Williams et al., 2005). The goal of adherence is thus to facilitate a self-directed process by which patients identify individual and social factors that influence their success in adherence to medication regimens; and that, when recognised, can lead to more effective self-management of medication (Williams et al., 2005). The clinical concern is that missed medication doses may lead to suboptimal drug levels, drug resistance, and reduced drug efficacy.

Over the past twenty years, as they confront the HIV/AIDS epidemic, patients and clinicians have come to recognise the crucial importance of social context and its profound influence on individual health and well-being. The daily experience of patients in their communities influences how they understand their illness, the importance they attach to their medication, and how they solve or fail to solve challenges associated with managing their illness (Williams et al., 2005). A socially driven intervention promotes action on a social level to facilitate adherence behaviour on a personal level.

Psychosocial factors, such as quality of social support, can influence adherence to treatment. Power et al. (2003) propose that social support links the social and the individual, and conclude that most people view the satisfaction of their social relationships as being one of the most important determinants of their overall feelings of life satisfaction. They further state that satisfaction with social support correlates highly with antiretroviral regimens, while poor quality of support is associated with suboptimal adherence rates.

Orford's (1992) work describes social support according to two broad approaches: functional and structural support. Functional support looks at the

quality of the individual's relationships or the ability of those relationships to serve certain supportive functions. The functional approach to social support is considered here in more detail. Functions of social support are material, emotional, cognitive-information or advice-giving support, acknowledgment support and provision of company (Orford, 1992).

Social companionship entails spending time with others in leisure and recreational activities, which may reduce stressful life experiences by fulfilling a need for affiliation and contact with others, by helping to distract people from worrying about problems, and by facilitating positive affective moods. Orford's study further found that the presence of social support in an individual's life was related to a reduction in levels of depression.

Special support is explained by Orford (1992) as the kind of support that people do not necessarily receive from family, friends and acquaintances. It is based on special needs or stressors that an individual faces, which can be met or alleviated by a specific source of useful support. For example, in a study of women who had just undergone a mastectomy (Orford, 1992), it was found that the most meaningful support came from friends and other women who had survived a mastectomy and as a result offered a special kind of support. The women's behavioural attempts to achieve a healthy adjustment to the life-changing experience, and the husband or partner's reaction to the mastectomy, were also taken into consideration (Orford, 1992).

Support from family members, peers or community members have also been shown to also affect health outcomes and behaviours. There is evidence that support can improve adherence to therapy (Williams et al., 2005). Negative public opinions and beliefs associated with people living with HIV may cause family and friends to distance themselves from the patient and withhold support. It is therefore important for patients to be realistic about who may offer them support (Kimberly & Serovich, 1996). Patients can only receive

support if they reveal their positive status. Patients encounter problems when they have to decide who to disclose to, due to the potential negative consequences of disclosure. However, patients stand also to benefit by gaining support which they would otherwise not receive (Schlebusch & Cassidy, 1995).

An issue related to social support is the physician-patient relationship, which has been shown to be strongly related to adherence (Roberts, 2002). Heyer and Ogunbanjo (2006) state that as much time as necessary should be spent with the patient explaining the goals of therapy and the need for adherence for the client to understand the importance of adherence and commit to this. Perceptions of competence of the healthcare provider, as well as the communication skills that include clarity, compassion and willingness to include the patient in the treatment decision-making process, are of high importance.

The treatment regimen should also be tailored to patients' lifestyle: it should be patient focused. A treatment plan should be negotiated and the patient should understand and commit to it. The relationship that should be fostered is one of partnership between the patient and the healthcare provider (Heyer & Ogunbanjo, 2006). The relationship between patient and provider should draw on the abilities of both. Heyer and Ogunbanjo (2006) believe that adherence can be achieved if the therapeutic relationship is based on exploring alternative therapeutic means; if the regimen is negotiated; if adherence is explored and follow-up is planned.

Gray (2006) lists the quality of the patient/provider relationship and support from family and friends as predictors of adherence. Interviews with the youth also describe distrust and dislike of medical professionals, which affect their willingness to discuss treatment options or seek medical care. Nordqvist et al. (2006) report that many youths who were infected during adolescence were

without familial support and felt lonely and isolated. They were likely to face decisions about treatment without significant support. A specific problem one youth mentioned was the difficulty in taking medications that caused disruption to her social routine, such as being asked at sleepover parties what her medication was for.

3.2 Education, Employment and Social Class

Ignorance of the lifelong nature of ARVs has been cited as one of the reasons for non-compliance. Patients need to know before they commence the treatment that it is for life. This is confirmed by Wynsberghe, Nobuck and Corolla (1995), who add that it is difficult for patients to comply with or sustain such rigorous treatment, especially if they are homeless and are addicted to drugs. Poverty tends to increase the vulnerability of women to HIV infection, because they lack access to means of protection and consequently engage in unsafe sexual practices. Booysen and Summerton (2002) found that the increasing numbers of women with tertiary qualifications are able to find employment that renders them financially less dependent and increases self-confidence, which in turn promotes sexual assertiveness in negotiating condom use.

3.3. Domestic Violence

South Africa has the highest statistics of gender-based violence in the world, including rape and domestic violence, which are high predictors of potential non-compliance. For the purposes of this study, domestic violence is defined as a pattern of behaviour used to establish power and control over another person through fear and intimidation, often including the threat or use of violence, when one person believes they are entitled to control another (Onyejekwe, 2004). Due to the problems of unemployment and poverty that many South Africans face, most of the women in this study were unemployed,

and depended on their partners for survival. As a result, their partners used this dependency to their advantage by threatening to leave them and go to other women who would not insist on condom use.

A study by Lichtenstein (2006) showed that domestic violence diminished women's ability to obtain regular healthcare. The women in this study were reluctant to keep the appointments due to fear of their partners. The study further stresses the importance of consistency for the HIV treatment to be effective, and notes that domestic violence acts as a barrier for affected women.

3.4 Disclosure, Stigma and Rejection

Stigma is a quality that significantly discredits an individual in the eye of others (Aggleton & Parker, 2002). Stigma and discrimination associated with HIV/AIDS have been identified as major barriers to HIV control and adherence (Cao, Sullivan, Xu & Wu, 2006). Discrimination is said to occur when people are singled out in a way that results in them being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group. Where stigma exists people are reluctant to get tested or get involved in education and preventative measures. Much of the stigma concerning HIV has been found to be associated with lack of understanding of the disease, myths about how HIV is transmitted, fear, shame and blame.

Emlet (2006) adds psychosocial issues such as anger, mental strain, guilt and feelings of self-loathing as factors that reduce adherence. The initiation and continuation of antiretroviral therapy has been associated with symptoms of depression in a variety of HIV-infected individuals. Many people refuse or delay testing for fear of discrimination should their positive status becomes known. This is a barrier to the adequate provision of psychological and social

support and appropriate medical care (Kylma et al., 2003). When reporting the results of the HIV test, healthcare workers are obliged to inform the patient of their responsibility to inform their sexual partners of their status. This is an important and ethical action in promoting safe sex, and reducing HIV transmission and re-infection. Failure to disclose one's HIV/AIDS status places infected individuals' partners at considerable risk of infection or re-infection.

In a study conducted on serostatus disclosure and its relationship to risky sexual behaviour, it was discovered that 78% of the infected participants had not disclosed their HIV status to their partners, while 46% had no knowledge of their sexual partner's serostatus (Olley et al., 2004). These researchers further state that participants who did not disclose were more likely than those who had disclosed to be male, to not have used a condom during their last sexual encounter, to have used alcohol heavily before sex, to have multiple sexual partners, and to have engaged more frequently in sexual intercourse in the six months preceding the study. The study concludes that being married, having more than two sexual partners, and non-use of condoms during the last sexual encounter were significantly associated with non-disclosure of HIV serostatus (Olley et al., 2004).

Studies done in the United States show that more women are infected with HIV than men and that the percentage is increasing. AIDS has become the fourth leading cause of death among American women between the ages of 25 and 44, and the rate is increasing rapidly (Hackl, Somlai, Kelly & Kalichman, 1997). The most affected women are women of colour, who face the double challenge of being infected and of being caregivers. Although women disclose their HIV status more often than men, reasons for non-disclosure include fear of rejection, isolation or abandonment, stigmatisation, lack of social support, separation or divorce, and even prosecution (Olley et al., 2004). A small percentage of women are afraid to disclose their HIV status due to fear of

violence, which includes verbal, physical and emotional abuse from partners as well as others. Gielen, O'Campo, Faden and Eke (1997) report that women are sometimes physically beaten by their partners for infecting them.

Disclosure has been identified as denoting a positive attitude towards the disease, and consequently increased compliance. Disclosure means that family and friends know of the individual's HIV/AIDS status and as a result may offer needed support (Schlebusch & Cassidy, 1995). According to Heyer and Ogunbanjo (2006), family and friends should encourage each other to disclose their HIV status so that they can support the patient in adhering to the treatment plan where necessary. However, non-disclosure can also be viewed as "protective silence" in cases where the power of the stigma associated with HIV may override the need for support.

One of the most significant psychosocial issues for persons diagnosed with HIV/AIDS is its association with homosexuality and intravenous drug use. It has long been recognised that certain illnesses are associated with stigma or membership in a social category that results in a spoiled identity, setting the individual apart from others (Fife & Wright, 2000). HIV infection is associated with behaviour that is considered deviant. It is classified as a sexually transmitted disease and so is viewed as the responsibility of the individual, is thought to be acquired through immoral behaviour and is perceived as contagious and dangerous to the community. It is furthermore associated with "a blame the victim" ideology as well as with all three types of stigmatisation: physical imperfection, character flaws and membership of an undesirable social group.

Disclosure of HIV status opens up the potential for stigma. Stigma manifests in several ways, broadly grouped into physical and social isolation/exclusion (Cao et al., 2006), which leads to decreased adherence. Stigma is associated

with social rejection, internalised shame, social isolation, financial insecurity and decreased self-esteem.

3.4.1 Social rejection

Social rejection pertains to individuals' perception that they are discriminated against at work and in society generally, including the perception that others have less respect for them, do not act as though they are competent, avoid them, and appear to feel awkward in their presence.

3.4.2 Financial insecurity

Financial insecurity is a specific consequence of discrimination in the workplace that is associated with inadequate job security and inadequate income. It is a consequence of discrimination which directly affects feelings about the self and interpersonal interaction.

3.4.3 Internalised shame

Internalised shame indicates the extent to which the experience of rejection and financial insecurity has been turned inward, and includes feeling set apart from others who are well, and blaming oneself for the illness. Social isolation signifies a feeling of aimlessness, incorporating feelings of loneliness, inequality with others, and uselessness. Three dimensions of the self have been included that are potentially influenced by stigmatisation in this analysis: *self-esteem*, *personal control* and *body image*. Fife and Wright (2000) hypothesise that the individual's perception of stigmatisation accounts for significant differences in the impact of the illness on the self.

Recently, an interest has developed in identifying the mechanisms by which stigma operates to affect the lives of individuals labelled as mentally ill. Demi, Bakerman, Moneyham, Sowell and Seals (1997) state that stigma is highly relevant from a healthcare perspective as it increases the stress associated with the illness, contributes to secondary psychological and social morbidity, and

affects quality of life and physical well-being, thus decreasing levels of adherence. It is a socially constructed phenomenon that has a profound impact on the patient and the family. These authors believe that if the problems resulting from stigmatisation are to be addressed effectively, it is critical that we understand the social-psychological mechanisms by which stigma operates.

Crocker, Voekl, Testa and Major (1991) further argue that stigma is a complex phenomenon expressed both subtly and overtly, and that it is subjectively experienced in multiple ways that are partially dependant upon the nature of the stigmatising condition and the social circumstances of the individual. These authors believe that stigmatised persons lose social status; they are discounted and discredited, and reduced in the minds of others from being whole and acceptable individuals to people whose identities are spoiled or tainted. Stigmatised persons' life chances and opportunities are lessened, they are set apart from others, and are considered to be inferior and to represent a danger to society, all of which lead to social rejection and social isolation. Not surprisingly, stigma has been demonstrated to have a negative impact on social interaction, employment opportunities, emotional wellbeing, self perception and adherence levels (Link, Struening, Rahav, Phelan & Nuttbrock, 1997). In other words, stigma has a negative impact on both the individual's self-concept and on the social responses of others.

Illnesses are stigmatised because they represent potential or existing physical limitations; they are associated with particular negative images and myths. For this reason they take on symbolic meaning. The specific nature of the stigma associated with a serious illness may be dependant on whether the individual can be blamed or held responsible for its occurrence, whether the illness has potentially serious consequences for others, whether there are outward manifestations of the illness, and whether it results in a decreased level of competence. The impact or consequences of stigma on the quality of life of

patients with debilitating illnesses is extreme. According to Rosenfield (1997), stigma is considered primarily harmful because of the impact it has on the individual's self-perception. The manner in which individuals perceive themselves determines whether they disclose their HIV positive status, seek treatment interventions and comply with healthcare workers' prescriptions to promote better health.

4 CONCLUSION

Unlike other chronic conditions, HIV/AIDS has the unfortunate distinction that the medication can only offer meaningful benefits if near perfect adherence (95%) is observed. There are no established methods to assist healthcare providers in assessing and predicting patients' treatment readiness to comply with these high levels of adherence. The inability to predict patient readiness to adhere has significant consequences for the patient, the healthcare delivery system and the economy of the country. The system currently uses the CD4 count as the only measure for initiating medication without a consideration of the potential success of the treatment. Hence, this study focuses on adherence to enhance the capability of the HIV/AIDS healthcare system in delivering effective interventions.

Adherence to treatment regimens is an important but under-researched topic in South Africa. The factors that impact on adherence have been broadly discussed in this chapter within the *individual* and the *social* context. Within the *individual* context factors that were identified were emotional response to the diagnosis, active mental illness, drug and alcohol abuse, health literacy, educational level and decision making, belief systems, side effects, self-efficacy, current symptomatology and condom use. Within the *social* context, factors that were identified were employment and social class, domestic violence, disclosure, stigma and rejection.

A holistic approach to interventions is needed to promote adherence. Based on the studies that have been discussed in this chapter, it seems clear that patients are struggling with adherence. As South Africa is in the early phase of the ARV rollout programme, it is critical to use state resources effectively to ensure success in the fight against HIV/AIDS. To achieve this, the psychosocial aspects that impact on adherence should be given more recognition, as the interventions to poor adherence are more rigorously developed.

CHAPTER 3

MODELS OF ADHERENCE

This chapter focuses on health-behavioural models that attempt to address adherence to medication regimens for people living with HIV/AIDS and chronic diseases. Models that focus on individuals as well as those that address the social context of the individual were taken into account when selecting approaches that aim to address poor adherence (especially when addressing adherence to antiretroviral regimens that demand 95% to 100% adherence). This chapter thus focuses on both individual and social approaches to adherence to the drug regimens and prescribed lifestyle changes required to enhance the effectiveness of antiretroviral medication. The models discussed in this chapter are the health belief model (HBM), which addresses individual characteristics pertaining to change, and the transtheoretical change model (TTM) and the motivational interviewing model (MI) that address both individual factors and social contexts pertaining to change.

1 HEALTH BELIEF MODEL (HBM)

The health belief model (HBM), developed by Rosenstock (1966), is a medical model that addresses non-compliance. The role of health beliefs or cognitions in influencing health-related behaviour has held a prominent place in health behaviour theory and research for over three decades. The fundamental presupposition of the HBM is that individuals are rational decision makers who select a course of action after systematically evaluating and comparing the values and probabilities associated with each possible

alternative (Christensen, 2004). Christensen further states that, according to the HBM, individuals are most likely to adopt a particular behaviour when a perceived health threat is high and when the perceived health benefits of the behaviour in question outweigh any barriers.

The HBM focuses on variables like perceived severity of the disease, perceived susceptibility or barriers to health, and illness behaviour. Perceived benefits generally refer to the extent to which the individual believes that adopting the behaviour in question will avert the negative health outcome. Perceived barriers to adherence are construed broadly in the model and include both tangible barriers (e.g., monetary cost of the treatment; time investment required) and more subjective or socioeconomic barriers (e.g., concern over side effects; social stigma associated with regimen).

Orford (1992) reports that the HBM is likely to be more successful at explaining behavioural intentions or self-reported motivation to adhere, and somewhat less successful at predicting actual behavioural change and adherence. Individuals tend to over-estimate their self efficacy in taking medication and tend to tell healthcare workers what they believe they want to hear. Orford (1992) sees this as an indication of the need for an interpersonal or holistic approach (rather than an individual approach) for assistance and motivation in dealing with chronic diseases and lifelong medication, especially those that have debilitating side effects and involve lifestyle changes.

The most common approaches to improving medication adherence are based on models of individual behaviour that emphasise the individual's personal responsibility (and ability) to change his or her own behaviour. For example, the health belief model (HBM) is an explanatory framework suggesting that individual behaviour is driven by a personal assessment of the costs and benefits of taking medications (Williams et al., 2005). This model has been

criticised, however, especially by European social scientists who say that it concentrates on rationalisation processes and is individualistic in its approach (Chesney, Morin et al., 2000). Although the HBM has enormous intuitive appeal, the ability of the model in predicting health behaviour in general and treatment adherence specifically has proven to be modest. Rosenbaum and Ben-Ari Smira (1986) concluded that a failure of the HBM to predict adherence more consistently among some chronic illness groups was due to the difficulty inherent in executing and maintaining the required behavioural changes even among well-intended patients. Due to the limitations that were demonstrated by the individual models to bring about change, the decision was made by the researcher to include the models that also address the social context. The transtheoretical model of change and the motivational interviewing model both address both the cognitive (individual) and the social context.

2 TRANSTHEORETICAL MODEL OF CHANGE

The models that have been selected that address both the individual and the social context in order to promote adherence are the transtheoretical model of change (TTM) and the motivational interviewing model (MI). Both these models are theories of readiness, which are informed by the general theories of motivation, change and compliance. These two theories are discussed by integrating the transtheoretical model of change with the practical principles and skills of motivational interviewing in order to promote health, bring about behavioural change, and promote as well as adherence.

The transtheoretical model of change as a theory of behavioural change emerged from Diclemente and Prochaska's research efforts (1998). It was later reformulated as the six stages of change model (Nordqvist et al., 2006). Most of the research carried out on this model was targeted at changing addictive behaviours like smoking, eating disorders, drug abuse, obesity,

gambling, lack of exercise and condom non-use (Shinitzky & Kub, 2001). This model has been successfully applied in first world countries, and was later adapted by Mash (2004) to the third world context of care for chronic conditions. This model describes behavioural change as intentional. The model has three organising constructs: six stages of change; process of change; and levels of change. Mash (2004) emphasises the importance of these stages of change being known and familiar to healthcare workers. In this way, healthcare workers can determine the patient's stage and readiness to change before instituting the treatment plan or intervention.

2.1 Stages of Change

Pre-contemplation

This first stage in the model takes place when individuals are unaware of or not concerned about the problem, and are not considering change within the next six months.

Contemplation

Contemplation becomes evident when the patient is in an ambivalent state. Patients become aware of the reasons for change, and consider the advantages and disadvantages of the proposed change as well as reasons for not changing. They begin to discuss the negative aspects and the benefits of change, as well as the consequences of their decision. During this stage, patients are more open to collaboration, and more likely to discuss changing their high-risk behaviour within the next six months.

Preparation

Preparation is the third stage and it takes place when individuals decide to initiate change. They plan seriously to institute change within thirty days. They express a high degree of motivation towards the desired action and outcomes. By this phase, patients have become aware that the costs of

maintaining their current behaviour exceed the benefits. This phase heralds a movement from merely thinking about change to actually initiating new behaviours.

Action

Action, the fourth stage, takes place when patients take action to create the desired change, and may occur over a period of up to six months.

Maintenance

Maintenance is the stage when the individuals are involved in working towards preventing a relapse. This stage may last for a period of three to six months. During this phase patients make lifestyle modifications in order to avoid relapses and maintain the behavioural change (DiClemente & Prochaska, 1998).

Termination

Termination is the last step, and occurs when individuals are no longer tempted to return to their former behaviours. In this stage, patients feel as if the problem had never been part of their lifestyle (Nordqvist et al., 2006).

The decision-making process, which reflects the individual's process of weighing up the pros and cons of changing the high-risk behaviour, helps patients to gain insight and make informed decisions about changing. This approach was also found to be respectful of the patients, as it acknowledged their reasoning and thinking. The constructs self-efficacy and temptation have been also included in the model. Self-efficacy is an individual's belief in his or her personal capacity to cope with high-risk situations in their daily life without relapsing to the former unhealthy behaviour. Temptation is the urge to resume the former behaviour. The patient needs to focus on the process of change in order to increase self-efficacy and decrease temptation (Nordqvist et al., 2006).

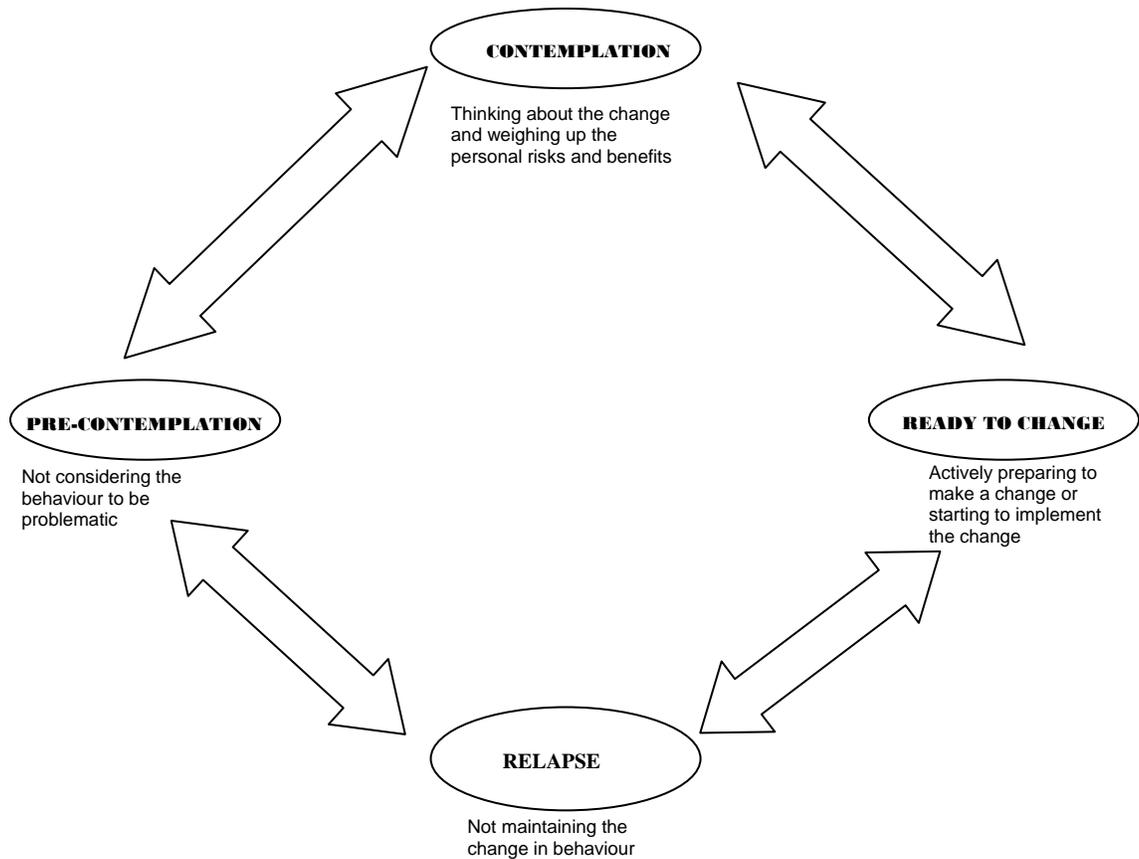


Figure 3-1: An adaptation of the TTM by Mash (2004)

The above figure illustrates the four stages of change model which was adapted by Mash (2004) from the six stages of change model by DiClemente and Prochaska (1998). The original model by DiClemente and Prochaska (1998) included maintenance and termination as the two last stages. The two last stages form part of a successful treatment intervention. If maintenance and termination are not successful, the patient will relapse and the above cycle will start all over again.

2.2 Process of Change

The process of change facilitates movement through the stages of change. There are ten processes that have been identified by DiClemente and

Prochaska (1998). Five of these processes are cognitive and the remaining five are behavioural.

2.2.1 Cognitive processes

Consciousness rising

Consciousness rising is described as encouraging individuals to increase their levels of awareness, seek new information or gain understanding about the risky behaviour.

Dramatic relief

Dramatic relief refers to people's ability to experience and express their feelings about the behaviour.

Environmental re-evaluation

Environmental re-evaluation involves assessing how individuals' behaviour affects their physical environment.

Social liberation

Social liberation refers to increasing the number of alternatives for non-problematic behaviours in society.

Self-re-evaluation

Self re-evaluation refers to how individuals think and feel about the problem in relation to themselves (DiClemente & Prochaska, 1998).

2.2.2 Behavioural processes

Prochaska, DiClemente and Norcross (1992) and Cassidy (1997) discuss the remaining five processes.

Counter-conditioning

Counter-conditioning substitutes alternatives for the behavioural problems, like using meditation in order to cope with unpleasant emotions.

Helping relationships

Helping relationships are those relationships that foster trust, support and acceptance. This means that patients have access to people who listen and pay attention when they discuss their situation. It has been shown that patients who receive support from clinicians, partners, friends and family have a more positive attitude towards their circumstances, and are more likely to be compliant, than those who do not receive such support.

Reinforcement management

Reinforcement management is the use of appropriate and positive reinforcements and goal setting in collaboration with the patient.

Stimulus control

Stimulus control helps patients to restructure aspects of their social environment which may affect adherence, so that the triggers or stimuli for the negative behaviour are brought under control.

Self-control

Self-control is the last process, and it takes place when individuals begin to believe in their ability to change (self-efficacy). There is a match between the stage the individual is in and the intervention that is instituted; for example, individuals in the contemplation phase will be most open to consciousness raising, dramatic relief use and environmental re-evaluation. In the action stage, behavioural processes will be the most effective (Prochaska, DiClemente & Norcross, 1992; Shinitzky & Kub, 2001). Cognitive processes also take into consideration the importance of the social context, which may

affect adherence. It is important for clinicians to assist the patient to address those barriers in order to promote adherence.

2.3 Levels of change

Healthcare professionals should be able to recognise that individuals have multiple problems that might be related, and that may occur simultaneously. For example, drug addiction may be associated with marital problems, financial problems, personality disorders, depression, and violence. The transtheoretical change model incorporates five levels of change to address the above overlapping problems. These include changes that relate to symptoms or the situation; maladaptive cognitions; interpersonal problems; family or systems problems; and interpersonal conflicts.

Adherence is more likely to occur when the patient's multiple problems are addressed. Understanding the patient's life context (from the patient's point of view) will enable interventions to be tailored for the specific patient. The consultation is considered successful if it follows a holistic approach. If healthcare workers enter into the counselling relationship with the idea that they have to assess, diagnose and treat only the most obvious symptom, the chances of overlooking the underlying symptoms are high. Healthcare workers should be open-minded about the possibility of multiple factors affecting the patient's lives, and should therefore include rather than exclude potential issues (Mash, 2004).

After determining the stage of readiness for that particular patient, the intervention may be tailored to match the patient's position. By so doing, the impact and effectiveness of the intervention is increased. For those patients who have not made the conscious decision to change, it is important for healthcare workers to develop interventions that will help to shift high-risk patients from pre-contemplation to action.

Shinitzky and Kub (2001) found that stage-matched programmes or interventions can assist 80% to 90% of high-risk patients.

Patients that relapse usually fall into the category of patients that are trying to take action to change behaviour. Therefore they should not be labelled as 'non-compliant' or 'unmotivated'. Rather, the relapse reflects a poorly created treatment plan that does not consider the stages of change that the patient is currently undergoing. In blaming the patient, the healthcare provider externalises responsibility instead of reflecting upon his or her lack of skills. Therefore knowing and being familiar with the stages of change before the treatment plan is drawn up is imperative to achieving adherence (Mash, 2004). If healthcare providers assess the patient, knowing the stages of change, then the interventions may be better tailored to suit that individual patient's needs; the possibility of treatment failure may be reduced, and the impact and effectiveness of the intervention increased.

3 MOTIVATIONAL INTERVIEWING APPROACH

Once a patient's stage of change is identified, the healthcare worker needs to apply clinical skills that will help facilitate the patient's progression and movement along the continuum to ensure adherence (Shinitzky & Kub, 2001). Motivational interviewing (MI) is a framework developed by Miller and Rollnick (1991) to empower both patient and healthcare worker with necessary communication techniques or skills, thereby ensuring that the patient's needs are met and adherence is maintained. Most of these techniques are centred on behavioural change. The HIV/AIDS epidemic in South Africa has highlighted the relevance of behavioural change in order to improve people's health and ensure adherence. MI can make a valuable contribution to consultations or counselling in South African healthcare settings, where HIV infected patients' health status is poor compared to developed countries.

A concept called empowering potential (Nordqvist et al., 2006) consists of three stages that aim to augment patient's individual growth and development. Firstly, with help from the healthcare provider, patients consider their readiness for change by constructing a plan to initiate and sustain the health behaviour. Re-evaluating lifestyles, identifying barriers and owning and being committed to change are included in this step. The second stage occurs when the intention is transformed into action, and change occurs. Finally, social support is provided throughout the process of empowering potential. This stage is discussed in more detail below.

3.1 Social Support and Motivational Interviewing

Social support reflects the individual's images of the self and contains examples of both desirable and undesirable images, and the creation of plans to realise or avoid these images. Social support systems are perceived as sources of feedback, reinforcement and assistance for the individual initiating lifestyle changes. Social support systems can, however, also be viewed as a potential barrier for change, leading to decreased perceived autonomy and responsibility for sustaining change for the individual. This occurs if supportive others construct barriers with the aim to assist the individual. Williams et al. (2005) notes that key characteristics of a social approach include attention to interpersonal processes such as interactions with family, friends and healthcare professionals, as well as attention to the aspects of the social context that could affect the individual's ability to act to care for the self. On a micro-level, patients and their families need information, motivation and preparation to be able to manage the condition by themselves (Mash, 2004).

A socially-driven intervention promotes action on a social level to facilitate adherence behaviour on a personal level. The healthcare worker's duty is also

to assist patients with their social problems through brainstorming solutions. By applying these skills, a more holistic approach to care is facilitated. In order to implement these skills, healthcare providers need to develop an approach to counselling that is consistent with an MI style. MI is an interpersonal style that views the relationship between the patient and the healthcare provider as a partnership. It starts by establishing an environment that feels safe for patients and their families, so that they are comfortable with revealing personal information without fear of being judged.

3.2 Motivational Interviewing Techniques

The relevance of the MI model, especially in terms of HIV/AIDS, is that it empowers clinicians with skills that enable them to help clients explore and resolve ambivalence towards making change, thus moving them closer to the desired behavioural goal. The goal of healthcare providers in counselling patients is to assess them for readiness to change. The counsellor emphasises the patients' autonomy, but also guides them towards positive behaviour change and patient-identified goals. This is important as HIV-positive patients report many challenges to achieving adherence to antiretroviral therapy, such as forgetfulness, fear of HIV status disclosure, medication side effects, changes in daily routine and depression (Thrasher et al., 2006).

The skills underlying the MI interviewing discussed here have been from Miller and Rollnick (2002). The art of MI is a dance between the patient and the healthcare worker, who must suspend judgment and avoid confrontation in order to prevent defensive behaviour by the patient. This innovative style of communication was developed around collaborative consulting, using a patient-centred approach. Healthcare workers need to challenge patients without eliciting defensiveness. It is normal for individuals to become defensive if they feel judged or misunderstood. As all behaviours are purposeful, it is the responsibility of the healthcare provider to understand

what the patient stands to gain by holding on to the high-risk behaviour, like substance abuse. In order to reach patients, the healthcare worker needs to accept them, which does not necessarily mean agreeing with the patient's negative behaviour (Shinitzky & Kub, 2001).

The MI interviewing skills, adapted from Miller and Rollnick (2002), are based on the concepts of collaboration, evocation and autonomy. These are discussed in greater detail below,

Collaboration

Collaboration refers to the relationship between the patient and the healthcare worker. The healthcare worker's aim is to generate a climate suitable for change to take place. The relationship between the patient and the healthcare providers should draw on the abilities of both. Adherence can be achieved if the therapeutic relationship is based on exploring alternative therapeutic means, of the regimen is negotiated, adherence is explored and follow-up is planned. The patient's point of view should also be valued. An issue related to social support is also part of the physician-patient relationship, which has been shown to be strongly related to adherence (Roberts, 2002).

Evocation

It is believed that the patient possesses the knowledge, motivation and skills to change. The approach of the healthcare is to draw out the patient's views and values. The paternalistic, confrontational style that has been used by physicians in the past has proven to be counterproductive. A more enduring change is experienced when patients themselves make the decision to change, and when they feel they are not judged for non-compliance by the healthcare worker (Shinitzky & Kub, 2001).

Autonomy

The patient's right and ability to make informed decisions independently is encouraged. The healthcare worker plays a supportive role rather than a dictatorship role. Support is offered through hopeful talk, providing alternatives and encouraging an awareness of consequences. This in turn promotes the patient's self-efficacy. The duty of the healthcare worker is to help the patient become aware that certain behaviours lead to desired outcomes, so that they own their behavioural change.

The study done by Mash (2004) indicates that it is as difficult to change the patient's behaviour as it is to change that of the healthcare workers, whose style of consultation is often more confrontational, and doctor-centred rather than patient-centred. This study places a high value on the healthcare workers adopting an educational approach that is congruent with the spirit of motivational interviewing. Applying these skills requires a shift in thinking away from technical, outcome-centred programmes that are centred on compliance and the need to control patient behaviour, towards a process-oriented approach that is patient-centred. The result of this is compliance that is more sustainable and enduring.

4 CONCLUSION

Approaches to improve adherence for HIV treatment discussed in this chapter are based on individual and social factors. The use of at least three models (compared to a single-model approach) helps to construct a holistic approach that is more effective in addressing the problems in behavioural change necessary for optimum adherence. An individual approach has proven to be limited in addressing behavioural changes, even for well-intentioned patients, due to the difficulties inherent in translating knowledge into action (behavioural change) and maintaining this change.

A more comprehensive approach based on three perspectives (health belief model, transtheoretical model of change and motivational interviewing framework) may allow for a better understanding of behavioural change, which is inclusive of the patient, healthcare provider, the disease process and the social context. Healthcare providers need to be more open to the patient's life context, and approach the patient's problem from a holistic view (Mash, 2004). Few HIV-positive patients who seek help from healthcare facilities have no emotional problems. It is therefore advisable for healthcare providers to begin by addressing patients' concerns. To avoid addressing the patient's problems suggests that the healthcare provider is controlling the encounter; however, for the consultation to be successful it should be patient-centred.

Over the past twenty years, as they confront the HIV/AIDS epidemic, patients and healthcare workers have come to recognise the crucial importance of social context and its profound influence on individual health and well-being (Williams et al., 2005). If the full potential of the motivational interviewing and transtheoretical change model is to be realised, the content will need to be adapted to local clinical settings. The following chapter deals with the manner in which the research process was conducted.

CHAPTER 4

METHODOLOGY

1 RESEARCH DESIGN

Patients struggling with adherence were referred to the researcher for the study. These patients were asked to participate in a voluntary interview with the researcher. Consent was obtained from these participants for research purposes, after the aim of the study was explained to them.

Kumar (2005) suggests that for the researcher to have explored the diversity of the topic, a saturation level has to be reached. That is achieved by continuing with data collection for as long as there is new information to be gathered. When no new information is gathered, then the researcher is considered to have reached the saturation point. The number of participants that partake in the study is determined by the saturation of the data.

2 PARTICIPANT SELECTION

English, Zulu, Tswana and Southern Sotho-speaking men and women between the ages of 20 and 40 were included in the study. Fifteen participants were interviewed (13 females and two males). Of the fifteen participants, only one female participant was employed.

3 RESEARCH PROCESS

3.1 Research Site

The study was carried out at Kalafong Hospital, which is based in Atteridgeville on the Western side of Pretoria. The district is mainly inhabited by Tswana-speaking people, and is characterised by a number of informal settlements, low socioeconomic status and high unemployment rates. Background information on the demographic profile of Atteridgeville was collected by the researcher from medical doctors, nurses, lay counsellors, statistician, and her own observations of the context. The overall literacy level of the population that is served by the Kalafong hospital is rated at 60%.

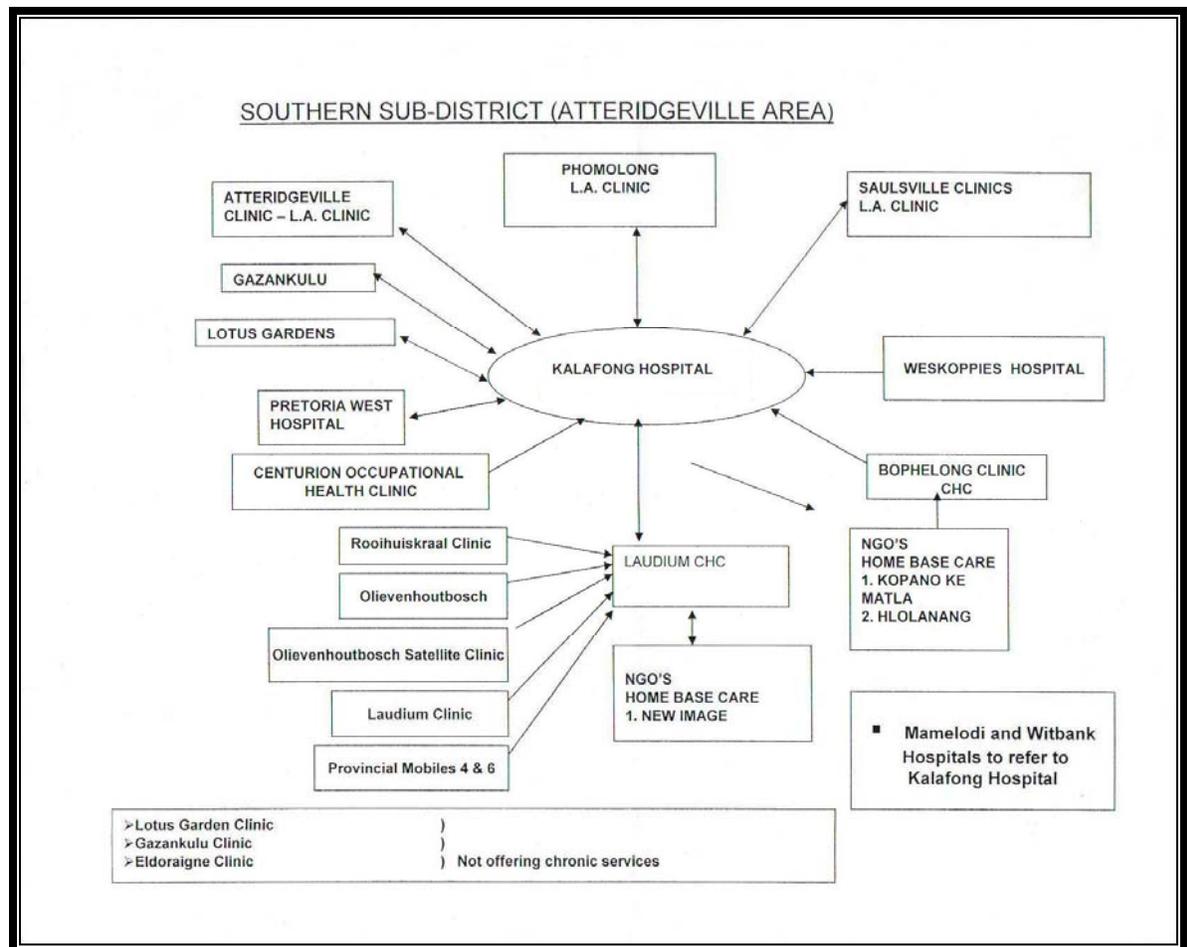


Figure 4-2. A schematic representation of clinics and hospital that refer to Kalafong Hospital.

Figure 4-2 shows the clinics and hospitals that refer their patients to Kalafong Hospital for antiretroviral medication and all HIV/AIDS-related healthcare services.

The ARV roll-out was started in April 2004. They are currently serving a total of 2813 patients, comprising 837 males and 1976 females. According to their statistician, 270 people have since left the programme and 188 have died (that they know of). In addition, the hospital is aware of 10 patients who stopped the medication due to severe side effects. According to the available statistics, the mortality rate is increasing, indicated by the following figures: 23 deaths in 2004, 41 deaths in 2005 and 71 deaths in 2006. These statistics only reflect the deaths that have been recorded by the hospital and indicate a year-by-year increase in the mortality rate.

3.2 Criteria for HAART Medication

People who conform to the following five criteria qualify for antiretroviral medication:

- South African citizens
- HIV positive
- CD4 count below 200
- Patients that are willing and committed to take ARVs
- Patients that are able to return for all visits

3.3 Multidisciplinary Team

The team comprises two doctors (although doctors from family medicine also assist), two professional nurses, one pharmacist with two assistants and one student, one phlebotomist, one dietician, one social worker, one dentist and fourteen lay counsellors.

Doctors

All patients at the Immunology clinic are seen by a medical doctor for a one-on-one consultation during which the physician physically examines the patient and enquires about opportunistic infections and health status. The physician also determines the patient's readiness level for treatment. This is done before therapy is initiated, where the physician has an opportunity to explain to the patient how the antiretroviral medication functions. The physician explains that the medication is for life and discusses the relevance of adherence as well as the results of poor adherence.

Professional nurses

The professional nurses assist the medical doctors by checking the patient's vital signs before they are seen by the doctor. They check the patient's weight, blood pressure, temperature and analyse the urine. They are responsible for detecting high-risk patients based on poor follow-up visits and the collection and possible abuse of the medication. They also enquire about the emotional and medical problems of the patients attending the clinic. Patients also attend sessions with professional nurses about side effects of the antiretroviral medication and the importance of adherence.

Pharmacist

The pharmacist is responsible for filling the doctor's prescription and explaining in detail, and at the level that will be understood by the patient, when and how the medication should be taken. They are also able to detect

non-compliance because patients are asked to bring their previous medication with them. If they suspect that the patient does not understand the implications of strict adherence, they may give the patient two weeks' medication instead of one month so that they can monitor the patient's progress more often and identify non-compliance as soon as possible.

Phlebotomist

The phlebotomist's role is to draw blood from patients, obtain blood results from the laboratory and communicate the findings to the doctors. These blood tests are done to analyse the CD4 count levels. The viral load is done on first visits to confirm the HIV results, as well as every six months to monitor the HIV status of the patient and any changes in the CD4 count.

Dietician

The dietician gives a group talk to the patients on their first visit. The dietician explains the importance of a proper diet and how to negotiate a (special dietary) healthy lifestyle, especially in view of financial constraints. They explain the effects of certain foods, such as fatty foods, while on medication. Food parcels are arranged for patients with severe financial difficulties. They also emphasise the importance of eating three meals that include fruits and vegetables, and eating before medication is taken.

Social worker

The duty of the social worker is to negotiate HIV social grants. This is arranged for those patients whose CD4 count is below 200, who are on medication, and who cannot work due to their illness.

Counsellors

There are fourteen counsellors on the staff and their duties vary from clerical work to counselling. On the first visit, which is called preparation visit, a file is opened for each patients. The patients schedule three visits with the

counsellors, during which they are closely monitored and their readiness levels assessed. On the first visit, in addition to opening a file, the counsellor's duty is to give a group talk to the patients on the following topics:

- How to manage HIV/AIDS
- How to take ARVs in order to control HIV
- The importance of a healthy diet
- Lifestyle changes such as condom use (including how to use and store them), exercise, substance and alcohol use
- Information about the prevention and treatment of opportunistic infections

The second visit is called the initiation visit; this refers to treatment initiation. The counsellor also verifies that the patient understands how to take the medication. On the third visit, the counsellor ascertains to what extent the patient is coping on the medication. If problems are detected the patient is referred to the adherence counsellor. The counsellors also assist the doctors by acting as interpreters where there are communication barriers.

4 DATA COLLECTION

4.1 Interviews

The data were collected by means of semi-structured interviews. These interviews were conducted individually in the privacy of an office. Bogdan and Biklen (2003) define an interview as a purposeful conversation usually between two people (but sometimes involving more) that is directed by one person in order to obtain information.

Semi-structured interviews were selected as a method of choice as they give the participants opportunities to express themselves in ways that they cannot

do in questionnaires. They provide an opportunity for participants to express their feelings, beliefs, knowledge and point of view. Interviews also provide an opportunity for immediate verification of answers, room for expression of ideas and clarification. Kumar (1995) agrees that interviews are more appropriate for complex situations, giving the interviewer the opportunity to prepare the participant before asking sensitive questions, and explaining difficult questions in person. It also has wider applications, and can, for example, be used with children as well as illiterate people. An opportunity is also provided for insight into the construction of participants' answers and how it reflects on their ideologies or interests. Qualitative interviews should be interactive and sensitive to the language and concepts used by the interviewee, and interviewers should thus keep the agenda flexible (Britten, Jones, Murphy & Stacy, 1999). The data were recorded using audio tapes, and notes were also taken with the consent of the patients. Kumar (1995) notes that disadvantages of interviews include that they are time-consuming and are dependent on the quality of the interviewer.

The researcher used a semi-structured interview approach, which is defined as being located between the extremes of completely standardised and unstandardised interviewing structures. This type of interviewing entails a number of predetermined questions and/or special topics that are typically asked of each interviewee in a systematic and consistent order; although the interviewer is permitted to probe far beyond the answers to predetermined questions (Berg, 1998). The questionnaire used in this study is included in the appendix.

4.2 The Interview Process

Permission from both Kalafong Hospital and the University of Pretoria was obtained before the data collection process commenced. Use of a private office was secured for the interviews. The interviewer ensured that the

participants understood their rights and what was expected from them before signing the informed consent form. The researcher used a semi-structured interview and followed this with unstructured questions based on the information that the participants had given. The interviews were audio recorded, field notes were taken, and additional post-interview notes were written afterwards.

4.3 DATA ANALYSIS

According to Pope (1999), the researcher's task includes not only recording descriptive data and analysing them, but also making sense of the data by shifting and interpreting them. According to De Vos, Strydom, Fouche and Delport (2002), data analysis is a process of bringing about order, structure and meaning to collected data. It is a search for general statements about relationships among categories of data (Marshall & Rossman, 1995).

Before data collection commences, the researcher should plan to collect and record data in a systematic manner that is appropriate and will facilitate analysis. Erlandson, Harris, Skipper and Allen (1993) indicate that another methodological tool that can be used during data collection is the development of the working hypothesis. This means that the researcher reviews collected data and forms hypotheses about the phenomena studied. The next step is the management and preservation of the data through recording, transcription and preliminary analysis.

In this study, the data were analysed manually by the researcher using content analysis, in which the contents of the interview are analysed to identify main themes from the participants' responses. This was done according to the following four steps suggested by Kumar (2005).

- **Identify the main themes**

This is achieved by carefully going through the descriptive responses given by the participants in order to understand the meaning. From these responses, broad themes are developed that reflect these meanings. Individuals use different words and language to express themselves and researchers should word their themes in a manner that accurately represents the meaning of the responses categorised under that theme. These themes become the basis for analysing the text of unstructured interviews.

- **Assign codes to the main themes**

This can be done in several ways, including by counting the number of times the theme occurs in an interview. The researcher identifies the theme by randomly selecting and examining responses to the open-ended questions. The researcher continues to identify themes from the same question until saturation point is reached. These themes are then written down and assigned a code using keywords or numbers.

- **Classify responses under the main themes**

After identifying the themes, the researcher examines the transcripts of all the interviews and classifies each response according to a theme.

- **Integrate themes and responses into the text of your report**

After identifying the themes, the next step is to integrate the data into the text of the report. The researcher can integrate the text by discussing the main themes that emerged and use verbatim responses to preserve the feel of the responses. Alternatively, the researcher could count the frequency of the occurrence of the themes and provide a sample of the responses.

5 BIAS

According to Kumar (2005), bias differs from subjectivity, and is unethical. Subjectivity is based on the researcher's competence, training, educational background and philosophical perspective, whereas bias is a deliberate attempt by the researcher to either hide something or highlight something disproportionate to its true existence. Denzin and Lincoln (1994) add that complete elimination of bias in qualitative research is not possible; however, the researcher should make every effort to minimise it so that fresh and new experience can be absorbed.

Patton (in Whittemore, Chase & Mandle, 2001) believes that the human factor is both the great strength and the fundamental weakness of qualitative enquiry and analysis. This is because qualitative enquiry is dependent on the researcher's capabilities, training, issues and insight. In this study, researcher subjectivity will be addressed through ongoing discussions with her supervisor at the University of Pretoria.

6 SEEKING SENSITIVE INFORMATION

Kumar (2005) warns that questions of a sensitive, personal or invasive nature may be threatening to participants, who might feel embarrassed or upset by them. Such questions may include those that investigate sexual behaviour, drug use, marital status, age, or income.

The nature of this study was such that sensitive questions were included, and the researcher was obliged to consider how best to approach this dilemma. According to Kumar (2005), it is not ethical to ask such questions unless the participants are clearly informed about the nature of the questions and are given enough time to decide if they still want to participate, without any inducement. In addition, the researcher must ensure that the interview does not cause harm to the participants. If the information gathered has the

potential to cause discomfort, anxiety and a sense of being harassed, then the researcher needs to take steps to prevent this from occurring.

7 ESTABLISHING CREDIBILITY

The validity of qualitative research relates to the credibility of the study. This is dependent on the instrument, which in this case is the researcher's ability and efforts. For the study to be considered valid it should be credible, transferable and trustworthy (Golafshani, 2003). The quality of the research is related to the trustworthiness and integrity of the research study. Validation also depends on the quality of the researcher's work during the investigation. . Researchers should continually check, question and theoretically interpret the findings as they go. Validation does not refer to the final verification of the product control, but rather the continual checks on the plausibility, trustworthiness and the credibility of the findings (Kvale, 1996). According to Denzin and Lincoln (1994), fairness is an important factor, and is described as the deliberate attempts to prevent marginalisation, and to act affirmatively with respect to inclusion so that all the participants' voices are heard and their stories treated with fairness and balance. To ensure validity in this study, the following steps were taken:

- The interviews were recorded using an audio tape, and written notes were taken and numbered accordingly during the interviews to eliminate the possibility of data being missed during the process (Denzin & Lincoln, 1994).
- Interviews were conducted in the participant's home language in order to avoid misunderstandings.
- The researcher tried to ensure that no distortions took place while the participants were interviewed by allowing for free flow of information.

- The project was subjected to inspections on regular basis by the supervisor to check for flaws and problems in the study, and to assist the researcher regarding her working hypothesis.
- Participation of the participants in the interview was voluntary and their privacy and confidentiality was maintained at all times.
- The use of multiple methods (Bergley, 1996) was utilised during data collection to ensure validity through the following steps:
 - The interviews with the participants were recorded by means of audio tapes.
 - Extensive field notes were kept at all times.

8 TRANSFERABILITY OF THE STUDY

Transferability is the burden of demonstrating the applicability of one set of findings to another context, which rests more with the researcher who would make that transfer rather than with the original investigator (De Vos, Strydom, Fouche & Delport, 1998). According to Mostofa (2001), if the setting of the study is similar to other parts of South Africa given variations of different parameters like age, gender diagnosis and treatment regimen, the transferability of the results may be extended to other similar sociocultural settings.

Although qualitative studies are not usually intended to be generalised, Green (1999) suggests that using a single site or a small size sample does not in itself threaten the potential generalisability of a qualitative study. Like other qualitative studies, this study aims to describe the experiences of particular participants in dealing with psychosocial problems resulting in poor adherence. It is intended to understand the severity of the problem pertaining

to this specific setting. It is hoped that this may enable the medical staff at Kalafong Hospital to design suitable interventions to address the problems specific to this setting that result in non-compliance, and that the study will also generate information for further research.

Instead of generalisability, the strength of qualitative study lies in its transferability. To decide if a study is transferable, it is necessary to describe the demographic variables and the context of the study (Hamberg, Johansson, Lindgren & Westman, 1994). It is then possible for others to make use of the study if they find it relevant to their situation. Research meets the transferability criterion when the findings from one study fit other contexts, as determined by the degree of similarity or goodness of fit (De Vos, Strydom, Fouche, Poggenpoel & Schurink, 1998).

9 ETHICAL CONSIDERATIONS

Participation of the participants was voluntary and confidentiality, privacy and autonomy were maintained at all times. In line with Strydom (2002), the participants were assured that the information they provided would be used only for the purposes that were outlined and would also be treated with confidentiality. The researcher needs to make sure that after the information has been collected, its source cannot be identified. Confidentiality in the report was guaranteed by using anonymous quotations. The participants were also informed of various aspects of the study, especially its purpose and how the results would be communicated to them.

10 CONCLUSION

This chapter described the research method used in the study, including the paradigm, participants and data analysis process. The results of the study are presented in chapter 5.

CHAPTER 5

RESULTS

This chapter reports on the results of the data analysis in terms of the themes identified in the participant interviews. The themes refer to psychosocial issues that relate to non-compliance to ARVs amongst the participants. Background information on each participant is described by way of introduction. Each theme is briefly defined and introduced, and is followed by direct quotations that provide support for and clarity on the themes and the participant's experiences.

1 PARTICIPANTS

The study was carried out at Kalafong Hospital in Atteridgeville on the Western side of Pretoria. The district is mainly inhabited by Tswana-speaking people, and is home to a number of informal settlements, a population with a generally low socioeconomic status, and high unemployment rates. The overall literacy level of the population served by Kalafong Hospital is 60%. Fifteen participants were interviewed, (13 females and two males), and of the total, only one female participant was employed. In the following section, the participants are introduced in order to provide background information. Consideration was given to the amount of information that could be shared without revealing identifying biographical information. This was done with care to preserve the anonymity of the participants.

1.1 Participant 1

Participant 1 is a 25 year-old single woman. She lives with her mother and 23 year old brother. She has a Grade 11 level of education. She took the HIV test

because she was pregnant, and was diagnosed as positive in February 2006. She informed the father of her unborn child who responded by leaving her. Her mother and brother know her status; and although they are supportive, her brother avoids the subject. Her son died in December 2006. She was already on antiretroviral treatment when he passed away, and her mother informed her that according to their culture she has to go through a cleansing ceremony. She was told to discontinue antiretroviral medication while taking the traditional cleansing medication. She fell ill and had to be admitted to the hospital, where she resumed the antiretroviral medication. She is not currently in a relationship due to fears of intimacy.

1.2 Participant 2

Participant 2 is a 23 year-old single mother of a five-month old daughter. She is currently unemployed and lives alone with her daughter in a one-room informal house. She has a Grade 8 level of education. Her mother is her only living relative, and is a live-in domestic worker. Her relationship with her mother collapsed after she informed her of her HIV status, as the mother distanced herself from her daughter and is no longer supportive of her and her granddaughter. In addition, Participant 2's relationship with her child's father ended when she disclosed her HIV status. According to him, he is HIV-negative and he fears being infected by her. Her major stressor at the time of the interview was financial problems. She also displays signs of depression.

1.3 Participant 3

She is a 25 year-old mother of a 16-month old boy. She was tested for HIV when she fell pregnant. She is married and her husband left her four months ago due to her insistence on condom use. She lives alone with her son who is HIV-negative, and is currently symptom-free. She works as a cleaner and has a Grade 10 school qualification. She stopped taking antiretroviral medication

after she heard about a church that cures HIV/AIDS. She presented herself to the hospital for HIV tests, convinced that her belief in God had cured her. She believes that AIDS is given by God through witchcraft and the Devil because people have forgotten God; consequently, only God can cure it. She reports that six people in her church presented proof of their HIV-negative status due to belief and prayer.

1.4 Participant 4

This participant is a 39 year-old woman. She is single with two children, a son and daughter, aged thirteen and eight respectively. She has a Grade 8 level of education. Both her children are at school, in Grade 6 and Grade 2. They are both HIV negative. She decided to get herself tested because of her risky sexual lifestyle; and she was diagnosed as HIV-positive in 2005. Her mother, boyfriend and children know about her HIV status. Her boyfriend is also HIV-positive but he refuses to use condoms. The family lives with her boyfriend, and he is the only one who is employed. She receives a children's social grant as well as the HIV grant, which she considers too modest to enable her to eat healthily. Her dreams are to live longer, support and love her children. She assigns her feelings of strength to her positive attitude. She attributes her healthy status to the fact that she has disclosed to everyone in her family; and as a result she has all the support she needs.

1.5 Participant 5

This participant is a 34 year-old mother of two. She has a baby boy aged six months and a girl of 20 months, who stay at home with her during the day. She has been married to the father of her children for nine years. She found out she was HIV-positive when she was tested during her pregnancy with her last-born child. Her daughter is HIV-negative. The family lives together in an

informal settlement, and her husband is the sole provider for the family. She has a Grade 6 level of education. She assumes that her husband is HIV-positive, even though he has never tested and he also refuses to use condoms. Her initial reaction to her diagnosis was to use traditional medicines. However, these made her ill and so she was admitted to hospital, where she received antiretroviral treatment. As a result, she is convinced that antiretroviral medication works and she states that she will never use them concurrently with traditional medicines. She hopes to live longer in order to see her children grow.

1.6 Participant 6

Participant 6 is a 38 year-old mother of four children. Her children are aged 21 (a boy), 17, 14 and 11 (all girls). She is currently living with her mother and children. Her 21 year-old son left school after Grade 11. The three girls are still at school in Grade 11, 7 and Grade 4 respectively. The participant has a Grade 4 level of education. As she is unemployed due to ill health (painful feet), the family is dependent on the children's social grant as well as the grandmother's pension. Her mother, son and the 17 year-old daughter know about her HIV status. She was diagnosed in 1995, a year after her husband's death. She was aware that her husband died from an AIDS-related illness. She recommenced antiretroviral medication in 2006 after she fell sick due to defaulting on her medication and taking it concurrently with traditional medicine.

1.7 Participant 7

Participant 7 is a 29 year-old single and unemployed woman. She has a 15 year-old daughter from her previous marriage. She has a Grade 12 level of education. She is currently living with her boyfriend and they are engaged to be married. Her family decided that it was better for the participant's

daughter, who is in Grade 8, to live with them. Her husband passed away from an AIDS-related illness five years ago, and that is how she was diagnosed. She has been on antiretroviral medication for the past five years. When she became involved in her current relationship, she informed her boyfriend that she was HIV positive. He told her that he was HIV negative, even though he refused to show her the results. She believes that she has infected him because of his refusal to use condoms. She reports that he is also physically abusive, controlling, jealous and possessive.

1.8 Participant 8

This participant is a 38 year-old married woman. She has two children, a son aged 15 and a daughter aged seven. They are still at school, in Grade 7 and Grade 1. She discovered she was HIV-positive when she was pregnant with her third child, who has since died of an AIDS-related illness. Participant 8 is currently unemployed and has a Grade 10 level of education. Her husband has tested negative for HIV. This participant is struggling to come to terms with her husband's negative status; at the time of the interview she felt very angry with her husband and expressed her hatred for him. She also reported symptoms of depression. She said that she thinks it would be better if she died or killed her whole family, stating "why should she die and they live". She tried to commit suicide by throwing herself in front of an oncoming train, but was subdued by other commuters. Her 15 year-old son knows about her HIV status because she collapsed in the bathroom and he found her and had to call the ambulance.

1.9 Participant 9

Participant 9 is a 35 year-old woman. She is single with a three year-old son who is also HIV-positive. Her boyfriend passed away in February 2006 from an AIDS-related illness. She was diagnosed when she was pregnant with her

son. She is unemployed and has a Grade 8 school qualification. She lives with her mother and is dependent on the child's social grant, although she reports that she needs to apply for the HIV grant as the family is not coping financially. She is using traditional medicines and has not started ARV treatment. At the time of the interview, she had made three visits to the hospital, and was still not ready to commence with antiretroviral medication. She says that she has not received sufficient information from the healthcare workers because they are always busy and the clinic is always full; and she does not want to waste their time. She believes that she will use both traditional and Western medications concurrently. She is not interested in becoming involved in a new relationship, because she is scared to start all over again.

1.10 Participant 10

Participant 10 is a 30 year-old woman. She is involved in a polygamous relationship and is her husband's second wife. She is unemployed and her level of education is Grade 7. She has three children, aged 13, 10 and one year respectively. The two oldest children are at school in Grade 6 and Grade 3. Her first husband (father to her two eldest children) died in 2002. According to his relatives, the cause of his death was an AIDS-related illness; however, Participant 10 believes that he was bewitched. At the time of the interviews, this participant had only recently learned of her HIV status. She was admitted to hospital because she experienced recent weight loss, abdomen pain and diarrhoea, and her body felt hot. She believes that antiretroviral medication is dangerous, because her sister died while she was taking it. As a result, she is sceptical of ARVs.

1.11 Participant 11

Participant 11 is a 32 year-old woman. She is married with a four year-old son

who attends a pre-primary school. She is unemployed and in the late stages of pregnancy. She has a Grade 11 level of education. At the time of the interview she had known about her HIV status for three months because of her pregnancy, but had delayed coming for consultation. Her main concern was to prevent mother-to-child transmission of the illness, and was less interested in long-term treatment. She seemed to be at peace with her decision, saying that there was no point of taking the medication because her husband had always been promiscuous and refused to use condoms, so it would be a waste of time. This participant views HIV/AIDS as a disease that is part of our daily lives. Everybody seems to have it and if you are negative then there is something wrong with you. She added that she now views having HIV/AIDS as a status symbol.

1.12 Participant 12

This participant is a 39 year-old Indian woman with six children who are all married besides her 19 year-old son. She is currently unemployed and has a Grade 12 school certificate and a diploma in beauty therapy. Her husband died five years ago. She was told that it was from kidney failure; although after she became sick and was diagnosed with TB from HIV, she questioned this diagnosis. She has not disclosed her status to anyone for fear of rejection and the shame associated with it, especially from her community. She mentioned that when she is at the clinic and people look at her, she assumes it is because they are thinking she must have been a prostitute to have been infected with HIV. She is still angry with her husband for dying without telling her that he was HIV-positive. She also blames God. She presents with symptoms of depression and is not on any medication.

1.13 Participant 13

This participant is a 33 year-old single mother of a 16 year-old daughter. She

and her daughter are presently living with her boyfriend of seven years. Her daughter is in Grade 9. She is unemployed and her level of education is Grade 10. She was diagnosed nine years ago when she fell pregnant with her second child, who died when he was nine months old. Her boyfriend refuses to be tested or to use condoms, and also rejects the existence of HIV/AIDS, despite her having been sick with AIDS-related illnesses. She has accepted her condition and reports that she is living positively with the illness.

1.14 Participant 14

Participant 14 is a 40 year-old father of six children. He is currently living with his older sister; her sister's married son and his wife. He stays in a room at the back of the house. He left his wife five years ago because he believes that she bewitched him. The couple are not legally divorced, although he has not had contact with his wife or children for the past five years. His level of education is Grade 6 and he is currently unemployed. At the time of the interview he appeared very sick, weak and emaciated. He was diagnosed with AIDS two months ago and was prescribed antiretroviral medication which he took haphazardly. For example, instead of taking his medication twice a day, he took it three times a day. He demonstrated a significant lack of information on HIV/AIDS and said that he had not attended any of the three initial counselling sessions.

1.15 Participant 15

The final participant is a 34 year-old childless man. He lives with his mother, a pensioner, and his 28 year-old sister. He is presently unemployed and his level of education is Grade 10. He lived alone in an informal settlement until his mother fetched him after she was informed that he was very ill. His mother became suspicious that it was HIV and forced him to get tested. He was diagnosed as HIV-positive around October 2006. He has a 28 year-old sister

who also lives with them. Due to his beliefs about his illness and suspicions about HIV he delayed starting the medication and first consulted traditional healers. He is currently on medication, apparently only to appease his mother. He also indicated a strong mistrust of other cultures. He is currently not involved in an intimate relationship, although he made it clear that he has never believed in using condoms and was not planning to start now.

2 IDENTIFIED THEMES

This section reports on the themes that were generated from the interviews with all the participants. Some of the statements may appear in more than one theme where they reflect different meanings.

2.1 Emotional Reactions

Any reported emotional reaction to the diagnosis was considered for this theme. After being diagnosed with HIV, the participants' reactions to the news varied from depression, anger, denial, suicidality and fear, to acceptance. Some participants did not struggle to accept their condition, while others continue to experience difficulty in coming into terms with the illness and its implications. Most of the participants who experienced difficulty in coming to terms with their diagnosis, and who did not receive individual counselling, adhered poorly to the medication or refused to take ARVs altogether.

Depression and anger

Of the 15 participants, three participants (all female) reported feelings of depression. Depression, anger and suicidality are all discussed here because of their tendency to occur either in isolation or concurrently in reaction to being diagnosed with HIV. Participant 2's reacted to the diagnosis by developing

symptoms of depression: she cried constantly, lost her appetite, and withdrew socially from her relatives. She found out that she was HIV-positive when she was tested during pregnancy. Her boyfriend rejected her after she informed him of her HIV status, leaving her unemployed, without financial support, and with a five month-old daughter to support.

Participant 2 states that:

“The father of my five month-old baby girl left me two months after I was diagnosed. He told me that he is negative, so if he stays with me, I will be killing him. I feel stressed most of the time and I have been struggling with eating for the past month”.

Participant 12 also developed depression in reaction to the diagnosis. She has yet to inform her six children of her diagnosis, for fear of the stigma associated with the illness. She added that her husband’s failure to inform her of his status prior to his death resulted in feelings of anger and hatred towards him. She also blames God for allowing this to happen.

Participant 12 also lost her business as a result of the illness, as she was hospitalised for a long period of time. As a result, she finds herself having to wait in queues for service, which she previously did not have to do as she could afford better care. She also finds it difficult to collect the medicines from the clinic in case someone finds out about her status, which resulted in her defaulting on her medication. Her anger and depression has also affected her ability to maintain a positive mindset and maintain a healthy immune system. This is apparent in the amount of weight she reports losing, her generally poor medical condition, and insomnia.

Her feelings are evident in the following statement:

“I am still angry with my husband and God; I don’t go to church or pray anymore. My husband’s portrait hangs in our dining room, when I pass it I still swear at him”.

Suicidal reaction

Two of the female participants expressed a desire to end their lives. One of the participants has suicidal ideation while the other has tried to commit suicide by jumping out of a moving train. At the time of the interview, she was still very angry because she believes that her husband infected her despite his claims that he was HIV-negative.

The following statements illustrate these participants’ views:

Participant 9: “I think of ending it all and take my whole family with me. I have tried to kill myself by jumping out of a moving train but people stopped me.”

Participant 12: “I think of killing myself all the time, especially at night when I can’t sleep.”

Spousal denial of HIV/AIDS

Five participants reported that their spouses refuse to use condoms. The initial reaction of most of the women to the diagnosis was acceptance; the difficulty was with their partners. They refused to get tested for HIV and insisted that they were not sick, so they continue living as if nothing has changed, in spite of their partners getting sick and repeatedly being admitted due to re-infection.

Participant 11 is in her third trimester of pregnancy. She was recruited to the study during her first visit to the clinic after she was diagnosed with HIV. She

has accepted the diagnosis, but her husband refuses to use condoms or to be tested. He believes that he is not HIV positive because he is not sick. She stated that her husband told her: *“If I was HIV positive then I will be sick and I am feeling very healthy”*.

Fear

Fear of dying and not being able to raise their children were expressed by many of the participants. Some mentioned that they had been through stages where they experienced fear constantly. They attributed this to a fear of rejection and dying. Others stated that even though they had suspected they were infected, they postponed testing because of these fears. Thoughts of leaving their children without a mother, being unable to raise them, and leaving them without someone who would love and take care of them was the source of most of the women’s fears.

The following represent some of the participants’ views:

Participant 5: “Treatment will make me live longer to see my children grow, I cannot die so soon.”

Participant 4: “To live longer, to take care and love my children.”

Participant 9: “I knew I was HIV positive because my boyfriend died from it, but when I became ill I was scared to get tested, until I was too sick.”

Acceptance

This sub-theme refers to the participants’ acceptance of HIV as part of their lives, and coming to terms with the disease. Adherence behaviour such as regular follow-ups and taking the medication as prescribed indicate a degree

of acceptance of the diagnosis. Three of the participants had not accepted that they were HIV-positive by the time that they were interviewed. One of the participants stated that acceptance led to a more positive state of mind, which promoted adherence to medication because she made a decision to live. This changed her approach to adjusting to the new lifestyle. Other individuals indicated their acceptance by consulting traditional healers. One of the participants stressed the importance of accepting the diagnosis and not blaming others, because only then can healing begin. Religion and hope played an important role in other participants' decisions to accept their positive status.

One of the participants indicated her frustration with her HIV status. It has been five years since she found out that she was HIV-positive. She lives with two of her six children and the youngest is 19 years old. She stated that she knew that it was something she needs to work on. She reported that her struggles with acceptance, anger and forgiveness of her partner are because he died without informing her of his HIV status; her anger at this is still intense. This anger has had a negative effect on her adherence.

The following statements reflect these views;

Participant 11: "Everybody seems to have HIV and if you are negative then, there is something wrong with you, having HIV/AIDS is now like a status symbol."

Participant 3: "I accept that I am positive, it is all now up to God."

Participant 4: "The doctors told me that I will be okay, so long as I take my medicines."

Participant 11: "I have forgiven my husband for infecting me, I have accepted and I just live in hope that he is a changed man, he has not tested."

Participant 12: “It will take time for me to forgive God and my husband; I cannot accept this happened to me.”

2.2 Domestic Violence

One of the fifteen participants (Participant 7) is abused by her boyfriend sexually, physically, and verbally; also in public. She is unemployed and is dependent on her boyfriend for financial support. He abuses alcohol and behaves recklessly by getting into unnecessary fights. She has decided to stay with him because she believes she infected him because he refuses to use condoms. He tells her that she killed her husband and she is now going to kill him, which makes her feel responsible. She therefore submits to the abuse, even though she acknowledges that he could have been already HIV-positive when they became involved.

Participant 7’s reasons for non-compliance were that she does not care; after all, nobody cares about her. Her husband died three years ago and she has a 15 year-old daughter who lives with her parents. She seems to be pessimistic about the future, and states that she is going to die anyway. She explains: *“When we met I told him that I am HIV-positive and he said he was HIV-negative. It worried me because he was sexually abusive and reckless by not using the condom. He hits me if I refuse to sleep with him without a condom... I have never seen his results, but he is always sickly.”*

2.3 Social Withdrawal and Disclosure

Comments that reflected participants’ feelings of loneliness, not belonging and choosing to isolate themselves were considered for this theme. Two participants experienced problems with rejection. Participant 2 informed the father of her daughter and her mother, who both reacted by distancing

themselves from her. Her boyfriend is currently involved in another relationship. Participant 12 decided not to disclose to anyone for fear of potential rejection from her family and community. Both these participants reacted to the diagnosis by withdrawing socially, and experienced depression due to the potential and actual rejection. This affected their ability to comply with their medication.

The abovementioned participants mentioned the fear of being stigmatised and of others finding out that they are HIV-positive as reasons for their social withdrawal as well as for their unwillingness to collect their medication. They are reluctant to fetch their medication because they fear being seen there by people who know them. As a result these participants prefer to keep to themselves. One of the participants (the mother of a five month-old daughter) locks herself in her single-roomed house in the informal settlement where she lives with her daughter. She mentioned that her social withdrawal has made her life difficult, as she used to be an outgoing person; this changed after the diagnosis. She reports that she is struggling with making the necessary adjustments towards accepting and disclosing her HIV status. She also has financial difficulties and a five month-old child to take care of.

The following statements confirm their reactions:

Participant 12: “I don’t like to be with people, I prefer to keep to myself, that way no one will know that I am HIV-positive. I also hate attending the clinic because of fears of meeting people I know.”

Participant 2: “I have a five month-old baby and I live alone; my boyfriend left me. He told me that he is now dating other people, he sometimes brings money for the baby”

2.4 Condom Use

The refusal to use condoms was considered for this theme. Seven of the participants, including one male, stated that men do not want to use condoms because it interferes with spontaneity and it goes against their culture. They also reported that using condoms removes the joy of the sexual experience, since all the focus is on the condom. Some of the participants voiced their concern that if they obliged their partners to use condoms, they would seek other relationships outside, where condom use was not imposed. All of these participants stated that they never used condoms before being diagnosed, and six of them still do not, because they are unemployed and need financial support from their partners, who refuse to use condoms, and so they have no choice.

Participant 4 has reconciled herself to the risks of not using a condom and hopes that her partner does not sleep with other people. Some of the participants have explained to their partners the importance of using the condoms as part of treatment compliance. Six of the participants in the study were not using condoms. They blamed this on their partners and the fact that they are women. One of the men in the study insisted that he has never used a condom and is not about to start now; it is against his culture.

Refusal to use condoms is reflected in the following quotations:

Participant 13: “I do want to take the medication, but what is the point because he interferes with my medication by refusing to use the condoms.”

Participant 11: “I am taking the treatment, but I know it is useless, he refuses to use condoms.”

Participant 7: “My boyfriend pokes holes in the condoms to make them useless, I have to be always on guard, he has many tricks.”

Participant 15: “I am already sick, so what difference will it make? I have never used condoms and I am not about to start now, it is against my culture to use condoms anyway.”

2.5 Side Effects

All the participants in the study reported experiencing side effects from the medication. This was also one of the reasons given for non-compliance. The unpleasant nature of the side effects, especially nausea, vomiting, lethargy, diarrhoea, lower abdominal pains and painful feet, increases patients’ reluctance to adhere, despite participants reporting that they can manage the side effects. Participants did not discontinue their medication as a result of these side effects, but they took them randomly. The participants reported that the counsellors had explained the side effects to them, and how to manage them in an effort to prepare them. However, they felt that this preparation did not make it better when the reality occurred.

The following statements confirm their experiences:

Participant 3: “I thought I was prepared for the side effects but nobody tells you it is going to be this bad.”

Participant 10: “My sister died from this medication, but I have no choice.”

Participant 6: “I cannot work because of sore feet”

Participant 5: “I have a distended stomach and sores on the face.”

Participant 8: “It makes me have nausea and vomit most of the time and I hate food.”

2.6 Access to Information on HIV/AIDS

The need for education on HIV/AIDS and the education available were considered for this theme. The clinic makes information available to patients through group counselling during ‘preparation interviews’. One participant, a 40 year-old male, stated that he did not attend the initial group sessions for preparing patients before he commenced his medication. As a result, he was not informed about HIV, antiretroviral medication and the side effects; he doubled the dosages; and he was confused by the instructions that were given to him. Some of the participants reported that the counsellor’s accessible and friendly attitude made it easy for them to ask for help and clarification, and they could share their difficulties. Yet others complained that the counsellors looked too busy and there was no time; they spent the whole day in the clinic and got hungry.

None the participants in the study expressed any interest in seeking out information on their own in order to educate themselves. They also did not know about the support group that operates in the Pretoria city centre, and its relevance for sharing, and empowering each other with support and information about HIV. One of the male participants showed a lack of knowledge about HIV, and was suspicious about the illness. He thought that he had been infected through sharing drinks with his friends, or that his wife had bewitched him. His sister brought him to the clinic against his will. His medication was finished in mid-month because of over dosage. The traditional medicine that he has been taking for the past year did not work; he got sick and was admitted in the hospital for two weeks.

The second male patient indicated a strong mistrust of other cultures; he made

it clear that one needs to question who brought the disease in the first place and what their motive was. He thought that HIV might have been introduced to destroy black people, just as condoms are meant to control the number of children black people have. Both of the male patients had no knowledge of HIV and had not brought a treatment buddy with them to the clinic. The second male participant (34 years-old) lives with his mother and is unemployed. His view on continuing to take the medication is that he does not have a choice; after all, it is his mother's house.

The two men in the study lacked information to the extent that their use of the medication rendered it toxic. One of the participants reported that he misunderstood the information he was given and he does not remember additional information regarding side effects and the importance of adherence. Language was seen as a barrier to compliance since most of the physicians were English-speaking, which resulted in confusion and misunderstanding leading to non-compliance. Most of the women that were interviewed had some basic knowledge of HIV/AIDS. They appeared satisfied with their knowledge, although their actions were incongruent with their knowledge (for example, the absence of condom use).

Participant 15: "I took all the pills they gave, three times a day, at any time before meals."

Participant 14: "I take the medication three times a day at any time, so long as it is before meals, sometimes without food; there is no one to cook during the day. One day I took the one that makes you sleepy in the morning and went for a walk, people brought me back thinking I was drunk."

2.7 Belief Systems

Spiritual beliefs

Different explanations for their illness were considered for this sub-theme, and included an enquiry into how participants use religion as a form of coping with the diagnosis. The different belief systems of participants and their families also emerged as one of the issues that contribute to non-compliance. In an attempt to deal with her situation, Participant 3 turned to religion. This affected her compliance because she discontinued the medication in the hope that God would heal her. She believes that AIDS was sent by God as punishment for our lack of respect and faith. She believed that her spiritual belief alone would cure her infection. She explained that her church told her that this is possible. The pastor asked those that have been healed to bring their certificates and stand in front of the congregation as proof. They showed the congregation their certificates that indicated that they were HIV-negative. As a result, Participant 3 came to the clinic for blood tests to prove that she has been cured.

Participant 3 stated: "I can become negative by believing and praying in God. I have seen six people with negative results as proof of God's work. If I believe in God enough, then God can cure me; that is why I came for testing."

Traditional\cultural beliefs

Comments that reflected lack of trust in the antiretroviral medication and trust in traditional medicines were considered for this sub-theme. One participant defaulted treatment because of her traditional beliefs, and became sick as a result. Use of traditional African medicine is common in South Africa. Three (female) participants in the study explained that their non-compliance was due to pressure from family members to rather use traditional medicine. One of

the male participants explained that his infection was because his wife had bewitched him – as a result he first tried traditional “Zulu medicine” as a cure. The only other male participant reports being forced by his mother to take ARVs; he claimed that he would not do so otherwise as he believes in traditional medicine.

The following was expressed by participants to confirm the above theme:

Participant 1: “My mother told me to stop the pills and use traditional medicine for a cleansing ceremony after the death of my child.”

Participant 9: “I have not started ARVs yet because I am still taking traditional medicine, I was forced to come here.”

Participant 6: “My mother took me to a traditional healer at Soshanguve and told me to stop the pills.”

Participant 14: “I believe that I was bewitched by my wife, so I decided to take Zulu medicine because I know that my wife bewitched me.”

Participant 15: “I will use them together, traditional and western medicine, because traditional medicine also works.”

The traditional role of women

Nine of the 13 women indicated their lack of power or influence in the management of their lives, except for four women who were not in relationships. The participants who were in relationships were subservient to their partners, and they seemed to have accepted their role, and it did not bother them. The traditional role meant that they could not negotiate or suggest condom use. Participant 3, who did insist on condom use, was left by

her husband. Even though these women know that by not using a condom they are further endangering their lives, they state that this is simply how their life has always been and they are used to it. One woman clarified this by stating that she is used to it; after all, she was brought up with the men as the head of the family. Most of the women in the study do not work; as a result they are financially dependent on their partners. Their dependency worsens their situation because they are obliged to risk their lives by not insisting on condom use. Not using condoms seems to be a very important factor in their struggle with compliance.

The subservient role of women is supported by the following statements:

Participant 7: "I do what he tells me to do, for peace's sake."

Participant 5: "I don't have much of a say when it comes to condoms, I am not complaining, I am okay."

2.8 Support Systems

The involvement of family, friends and others in helping the patient to deal with the disease was included in this theme. One participant expressed lack of support from her family and partner, which contributed to her non-compliance. In some cases the family members distanced themselves from issues pertaining to HIV/AIDS, by not showing interest. Better understanding from family and friends has been cited as being helpful in improving compliance to treatment. Some participants mentioned that they received support when they disclosed their condition. The level of support was in some cases is more than they expected. Partners seemed to pose a unique problem in that even though they accepted their partner's HIV status, they ignored the healthcare provider's instructions, especially to use condoms. Three of the participants did not receive support: one participant disclosed to her mother

and boyfriend and they consequently left her; one participant has not told anyone; and the third participant's boyfriend did not reject her after her disclosure; however, he is abusive and unsupportive.

The following was expressed by participants to confirm the above theme:

Participant 1: "I am not sure if my brother knows or he is pretending not to know, he is the only one in the family who does not discuss my HIV status with me, but I receive total support from my mother."

Participant 7: "My boyfriend physically, sexually and sometimes verbally abuses me in front of people and that makes it difficult for me to have strength to continue without his support."

Participant 2: "I stay alone in an informal settlement, my mother and the father of my child distanced themselves after I told them."

Participant 4: "Everybody in my family and friends knows and they support me."

Participant 12: "I travel a lot to visit my children, but I always feel alone because I cannot share my condition which I call my secret with anyone because it will disgrace my children."

Of the 15 participants, only one was rejected by her family and boyfriend. As a result, she has never disclosed to her friends and neighbours for fear of further rejection. She is not compliant as she is struggling to cope alone. Twelve participants received support from their families, friends and partners (although this was sometimes conditional). According to one of the participants, this support has meant that she is not scared of discussing her status with other people and she is not ashamed. Two participants have

decided not to disclose to anyone, one of them because of the initial rejection from her mother and boyfriend.

2.9 Unemployment and Social Class

Fourteen of the 15 participants that were interviewed were unemployed, 12 of whom were women. Five of the women choose not to be in a relationship due to their concerns over issues such as lack of trust. Six of them felt they had no choice but to stay in their current relationship because of the financial support they receive. In these eight relationships, the partners refuse to use condoms or get tested, and some even question the existence of the disease. Even though these participants are taking their medication, they are non-compliant as they do not follow the lifestyle changes prescribed by their healthcare givers, for example with respect to condom use. They attribute this to poverty and lack of power in their relationships. These women's partners have made it clear that they will not get tested or use condoms, and the women have decided to accept these terms due to their financial dependence.

Some of these women have defaulted on medication or failed to arrive for follow-up visits due to financial difficulties. The financial difficulties contribute to their falling ill, which further affects the quality of their life and illness management (including adequate nutrition and clinic follow-ups). Participants that have been diagnosed are less likely to find employment, and if they do secure a job, they are less likely to keep it due to repeated illnesses and absences from work.

This was indicated by following statements:

Participant 2: "I do want to collect my medicines but sometimes I don't have money for transport."

Participant 4: “I cannot afford healthy foods like fruits and vegetables because the grant is too small, I don’t have money to eat healthy. I have four children and we stay with my mother and we are both unemployed.”

Participant 6: “We are dependent on the grants for food, and who is going to employ me, I have tried, but I am absent most of the time.”

Participant 9: “I need food parcels because the children’s grant is not enough.”

2.10 Rejection and Stigma

Actions, comments and feelings from others after disclosure were considered for this theme. One of the 15 participants reported rejection and stigmatisation after disclosing. According to most of the participants, most people have lost a loved one through HIV, so they are more understanding and accepting. As a result, they believe that being infected with HIV is no longer the major problem it was a few years ago. Fear and indifference, contributing to a lack of family support and not having a treatment buddy, contributed to non-compliance in some cases.

Rejection and lack of understanding from others has been described as contributing to non-compliance, while a better understanding contributes to increasing compliance due to the assistance patients receive from their support group. Participant 1’s boyfriend left her after finding out that she is HIV-positive, telling her that he was negative and that he did not want to get infected. As a result, she has become scared of intimacy and has no friends due to her diminished trust in people. Two patients made the decision not to disclose their HIV status to their family due to fear of rejection. One participant views HIV/AIDS as a positive status symbol.

This was indicated by following statements:

Participant 1: “The way he left me, hurt me a lot, it will take time to trust anyone again”. I am very scared of being in a relationship”. I used to have friends; not anymore, don’t trust anyone, so I never told even my friends.”

Participant 11: “Everybody seems to have HIV, and if you are negative then there is something wrong with you. I view HIV/AIDS as a status.”

Fear of perceived rejection was cited by the following participants:

Participant 12: “I cannot tell my family because I am afraid of how they will look at me afterwards. When people look at me here in the clinic, I think they must be thinking I am a prostitute.”

Participant 5: “I am the firstborn in a family of six siblings; they all trust me, so how ca I let them down?”

3 CONCLUSION

Participant’s background information was presented first. Their experiences divided into categories or themes were firstly defined and than described. The following chapter will discussion and integrate the results with literature.

CHAPTER 6

DISCUSSION

This chapter integrates the literature with the results from the study. The majority of the participants in the study (13 out of 15) were unemployed women, with children; some of them remained in their relationships while others had made a conscious decision to avoid relationships. Only two of the participants were male; both were unemployed. The discussion that follows examines, firstly, findings relating to individual barriers to compliance, after which social barriers to adherence are explored.

1 BARRIERS TO ADHERENCE

2.1 Individual Barriers

Non-adherence to antiretroviral therapy has become a major threat to those who are living with the HIV condition. Different individuals react differently to the diagnoses of HIV. Emotional reactions to the diagnosis, such as depressed mood, anger and suicidal reaction, were present amongst three participants in the study. The reaction of one of these participants was not directly due to her diagnosis, but rather due to the rejection, financial difficulties and lack of support she experienced from her boyfriend and mother. Only two participants had not yet dealt with the shock of learning that they are HIV-positive, despite some time having passed since learning of their diagnosis. It is unlikely that these two participants will be ready to adhere to treatment before they have come to terms with being HIV-positive, especially given the life-changing nature of the disease. Most of the other participants

have made up their minds that they are going to live long for the sake of their children, which is an attitude that encourages adherence.

Depression was cited by two of the participants as a barrier towards accepting their condition and a barrier towards developing a positive outlook on life. According to Fogarty (2002), depression is the strongest predictor of non-compliance with antiretroviral medication. The feelings of hopelessness and negativity reduce individuals' ability to take care of themselves. This was apparent in the responses and attitudes of the above two participants. Although these participants could benefit from psychological intervention, neither had received psychological counselling, and it is likely that their anger, depression and self-isolation may worsen their condition and further interfere with adherence.

Suicidal ideation was reported by Participant 8. She had thoughts of suicide during bouts of depression and it made it difficult for her to accept her diagnosis and move on. Anger is an integral part of the grieving process with hate closely related to it. Hate is usually directed towards people that the patient thinks may have infected them (Simos, 1979). Participant 8's anger and hatred was directed at her family, especially her husband who was HIV-negative. She felt resentful that she was going to die and her family was going to live on without her. According to this participant, she would rather kill her whole family and then commit suicide than die alone. Even though she acknowledged having seen her husband's negative results, she still insists that he infected her.

Although Rowe et al. (2005) state that acceptance of one's HIV-positive status is important in promoting adherence, they add that it is also necessary to believe in the efficacy of the antiretroviral therapy. The participants in the study stated the importance of acceptance as part of a healthy approach towards healing. They indicated that it is better to accept their status than to

hold on to anger about the source of the infection. Individuals took varying periods of time to adjust to this life-changing diagnosis. According to Hunt and Monarch (1997), individuals do not reach the acceptance phase of their HIV diagnosis at the same time; it follows different patterns for different individuals. At the time of the study, 13 of the 15 participants seemed to have accepted their HIV status.

The doctors in the Immunology clinic indicated that a considerable period of time passes from the time the patient is diagnosed as HIV-positive to the time they come back to commence antiretroviral therapy. This indicates that it takes time for different individuals to accept their diagnosis and take the necessary steps to seek help. Hoffman, Rockstroh and Kamps (2005), suggest that healthcare workers should be aware of those patients who are emotionally not ready to commence antiretroviral therapy and refer them for motivational counselling. The aim of such counselling is to establish 'readiness' to take medication and provide guidance to facilitate this transitional phase.

Another significant emotion, mentioned mainly by women with children, was fear. The kind of fear most of the women indicated was fear of leaving their children without mothers to love and nurture them. Their children's well-being was an important consideration for most of the mothers. They also worried about the financial implications of their illness and the impact this had on their ability to eat healthy food.

Scepticism about drug efficacy was also mentioned by three participants. They were sceptical of the antiretroviral medication and stated their preference for traditional medicines. Inadequate knowledge and negative attitudes towards the treatment, such as lack of trust in medication safety and efficacy, are considered to be barriers to commencing medication (Nordqvist et al., 2006). A belief in the efficacy of the medication has consistently been associated with higher levels of adherence. This emphasises the importance of

assessing the patient's beliefs regarding medication (Heyer & Ogunbanjo, 2006). Two male and one female participant described how their traditional beliefs interfered with their adherence to medication. Participant 10 lacked trust in the antiretroviral therapy because her sister died while on treatment. This fear of the medication prolonged her decision to start the medication. She doubts the efficacy of the drugs and says that they are harmful even though they help others.

Internalised shame was also indicated by one participant as an emotional reaction that interfered with her visits to the clinic. She feared that people who know her might see her in the clinic and know that she is HIV-positive; she also thought that people who see her at the clinic conclude that she must be a prostitute to be infected with HIV. Participant 12 was the only participant who associated HIV with promiscuity, which according to Bennett (1990) is generally a common perception amongst women.

Denial and social disengagement have been known to be one of the maladaptive coping mechanisms that individuals use (Olley et al., 2004). Denial contributed to non-compliance in most of the female participants, although this occurred indirectly in the form of spousal denial. Although many of these participants took their medication as prescribed, they came for follow-ups sporadically. Participant 7 stated that she does not care anymore because even though she takes her medication, but her boyfriend refuses to use condoms.

Most of the female participants reported difficulties with their partners, who denied that they were positive, refused to be tested, and refused to use condoms. Denial, refusal to test for HIV and condom use is discussed under the same category because they all led to non-compliance amongst the participants that were interviewed. Most of the participants stated that men do not want to use condoms. Participant 4 stated that she has resigned herself to

the risk of not using condoms, and simply hopes that her partner is faithful to her.

The resistance to condom use is alarmingly high amongst these participants' partners, in a social context where poverty and unemployment are rife and the women have no sexual decision-making power. According to Booysen and Summerton (2002), the inability to negotiate condom use with partners is a result of entrenched gender roles and power relations. The traditional role of women, especially in South Africa where women still play a subservient role, has put women in a vulnerable position. Women are not expected to be educated, or work outside their homes, or own property. As the result, women are financially dependent on their husbands. There is evidence that poverty puts women at risk for HIV due to poor access to resources, including means to protect themselves (condoms), good nutrition, and power to negotiate condom use (Kasiram et al., 2006). Six of the 15 participants in the study indicated their inability to negotiate condom use as being due to being dependent on their partners as well as the traditional role they hold as women. One participant stated that this is acceptable to her because this is how she was raised.

In a study by Buve et al. (2002), it was reported that women are still subordinate to men in many areas of sub-Saharan African, which contributes to the spread of HIV. Women are expected not to have sexual knowledge before marriage and are expected to stay faithful to their husbands. However, men are expected to have premarital sex and extramarital affairs (Buve et al., 2002). These traditional beliefs can become treatment barriers if they are not dealt with appropriately.

Traditional beliefs also play a major role in how the individual explains the aetiology of HIV. In this study, the way that individuals perceived their illness contributed to both compliance and non-compliance. Some of the participants

turned to traditional medicine for answers and a cure. Religious beliefs about morality and sin could also influence an individual's decision to seek medical treatment for HIV/AIDS. In the case of Participant 3, religion also had a negative influence on health behaviour due to inadequate information. She stopped taking antiretroviral medication due to her strong belief that HIV is God's way of punishing people for sinning; and if she stops sinning and believes in God, her HIV infection will disappear. As a result, she has discontinued her medication and has focused all her attention on God's powers to heal her.

Some of these participants only came into contact with Western medicine when they were already very ill and they were brought in by their relatives. In such cases studies have shown that the healthcare professionals need to provide information to educate these patients about HIV in order to avoid relapses and poor adherence. Participant 15 indicated his mistrust of other cultures, and ascribed the fact that he was continuing to take the antiretroviral medication to having no choice because his mother insists and he is living in her house. Such beliefs may pose a problem if individuals who believe that they were bewitched come into contact with Western medicine. The unfamiliarity with Western medicine as well as lack of trust in another culture's way of doing things may contribute to non-compliance. Participant 15 also indicated a lack of confidence in and literacy about antiretroviral treatment and its efficacy. In such cases, patients who commence treatment without individual and thorough counselling are likely to default treatment, because their beliefs about the aetiology of their illness have not been addressed.

In addressing belief systems, it is important to consider the belief systems of the patients' relatives. It was found in this study that in some cases, the relatives were responsible for coercing the patients to stop medication and use traditional medicine instead. This was evident in Participant 1's experience,

where her mother took her to a traditional healer for a cleansing ceremony after the death of her child. The traditional healer instructed her to discontinue the antiretroviral medication; as a result she relapsed.

Secondly, patients may prefer traditional medicine to Western medicine, or they may use both. For example, Participant 15 stated that he will continue to use both medicines together because traditional medicines also work. A study that was carried out by Rowe et al. (2005) discovered that some patients put more trust in traditional healers because they are supposed to heal HIV, while Western medicine only slows the process down. Even though they were on antiretroviral medication, some participants expressed doubts about it and voiced their preference for traditional medicine. The belief that traditional medicine can cure HIV can influence adherence mainly in two ways. According to Hoffman et al. (2005), firstly, there may be an interaction between the traditional medicine and the antiretroviral drugs, leading to high toxicity levels or virus resistance.

Some of the participants in this study were knowledgeable about the importance of not mixing ARVs with traditional medicine. Participant 5 mentioned that after her recovery from a bout of illness, the most important lesson she learned was not to mix antiretroviral medication with traditional medicines. However, some participants were still combining the two medicines. Treatment illiteracy can lead to interruption of antiretroviral medication (Rowe et al., 2005). This was indicated by Participant 14 who held the traditional belief that he had been bewitched, did not follow the health professional's instructions and consequently overdosed himself on the medication.

The majority of the participants involved in the study were from a low socioeconomic background. They lacked information about HIV/AIDS except for functional knowledge, that is, how to take medication and the lifestyle

changes necessary in order to avoid non-compliance. Participant 9 indicated that her lack of compliance was due to lack of communication and information by the healthcare workers. She claimed that her lack of information was because the healthcare professionals are busy and the clinic is always full; as a result she does not want to bother the staff with her questions. Although the majority of the participants were satisfied with the information and knowledge they had received at the clinic, this participant's experience acted as a hindrance to effective health care and compliance.

2.2 Social Context

A social approach to medication adherence asserts that the experience of living with a chronic illness such as HIV is not solely the result of biological processes but is also a product of social influences. A socially driven intervention prompts action on a social level to facilitate adherence behaviour on a personal level. Power et al. (2003) propose that social support links the social and the individual context, and conclude that most people view the satisfaction of their social relationships as being one of the most important determinants of their overall feeling of life satisfaction.

As a result, social support is strongly correlated with compliance. It is generally believed that people suffering from stressful life situations will fare better if they have social support system, including treatment buddies, group therapy, family involvement and participation in a behavioural support therapy (Fogarty et al., 2002). Social support also operates as a buffer against stress. Fogarty et al. (2002) add that a positive attitude to the future with long-term goals has also been associated with better adherence.

A supportive patient/health provider relationship also improves adherence. This refers to relationships where the patient is involved in treatment decision making and there is open communication and compassion (Chesney, Ickovics et al., 2000). Orford (1992) discusses cognitive-informational support as the

type of support that provides education, information sharing and advising, which assists the individual to make better, informed decisions. Orford (1992) also mentions structural and functional support as the different kinds of support that patients need at different times. Structural support refers mostly to financial support. In this study, a lack of this kind of support was found to jeopardise many of the female participants' health: unemployment and their consequent dependence on men obliges them to accept unsafe sexual practices, such as lack of condom use.

Lack of social or family support and a fear of stigmatisation are generally associated with poor adherence (Fogarty et al., 2002). In this study, the level of support from friends and family was greater than expected when compared to the literature; it seems that people are becoming more accepting of HIV, and those participants who decided to disclose their HIV status generally received support from their family and friends. Only one participant did not receive support from her family after disclosing her status. Participant 4 attributes her healthy status to her positive attitude and the fact that she has disclosed to everyone that is important in her life; as a result that is why she has all the support she needs.

The experience of rejection was not the same for all the participants in this study. Participant 12 decided not to disclose because of her fear of possible rejection and discrimination. Most of the patients in a study conducted by Kylma et al. (2003) indicated that their fear of being discriminated against interfered with their adherence. One of the participants in Kylma et al.'s (2003) study indicated that his fear of being discovered to be HIV-positive kept him from accessing information and help from the healthcare facility.

Onyejekwe (2004), states that South Africa has the highest statistics of gender-based violence in the world, including rape and domestic violence. In line with the high unemployment and poverty rates in South Africa, most of

the women in the study were unemployed. They depended on their partners for survival. This exposed them to abuse: for example, their partners threatened to leave them and go to other women if they insisted on condom use.

Most women report the use of intimidation and threats as contributors to non-compliance, although in this study Participant 7 cited physical abuse as a reason. This participant reported that her partner went as far as his poking holes in the condoms. This participant lost motivation to adhere and consequently defaulted often; she summarised her feelings by wondering, “What is the point?” According to a study done by Lichtenstein (2006), domestic violence diminishes women’s ability to obtain regular health care. Women may be reluctant to keep the clinic appointments due to fear of their partners. The study further stresses the importance of consistency for the HIV treatment to be effective, and states that domestic violence acts as a barrier for these women. It was apparent in this study that the female participants’ dependence on their partners puts them in a position where they are unable to negotiate condom use or leave the relationship.

3 CONCLUSION

The goal of this study was to contribute to the understanding of the role of psychosocial barriers in affecting adherence to HAART. These data are intended to assist healthcare workers to detect high-risk patients that will need interventions (such as motivational interviewing) before HAART treatment plans are initiated; and also to assist those patients that are non-adherent. Factors that influence adherence to HAART can be divided into personal attributes, institutional resources, factors related to the treatment regimen, and psychosocial factors. The factors uncovered by this study examined the individual as well the individuals’ interaction with the environment (social context). This is necessary because it seems that healthcare providers are

struggling to predict poor adherence.

Adherence to medication is probably the first important factor to be addressed when planning HAART service. In addition, treatment should be accompanied by lifestyle changes including monogamy, condom use and good nutrition. Although studies have shown that people from both high and low socioeconomic groups have access to information and knowledge about HIV/AIDS, many have failed to translate the knowledge into behavioural and attitude change (Booyesen & Summerton, 2002). The best way to deal with HIV/AIDS is to take a preventative approach; however, if one is already infected, behavioural change is of vital importance.

The results of this study show that, in addition to addressing the factors mentioned above, there is also a great need to address people's spiritual and traditional beliefs. This may be done by involving their traditional or spiritual healers in the healthcare team, as these individuals fulfil an important leadership role within society. The results of this study underline the importance of discussing and addressing a patient's religious and traditional beliefs as part of medical care, because religious beliefs may impact either negatively or positively on adherence. This increases the responsibility of healthcare workers to assess patients' beliefs regarding medication and, to understand their patient's culture and spirituality. Healthcare workers should also investigate the level of the patient's trust in the effectiveness of the medication.

This study also indicated the importance of men becoming involved with HIV/AIDS treatment in order for change to occur. Because the effectiveness of HIV treatment is dependant on consistent lifestyle changes, partner abuse, denial and refusal to use condoms is a crucial barrier to treatment for many women. Many of the women in the study stated that they stay in these abusive relationships because they are poor; their illness also makes it even more

difficult to find and keep employment. They also reported that some of their partners refused to acknowledge their HIV status, and denied or distanced themselves from this knowledge. Half of the female participants indicated that their partners refused to use condoms, to an extent of threatening to leave their women if they insist, as was the case with Participant 3.

Cognitive interventions that are combined with behavioural or psychological strategies are associated with better adherence. Interventions that include stress management or supportive therapy, and which include motivational interviewing, could improve self-efficacy and adherence (Mash, 2004). Motivational interviewing and other similar interventions could assist patients who are experiencing difficulties with adherence. Motivational interviewing is patient-centred, which is important in promoting a good relationship between the healthcare provider and the patient. In this way, a treatment plan that a patient can commit to can be negotiated prior to commencing the medication. It is also important for the families of patients to become aware that through their understanding and support, problems with non-compliance may be overcome. Improving HAART adherence requires a multidisciplinary approach that embraces cognitive, behavioural and affective strategies; and includes links with traditional and spiritual healers and community-based organisations.

The research question was explored through a qualitative design, using semi-structured interviews. It shed more light on the understanding of social and psychological factors affecting adherence to medication. It is hoped that recommendations generated by this study may be translated or used for further research. The results may further be used to assist healthcare providers to be proactive in predicting poor adherence, to overcome the challenge that this presents in using antiretroviral medication in the fight against HIV/AIDS.

4 LIMITATIONS OF THE STUDY

The participants who were willing to cooperate in this study and share their difficulties with compliance were mostly women; although it should be noted that the interviews were conducted by a woman and that men might therefore been reluctant to discuss their personal experiences with a woman. Twelve out of the 13 women that were interviewed were unemployed, two of the participants were men, and all hailed from a low socioeconomic background.

The results of this study are not representative of people from other locations. A greater number of male participants in the study could have allowed the emergence of more themes, as well as insight into gender-specific challenges. It could also have opened a platform for education to take place for men, because the level of refusal to use condoms and denial about the existence of HIV/AIDS appears to be high.

Finally, the researcher also encountered difficulty in identifying participants that were prepared to disclose their non-compliance status, as studies have shown that patients tend to overstate their level of adherence, and may tell healthcare workers what they want to hear or what is acceptable. The data were also not cross-checked with treatment buddies.

5 RECOMMENDATIONS

5.1 Healthcare Authorities

The Department of Health and Population Development (1994) states a need to address local beliefs in health education, and possibly find ways of involving traditional and spiritual healers to work together with the Western medical professionals to prevent non-compliance. Healers could work together with the Western medical professionals by supervising treatment and

providing HIV education. Their resourcefulness, influence and the authority they possess within their communities are assets that would make their contribution very valuable.

Traditional and spiritual healers function as psychologists, physicians, priests, tribal historians, legal advisers, marriage and family counsellors within their communities (Van Dyk, 2001). They are the guardians of traditional code of morality and values; and are legitimate interpreters of customary rules of conduct. As a result, they have the authority to be influential in translating HIV/AIDS knowledge to behavioural change. They often have more credibility within their communities than healthcare workers. Consequently, their inclusion in the healthcare team may make a significant contribution in bringing about behavioural change.

5.2 Healthcare Professionals

Healthcare professionals should provide all information to the patients in a manner that they can understand. This should be done in a caring and empathic way. Patients should be encouraged to report on their psychological state and coping mechanisms, and express their emotional experiences. In this way they are provided with an opportunity to express their frustrations and worries, report verbal or physical abuse, and allow the healthcare worker to monitor, for example, for signs of alcoholism. Problems arising in these areas should be dealt with appropriately before individuals commence antiretroviral medication.

Participants should be encouraged to bring their treatment buddies to the clinic, especially for the initial interview. The large amount of information given out during this interview is often too much for the patient to take in and interpret. The treatment buddy may assist the patient in remembering and making sense of the information, and so prevent them from becoming

overwhelmed and confused, which may promote poor adherence.

The medical staff should make sure that no patient starts medication without going through three preparation visits or counselling to ensure readiness. This preparation counselling should include the following:

1. Explaining the goals of therapy and near perfect adherence.
2. Monitoring the patient's medication (e.g., count the pills,) where non-compliance is suspected.
3. Informing patients of potential side effects, including severity and duration; and investigating coping mechanisms.
4. Providing adherence tools where necessary, such as a written calendar of medications and pill boxes.
5. Encouraging the use of alarm clocks as reminders.
6. Establishing a support group as part of the intervention in which discussions on adherence are encouraged.

Support groups should be facilitated in the clinic in order to assist patients with knowledge sharing. Women can also assist each other (especially in cases of abuse) with information and knowledge based on experience, so that they are able to take more control in sexual decision making and insist on safe sex.

In spite of the high patient-physician ratio, healthcare workers, counsellors and physicians are encouraged to receive training in MI techniques. These clinical skills may help facilitate patient readiness for adherence. This model may help to empower both patients and healthcare workers with effective communication skills that are based on the inputs of both the patient and the

healthcare providers. This may help to ensure that the patient's needs are met and adherence is maintained. Most of the communication in MI is centred on behavioural change. MI also emphasises the importance of the social support role that healthcare professionals provide. It stresses that a good relationship between the healthcare professional and the patient is strongly associated with adherence. Managerial and collegial support and encouragement for the implementation of this programme is crucial to empower healthcare providers to promote successful chronic care and behavioural change amongst their patients.

It is important for healthcare workers to enquire about the patient's health beliefs regarding their illness (especially their ideas about what caused the illness). Healthcare workers could improve adherence by being more knowledgeable about the different cultural groups that they come into contact with on a daily basis. This can be achieved by taking time to talk to the patients, allowing them to express their concerns, and listening actively to them. Listening can help to lessen the anxiety and fear evoked by a patient's encounter with the possibly foreign cultural climate of a hospital. It is consequently the duty of healthcare workers to recognise patient's beliefs, both spiritual and traditional, in order to incorporate their beliefs with the Western medical approach. If these beliefs are ignored, then the patient is more likely to be non-compliant. This kind of interference with adherence emphasises the importance of treatment literacy. It is therefore important to encourage patients who are entrenched in their cultural beliefs to buy into the Western medical approach through sensitivity, understanding, education and knowledge.

The multidisciplinary team at the Immunology clinic at Kalafong hospital includes doctors, nurses, lay counsellors, dentists, pharmacists and a social worker. It is recommended that traditional and spiritual healers be included in the multidisciplinary team, and that the team's approach incorporates

cognitive, behavioural and affective strategies. In addition, the services of a psychologist may be included to address psychological and emotional barriers to compliance. In this study, some of the participants interviewed seemed to be in need of psychological intervention; however, Kalafong hospital has only one psychologist, and none of the Immunology clinic patients were referred to the psychologist for individual counselling.

To reduce the probability of non-compliance, healthcare providers could use the following points to proactively screen for and predict poor adherence, and take the necessary measures before the patient commences medication:

<ol style="list-style-type: none"> 1. Emotional reactions <ol style="list-style-type: none"> a. Depression and anger b. Suicidal reaction c. Spousal denial of HIV/AIDS d. Fear e. Acceptance 2. Domestic violence 3. Social withdrawal 4. Condom use 	<ol style="list-style-type: none"> 5. Side effects 6. Information about HIV/AIDS (Health literacy) 7. Belief systems: <ol style="list-style-type: none"> a. Religious b. Traditional c. Traditional role of women 8. Support systems 9. Unemployment and social class 10. Rejection/stigma
---	--

Figure 6.3. Factors affecting compliance

5.3 Family and Friends (Support System)

Consistent social and family support is important, because a lack of this, including abuse, can act as a barrier towards effective ARV treatment. Partner abuse diminishes the patient's ability to obtain regular health care. Abused individuals, usually women, are less likely to keep regular appointments due to fear and submission to the partner's control over their activities and movements. Patients report that their perception of and satisfaction with social support is determined by the encouragement they receive from family and friends to comply with medication.

Treatment buddies or caregivers should be informed about HIV/AIDS to enhance compliance. Such information should include the natural course of HIV, its prognosis, and the need for near-perfect compliance with ARVs in order to reduce the viral load and thus prevent drug resistance. The importance of learning about side effects and how to handle them is also emphasised. In addition, information should be given relating to structural and institutional support, such as social grants and food parcels.

This knowledge is more readily accessible if the treatment buddy or caregiver keeps contact with the health care professionals by accompanying the patient on follow-up visits. In this way, the friend or caregiver may obtain more clarity and so better empower themselves to assist the patient and thus increase compliance. If the patient's family, and especially the partner, has sufficient knowledge about the disease, they will be less likely to discourage treatment adherence or give advice based on misinformation.

6 FUTURE RESEARCH

The interviewees that were involved in the study were mostly unemployed black women from a low socioeconomic background. It is therefore suggested

that further research be conducted with more men, different races and social classes, because individuals from different backgrounds may yield different information on compliance.

More qualitative and quantitative studies need to be conducted in other urban areas as well as in rural areas with participants from both similar and different backgrounds. In this way, the results obtained in this study may be evaluated in terms of their transferability to other contexts. For example, the themes elicited here might have been different if more of the participants were employed, and if they represented different cultural groups. It is recommended that similar studies be carried out on other cultural groups and with people who are employed and therefore less financially vulnerable. Lastly, future studies could explore the implementation of motivational interviewing skills and the efficacy thereof, and so determine whether some of the recommendations made in this study are valid.

REFERENCES

- Abah, S.J., Addo, E., Adjei, P.C., Barami, A.S., Byarugaba, M.A., & Chibuta, C.S. (2004). There's hope – early observations of ARV treatment roll out in South Africa. **Draft paper on PRDUC field work for comment**, 22(39), 1-6.
- Aggleton, P. & Parker, R. (2002). **A conceptual framework and basis for action: HIV/AIDS stigma and discrimination**. Washington DC: Joint United Nations Program on HIV/AIDS.
- Babbie, E & Mouton, J. (1998). **The practice of social research**. Cape Town: Oxford University Press.
- Bandura, A. (1994). A social cognitive theory and exercise of control over HIV infection. In R.J. DiClemente & J.L. Peterson (Eds.), **Preventing AIDS: Theories and methods of behavioural interventions** (pp. 25-59). New York: Plenum Press.
- Bennett, O. (Ed.) (1990). **Triple jeopardy: Women and AIDS**. London: The Panos Institute.
- Berg, B. (1998). **Qualitative research methods**. Boston: Allyn & Bacon.
- Bergley, C.M. (1996). Using triangulation in nursing research. **Journal in Advanced Nursing**, 24(1), 122-128.
- Bogdan, R.C. & Biklen, S.K. (2003). **Qualitative research from education: An introduction to theory and methods** (3rd ed.). Boston: Allyn & Bacon.
- Booyesen, F. & Summerton, J. (2002). Poverty, risky sexual behaviour, and vulnerability to HIV/AIDS infection: Evidence from South Africa. **Journal of Health Population Nutrition**, 20, 1- 4.
- Britten, N., Jones, R., Murphy, E., & Stacy R. (1999). Qualitative research methods in general practice and primary care. **Family Practice**, 12(1), 104-112.
- Burke, L.E. & Ockene, I.S. (Eds.). (2001). **Compliance in health care and research**. New York: Futura.
- Buve, A., Bishikwabo-Nsrhaza, K. & Mutangadura, G. (2002). The spread and effect of HIV-1 infection in sub-Saharan Africa. **The Lancet**, 359(8), 2011-2017.

- Cao, X., Sullivan, S.G., Xu, J., & Wu, Z. (2006). Understanding HIV-related stigma and discrimination in a “blameless” population. **AIDS Education and Prevention, 18**(6), 518-528.
- Cassidy, C.A. (1997). Facilitating Behaviour Change. **American Association of Occupational Health Nurses, 45**(5), 239-246.
- Chesney, M.A., Ickovics, J.R., Chambers, D.B., Gifford, A.L., Neidig, J., Zwickl, B., & Wu, A.W. (2000). Self-reported adherence to antiretroviral medications among participants in HIV clinical trials: AACTG adherence instruments. Patient Care Committee & Adherence Working Group of the Outcomes Committee of the Adult Aids Clinic Trials Group. **AIDS Care, 3**, 255-266.
- Chesney, A.C., Morin, M., & Sherr, L. (2000). Adherence to HIV combination therapy. **Social Science & Medicine, 50**, 1599 – 1605.
- Chesney, M.A. (2003). Adherence to HAART regimens. **Aids Patient Care STDs, 17**(4), 169-177.
- Christensen, A.J. (2004). **Patient adherence to medical treatment regimens: Bridging the gap between behavioural science and biomedicine.** New Haven: Yale University Press.
- Clarke, D. (2002). Faith and hope. **Australian Psychiatry, 11**(2), 164-168.
- Cresswell, J.W. (1994). Research design: Qualitative and quantitative methodological debate. **Social Science Medicine, 40**(4), 459-468.
- Crocker, J. Voekl, K. Testa, M., & Major, B. (1991). Social stigma: The affective consequences of attributional ambiguity. **Journal of Personality and Social Psychology, 60**, 218-228.
- De Vos, A.S., Strydom, H., Fouche, C.B., Poggenpoel, M., & Schurink, E.W. (1998). **Research at grassroots. A primer for the caring professions.** Pretoria: Van Schaik.
- De Vos, A.S., Strydom, H., Fouche, C.B., & Delport, C.S.L. (2002). **Research at grassroots for the social sciences and human service professions.** Pretoria: Van Schaik.

- Demi, A., Bakerman, R., Moneyham, L., Sowell, R., & Seals, B. (1997). Effects of resources and stressors and depression of family members who provide care to an HIV-infected woman”. **Journal of Family Psychology**, **11**, 35-48.
- Denzin, N.K., & Lincoln, Y.S. (1994). **Handbook of qualitative research**, London: Sage.
- Department of Health and Population Development. (1994). Health care systems and traditional healers. **Salus**, **17**(5), 7, Pretoria.
- DiClemente, C.C. & Prochaska, J. (1998). Towards a comprehensive transtheoretical model of change. In W.R. Miller & N. Heather (Eds.), **Treating addictive behaviour** (pp. 2 – 24). New York: Plenum Press.
- Dilorio, C., Resnicow, K., McDonnell, M., Soet, J. McCarty, F., & Yeager, K. (2003). Using motivational interviewing to promote adherence to antiretroviral medications: A pilot study. **Journal of Association Nurses AIDS Care**, **14**(2), 52-62.
- Durante, A.J., Bova, C.A., Fennie, K.P., Danvers, K.A., Holness, D.R., Burgess, J.D., & Williams, A.B. (2003). Home-based study of anti-HIV drug regimen adherence among HIV-infected women: Feasibility and preliminary results. **AIDS Care**, **15**(1), 103-115.
- Ehman, J. W., Ott, B.B., Short, T.H., Ciampa, R.C., & Hansen-Flaschen, J. (1999). Do patients want physicians to enquire about their spiritual or religious beliefs if they become gravely ill? **Arch Internal Medicine**, **159**(15), 1803–1806.
- Ellis, D.A., Naar-King, S., Cunningham, P.B. & Second, E. (2006). Use of multisystemic therapy to improve antiretroviral adherence and health outcomes in HIV-infected paediatric patients: Evaluation of a pilot program. **Aids Patient Care and STDs**, **20**, 2.
- Emler, C.A. (2006). A comparison of HIV stigma and disclosure patterns between older and younger adults living with HIV/AIDS. **Aids Patient Care and STDs**, **20**(5), 350-358.
- Erlanson, D.A., Harris, E.L., Skipper, B.L., & Allen, S.D. (1993). **Doing naturalistic inquiry: A guide to methods**. London: Sage.

- Fife, B.L., & Wright, E.R. (2000). The dimensionality of stigma: A comparison of its impact on the self of persons with HIV/AIDS and cancer. **Journal of Health and Social Behaviour**, **41**(1), 50-67.
- Fogarty, L., Roter, D., Larson, S., Burke, J., Gillespie, J., & Levy, J. (2002). Patient adherence to HIV medication regimens: A review of published and abstract reports. **Patient Education Counselling**, **46**(2), 93-108.
- Fowler, M.E. (1998). Recognizing the phenomenon of readiness: Concept analysis and case study. **Journal of the Association of Nurses in AIDS Care**, **9**, 72-76.
- Geller, J., Cockell, S. J., & Drab, D. L. (2001). Assessing readiness for change in the eating disorders: The psychometric properties of the readiness and motivation interview. **Psychology Assess**, **13**, 189 – 198.
- Gielen, A.C., O'Campo, P., Faden, R.R., & Eke, A. (1997). Women's disclosure of HIV status: Experience of mistreatment and violence in an urban setting. **Women & Health**, **25**(3), 19-31.
- Gray, J. (2006). Becoming adherent: Experiences of persons living with HIV/AIDS. **Journal of the Association of Nurses in AIDS Care**, **17**(3), 47-54.
- Green, J. (1999). Commentary: Generalisability and validity in qualitative research. **British Medical Journal**, **14**, 319- 421.
- Golafshani, N. (2003). Understanding reliability and validity in qualitative research. **The Qualitative Researcher**, **8**, 597-607.
- Hackl, K.L., Somlai, A.M., Kelly, J.A., & Kalichman, S.C. (1997). Women living with HIV/AIDS: the dual challenge of being a patient and caregiver. **Health and Social Work**, **22**, 1-2.
- Hamberg, K., Johansson, E., Lindgren, G., & Westman, G. (1994). Scientific rigour in qualitative research: Examples from a study of women's health in family practice. **Family Practice**, **11**(2), 176 – 180.
- Haynes, R.B., Taylor, D.W., & Sackett, D.L. (Eds.), (1979). **Compliance in health care**. Baltimore: John Hopkins University Press.

- Heyer, A., & Ogunbanjo, G.A. (2006). Adherence to HIV antiretroviral therapy. Part 1: A review of factors that influence adherence. **South African Family Practice**, 48(8), 5-9.
- Holzemer, W.L., Henry, S.B., Portillo, C.J., & Miramontes, H. (2000). The Client Adherence Profiling-Intervention Tailoring (CAP-IT) Intervention for Enhancing Adherence to HIV/AIDS Medication: A Pilot Study. **Journal of the Association of Nurses in AIDS care**, 11(1), 36-44.
- Hoffman, C., Rockstroh, J.K. & Kamps, B.S. (2005). **HIV Medicine**. Paris, Cagliari, Wuppertal, Sevilla: Flying Publishers.
- Hunt, J., & Monarch, J.H. (1997). **Beyond bereavement models**. Oxford: Human Reproduction.
- In: Sabate, E. (Ed.). (2001). **Adherence meeting**. Geneva: World Health Organisation.
- In: Sabate, E. (Ed.). (2003). **Adherence to long-term therapies: evidence for action**. Geneva: World Health Organisation.
- Kaldjian, L.C., Jekel, J.F., & Friedland, G. (1998). End of life decision HIV-positive: The role of spiritual beliefs. **AIDS**, 1, 103-107.
- Kagee, A. (2004). Treatment adherence in South African primary health care. **South African Family Practice**, 46(10), 26-30.
- Kasiram, M., Dano B., & Partab, R. (2006). Intimacy and HIV/AIDS. **Family Practice**, 48(2), 54 - 55.
- Kelly, J.A. (1998). Group psychotherapy for persons with HIV-related illnesses. **International Journal of Group Psychotherapy**, 48(2), 143-161.
- Kimberly, J.A., & Serovich, J.M. (1996). Perceived social support among people living with HIV/AIDS. **The American Journal of Family Therapy**, 24(1), 41-53.
- Kumar, R. (2005). **Research methodology: A-step-by-step guide for beginners** (2nd ed.). London: Sage.
- Kvale, S. (1996). **Interviews: An introduction to qualitative research interviewing**. London: Sage.

- Kylma, J., Vehvilainen-Julkunen, K., & Lahdevirta, J. (2003). Hope, despair and hopelessness in living with HIV/AIDS: A grounded theory study. **Journal of Advanced Nursing**, **33**(6), 764-775.
- Lichtenstein, B. (2006). Domestic violence in barriers to health care for HIV/AIDS women. **Aids Patient Care and STDs**, **20**(2), 122.
- Link, B.G., Struening, E.L., Rahav, M., Phelan, J.C., & Nuttbrock, L. (1997). On stigma and its consequences: Evidence from a longitudinal study of men with dual diagnoses of mental illness and substance abuse. **Journal of Health and Social Behaviour**, **38**, 177-190.
- Marshall, C., & Rossman, G.B. (1999). **Designing qualitative research**. London: Sage.
- Mash, R.J. (2004) Managing chronic conditions in a South African primary care context: Exploring the applicability of brief motivational interviewing. **South African Family Practice**, **46**(9), 21 - 26.
- Mostofa, M.D. (2001). Reasons for non-compliance with drug treatment among psychiatric patients readmitted at Jubilee Hospital. Unpublished Master's dissertation. University of Pretoria, South Africa.
- National Department of Health, South Africa. (2004). **National Antiretroviral Treatment Guidelines**. Pretoria: Jacana.
- Nordqvist, O., Sodergard, B., Tully, M.P., Sonnerborg, A., & Kettis Lindblad, A.M. (2006). Assessing and achieving readiness to initiate HIV medication. **Patient Education and Counselling**, **62**(1), 21-30.
- Ogden, J. (2000). **Health psychology: A textbook** (2nd ed.). Buckingham: Open University Press.
- Olley, G., Seedat, S., & Stein, D.J. (2004). Self-disclosure of HIV serostatus in recently diagnosed patients with HIV in South Africa. **Rev Afr Sante Reprod**, **8**(2), 71-76.
- Onyejekwe, C.J. (2004). The interrelationship between gender-based violence and HIV/AIDS in South Africa. **Journal of International Women's Studies**, **6**, 34-40.

- Orford, J. (1992). **Community psychology: Theory and practice**. Chichester: John Wiley & Sons.
- Park, W.L.Y., Scalera, A., Tseng A. & Rourke, S. (2002). High rate of discontinuations of highly active antiretroviral therapy as a result of antiretroviral intolerance in clinical practice: Missed opportunities for adherence support? **AIDS**, 16, 1084-1086.
- Parsons, S.K., Cruise, P.L., Davernport, W.M., & Jones, V. (2006). Religious beliefs, practices and treatment adherence among individuals with HIV in the southern United States. **Aids Patient Care and STDs**, 20(2), 97.
- Patterson, D.L., Swindells, S., Mohr, J., Brester, M., Vergis, E.N., Squier, C., et al., (2000). Adherence to protease inhibitor therapy and outcomes in patients with HIV Infection. **Ann Internal Medicine**, 133, 21 - 30.
- Pope, C. (1999). **Qualitative research methods: A health focus**. Oxford: Oxford University Press.
- Power, R., Koopman, C., Volk, J., Israelski, D.M., Stone, L. Chesney, M. A., et. al. (2003). Social support, substance use, and denial in relationship to antiretroviral treatment adherence among HIV-infected persons. **AIDS Patient Care and STDs**, 17(5), 245 – 252.
- Prochaska, J., DiClemente C., & Norcross, J. (1992). In search of how people change. **American Psychologist**, 49(9), 1102 – 1114.
- Rabkin, J.G., & Chesney, M. (1999). Treatment adherence to HIV medication: The Achilles heel of the new therapeutics. In D. Ostrow & S. Kalichman (Eds.), **Behavioral and mental health impacts of new HIV therapies** (pp. 61 – 79). New York: Plenum.
- Roberts, K.J. (2002). Physician-patient relationship, patient satisfaction and antiretroviral medication adherence amongst HIV-infected adults attending a public a public health clinic. **AIDS Patient Care and STDs**, 16, 43 – 50.
- Rosenbaum, M., & Ben-Ari Smira, K. (1986). Cognitive and personality factors in the delay of gratification of hemodialysis patients. **Journal of Personality and Social Psychology**, 51, 357-364.

- Rosenfield, S. (1997). Labelling mental illness: The effects of received services and perceived stigma on life satisfaction. **American Sociological Review**, **62**, 660-672.
- Rosenstock, I.M. (1966). Why people use health services. **Milbank Memorial Fund Quarterly**, **44**, 94–124.
- Rowe, K.A., Makhubela, B., Hargreaves, J.R., Porter, J.D., Hausler, H.P., & Pronyk, P.M. (2005). Adherence to TB prevention therapy for HIV-positive patients in rural South Africa: Implication for antiretroviral delivery in resource-poor settings. **The International Journal of Tuberculosis and Lung Disease**, **9**(3), 263-269.
- Santelli, B., Turnbull, A. P., Lerner, E., & Marquis, J. (1993). Parent to parent programs: A unique form of mutual support for families of persons with disabilities. In G.H.S. Singer & L.E. Powers (Eds.), **Families, disability and empowerment** (pp. 25-57). Baltimore: Paul H. Brookes.
- Schlebusch, L., & Cassidy, M. J. (1995). Stress, social support and biopsychosocial dynamics in HIV/AIDS. **South African Journal of Psychology**, **25**(1), 27-30.
- Shinitzky, H.E., & Kub, J. (2001). The art of motivating behaviour change: The use of motivational interviewing to promote health. **Public Health Nursing**, **18**, 178–185.
- Simoni, J., Frick, P.A., Pantalone, D.W., & Turner, B. J. (2003). Antiretroviral adherence interventions: A review of current literature and ongoing studies. **Top HIV Medicine**, **11**(6), 185-198.
- Simoni, J.M., Frick, P.A., Lockhart, D., & Liebovitz, D. (2002). Mediators of social support and antiretroviral adherence among an indigent population in New York City. **AIDS Patient Care and STDs**, **16**(9), 431–439.
- Simos, B.G. (1979). **A time to grieve: Loss as a universal human experience**. New York: Family Service Association of America.
- Skinner, D. (1991). Qualitative methodology: An introduction. In J. Katzenellenbogen, G. Joubert & D. Yach, (Eds.), **Introductory manual for**

- epidemiology in South Africa** (pp. 77-84). Pretoria: Medical Research Council.
- Squires, K.E. (2003). Treating HIV infection and AIDS in women. **AIDS Reader**, **13**(5), 228-240.
- Strengthening health systems through anti-retroviral therapy. (2005). **AIDS Bulletin**. Retrieved May 01, 2007, from <http://www.mrc.ac.za/aids/aidsbulletins.htm>.
- Strydom, H. (2002). Ethical aspects of research in the social sciences and human service professions. In A.S. De Vos, H. Strydom, C.B. Fouche & C.S.L Delpont (Eds.), **Research at grassroots for the social sciences and human service professions** (p. 117). Pretoria: Van Schaik.
- Thrasher, A.d., Golin, C.E., Earp, J. L., Tien, H. Porter, C.& Howie, L. (2006), Motivational interviewing to support antiretroviral therapy adherence: The role of quality counselling. **Patient Education and Counselling**, **62**, 64-71.
- Tsasis, P. (2001). Adherence assesment to Highly Active Antiretroviral Therapy. **AIDS Patient Care and STDs**, **15**(3), 109-115.
- Uldall, K.K., Palmer, N.B., Whetten, K., & Mellins, C. (2004). Adherence in people living with HIV/AIDS, mental illness, and chemical dependency: A review of the literature. **Aids Care**, **16**(1), 71 – 96.
- Van Dyk, A.C. (2001). **HIV/AIDS care and counselling: A multidisciplinary approach** (2nd ed.). Cape Town: Pearson Education.
- Van Wynsberghe, D.V., Noback, C.R., & Corola, R. (1995). **Human Anatomy and Physiology**, New York: McGraw-Hill Inc.
- Veinot, T.C., Flicker, S.E., Skinner, H.A., McClelland, A., Saulnier, P., Read, S.E., & Goldberg, E. (2006). “Supposed to make you better but it doesn’t really”: HIV-positive youths’ perceptions of HIV treatment. **Journal of Adolescent Health**, **38**, 261-267.
- Wagner, G.J. (2002). Predictors of antiretroviral adherence as measured by self-report, electronic monitoring, and medication diaries.
- Whittemore, R., Chase, S.K., & Mandle, C.L. (2001). Validity in qualitative research. **Qualitative Health Research**, **11**(4), 522-537.

- Williams, A, B., Burgess, J.D., Danvers, K., Malone, J., Winfield, S.D., & Saunders, L. (2005). Kitchen Table Wisdom: A Freirian Approach to Medication Adherence. **Journal of the Association of Nurses in Aids Care**, 16, (1) 3-12.
- Worth, D. (1989). Sexual decision-making and AIDS: Why condom promotion among vulnerable women is likely to fail. **Studies in Family Planning**, 20(6), 297 – 307.

APPENDIX A

Informed consent

I hereby confirm that I have been informed by the investigator, G. Moratioa, about the nature, conduct, risks and benefits of the study. I have also read (or have had someone read to me) the above information regarding the study.

I am aware that the results of the study, including personal details regarding my age and diagnosis, will be anonymously processed into the report. I am also aware that interviews will be audio taped. I may at any stage, without prejudice, withdraw my consent and participation in the study. I have had sufficient opportunity to ask questions (of my own free will) and declare myself prepared to participate in the study.

Name of subject _____ **(Please Print)**

Subject's signature _____

Date _____

Investigator's name _____ **(Please Print)**

Investigator's signature _____

Date _____

I,.....here within confirm that the above patient has been informed fully about the nature, conduct and risks of the above study.

APPENDIX B

Interview schedule

- a) Attitude towards their HIV status and medication
 - (i) How long have you known about your HIV status?
 - (ii) How did you find out?
 - (iii) What is your feeling towards taking medication?
- b) Disclosure
 - (i) Who have you told about your status, for example children, family, sexual partners and parents?
 - (ii) Who else are you willing to disclose to?
 - (iii) Have you told anyone about your intentions to start medication?
 - (iv) If no, are you willing to disclose to a friend or a family member?
- c) Individual's habits, drug use, smoking alcohol use and sexual practices
 - (i) Are you prepared to use a condom (safe sex)?
 - (ii) Are you prepared to exercise and eat healthily?
- d) Support system (someone familiar with treatment)
 - (i) Who will your treatment buddy be?
 - (ii) If your treatment buddy is not available, who else can be there for you? (Name them)
- e) Any previous difficulties with adherence, like antibiotics and TB treatment
 - (i) Have you taken medication for more than one week? For what condition?
 - (ii) How many doses do you think you missed in a week or in a month while on that medication?
 - (iii) What were the reasons for missing the medication?
- f) Side effects
 - (i) What side effects have you experienced while on this treatment?
 - (ii) Do you know what side effects to expect?
 - (iii) Do you know what to do if they occur?

- g) Adequate information or knowledge and explanations?
 - (i) What do you know about HIV infection?
 - (ii) What do you know about HIV medication?
 - (iii) Were you provided with information regarding how the medicine works, how to administer it, why continuous treatment is needed, what to do if you forget medication?
- h) Consulting style, that is, interaction between patient and client provider
 - (i) Do you feel you can ask any questions from your health provider?
 - (ii) Do you trust, respect him/her?
 - (iii) Are you satisfied with the manner in which the health staff treats you?
- i) Patients beliefs
 - (i) What do you believe causes HIV/AIDS?
 - (ii) What do you think the treatment will do for you?
- j) Integration of medication to lifestyle and daily habits
 - (i) Do you have a fridge or a safe place to store medication?
 - (ii) Where do you normally keep your medication in the house?
 - (iii) What time of the day must you take your medication; is it practical for you?
 - (iv) Are there any other aspects of your lifestyle that will make it difficult for you to take your medication (e.g. shift work, deployment, courses, etc.)
- k) Any other signs of commitment to a healthy lifestyle like eating healthily, exercise and safe sex
 - (i) How far do you live from the clinic?
 - (ii) Can you get to the clinic easily and can you come every month?
 - (iii) If you are sick and cannot come to the clinic, is there anyone you can send to fetch your medication?
 - (iv) Do you know when and where can you get ARV re-supply?

- (v) How has your HIV status affected your sexual practices and other social habits?