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BARRIERS AND FACILITATORS TO ANTIRETROVIRAL THERAPY ADHERENCE: A PATIENT AND HEALTH-CARE PROVIDER PERSPECTIVE

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**A research project submitted to the Faculty of Arts,
University of Witwatersrand, Johannesburg
In partial fulfilment of the requirements for the
Degree Masters of Arts in
Community based Counselling Psychology
By Coursework and Research Report**

JANUARY 2009

DECLARATION

I hereby acknowledge that this research report is my own unaided work. It is submitted for the degree of Masters of Arts in Community-based Counselling Psychology at the University of Witwatersrand. It has not been submitted before for any other degree or examination at any university

_____ _____

Rabia Patel Date

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ABSTRACT

HIV/AIDS remains a global pandemic that is affecting millions of people. The advent of antiretroviral medication in the late 1980s has led to major advances in clinical treatment that has turned the deadly disease into a chronic condition for those who are infected. However, adherence to antiretroviral medication remains problematic. Whilst extensive international research has been done to identify various variables that contribute to rates of non-adherence, there is not much research being done in South Africa that provides a reliable prediction of non-adherence or generates a theoretical understanding of the issue. The main aim of this study was to ascertain the barriers and facilitators that contribute to the level of adherence to antiretroviral treatment. This was done from a biopsychosocial perspective that takes into account not only the biomedical factors that may have an impact on antiretroviral treatment levels but also includes the various psychological and socio-political factors that contribute to non-adherence. The qualitative research methodology was used. Data was collected from 14 participants using semi-structured interviews. The participants included 3 medical practitioners, 1 nutritionist, 2 counsellors, 2 treatment activist, 2 caregivers to PLWHA and 4 people on treatment. Interviews were audio-recorded and transcribed. Thematic content analysis was used to generate themes. Themes were categorised under individual, interpersonal level and systemic level barriers and facilitators to ARV treatment which included biomedical, psychological as well as social-political factors that facilitate non-adherence. The main findings in this study suggest that there is a complex web of interaction between the various biomedical, psychological and socio-political factors that impact on adherence levels. Additionally, the response by PLWHA to their illness and subsequently to ARV treatment is more complex than a mere conforming to a set of medical standards and instructions. As such intervention that looks to increase adherence levels cannot be a one-dimensional or one-sided endeavour and requires a multifaceted approach.

ABBREVIATIONS

AIDS	-	Acquires Immunodeficiency Syndrome
ART	-	Antiretroviral Therapy
ARV	-	Antiretroviral
HAART	-	Highly Active Antiretroviral Therapy
HBM	-	Health Belief Model
HIV	-	Human Immunodeficiency Virus
PLWHA	-	People Living with HIV/AIDS
SAM	-	Social Action Model
TAC	-	Treatment Action Campaign
UNAIDS	-	United Nations - AIDS
WHO	-	World Health Organisation

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CHAPTER ONE

BACKGROUND TO THE STUDY

1.1 INTRODUCTION

The background to this study and adherence to the treatment of HIV/AIDS (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome) is conceptualised and presented in this chapter. The epidemiology of the illness will be outlined first which will be followed by a brief discussion on antiretroviral treatment, and then a definition of the concept of adherence will be given. Thereafter the rationale for the study will be given, followed by the research questions and research aims. Finally, the layout of the report will be outlined. Throughout this report, reference to HIV/AIDS will be made as an illness rather than a disease (Radley, 1995), reflecting the position that the researcher has taken. According to the researcher, the treatment of HIV/AIDS cannot be limited to biomedical factors but has to be conceptualised within the broader psychological and socio-political contexts. The word "illness" in this study thus signifies a biopsychosocial stance to the virus whereas the word "disease" is mainly linked to the body. In keeping with this perspective, the word "patient" has been used sparingly. However, defining the patient cannot be totally avoided and has been limited to the biomedical discussions. Instead, a less medicalised discourse has been used around people who are on treatment.

1.2 EPIDEMIOLOGY

HIV/AIDS is a global pandemic that continues to escalate in a number of countries worldwide. According to the 2007 United Nations AIDS (UNAIDS) and World Health Organisation (WHO) (UNAIDS/WHO, 2007), the global number of people living with HIV/AIDS (PLWHA) ranges between 30.6 and 36.1 million. In 2007, approximately 2.5 million people were newly infected and AIDS-related deaths have been estimated to be

around 2.1 million people. Of the 2.1 million estimated deaths, 1.7 million are adults and 330 000 are children (UNAIDS/WHO 2007).

Essential findings in this report indicate that although the overall global pandemic rate (those who have been newly infected) appears to have stabilised, the number of people living with the virus has increased because of ongoing accumulation of new infections (UNAIDS/WHO, 2007). However, despite a broad trend of some stabilisation in some countries, Sub-Saharan African countries remain the worst affected (UNAIDS/WHO, 2007). Statistical estimations indicate that there are approximately 22 million people living with the virus in this region (UNAIDS/WHO, 2007). Newly infected figures are approximated at 1.7 million, and it is estimated that at least 1.6 million people have died in the past year due to HIV/AIDS-related causes (UNAIDS/WHO, 2007).

South Africa is reported to be one of the countries with the largest population of people living with HIV/AIDS (Avert, 2008a; UNAIDS/WHO, 2007). According to the statistical estimation by the South African Department of Health, the country has an HIV prevalence rate of about 6.5 million people (29.1%) (Avert, 2008a). In addition, the South African National HIV Survey conducted in 2005 shows that the annual number of registered deaths in South Africa increased by 87% between 1997 and 2005, with a disproportionate rise in deaths among people between the ages of 25 to 49 years (Avert, 2008a). This age group accounted for 42% of deaths in 2005 (Avert, 2008a). This places the number of people who died of HIV/Aids between 320 000 and 350 000, that is more than 800 deaths every day (Avert, 2008a). Notwithstanding statistical difficulties and contradictions, these results nonetheless provide substantial evidence of the continued seriousness and urgency of the situation in South Africa.

1.3 ANTIRETROVIRAL TREATMENT

For HIV infection to occur the virus needs to enter the body and attach itself to a particular set of host cells (CD4) in the immune system (Barnett & Whiteside, 2002). Once the virus has entered the cell, it copies and replicates the host DNA. This copying

of the host DNA allows the virus to replicate rapidly as the human defence system is unable to recognise and therefore destroy the foreign body (Barnett & Whiteside, 2002). Despite enormous resources being mobilised to find a cure or a vaccination, neither has been developed yet.

However, the advent of Antiretroviral Therapy (ART) in the late 1980s has led to major advances in clinical treatment that has the potential to suppress viral replication in those who are infected (Aids South Africa, 2006). Viral suppression in the body is primarily achieved by the course of medication interfering with the ability of the virus to replicate itself in the body, leading to minimum damage being caused to the immune system. As the immune functioning improves, PLWHA become less susceptible to other opportunistic illnesses. Antiretroviral medication (ARV) is not a cure, but has the potential of transforming the HIV infection into a chronic condition with a decline in morbidity and mortality rates (Webster & Barr, 1999).

ART is a drug treatment that requires a single, dual or triple regimen (Barnett & Whiteside, 2002). Currently, there are five groups of ARV drugs that are available and each of these works differently to stop the replication of the virus in the body (Aids South Africa, 2006; Avert, 2008b). The term “Highly Active Antiretroviral Therapy” (HAART) is used to describe a combination of three or more anti-HIV drugs. Due to the complex replication process of the virus, once it enters the human host it is possible that a person may be carrying different strains of HIV. A new strain may be produced that can be resistant to the effects of ARVs, allowing the resistant strain to be able to replicate quickly thus nullifying the benefits of the treatment (Avert, 2008b). HAART reduces the rate at which the resistance develops.

Treatment failure may lead to viral specified resistance. This may happen when PLWHA are rapidly put on mono-therapy which allows drug resistant mutation to take place (Mehta, Moore & Graham, 1997), or if the body fails to absorb treatment at an effective rate (Mehta et al., 1997). When there is a treatment failure, the entire drug combination has to be changed and a second-line regimen has to be started from a new class of drugs

to minimise the risk of cross-resistance (Mehta et al, 1997). However, a more crucial point that needs to be urgently considered is that many PLWHA have great difficulty in adhering to their treatment.

1.4 DEFINING ADHERENCE

Adherence refers to a complex concept that includes taking the medication as it is exactly prescribed. Studies have indicated that at least 95% adherence to ART regimen is optimal (Low-Beer, Yip, O'Shaughnessy, Hogg, Yip. O'Shaughnessy & Montana, 2000; Shuter, Sarlo, Kanmaz, Rhode, & Zingman , 2007). Adherence to treatment differs from compliance which only refers to a patient's behaviour that conforms to medical orders.

Non-adherence to ART refers to not taking the medication correctly, taking it inconsistently or in missing doses which is another factor that leads to increases in the frequency of opportunistic infections, faster progression of the disease and a substantial decline in health for the PLWHA (Avert, 2008b). The lowered amount of chemicals in the body also reduces suppression and thus the viral load rebounds, causing an increase in the risk of the viral strain quickly becoming drug resistant. Studies have found a strong statistical relationship between the failure to obtain scheduled pharmacy refills and a more rapid progression to AIDS (Bansberg, Perry, Charlebois, Edwin, Clark, Robertson, Zolopa & Moss, 2001; Hogg et al., 2000). Treatment options in this case become less as resistance to one drug will sometimes lead to resistance to other similar drugs in the same group leading to cross-resistance (Avert, 2008b).

1.5 RATIONALE

Adherence to ART within the South African context is located in the complex early history of the illness and the socio-political response to the illness. The highest HIV prevalence rate in South Africa occurred between 1993 and 2000 when very critical and major political changes were occurring in the country (Kaiser, H.J. Family Foundation, 2005). The South African government was slow to give the correct attention to the impact

of the epidemic and was hesitant to address the demands and challenges that presented themselves (Snieder, 2002). The initial HIV/AIDS plan was poorly conceptualised and disorganised. The Department of Health finally set up a National AIDS Council to oversee the development of a five-year plan to combat HIV/AIDS (Department of Health, 2000). However, the authorities remained hesitant about acknowledging the full impact and it was only in 2003 that the government approved of a plan to make ARVs available to the public, after the South African high court ordered that Neviripine be made available to pregnant women in an attempt to prevent mother-to-child transmission (Kaiser, H.J. Family Foundation, 2005). In March 2004 the government's treatment plan finally took effect and by mid-2005 at least one service point for HIV-related care and treatment was set up in each of the 53 districts (Kaiser, H.J. Family Foundation, 2005). However, by the end of 2006 only 33% of those in need of ARVs received treatment (Avert, 2008a). Despite these critical issues, an early field exercise conducted by Abah et al., (2005) found that the initial response to ARV treatment was very hopeful.

However, many problems relating to the adherence to treatment very quickly became a point of concern. It soon became evident that being on ARV treatment involved more than conforming to medical instructions and standards. Adherence to ARV medication involves an intricate interaction of emotional, cognitive, behavioural, social, cultural, political as well as medical factors (Frank, 2006). Affecting the success of ART include treatment variables like the medical regimen, pill burden, dosing frequency, nutrition requirements, convenience and toxicity. In addition, drug interaction profiles need to be compared with other regimens before treatment can be started. Psychological and behavioural aspects include mental health status like depression, anxiety, stress or substance abuse in patients. Other variables include lifestyle patterns, financial support, trust between clinician and patient, educational level, stigma, and patients' belief about the medication. These are all factors that act as predictors of adherence.

Whilst extensive research efforts have served to identify the various variables that contribute to non-adherence, there has been a failure to provide a reliable prediction of non-adherence or to decrease the prevalence rates of non-adherence (Amassarri, Trotta,

Murri, et al., 2002; Mehta et al., 1997; Mills, Nechega, Buchan, Orbisinki, Attaran, Singh, Rachlis & Wu, 2006). In addition, most of the research has been largely quantitative in nature and has failed to take into account the complex interaction of various biomedical, psychological, socio-cultural and political factors. Furthermore, the research has generally been carried out in developed countries, with some contribution from developing countries like China, Brazil and India. Studies from the African continent have been particularly lacking. South Africa has its own set of challenges and analyses have to take issues like poverty, lack of health care facilities and education into account in order to come up with a workable solution that will improve adherence levels.

Furthermore, much of HIV-related behaviour, including non-adherence, is based on looking at health behaviour from the point of view of the individual who is on treatment. PLWHA are seen to be able to take responsibility for their illness and any deviation is seen as a failure on the part of the PLWHA. Interventions therefore tend to look at the individuals' gaps in knowledge. In addition, attitudes and behavioural intention and practices become the target for addressing change at an individual level. Focus on the individual level of change has presented many challenges and it is necessary to look at other more systemic ways of engaging with the question of non-adherence.

This research represents a twofold endeavour. Firstly, on a practical level, there is an attempt to look at the various factors that impact on the adherence levels of those who are on ARV treatment, taking into account the multifarious interaction of various biomedical, psychological and socio-political factors. Secondly, as a result of the paucity of theoretical application, research also needs to examine the various theoretical underpinnings of health behaviour with regard to ARV adherence within the South African context. It therefore becomes imperative to make use of qualitative scientific research approaches to gather in-depth experiences in order to understand the behaviour patterns of PLWHA around ARV treatment adherence. The research questions that arise from this background are thus as follows.

1.6 OBJECTIVES & AIMS OF THE STUDY

The main objective of this study is to get a holistic understanding of the combined experiences of both the patients as well as the health-care providers that may guide towards bringing together the various biological, psychological as well as social factors that impact either positively or negatively on ARV adherence levels. This study will therefore examine two broad objectives within this aim: Firstly, to explore how health-service providers may perceive the challenges and facilitative factors experienced by those on ARV medication. The second objective is to explore the patient's perspective on the various challenges as well as factors that may contribute to the ease with which they may experience their ARV treatment regimen. It must, however, be noted that some health-care providers that were interviewed in this study are also on treatment and have therefore narrated their experiences across both roles

The main aim of this research study is to explore and understand the potential barriers as well as facilitators to antiretroviral medication adherence. More specifically the aim was to uncover how these either impinge on or increase the efficacy of antiretroviral treatment. The aim was therefore, to elicit and uncover the various narratives from both the patients and the health-care provider's perspectives pertaining to the experience of being HIV-positive and on ARV-treatment. These narratives are used to demonstrate and contest the biomedical discourse around the treatment of HIV/AIDS. Broader psychological, social-cultural and political discourses are used to demonstrate the wider contestations of power relations inherent in the treatment pf PLWHA.

1.7 RESEARCH QUESTIONS

The research questions that emanate from the objectives and aims of the study are:

- What are the perceptions of health-care providers and patients of the potential biological factors that impact on adherence to ARV treatment?
- What are the perceptions of health-care providers and patients of the potential psychological factors that impact on adherence to ARV treatment?
- What are the perceptions of health-care providers and patients of the potential socio-cultural and political factors that impact on adherence to ARV treatment?

1.8 LAYOUT OF THE REPORT OF THE PRESENT INVESTIGATION

The following is an outline of the layout of this research report:

Chapter 2 - This chapter presents the theoretical foundation of the research and the section is divided into ***two*** sections. A post-modernist argument on health, illness and disease as well as the biopsychosocial model of understanding of health and illness is presented *first*. The *second* section examines the relevance of the various health-related theories, models and concepts including individual health behaviour, models of interpersonal health behaviour and community and group models and concepts of health.

Chapter 3 - This chapter reviews some of the salient literature relating to the various barriers as well as facilitators which PLWHA experience and how they come to have an impact on the levels of adherence to ARV treatment. This section is organised into *three* sections. The literature around biological factors of adherence to ARV medication is presented under issues relating to the treatment regimen, the patient/practitioner relationship and health system concerns. Secondly, psychological issues relating to stress, depression, anxiety and post-traumatic stress will be discussed. In addition, consequences of treatment, health-related quality of life, coping, managing the self and the role of counselling will be reviewed under psychological determinants with regard to ARV

adherence. Lastly, the role of social factors relating to adherence in PLWHA is discussed. Under the social factors, a review of the literature regarding poverty-related issues, stigma and discrimination, social support, managing the environment, and knowledge and beliefs around the illness and treatment will be presented.

Chapter 4 - The methodology used in the collection of data and analyses of data is discussed in this chapter. It begins with a brief discussion of the research paradigm and research questions. This is followed by a description of the setting in which the research took place and a discussion around the sample of the study. Then follows the procedure, the manner in which the data was collected and a short discussion on the data analyses. Finally, the ethical considerations and limitations of this study are outlined.

Chapter 5 – In this chapter the findings, analysis and discussion of the data are presented. The themes of what biological, psychological and social factors may improve or impinge of ARV adherence levels are arranged into three broad categories. These are the individual level, interpersonal level and systemic level barriers and facilitators with regard to adherence. The findings also suggested that the levels of intervention are an important aspect that needs to be taken into account. This chapter further examines the different levels on which one can engage with PLWHA who are on treatment. This is also organised around individual level interventions and community level interventions

Chapter 7 – This final chapter presents a summary of the study, the conclusion, limitations and recommendations in terms of the research study.

CHAPTER TWO

THEORETICAL FOUNDATION OF STUDY

2.1 INTRODUCTION

This chapter serves as the theoretical foundation on which the study is based and includes relevant theories. The chapter is presented in ***two*** main sections. The ***first section*** starts by outlining the postmodernist argument to health, illness and disease, and goes on to present and discuss the biopsychosocial model. This is done so that the reader may be orientated to the biopsychosocial position taken in this research. The ***second section*** serves to locate the research in relevant health behaviour theory.

HIV-prevention efforts are traditionally based on an urgent need for risk education interventions based on the assumption that the greater the understanding of the behaviours associated with HIV transmission the more likely it will be for the adoption of HIV-prevention behaviour (DiClemente & Peterson, 1994). Consequently a rigorous attempt has been made at theoretical driven formulations that have relied on developing intervention methods based on the provision of risk information and behaviour change derived from behavioural science theory. This traditional use of engaging in individual level behavioural theory has been similarly used to engage with difficulties experienced with ARV adherence.

The premise of this research is that the complexity of ARV adherence behaviour require a more integrative theoretical formulation since it has been argued that collaboration across disciplines (medical and social sciences) as well as across roles (involving medical practitioners, counsellors and other service providers and PLWHA) is imperative in understanding the level of adherence so that effective and sustainable health behaviour interventions may be developed (De Bruin, Hospers, Van der Bon, Kok & Prins, 2005; Fisher, Cornman, Wynne & Fisher, 2006; Friedland, 2006; Garcia, Schooley & Badar, 2003). A number of theories have therefore been taken into account in this research in an

attempt to provide a basis for a more holistic framework and to demonstrate a need for a more integrative theoretical understanding of HIV-related behaviours and indeed for that matter any health related behaviour within the complexity of the South African context.

The theories that will be covered include the Health Belief Model which will serve as a model of individual health behaviour. This is one of the most popular and often used model in the study of health behaviour and it remains the most applied theory in HIV/AIDS intervention programs. However, there are many shortfalls to this approach and Social Constructionist and the Social Networks positions will be discussed as model of interpersonal health behaviour. Finally, the Community Organisation and Building Model will be covered to illustrate the position taken in this research in which it is argued that it is necessary to engage with a more integrative health conceptual frameworks.

2.2 POST MODERNISM & THE BIOPSYCHOSOCIAL MODEL

The field of medicine has traditionally been conceptualized through the positivistic scientific orientation and technological advancement based on facts and reality that an observer might know (Gilbert, Selikow & Walker, 2002; Puustinen, Leiman & Viljanen, 2003; Tauber, 2005). From this point of view, clinical science views biological formulations through the effectiveness of the disease-orientated model of care. In this clinical perspective, disease is viewed as a distinct entity that is usually revealed through symptoms, and the individual being treated (i.e. the patient) is a passive object of disease manifestation. The understanding of disease and the treatment of that disease is located at the level of the body (Nettleton, 2002)

More recently, advocates of postmodernist theory have argued against medicine's attempts to explain human illness through biological concepts and have incorporated psychological and social experiences into medical theory (Gilbert et al., 2002; Nettleton, 2002; Puustinen, et al., 2003; Richter, 1999; Tauber, 2005). Bury (1997) postulates that health, illness and medicine is a reflection of culture and society through a process of objectification, which is a separation of forms of knowledge that were once in the domain of the private setting into the public domain. Disease and illness became objectified

through the twin processes of the development of modern science and the separation of disease from an individual's experience to a scientific system of pathological anatomy. Secondly, through the acceptance of this objective view of disease, modern medicine became the "bounded profession we know today" (Bury, 1997, p6).

According to Foucault (1994), the "clinical gaze" brings the patient under the control of the powerful experts and knowledge of the disease becomes the product of a very specific configuration of the patient and doctor relationship. Medicine remains a major source of knowledge and action (Foucault, 1994). This process of medical expert knowledge then gets fed back, enters the everyday world and gets infused with added and newer, more powerful dynamics (Foucault, 1994). This is a rationalization of medical practices thus becomes a part of society and gets taken on as social reality in a myriad of ways (Bury, 1997). It is therefore, through this process of rationalization whereby people will absorb expert medical knowledge and reorganize their lives accordingly (Bury, 1997). Foucault (1998) argues, this medical power can be challenged. Foucault (1998) reasoned that there is no universal form of power but power is produced by quite specific social and cultural practices. This argument is pertinent as it allows for an analysis of medicine and medical practices to include the psychological and socio-political aspects that impact on medical behavior. ARV treatment can no longer remain within the confines of biomedicine but extends to include multilevel analyses.

An influential attempt at bringing biologically-based medical theory in line with clinical reality is the biopsychosocial model (Sarafino, 2002; Sulls & Rothman, 2004). Although this model does not deconstruct the multiplicity of medical knowledge and power, it has been utilized in this research as a way of presenting and understanding the psychosocial realties that impact on the medical practice. The biopsychosocial model was initially conceptualized by George Engel, professor of psychiatry and medicine at the University of Rochester in 1977 and is based on the general systems theory. Engel (1978) (as cited in Puustinen et al., 2003) argued that medical practice is built on multiple levels that include the biological basis for medicine. However, in order to fully understand disease, health and illness, a number of other psychological and social variables need to be taken into account. These three processes are also interactively involved in physical wellbeing

(Sulls & Rothman, 2004). Pellegrino and Thomasma (1981) (as cited in Puustinen et al., 2003) contend that medicine is not what doctors do and what patients expect, but rather a human relationship that ties two people together and is therefore a human activity. This widens medical practice to humanistic as well as social issues (Puustinen et al., 2003).

Such a multiple-level analysis may provide a more efficient way of understanding not only the illness aspect of HIV/AIDS but also the treatment of PLWHA in that it may recognize psychological and social settings in addition to the biomedical problems that PLWHA encounter. It has been found that by promoting the biopsychosocial model through an intensive training program amongst primary healthcare givers, there was a change in the physician's behavior that benefited the patient (Margalit, Glick, Benbassat & Cohen, 2004). Margilit et al., (2004) found an increase in interaction time between the patient and the practitioner, more psychosocial interventions being discussed and fewer laboratory examinations being requested. Similarly, Cohen (2000) reported that a combined interdisciplinary care allowed for a better understanding of the different aspects of living with HIV/AIDS and this led to a better response to treatment in PLWHA.

Building on the biopsychosocial model, the interactive biopsychosocial model provides a dynamic theoretical framework that understands disease, health and well-being through the concept of capital with regard to biophysical, psycho-cognitive and socio-economic inputs into health and comprises the health endowment of individuals (Lindau, Lauman, Levinson & Waite, 2003). Biophysical capital includes genetic composition, physiology, physique, nourishment, strength and appearance (Lindau et al., 2003). Psycho-cognitive capital includes intelligence, emotion, wellbeing, personal attributes, self-esteem, self-efficacy, coping and resilience (Lindau et al., 2003). Social capital in the other hand refers to networks of dynamic relationships with others, social connectedness and social constrains (Lindau et al., 2003).

Despite widespread recognition of the psychosocial factors that need to be addressed when dealing with disease and illness, many medical practitioners continue to show skeptism regarding the benefits of integrating these factors into medical diagnosis and treatment (Asten, 2008). In this it has been argued that the original biopsychosocial model holds true in describing the etiology of a disease but does not convert easily into therapeutic matters (Richter, 1999). Hence, it is argued that biological interventions seem more easily and successfully implemented rather than social or psychological interventions due to the internal condition of the medical system (Richter, 1999). However, integral to the argument of this proposal is the premise that the implementation and adherence to ART is inextricably and intimately linked to biological, psychological and social processes. Furthermore, the concept of biophysical, psycho-cognitive and social capital extends this argument to include the availability of these resources to protect against the adverse affects of the biopsychosocial processes.

2.3 THEORIES OF HEALTH BEHAVIOUR

2.3.1 Individual Health Behaviour

2.3.1.1 Health Belief Model

The Health Belief Model (HBM) has been one of the most widely used in the study of health behaviour (Janz, Champion & Strecher, 2002; Maiman & Becker, 1974). The HBM was developed around the theoretical understanding that suggests that beliefs form an important part of health-seeking behaviour. As a consequence, those individuals who know about and understand their health problems should perform better than those who are less knowledgeable (Rosenstock, Strecher & Becker, 1994). This model proposes four important components that will predict a health outcome. These are the broad concepts of perceived susceptibility, perceived seriousness, perceived benefits and perceived barriers (**Appendix 1**).

Perceived susceptibility is based on the idea that an individual will take the appropriate action to avoid ill health if they believe that they are personally susceptible to falling ill (Rosenstock, 1974). Susceptibility therefore refers to the subjective element around the risk being taken and individuals are believed to vary widely in their acceptance of personal susceptibility to a particular condition. These may range from an individual who on the one hand may completely deny any possibility of an illness occurring to the other extreme where an individual will believe that they are in real danger of harm (Rosenstock, 1974). Studies that have been conducted around perceived susceptibility and HIV/AIDS have shown a variation in the results, indicating that for individuals who exhibit high risk behaviour, the construct of perceived susceptibility is necessary in order to change high risk behaviour (Rosenstock et al., 1994).

Perceived seriousness of a health outcome is argued to be related to the degree of emotional arousal that may be created in the individual. This emotional arousal is related to the thoughts around a particular disease and also the kinds of difficulties that the individual believes may be created (Rosenstock, 1974). Health issues are therefore perceived in relation to their clinical consequence. These may include fears around reduced physical or mental functioning. The fear may also be around the issue of dying and death. Perceived seriousness may also include the broader implications such as the effects of the illness on the work environment, family life or social relations (Rosenstock, 1974). These health issues refer to social, psychological and economic components that are important in the understanding of health and illness. Studies conducted by Rosenstock et al. (1994) show that the perception of the severity of HIV/AIDS has to take into account the perceived cost of being HIV positive. This refers to a personal evaluation of problems, biomedical considerations, financial constrains as well as the social consequences of being infected with the virus. It has been argued that often this important measure is overlooked in the assessment of HIV-related health behaviour as it is assumed that all PLWHA would report that HIV/AIDS is an extremely severe disease (Rosenstock et al., 1994).

According to Rosenstock (1974), *perceived susceptibility and perceived seriousness* are based on the cognitive component and are partly dependent on knowledge. It is argued that these two components together move the individual to take some kind of action. However, the course of action that is likely to be taken by the individual is related to the perceived benefits and barriers to taking the action (Rosenstock, 1974).

Behaviour around the *perceived benefits* is thought to depend on the relative effectiveness of the known available alternatives that will reduce the disease threat (Rosenstock, 1974). Perceived benefits are more likely to be seen as beneficial to a person's health outcome if the person subjectively reduces their susceptibility to or the seriousness of the illness. Rosenstock (1974) puts forward that it is the individual's subjective beliefs about the availability and effectiveness of the various courses of action, and not the objective facts about the effectiveness of action, that will determine the course of action that an individual will take in relation to their health.

These subjectively held beliefs are in turn influenced by the norms and pressures of the person's social environment (Rosenstock, 1974). Hence, an individual may believe that a given action will be effective in reducing the threat of the disease, but at the same time they may see the action itself as being inconvenient, expensive, unpleasant, painful or upsetting (Rosenstock et al., 1994). These negative aspects serve as *barriers of action* and lead to conflicting motives of avoidance. According to the HBM several resolutions to this conflict may be possible. Hence, if readiness to act is high and negative aspects low, than action may be taken, whilst if readiness to act is low whilst the potential negative aspects are seen as strong then the negative aspects serve as barriers and prevent action. Finally where readiness to act as well as barriers to action is great, the conflict is more difficult to resolve (Rosenstock, et al., 1994).

According to Rosenstock (1974), alternative actions of nearly equal efficacy may be used by individuals to manage their health outcomes. However, if such alternatives are not available to resolve conflict than it is argued that one of two reactions may occur. In the first instance, the individual may psychologically remove themselves from the conflict by

engaging in activities that will not reduce the threat to their health. The second reaction may be an increase in the person's fear or anxiety response (Rosenstock, 1974). If the fear and/or anxiety becomes elevated the individual may not be able to think rationally or in an objective manner in relation to their health. In this case it is postulated that even if the person was offered a more effective way of managing their health problem, they might not be able to accept it (Rosenstock, 1974).

However, an important factor to consider as a mediation of the action taken is one of cues or events that occur to set the process of health behaviour into motion (Rosenstock, 1974). These cues can be internally driven, for example, by the individual's perception of their bodily states. The cues that act as mediators can also be external events, for example, interpersonal interactions or the impact of media communication. The intensity of the cue that can be said to be sufficient enough to trigger a health behaviour response may vary with the difference in perceived susceptibility and severity that the individual experiences (Rosenstock, 1974).

2.3.1.2 Evaluating Individual Health Behaviour Models

The Health Belief Model is based on cognitive science research and tries to identify patterns and ways in which people can assess various health beliefs and how people might respond to these beliefs. It represents the individual as an information processing unit, human action as volitional and people are viewed as rational free agents restricted by their ignorance about their health and illness (Lupton, 1999). The HBM proposes that if a number of perceptions are in place, individuals will then take steps to protect themselves. If the threat to oneself is perceived to have serious consequences but there is a belief that taking preventative action will be effective and that the benefits will outweigh the costs, then individuals will take the appropriate actions to protect themselves.

In this way, health behaviour is reduced to a specific and discrete set of cognitions that become amenable to educational interventions. The individual and perception become limited by how humans see and understand their world through their senses and brain functioning without acknowledging social and cultural meaning systems (Lupton, 1999). However, beliefs are stable characteristics that are acquired or learnt through a process of socialisation, and the argument postulated by models like the HBM that beliefs can be differentiated between individuals of the same background requires a close and more critical examination. According to Rimmer (2002), these models may be more applicable to a homogeneous middle class population since they may be more orientated towards a specific common health goal. When looking at populations where health is impacted by large systemic-level barriers like poverty, lack of a good health system, traditional belief systems and different ideas around health, these models do not provide an adequate theoretical foundation for intervention (Rimmer, 2002)

Apart from practical limitations, this model is further limited by its theoretical application (Rimmer, 2002). It is argued that some constructs in the HBM are not well understood and yet other constructs have low predictive value. In addition, in the application of the theory, researchers often choose some variables above others to focus on. This has an impact on the rigour of the theory itself. Other individual health belief models are argued to be more rigorously codified and are systemically able to identify person behaviour around specific health practises more than the HBM. However, even these theories those remain located at the level of understanding health behaviour at the individual as it does not take into account emotional responses (Rimmer, 2002). Strong emotional responses as well as socio-cultural and political factors around aspects of health drive very powerful behaviour and it is often very difficult to anticipate such responses

2.3.2 Interpersonal Health Behaviour

2.3.2.1 The Social Constructionist Position

As it has been argued in the previous section, a behaviour change model like the HBM, are based on looking at health behaviour from the point of view of ascertaining the knowledge, attitudes, behavioural intention and behavioural practices of individuals. Gaps in knowledge, attitudes and behaviours then become the target for addressing change at an individual level. However, focus on the individual level of change has presented many challenges (Shingal & Rogers, 2003). According to Shingals and Rogers (2003), these models fail to provide adequate explanations and change in attitude and behaviour for four reasons.

Firstly, behaviour change communication strategies are based on the assumption that all individuals are capable of controlling their context (Shingal & Rogers, 2003). Yet there are many social, psychological and political factors which place the individual in a context where they may be able to exercise only limited control. Secondly, these strategies make the assumption that all individuals are on an equal footing. Subsequently these models fail to take disparate factors like gender, race or socio-economic factors into account (Shingal & Rogers, 2003). Thirdly, there is an assumption that all individuals make decisions based on their free will. Lastly, the assumption is that all individuals make preventative health care decisions in a rational and logical manner, and therefore people would not willingly put their lives in danger (Shingal & Rogers, 2003).

According to Pavia (1995) (as cited in Shingal & Rogers, 2003), behaviour change communication strategies have constructed concerns around HIV/AIDS through the biomedical factors and interventions sometimes overlook the psychological, cultural and social concerns. Airhihenbuwa (1999) (as cited in Shingal & Rogers, 2003) believes that culture can be used as an ally with strengths and attributes that can be helpful in looking at issues around HIV/AIDS. Hence Airhihenbuwa (1999) (as cited in Shingal & Rogers, 2003, p. 218) argues that the “metaphorical coupling of culture and barriers needs to be

exposed, deconstructed and reconstructed so a new, positive cultural linkage can be forged". Tapping into the strengths of certain cultural practises thus becomes important (Curtis & Tucket, 1996; Shingal & Rogers, 2003). This is not to take away from those studies that very strongly show the disastrous consequences of certain cultural practices that can undoubtedly become an detrimental to PLWHA**.**

Furthermore, individual theories on health behaviour conceptualise health behaviour in relation to how well risk can be identified and calculated, the level of seriousness of the risk, the possible effects and why people respond to risk behaviour in a certain way (Lupton, 1999). Risk is seen as pre-existing and in principle can be identified by using scientific measurements and can be controlled by using knowledge. (Lupton,1999). These theoretical formulations represent human action as logical, and categorise risk avoidance behaviour as "rational" whilst conceptualising risk-taking behaviour as "irrational". Behavioural and cognitive models see a linear relationship between knowledge and risk, and individuals are seen as calculating and emotion-free actors (Lupton, 1999).

The social constructionist position puts forward the argument that risk is never objective and never lies outside a belief system, and therefore health behaviour including risk-taking behaviour should be identified and managed through pre-existing knowledge, reproduction of meaning and through social interactions (Gergen, 2001; Lupton, 1999). The way that the PLWHA manage their illness is therefore constantly constructed and reconstructed and negotiated through meaning-formation and social interaction. It is thus important to understand the perception of the various actors who are located in different contextual matrices and who therefore would have competing views on what it means to be on ARV treatment (Gergen, 2001; Lupton, 1999). Lupton (1999, p. 31) argues that for an activity or situation to become risky, the process of analysing harmful behaviour becomes a "rhetorical process, performed in specialised texts or in the public arena and often involves an intense struggle over meaning, particularly in relation to those actors who are deemed to be responsible for the risk object". In the construction and understanding of risky behaviour it is rarely the layperson who plays a major role of constructing risk objects at public debates but rather the experts with scientific

knowledge, particularly those emerging from science, medicine and psychology disciplines, that embed risk at an organisational level. Hence nothing is a risk in itself but needs to be deconstructed through the eyes of those who are living with the illness (Gergen, 2001; Lupton, 1999).

2.3.2.2 Social Networks and Social Influence Model

Social relationships have a very powerful influence on health behaviour and outcomes (Heaney & Isreal, 2002), and this has been a particularly favoured method of medical behaviour intervention with PLWHA. The social network refers to the social relationships that surround the individuals whilst social support defines an important function of the social relationship. Social networks may or may not provide social support. They may also provide for functions other than support (Heaney & Isreal, 2002).

Structures of social networks can be dyadic between the individual and other individuals and these kinds of dyadic relationships are reciprocal in terms of give and take, intensity of emotional closeness, complexity and variedness of relationship (Heaney & Isreal, 2002). However, social networks also imply entire networks of members limited only by the extent to which collective members know and interact with each other. These can be relatively homogeneous groups similar in characteristics like race, ethnicity, age, gender, geographic dispersion or socioeconomic status. Social networks may also reflect heterogeneity based on diversity (Heaney & Isreal, 2002). Social networks may provide social support based on behaviours or acts that include emotional support (empathy, love, trust, care), instrumental support (provision of tangible aid and service that directly assist in needs), informational support (advice, suggestion, knowledge base) or appraisal support (constructive feedback, affirmation) (Heaney & Isreal, 2002).

The mechanism through which social support and social networks may have a possible positive effect on health outcomes can be through utilising both individual coping resources as well as community resources (**Appendix 2**). By meeting the basic needs for companionship, intimacy, sense of belonging and reassurance of a person's worth,

supportive ties may enhance heath outcomes (e.g. adherence to medication) regardless of the stress levels that the PLWHA may experience. This will in turn increase the individual's coping resources by providing for the accessing of new contacts, knowledge and helping PLWHA to identify and solve specific problems. Therefore, support systems may assist is reducing uncertainty and unpredictability, or they may help to produce the desired outcomes resulting in a sense of personal mastery and control for the PLWHA (Heaney & Isreal, 2002). Furthermore, the strengthening of social networks and social support in community networks bolsters the ability for that community to procure additional resources and to solve problems, enhancing community capacity and control. In this way adherence levels to ARV treatment regimens can be improved.

The symbolic interactionist theory provides useful insight into the interaction between the individual and his or her social environment (Mead, 1934). It is argued that the manner in which one constructs the self and the meaning that one attaches to the environment is not limited to the personal but emerges out of social processes (Mead, 1934). Furthermore, social processes do not occur in isolation but interact on a symbolic level with the individual with consequences in the development of that person. People are therefore influenced by the attitude and behaviour of other people in their environment and are constantly readjusting their behaviour in an anticipated reaction to others (Mead, 1934).
It has been found that PLWHA will often internalise the perception and behaviours of others. This internalisation will than be used as a frame of reference from which PLWHA would make meaning of their experiences (Patel, 2005). According to the study conducted by Patel (2005), PLWHA are likely to construct themselves through a negative self-concept, engage in devaluation of the self and many may withdraw from social interactions. Social networking and support is an important resource for PLWHA and these structures can assist in reducing fear, guilt, denial, anger and isolation thereby promoting their ability to adhere to treatment.

Results from several studies strongly indicate that support-enhancing interventions should begin with assessments of the individual's social networks (Heany & Israel, 2002). Network mapping can assist in identifying the strengths and weaknesses of an

individual. This can in turn lead to a reciprocal relationship of mutual trust and care, and foster a helping relationship based on interdependence and exchange between the various team members. The challenge of this type of assessment lies in identifying who or what can perform effective protective functions with regard to social networks (Heany & Israel, 2002).

Studies also reflect that it is important to take into account a number of various options that may be available to the individual (Heany & Israel, 2002). Intervention type can be based on enhancing existing social networks or developing new social linkages. Although the former has untapped potential, the latter may provide challenges that include identifying such groups and members who are willing to commit to and sustain the group. The latter may provide to be more useful when the existing networks of those who are struggling with health-related issues have relative small or no social networks. If a support system is overburdened, then introducing new social linkages could prove to be useful in providing encouragement and support (Heany & Israel, 2002).

2.3.4 Community Health Behaviour

2.3.4.1. Community Organisation & Building

Nguyen, Ako, Niamba, et al. (2007) put forward a compelling argument that PLWHA living with no social security and with minimal or no medical care are often faced with being ostracised, victimised, deserted, left destitute and face death alone. This is a response to what is a “moral economy” which can be understood as a cultural basis for evaluating value based on kinship and social relationships (Nguyen et al. 2007)). Hence, a person’s position in the kinship hierarchy can determine the person’s position in the social setting and therefore their vulnerability. Social triage on the other hand refers to the manner in which scarce treatment resources are applied to decide who will receive prioritised care (Nguyen et al., 2006).

Since the advent of ARVs in the late 1990s, the demand for the medication still remains higher then what can be supplied by many developing countries and the question arises as to who should benefit from the limited resources. Those who are most likely to live are prioritised to receive care whilst those people whose prognosis is poor may be left to die. Ngunyen et al. (2006) argue that how ART becomes available largely depends on the social triage of moral economy. This is very strongly reflected by those who have become the strongest activists in South Africa and elsewhere on the continent. Treatment activism has become based on a process of producing activism through the access of treatment and not shaped solely by social forces (Ngunyen et al., 2006).

Therefore the argument put forward is that the social response to the epidemic should shift its focus to include the concept of empowerment that will allow PLWHA to negotiate and gain access to lifesaving treatment and the ongoing challenges of adherence. This can largely be understood as improving the conditions of those who are most vulnerable to HIV by emphasising their basic human rights to receiving the necessary medication. Van der Vliet (1996) makes a compelling argument that HIV/AIDS can be viewed as a product of both macro- as well as micro-political processes, and in order to turn this epidemic around one would have to take a careful look at power relationships and political processes that trap people into powerlessness stopping them from accessing the much needed treatment to stay alive for longer.

In this regard, Foucault's (1998) discussion on power has particular significance. According to Foucault (1998**,** p.89) "power must be analysed as something that circulates, or rather something which only functions in a form of a chain. It is never localised here or there, never in anybody's hands, never appropriated as a commodity or a piece of wealth. Power is employed through a net like organisation and not only do individuals circulate between its threads; they are always in a position of simultaneously undergoing and exercising this power. In other words, individuals are the vehicles of power, not its point of application" This is a critical point as it may allow people through community engagement to reflect more openly about what it means to be HIV-positive in a move away from the various forms of "expert" knowledge that governs their health and

health behaviour. Those who are HIV-positive may thus be able to move from being passive objects and bystanders in their medical experiences to having more agency.

Empowering individuals and communities through civic associations may be useful when engaging with the question of the social triage and moral economy. Empowered citizenship where there is a high level of understanding of HIV/AIDS reinforced by community advocacy and the mobilisation process that promotes the rights of PLWHA (Robins, 2004) can be extended to include macro-political systems.

Community organisation is a process in which community groups are assisted in identifying common problems and goals to mobilise resources and implement collective strategies (**Appendix 3**). Implicit in this definition is the concept of empowerment, critical consciousness as well as social action. This model is thus viewed as a process in which both individuals and communities can take control of their lives and their environment to ensure better health outcomes for themselves (Rappaort 1981). This fairly recent and more expanded view of and emphasis on community participation that leads to better health outcomes initially began in the 1970s (Minkler & Wallerstein, 2002). The World Health Organisation adopted this view in 1986 whereby they focused on increasing people's control over their determinants of their health with high level public participation. The aim of this model to health is to create a sustainable environment through both government as well as non-governmental sectors in partnership with the communities to can create public health policies, achieve high level participation in community-driven projects and to ultimately reduce inequities and disparities between groups (Minkler & Wallerstein, 2002). Alongside this is the idea of community building rather than just community organisation. This implies that the people in the community engage in the process themselves (Minkler & Wallerstein, 2002).

This link between individual organisational and community level empowerment that calls for liberation is the process in transformation (Friere as cited in Hope & Timmel, 2003; Connolly 1980). This requires a critical look at what keeps and reinforces powerlessness in PLWHA. Through critical dialogue group participants can look and listen for issues

contained in their own experiences, understand root problems and devise strategies to transform their reality (Friere as cited in Hope & Timmel, 2003 & Connolly, 1980). According to Rappaort (1981) empowerment is a dynamic construct that links the strengths of individuals and communities to bring about social change. One of the major goals of empowerment is to assist those people who are marginalised to develop a critical understanding of the socio-political environment through collective participation. In this manner, health can be seen through the extended lenses of wellness, competencies, strengths, capabilities and the impact of environmental influences of social problems and there is less focus on disease, deficits, weaknesses, blaming, categorising and risk factors (Rappaport 1981).

Community empowerment is multi-layered and represents both the process and the outcome of change for the individual and the community social structures (Nelson & Prilleltensky, 2005). Empowerment can also challenge both perceived as well as real powerlessness (Nelson & Prilleltensky, 2005). At the level of the individual one can refer to psychological empowerment where there is an extension of intrapsychic abilities like self-esteem and self-confidence that will allow people to attain better control over their lives, make them more aware of their social context and of political efficacy (Nelson & Prilleltensky, 2005). Organisational empowerment, on the other hand, can look at resources and at greater participatory activities. This allows for better collective problem-solving abilities and working towards collective empowerment (Nelson & Prilleltensky, 2005). Hence it becomes important to understand health behaviours and outcomes from a place of empowerment, concientisation and community connectedness where there is a deep understanding and awareness of their lived situation and of the capacity for PLWHA to transform their lives

The Social Action Model (SAM) takes on an active stance in understanding liberation through the act of transformation (Mann, 1978). In a bottom-up approach, the SAM challenges the notion of social inequality arguing that there is a link between inequality and psychosocial difficulties. In terms of the SAM, traditional models of understanding health therefore remain inadequate in explaining and understanding health behaviour.

Analysis should not stop at the individual level. According to this model, it is also not enough to include aspects of the social environment without taking into account how the various socio-political structures impact on a person's life (Mann, 1978).

Closely related to the concept of empowerment is the notion of community capacity (Minkler & Wallerstein, 2002). Community capacity can be defined as the characteristics that a community has that affect their ability to identify, mobilise and address social and public health problems. Goodman et al. (1993) (as cited in Minkler & Wallerstein, 2002) postulates that community capacity has multiple dimensions of active participation, leadership, rich support networks, skills, resources, critical reflection, sense of community, understanding of their history, articulation of values and access to power. Community capacity includes the various components of the community members who are able to collaborate effectively in order to identify problems and any needs in the community, to achieve working consensus of goals and priorities, to agree on ways and means to implement the agreed-upon goals and to collaborate effectively in the required actions (Minkler & Wallerstein, 2002)

2.4 CONCLUSION

In this chapter the theoretical foundation for the study has been presented. A post-modernist argument on health, illness and disease as well as the biopsychosocial model of understanding of health and illness were presented first. The relevance of the various health-related theories, models and concepts including individual health behaviour, models of interpersonal health behaviour and community and group models and concepts of health behaviour has been explained and examined. Thus the foundation has been laid on which this research study regarding adherence to HIV treatment is based.

CHAPTER THREE

LITERATURE REVIEW

3.1 INTRODUCTION

This chapter reviews some of the salient literature relating to the various barriers as well as facilitators which PLWHA experience and how they come to have an impact on the levels of adherence to ARV treatment. This section is organised into three subsections. The literature around biological factors of adherence to ARV medication is presented under issues relating to the treatment regimen, the patient/practitioner relationship and health system concerns. Secondly, psychological issues relating to stress, depression, anxiety and post-traumatic stress will be discussed. In addition, consequences of treatment, health-related quality of life, coping, managing the self and the role of counselling will be reviewed under psychological determinants with regard to ARV adherence. Lastly, the role of social factors relating to adherence in PLWHA is discussed. Under the social factors, a review of the literature regarding poverty-related issues, stigma and discrimination, social support, managing the environment, and knowledge and beliefs around the illness and treatment will be presented.

3.2 BIOMEDICAL FACTORS CONTRIBUTING TO NON-ADHERENCE

3.2.1 Treatment

3.2.1.1 Complexity of treatment

The clinical goal of ARV treatment has been defined as the suppression of HIV replication, immune reconstitution, a slowing of disease progression, increased survival, reduced morbidity and mortality, and a better quality of life (Hart, Curtis, Wilkins & Johnson, 2007). Yet ARV treatment is not an easy task since it is a life-time commitment

in managing the durable suppression of the HIV viral replication to below the level of detection.

Studies (Altice, Mostashari & Friedland, 2001; Hart et al., 2007; Lesho & Gey, 2003; Maneesriwongul, Tulathong, Fennie & Williams 2006; Seguy, Diaz, Pereira et al., 2007) have revealed that the duration of the treatment can determine the effectiveness of adherence to ARV. According to Altice et al. (2001), with extended therapy there is an increased possibility of treatment interruptions, which will lead to virologic failure due to non-adherence. However, it has also been found that the longer people stayed on treatment, the more experienced they would become in the treatment and ultimately leading to better adherence (Maneesriwongul et al., 2006). Often this is because individuals who remain in the system for a long period of time receive on average a higher quality of care (Maneesriwongul et al., 2006).

In addition, those who were put on nucleoside mono-therapy showed a better adherence level than those put on dual-nucleoside combination therapy, suggesting that the more complex the treatment regimen the higher the possibility of not taking the medication as it has been prescribed (Altice et al., 2001, Lesho et al., 2003).

3.2.1.2 Side effects

All classes of ARV drugs are associated with toxicities and adverse side effects that vary from being mild to severe and from acute to chronic. Some side effects can be lethal (Murphy, 2003). Specific toxicities that have been reported include coronary heart disease, lipodystrophy, bone disorders, lactic acidosis, glucose intolerance/diabetes, pancreatitis, liver disease, renal insufficiency, sensory neuropathy and neuropsychiatric conditions (Murphy, 2003). Full awareness of the potential toxicities, the individual's tolerance to side effects and the management of these by medical practitioners is critical to ensure patient safety.

Ammassari et al. (2001) found that symptoms of side effects of the medication were frequent in people treated with ARV. Amongst protease inhibitor–treated cohorts up to 29% to 36% of subjects after 14 to 19 months of observation were found to be suffering from some type of side effect symptom (Ammassari et al., 2001). Similarly, Altice et al. (2001) reported that the most predictive factor associated with non-adherence was the side effect variable (92% of the sample population).

Fear that results from powerful negative images of medication appears to have a substantial impact on adherence levels (Altice et al., 2001). Many respondents stopped taking or missed treatment because of a perception of what would happen if they had to take the medication (Altice et al., 2001; Ammassari et al., 2001. In addition, those individuals who stopped taking their medication immediately if they thought they might experience some kind of a side effect (i.e. perceived and not real experience of symptoms), had a much lower adherence level then those who would keep taking their medication until they could speak to someone about their actual symptoms (Altice et al., 2001). Furthermore, it appears that trust in the medication's efficaciousness to not cause harm is an essential factor in adherence (Stone, Hogan, Shuman, Rompalo, Howard, Korkonzelou & Smith, 2001). Providing reassurance over medication and timely management are components that increase the rate of adherence (Hardon, Akurut, Comoro, Ekezie, Irunde, Gerrits, Kglatwane, Kinsman, Kwasa, Maridadi, Moroka, Moyo, Makiyemba, Nsimba, Ogenyi, Oyabba, Temu & Laing, 2007; Nakiyamba, Kwasa & Akurut, 2006). Often side effects will decrease or disappear over time but this valuable information is often not communicated to the PLWHA (Hardon et al., 2007; Nakiyamba, et al., 2006). Where side effects have been discussed extensively through counseling, adherence levels have had a more positive outcome (Hardon et al., 2007; Nakiyamba et al., 2006)

Information regarding the potential long-term adverse consequences must be investigated as such new information may lead to doctors prescribing medication that has fewer side effects. This can assist in stopping the decrease or delay of the acceptance of ARVs in individuals who perceive the consequences of being on treatment as being worse than the progression of HIV itself (Altice et al., 2001).

3.2.1.3 Nutrition

Individuals with HIV have special nutritional needs due to the response of and the extra energy needs that are required of the immune system. This is irrespective of whether they are on ARV medication or not (Castleman & Seumo, 2003; Nakiyamba et al., 2006). Malabsorption and other digestive problems lead to protein loss which leads to a breakdown in muscle tissue (Castleman & Seumo, 2003; Nakiyamba et al., 2006). Furthermore, various complications related to repeated infections and fatigue may often result in poor appetite, leading to further loss of nutrients in the body (Castleman & Seumo, 2003; Nakiyamba et al., 2006). Proper nutrition helps to strengthen the immune system and to slow down the progression of the illness.

ARV medication and food intake play an important role since they interact with each other and issues such as the following need to be taken into account: the effects of food medication efficacy, the effects of medication on the use of nutrition by the body, the effects of medication side effects on food consumption and the unhealthy side effects caused by medication and contraindicated foods (Castleman & Seumo, 2003). Certain foods can affect the medication absorption, metabolism, distribution and excretion of ARV medication. In particular, foods that are high in fat and protein content may decrease the absorption of certain ARVs (Castleman & Seumo, 2003; Kotler, 2000; Sharpstone, Murray, Ross, Phelan, Crane, Cozi, Allessandrod, Nelson & Gazzard, 1999). Some ARVs need to be taken on an empty stomach. It has been found that that medication can impact on the absorption of nutrients into the body resulting in elevated blood cholesterol levels that may in turn lead to an increased risk in coronary diseases (Kotler 2000; Sharpstone et al., 1999). Another factor to consider are the toxicity levels produced by ARV medication which lead to side effects like nausea, diarrhoea, dryness of the mouth, vomiting and changes in taste or loss in appetite and nutritional loss (Kotler, 2000; Sharpstone et al., 1999). It should also be noted that PLWHA often have to take other medication to treat opportunistic infections and this may affect nutritional needs (Castleman & Seumo, 2003)

Failure to manage these interactions between ARV medication and food intake often results in a failure to follow through on drug schedules or even in stopping the consumption of the drugs altogether (Castleman & Seumo). Although service provides, counsellors, home-based caregivers and communities are educated to understand the implications of a lack of nutrition, for many households the economic impact of HIV can be severe. Merely providing information on nutritional needs is clearly not enough (the social aspects of nutritional needs will be discussed later under the impact of poverty on adherence levels).

3.2.1.4 Managing the regimen

Other reasons cited by PLWHA for missing treatment included forgetting, being busy or being away from home (Conway, 2007). Surveys in developed countries have shown that there is a strong preference for a once-daily dosage and compact therapy which is more likely to yield better long-term adherence and virologic suppression (Conway, 2007). Conway (2007) also believes that some twice-daily dosages may be safely and effectively administered once daily. Allowing for the forgiveness of dosing that is delayed or missed is critical and it is important for health-care providers to emphasise that if a treatment dose is missed it is always better to take a dose late than not at all (Conway, 2007).

As taking ARVs is a long-term commitment, tailoring the regiment where PLWHA are better able to pragmatically incorporate their medication regimen into their lifestyle using strategies which include habit development and choosing a regimen that fitted into a particular lifestyle, increased adherence levels (Lewis, Colbert, Erlin & Meyers 2006). Secondly, those individuals who were better able to accept the trade-offs between the benefits of the medication in relation to the limitations (for example, keeping the side effects in perspective, understanding that treatment is beneficial to health of self and for survival, or understanding that there were limited treatment options) were able to recognise that adherence to the medication was important (Lewis et al., 2006). Thirdly, acknowledging the role of medication in avoiding illness and death, the strong belief in the efficacy of their medication and acknowledging that adherence to treatment played a

major role in avoiding illness and death seemed to contribute to the facilitation of high adherence (Lewis et al., 2006).

3.2.2 Patient/Practitioner Relationship

The relationship between the patient and practitioner is generally characterized by the provision of support, empathy, trust, communication and the practitioner's knowledge of the patient (Leopold, Cooper & Clancy. 1996; Forest, Shi, Voon Schrader & Ng, 2002). In addition, the field of medicine has been increasingly analysed from a social control point of view (Hillier, 2002). Professional control over issues of health and illness remain under the control of the medical profession and it has been argued that medical doctors have come to exert an enormous amount of power and control over those whom they treat through their specialised knowledge and professional status. The opinion of the medical practitioner is seen as having greater value and insight than others (Hillier, 2002).

The strength of the patient/practitioner relationship is therefore not always benign or existing in a vacuum and should not be overlooked when looking at the levels of adherence in PLWHA. A pertinent issue that relates to the patient/practitioner relationship is that often there is a concentration of the problem on the individual patient with a focus to change the patient's behaviour patterns rather than on the wider psychosocial issues that may be impacting on such behaviour (Hillier, 2002). In addition, attention needs to be paid to the interaction process between patients and health care workers (Sixma, Spreeuwenberg & Van der Pasch, 1998,). The general practitioner's role in the provision of health care should include responses to social issues and specific tasks should include the responsibility for the care of individuals; the role of gatekeeper; broad knowledge of curative, preventive, and rehabilitative medicine; teamwork; management; and development of population-based strategies (The Joint Working Party of the Welsh Council of the Royal College of General Practitioners and the Welsh General Medical Services Committee, 1994). Clinical work remains imperative and foremost in the treatment of HIV/AIDS, but studies indicate very strongly that this has to be done in

combination with issues like better equity and access of care to benefit all patients, and these issues need to be actively engaged in (Sixma et al., 1998).

According to Altice et al (2001), those individuals who have continuity in care from their physicians were overall more adherent, whereas those who were more socially isolated from their health care practitioners were less likely to keep to their medication regimen. This emphasises the importance of the relationship between the clinician, other health care professionals and the person receiving medical care. Furthermore, according to Kumarasamy et al. (2005) a major facilitator in the level of adherence remains the management of the illness in relation to controlling the virus, keeping one's body in good healthy condition and strengthening the immune system. Where PLWHA felt lowered side effects, and managed to maintain their weight and had a healthier look, they were better able to engage with themes of general overall feelings of health and well-being (Kumarasamy et al., 2005).

Trust in the physician and a high level of satisfaction with health care providers remain important factors for those on ARV medication. Those who have a higher level of trust in the medical providers show better adherence levels (Altice et al, 2001). Facilitating factors that emphasise a trusting relationship with medical caregivers include competence, comprehensiveness, consistency, continuity of care and compassion (Laince, & Davidhoff 1996; Lewis et al, 2006; Kaplan & Rogers, 1993). Conversely if there is a high level of social mistrust, especially from those who are marginalised and come from disadvantaged societies, this can affect adherence levels negatively. Such interactions in community health beliefs and medical outcomes play a prominent role in adherence to ARV. According to Gordillo, del Amo, Soriano and Gonzalez-Lahoz. (1999), satisfaction with the clinician does not necessarily translate to medication adherence. Therefore, although maintaining an honest, open and non-paternalistic relationship to those PLWHA remains crucial, in some cases well-intentioned interventions may paradoxically lead to the person's disengagement with their medication intake (Conway, 2007). For example, admission to poor adherence may lead to the disapproval of the physician (Conway, 2007) or the well-meaning intervention of medical alarms to remind the individual that it

is time to take their medication may have a negative impact of experiencing stigma and discrimination by the PLWHA (Mannheimer, Morse, Mats, Andrews, Child, Schemetter & Friedland, 2006).

The level of trust that the individual has in the medical system and the practitioners also intersects with the experience of side affects and the level of adherence. Those individual who had a higher trust in the medical system and the practitioners were better able to deal with the various side effects, and as a result managed to stay longer on the medication (Altice et al., 2001). Furthermore, it appeared that women in general were more likely to have longer visits with their medical practitioners and they were more likely to discuss emotional issues relating to their illness (Altice, 2001). Social desirability and the need to project a positive image seem to have impacted on the reported overestimation of adherence levels (Altice et al., 2001; Murri, Ammassari, Trotta, De Luca, Melzi, Minardi, Zaccarelli, Rellecati, 2004). PLWHA who are on ARV treatment have to be informed and reassured that their adherence response will not interfere with the care that they are receiving.

3.2.3 Health Care System

The health care system is found to have an impact on adherence levels. In some countries the waiting time to renew a prescription in public facilities can be on average five hours long (Hardon et al., 2007). The top end of this waiting time has been found to be approximately 12 hours. This translates into a loss of at least one working day per month and can present a host of issues for PLWHA (Hardon et al., 2007). Often those who have not disclosed their status or who do not have adequate support from those at work have the extra burden of explaining this time that they need (Hardon et al, 2007). In some situations these individuals may ask others to fetch the re-fills and requests are often made for three to four month refill time periods. However, paradoxically one month refills are used to monitor levels of adherence, and extended time periods may create added constraints (Hardon et al, 2007). Hardon et al. (2007) recommends that giving appointments may reduce waiting times. However, in the face of too little staff members,

inadequate training and heavy workload at most public medical services, this may not be a workable solution in most developing countries where resources are scarce.

3.3 PSYCHOLOGICAL FACTORS CONTRIBUTING TO NON-ADHERENCE

There has been much research conducted on the difficulty PLWHA experience in relation to their physical, emotional and interpersonal wellbeing (Kalichman, Di Marco, Austin, Luke & Di Fonza, 2003; Simoni, Demas Mason, Drossman & Davis, 2000). PLWHA will very often experience a series of losses including fear around losing their future (Shisana & Simbayi, 2002), fear of becoming ill and dying (Van Dyk, 1993), fear of losing their identity and self-esteem (Van de Walt & McKay, 1991). The fear of being alone and loneliness also feature very strongly for PLWHA as many find themselves being ostracised and discriminated against (Siegal & Schrimshaw, 2006). Furthermore, feelings of guilt may be pervasive around the belief that certain behaviours or lifestyle choices resulted in them contracting the virus, or PLWHA may feel guilty about the shame that they may have brought on those around them (Deacon, Stephney & Prosalendis, 2005). Guilt may also be experienced around the extra expenses that the families have to endure in the face of already strained resources (Van de Walt & McKay, 1991).

3.3.1. Stressful life situations

Considering the many psychological issues that PLWHA may have to face, much less research has been conducted on the psychological effects of being on ARVs. This area is poorly understood as the focus still appears to be primarily around the physical health and benefits of ARV treatment. However, findings indicate that the experience of psychological stressors on the PLWHA often result in poor health practices and thus lead to poor adherence levels (Bottonari, Roberts, Ciesla & Hewtitt, 2005). It was also found that that perception of stress was a greater predictor for poor adherence than acute stressful life situations (Bottonari et al., 2005). In addition, the number of stressors that the individual has to endure further complicates adherence levels (Mellins, Kang, Havens

& Chesney, 2003; Murphy, Greenwell, & Hoffman, 2002). With regard to acute stress, adherence to ARV medication may drop after a major life stressor but will return to previous levels once the stress has subsided (Bottonari et al., 2005). Finally, stress is known to indirectly affect the immune system, causing those who are infected to become more vulnerable to other opportunistic illnesses (Van Dyk, 1993). It is therefore is imperative to understand how stress may further complicate ARV treatment outcomes.

3.3.2 Depression, anxiety, PTSD symptoms

It appears that individuals who have been diagnosed with HIV suffer from disproportionally high rates of post-traumatic stress disorder and depression with an increased likelihood of suicide (Boarts, Sledjeski, Bogart & Delahanty, 2006; Kalichman et al., 2003; Simoni et al., 2000; Sledjeski, Delahanty & Bogart, 2005). In addition, as symptoms related to the HIV infection increase, PLWHA become more vulnerable to experiencing symptoms of anxiety (Boarts et al., 2006; Sledjeski et al., 2005).

Depression in PLWHA remains under-diagnosed, but it plays a significant role in non-adherence to treatment. (Gordillo et al., 1999). Depression is also an indicator of a shorter survival period in HIV-positive men and appears to be mediated by poor health habits and reduced adherence to treatment (Gordillo et al., 1999). The causal effect between poor adherence and depression is difficult to ascertain as less than optimal adherence may lead to depression, yet depressed individuals may be less motivated to take their medication (Nakiyemba et al., 2006). However, according to Schonnesson, Ross and Williams (2004), given the chronic nature of the HIV infection and the complicated treatment regimen, it may be that the constant intrusive thoughts around the illness and treatment may increase stress in PLWHA and the accompanying depressive symptoms. Hence, medical concerns can become a substantial marker for depression for those on ARV treatment (Schonnesson et al., 2004). This indicates that there is a close relationship between the experience of treatment and psychological distress, and it is an indicator that symptoms like depression or anxiety must be acknowledged and worked with before treatment is changed because of the reported negative experiences.

There also appears to be a high prevalence of PTSD in PLWHA, reflecting a high experience of traumatic events related to being diagnosed with HIV (Boarts et al., 2006). Studies (Gore-Felton, Butler & Koopman, 2001; Gore-Felton & Koopman, 2002; Kimerling, Armistad & Forehand, 1999a; Kimerling, Calhoun, Forehand, Armistad, Morse & Morse, 1999b) indicate that PLWHA have experienced at least one traumatic event that has been severe enough to meet the DSM-IV criteria for PTSD. Significant amongst these is the experience of some act of violence perpetrated against PLWHA as a result of their HIV status (Delius & Glaser, 2005; Parker, Aggleton, Hawell, Pulerwitz & Brown, 2002; Strode & Grant, 2001). In addition, a diagnosis of a life-threatening illness like HIV infection may lead to the development of either acute stress or PTSD symptoms. However, some studies have found that PTSD in itself does not impact on the adherence rate to ARV treatment in PLWHA, however, the relationship between PTSD and non-adherence may be driven by the presence of co-morbid depressive symptoms (Safren, Kumarasamy, James, et al., 2005; Sledjeski et al., 2005).

3.3.3 Health-related quality of life

Quality of life refers to the appraisal on one's life which contains features that are satisfying and meaningful. Quality of life is important in medical decisions that enable the individual to survive (Sarafino, 2002). The quality of life that may be experienced by PLWHA who are on ARV can be influenced not only by the PLWHA but also by the clinician (Gordillo et al. 1999). This fact challenges medical doctors to collaborate with professionals in other areas like the social and behavioural sciences so that they may collectively explore the gap between the intention by the PLWHA of adhering to treatment and action outcome of such an intention (Gordillo et al., 1999). ART can prevent the progression of HIV, prolong life and improve the quality of life for those who are infected. The individual's motivation around their illness and treatment as well as their lifestyles needs to be considered to understand levels of adherence (Gordillo et al., 1999).

Amongst the lifestyle variable, Holmes, Warren, Wang, Chapman and Gross (2007) argue that financial worries are a significant, strong and independent predictor to non-adherence. PLWHA who worry that they are not going to be able to meet their financial needs often take limited care of themselves in order to minimise expenditure brought on by the illness (Holmes et al., 2007). Having this lifestyle attitude leads to self-rationing of medications and a lower level of adherence (Holmes et al., 2007). In addition, people competing with sustenance needs were found to have poorer access to medical care. Holmes et al. (2007) believe that asking people about how frequently they experience worries about financial needs, like meeting the payment of accounts and taking care of themselves, will often provide useful information for identifying higher-risk individuals. This information can also be useful when addressing behavioural interventions in relation to the level of adherence.

A particularly vulnerable group of people are those who are homeless and who are at an increased risk of negative health outcomes (Kidder, Wolitski, Campsmith & Nakamura, 2007; Webster & Barr, 1999). These individuals suffer from more chronic diseases, are at higher risk for infectious diseases, have more mental illnesses and suffer from more physical problems in comparison to the general population (Kidder et al., 2007; Webster & Barr, 1999). Drug and alcohol use further compound health outcomes for the homeless or those living in inadequate housing facilities. This group of people also are far less likely to get the quality of care that may be optimal for adherence to ARV treatment, and improving their quality of life is a potentially important mechanism (Altice et al., 2001).

3.3.4 Coping and managing the self

As has been discussed, PLWHA undergo great difficulty in relation to their physical, emotional and interpersonal wellbeing. The stress that they may experience involves a perceived discrepancy between the demands of a situation and the resources of that individual (Sarafino, 2002). Coping is the process by which PLWHA try to manage the perceived discrepancy between the various demands placed on them and the resources that are seen to be helpful in the stressful situation (Sarafino, 2002).

The level of adherence to antiretroviral treatment by PLWHA may depend on their ability to adapt to the situation of living with HIV/AIDS (Cederfall, Langius, Lidman & Wredling, 2002; Siegel & Schrimshaw, 2007). According to Antonovsky (1987) (as cited in Cederfall et al., 2002), a good sense of coherence, with a focus on how the individual may comprehend, find meaning and manage his or her illness, may lead to better stress management and coping capacity. A patient who understands and finds meaning in the necessity of strict adherence often manages to take the ARV medication more successfully (Cederfall et al., 2002). In addition, cognitive coping strategies also have stress-buffering properties that can lead to improved coping. Cognitive coping models are based on the concept of finding benefits that can help PLWHA with the psychological adjustment to the chronic stressors, thereby increasing their rate of adherence to ARVs (Siegel & Schrimshaw, 2007). However, it must also be noted that finding cognitive benefits to a stressor like HIV/AIDS may not to have much of an impact on individuals who are experiencing multiple HIV/AIDS-related stressors. Other stressors like social conflict or poverty may impose an added burden that may decrease psychological adjustment through cognitive processes and these needs must be taken into account as well (Siegel & Schrimshaw, 2007).

In managing the self in the face of severe multiple stressors, PLWHA who managed to overcome self-blame and who found meaning in the suffering that they had to endure tend to have better levels of treatment adherence (Lewis et al., 2006). These individuals also recognised the need for personal accountability, to regain control over their lives and their health and to confront the disease. Investing in themselves and taking pride in their accomplishments of managing their illness and medication allowed them to adhere to the medical regimen. According to Lewis et al. (2006), individuals who described an experience of personal development through self-reflection and education, learning from life experience, adopting a realistic future outlook and making themselves a priority had a better chance of staying on course. In addition, PLWHA who were optimistic about their future and experienced health within the illness despite living with a disease were better able to make plans for a future that might have been previously impossible (Lewis et al., 2006).

3.3.5. Counselling needs

HIV/AIDS counselling is a vital part in the dissemination of information. HIV/AIDS education is generally aimed at informing PLWHA about the disease in order to alleviate fear as well as ignorance so that they may better manage their illness (Van Dyk, 2001; Van Dyk & Van Dyk, 2003) Counselling in relation to its educative purpose is also beneficial in prompting people to change their behaviour around HIV/AIDS in order to prevent further spread of the disease and to stop the individual from being infected by different strains of the virus (Van Dyk, 2001; Van Dyk & Van Dyk, 2003). In addition, counselling serves a vital purpose in providing much needed emotional and social care and support to PLWHA (Van Dyk, 2001; Van Dyk & Van Dyk, 2003). The dissemination of information and provision of care and support that the PLWHA receives through counselling should be extended to include the facilitation for better treatment adherence.

Therefore, whilst the physician may provide the preliminary explanation of treatment and the biomedical reason for adherence, the HIV/AIDS counsellor spends a greater time covering ART adherence and other HIV-related issues in much more detail (Safren et al., 2005). Additionally, even though medical doctors are revered due to their status in culture, counsellors may be perceived to be more approachable and easier to speak to (Safren et al., 2005).

In settings with poor resources, lay counsellors serve a more important function. According to Hardon et al. (2007), the quality of counselling given to PLWHA differed greatly between countries and also between different facilities within a country. In resource-strapped countries and situations only a small proportion of ARV users see a counsellor at each visit. Most PLWHA come into more frequent contact with a pharmacist, nurse or doctor (Hardon et al., 2007). In public care facilities health care workers are generally overworked and struggle with the large volume of work. Low motivation and work fatigue can have a severe impact on how PLWHA are managed. Non-adherence to ARV treatment places an additional burden on the medical

practitioners, creating a cycle of burn-out and lowered attention (Hardon et al., 2007). In resource-strapped situations the training and use of lay counsellors regarding ARV adherence may take the burden off the medical system and allow the PLWHA to gain access to the much needed support they need in order to keep to the treatment regimen.

3.4 SOCIAL FACTORS CONTRIBUTING TO NON-ADHERENCE

3.4.1. Poverty

The chance of being exposed to the HI virus is equal between those who are wealthy and those who are living in poverty and there is no single formulation that can be used in the examination of the interplay between poverty and HIV/AIDS (Mosley, 2004). However, research indicates that HIV has come to be known as the disease of poverty (Jackson, 2002; Barnett & Whiteside, 2002; Mosley, 2004; Van Der Vliet, 1996; Whiteside & Shunter, 2000). An indirect association remains between poverty and the rate of HIV infection and this can be described by several factors like poor nutrition, lack of access to health care and having limited resources in meeting basic needs (Barnett & Whiteside, 2002; Kalichman, Simbayi, Jooste, Cherry & Cain, 2005). Whilst poverty relief will not stop HIV/AIDS, Crothers (2001) postulates that raising individuals and communities out of poverty will enhance their capacity to resist HIV/AIDS once infected. Furthermore, the literature reveals that people who have a higher income have less difficulty when adhering to their treatment than those who are poverty stricken (Nakiyamba et al., 2006). This is especially relevant in underdeveloped countries where many thousands of people are living in poverty, and HIV adherence is increasingly becoming an issue (Nakiyambaet al., 2006).

3.4.1.1 Hunger and food needs

Not only does the PLWHA need extra nutrition (Kotler, 2000; Sharpstone et al., 1999), but there is an additional nutritional need during the initial stages of treatment as the body regains strength and weight (Au, Kayitenkore, Shutes, et al., 2006; Jimenez, Garcia-

Lorda, Allonso-Villaverda, de Virginia Sola, et al., 1998). In addition, PLWHA who are on treatment have reported that treatment increases their appetite (Au et al., 2006). Addressing poverty and nutritional needs as a social issue is critical to those who are on ARVs (Hardon et al., 2006; Kumarasamy et al., 2005; Nachega, Lehman, Hlatshwayo et al., 2005; Weiser, Wolfe, Bangsberg et al., 2003). Nachega et al. (2005) argue that on the surface, treatment to adherence sounds simple, but it is difficult for people to take their medication when they are hungry. One respondent in a survey commented that "the challenge is how do you link that person to a support mechanism that would ensure that there is some food on that person's table at least once a day" (Hardon et al., 2006, p.661). Often employed family members provide the necessary financial support for adherence including the provision of food. Some PLWHA have to resort to the extent of begging for the old age pension from their grandparents so that they can buy some food (Hardon et al., 2006; Kumarasamy et al., 2005; Nachega et al., 2005). Some PLWHA stop treatment because of a lack of food. In other cases it has been found that patients will not adhere strictly to the treatment often reducing the intake of medication from a twice-a-day regimen to once a day because they have only one meal (Hardon et al., 2006; Kumarasamy et al., 2005; Nachega et al., 2005). Government social grants are often a major concern for those who are unemployed and on treatment (Hardon et al., 2006; Kumarasamy et al., 2005); Nachega et al., 2005). Free treatment is clearly not enough and ARV programmes in resource-poor settings will also have to find ways to address hunger constraints with regard to treatment.

3.4.1.2 Transport and other costs

Even though PLWHA may receive free treatment, transport costs may be a reason why some individuals are not able to come to the health facility for refills of the medication (Hardon et al., 2006). This may be particularly of concern to those individuals who live in rural areas where HIV treatment points may be difficult to access. Kumarasamy et al. (2005) found this to be the most frequently and profoundly discussed theme. Even when facilitating factors like family help in getting patients to their treatment points are available, the cost of transport is a powerful barrier (Kumarasamy et al., 2005). In some

instances, individuals reported taking drastic measures, like sacrificing irrigation systems for their farming needs or getting into further debt, to ensure they could pay for transport and other costs (Kumarasamy et al, 2005). Such a situation thus leads to further poverty for the families who are than unable to manage the illness. In other cases the cost of the treatment led to self-imposed drug holidays where the patient would only resume taking medication when they could afford to do so again (Laniece, Ciss, Desclaux, Diop, Mbodji, Ndiaye, Sylla, Delaporte & Ndoye, 2003; Safren et al., 2005).

The increasingly high cost of ARVs, even with generic competition, is an important barrier to access, more especially in developing countries (Seone-Vazquez & Rodriguez, 2007). Several multi-national efforts by the Accelerated Access Initiative (AAI), which was set up in May 2000 and consists of several international organisations involved in the fight against HIV/AIDS, and various pharmaceutical companies have been negotiating price ceilings through shared expertise and technical resources on ARVs. However, there have been several problems related to drug regulations and policies (Seone-Vazquez & Rodriguez, 2007) and the high cost of ARV thus still remains a significant barrier.

3.4.2. Stigma and Discrimination

HIV/AIDS-related stigma is a social as well as psychological reaction to the epidemic that is rooted in denial, fear and distrust of those who are infected but also includes those who are affected by the disease by virtue of their association with the infected individual (Aggleton, Parker & Maluwa, 2003; Deacon et al., 2005). Many studies show the very deep and embedded nature of stigma-related discrimination (Aggleton et al., 2003; Kelly, Ntlabati, Oyosi, Van Der Riet & Parker, 2002; Niyonzima, 2003; Parker et al., 2002,). Discriminating attitudes include religious, moral and ethical positions that are taken around the perception that PLWHA are to be blamed, punished, that they bring on shame on the family and community or that they are deviant in some way.

Stigma and discrimination form a large part of the isolatory nature of PLWHA due to a lack of support from others around then (Hardon et al., 2007). People who hide their status also have to keep the treatment that they are receiving hidden and this has consequences for adherence, and taking medication in secret often leads to irregularity (Hardon et al. 2007; Kumarasamy et al. 2005, Nachega, Knowlton, Deluca, Schoeman, Watkinson, Efron, Chaisson & Maartens, 2006). In addition, these individuals are also not able to get adequate encouragement and support from others to take medication (Hardon et al., 2007; Kumarasamy et al., 2005). In some instances, individuals did not view the community members as people who could assist them with their medication at all and often feared being ostracised and mistreated (Kumarasamy et al., 2005).

Often individuals on ARVs expressed fear of a lack of confidentiality regarding treatment delivery (Laniece et al., 2003, Nachega et al., 2006). PLWHA feared that their status would be divulged to others in their communities and many participants wished to get treatment for two months or more to reduce contact with the medical staff. In a study conducted by Patel (2005), a participant reported that she would sometimes miss her treatment refills as a neighbour worked at the local hospital and she would wait for the days when he was on leave from the hospital before she refilled her scripts rather than risk being recognised. This participant feared that her HIV status would be discovered and revealed to the community and as a result she might be victimised. Using public pharmacy set-ups also led to ARV users to not adhere strictly to the regimen as they feared their HIV status would be exposed (Rief, Whetten, Lowe & Osterman, 2006). Some individuals would also travel longer distances so that they could access treatment further away from home in an attempt to hide their status for fear of some kind of repercussion from others (Rief et al., 2006). This often further complicated cost and put an extra financial burden on them.

3.4.3 Social Support Needs

An HIV diagnosis can place a substantial amount of stress and burden on those who are infected as well as those who are affected, and there are many psychosocial consequences following an HIV diagnosis. Social isolation is often a painful reality for many (Batohi, 2004). Support networks can be a powerful force that can prove to be a rich source of empowerment for those living with HIV/AIDS. These networks can supply information around issues such as challenging discrimination, promoting counselling needs, seeking legal protection for basic human rights and advocating for treatment in relation to ARV treatment, and some members may even become very useful in assisting others as they become experts in the latest treatment options or treatment combinations (Jackson, 2002, Nachega et al., 2006). Hence, PLWHA can become partners in their own treatment, shifting the patient/practitioner relationship to a point that ensures balance (Jackson, 2002).

3.4.3.1. Support groups

One of the key psychosocial consequences to being diagnosed with HIV is social isolation. PLWHA have been found to spend increasingly longer amounts of time being alone and engaging in socially solitary activities (Kalichman et al., 2003; Simoni et al., 2000). Others often avoid contact with PLWHA, leaving the individual with overwhelming emotional responses which require social support to help them cope (Kalichman et al., 2003; Simoni et al., 2000).

Unmet mental health needs related to counselling, substance abuse, loss, grief, depression and anxiety have been found to be significantly associated with low adherence levels in PLWHA (Rief et al., 2006). In addition, participants who experienced three or more different types of unmet needs were less likely to take HIV medication, indicating that multiple unaddressed needs may influence medication use. Rief et al. (2006) also argue that adherence levels are influenced more by a specific unmet need of mental health related issues rather than multiple unmet social support needs. Gordillo et al. (1999)

believe that depressed individuals who do not have adequate social support also have a problem in staying on their medication. However, perceived social support did not seem to increase improved adherence in the case of depression (Gordillo et al., 1999). Hence, depressed individuals may renegade on their treatment irrespective of whether they receive social support or not (Gordillo et al., 1999). On the other hand, PLWHA who did not show depressive symptoms were more likely to be assisted in adhering to their medication through a social support network (Gordillo et al., 1999). Social support groups continue to be among the most widely available psychosocial intervention for PLWHA (Walch, Roetzer & Minnett, 2006), and present an area that requires further research in relation to adherence to ARVs.

Furthermore, those individuals who are pessimistic about the effectiveness of the treatment that they are receiving and who do not have adequate social support remain highly vulnerable to becoming non-adherent in their treatment regimen (Diabate, Alary Koffi, 2007). There also appears to be an intimate relationship between stigma and social support (Kumarasamy et al., 2005). Although social support is very often needed, PLWHA are scared to disclose their status for fear of discrimination. However, the most frequent social facilitator to adherence includes help from others. Family members have been more frequently referred to in this context, but the benefits of the community as a social facilitator in this regard still remain poorly understood (Nayikamba et al., 2006; Wagner, 2002). Visnegarwala, Rodrigeuz-Barradass, Graviss et al., (2006) propose that de-institutionalising the approach to ARV adherence and using community outreach programmes may be a more cost-effective and acceptable way to deliver ARV therapy. Support groups incorporating those peers who can provide both the delivery of the ARVs as well as constant cognitive reinforcement and social support may be an area for further investigation (Visnegarwala et al., 2006)

3.4.3.2. Home-based care-giving

Home-based care-giving provides improved assistance to the PLWHA and also reduces the burden on overcrowded and under resourced health systems (Gupta, da Silva & Neves, 2006; Jackson, 2002). Integrated home-based care promotes an extended relationship between the healthcare team and the PLWHA, as well as increased attention for the family and community. This allows for more social and psychological support (Gupta et al., 2006). Concentrating therapy at home establishes primary caretakers within the home or community, fortifying social support networks and thereby increasing daily adherence. Research by The Brazilian Ministry of Health indicated that the cost of extended resources of integrated home care would be a justified and more cost effective measure to supporting PLWHA and also assisting in an increase in adherence levels (Gupta, 2006).

In addition, Hardon et al. (2007) found that children can be useful as facilitators to ARV adherence. They can be an important source of support when it comes to collecting medication for their parents or in contributing towards their food needs, as indicated by this comment made by a respondent in a survey, “My children, after seeing the state I was in and getting my ARVs, I called them and told them my state. They got encouraged and as a result they buy me passion fruits and sugar because they know that the drugs that I am taking is so strong” (Hardon et al, 2007, p. 662).

However, it has also been found that home- and community-based care-giving can actually lead to neglect for many PLWHA as they are kept out of the health system (Gupta et al., 2006; Hardon et al., 2007). The burden of home care on women and children also places those who are most vulnerable in the community at further risk as their work load increases (Gupta et al., 2006; Hardon et al., 2007) As such, home-based and community care have to be critically evaluated as an activity of social action.

3.4.3.3. Managing the environment

Participants who were able to manage the environment by recognising positive and negative sources of support are better able to adhere to their treatment (Lewis et al., 2006). Individuals who were better able to assess their support system as appropriate, gauged their level of disclosure, and avoided stressful people and situations were in a much stronger position. Secondly, if the participants could identify external cues, creative solutions and lifestyle habits like finding a convenient hour to take the medication, linking taking medication to a favourite time of the day, using partners and other supportive networks or establishing an active partnership with their health care team assisted them in adhering to their medication, i.e. their problem-solving attitudes helped in adherence (Lewis et al., 2006).

Mannheimer et al. (2006) used the initiatives of the Community Program for Clinical Research on Aids (CPCRA), a community-based HIV clinical trials network, evaluated two different approaches to promoting ARV therapy initiation and continuing support throughout follow-up. The first intervention, the Medication Manager (MM), was an initiative that involved trained research staff members who worked individually with participants to provide tailored adherence support. This was done in a guided manner identifying and addressing each participant's background information, motivation levels and skills base (Mannheimer et al., 2006). The second intervention was an electronic medication reminder system – A Little Reminder (ALR) device - that was devised to sound and flash at certain times to remind the person to take their ARVs (Mannheimer et al., 2006).

The MM intervention programme worked better on individuals who were on less complex medication regimen but showed less favourable results for those on more complex treatment plans (Mannheimer et al., 2006). This may have been due to increased toxicity for the more complex regimen group of individuals, but nonetheless the MM was a community initiative that appears to show some favourable results because of repetitive adherence support that may have been as a result of frequent contact and social support.

In comparison, the ARL programme showed much less success as direct support was not available (Mannheimer et al., 2006). The ARL also brought up other issues around confidentiality as well as practical issues of battery malfunctions, thereby limiting its effectiveness (Mannheimer et al., 2006). A technical reminder device falls short of addressing barriers that are likely to be dealt with in a more comprehensive manner through face-to-face contact.

3.4.4. Knowledge of illness/Belief about the treatment

Stemson et al. (2005) have put forward the argument that the first step in empowering patients to care for their health is by equipping them with information in the belief that high levels of basic knowledge will promote desirable behaviour. A better perception of at least one negative consequence of non-adherence, like side effects, lowered quality of health, weight loss, hastening death and increasing cost for treatment, allowed PLWHA to improve their adherence levels (Stenson et al., 2005). In addition, there is some indication that individuals who have a better education show a propensity towards better adherence levels to ARVs (Gordillo et al.1999; Kleeberger, Phair, Strathdee et al., 2001; Wong, Lawrence, Struthers, McIntrye & Friedland, 2006).

Using alternate treatment has proven to have become a significant barrier to ARV adherence (Owen-Smith, Diclemente & Wingwood, 2007; Wong et al., 2006). In a study by Owen-Smith et al. (2007), it was fond that women who use natural immunity boosters or vitamins are significantly more likely to miss doses of ARV, suggesting that they were using these as an alternative to ARV treatment rather then complementing treatment. Two possible explanations may explain this; firstly, patients may experience difficulty incorporating the immunity boosters into their day-to-day life. As a result those who use them may feel both logistically and psychologically overburdened and may find it necessary to sacrifice the prescribed treatment (Owen-Smith et al., 2006). Secondly, ARV treatment may be significantly disliked due its unpleasant side effects and therefore PLWHA may be relying increasingly on alternative treatment options. However, despite these findings, Wagner (2002) argued that attitude and beliefs around traditional healing

systems and alternative treatment options were largely unrelated to the level of adherence to ARVs by PLWHA.

3.5 CONCLUSION

This chapter has reviewed pertinent issues in this field of research and examined the various biomedical, psychological and social barriers and facilitators that impact on the levels of ARV adherence. It should be noted that this literature review has mostly presented the barriers as these are predominantly discussed in the literature. However, facilitators to ARV adherence are imperative as these may help to understand the full scope of ARV treatment and thus provide a more holistic understanding of the topic.

CHAPTER FOUR

METHODOLOGY

4.1 INTRODUCTION

In this chapter the methodology used in the collection and analysis of the data is discussed. This includes information regarding the research paradigm that has been utilised, setting, the sample, the procedure, data collection and analysis of data. This is followed by a reflection as part of a personal exercise on the part of the researcher. Finally, a discussion of the ethical considerations is presented.

4.2 RESEARCH PARADIGM

A qualitative research paradigm underpins this study. The decision to use qualitative data is based on the need to understand matters from the participant's perspective. (Babbie & Mouton, 2004; Neuman, 1994). The aim of this study is to describe and explain events as close as possible to the lived experiences of the participants. Consequently, every attempt has been made by the researcher to understand the worldview and belief systems of the participants (Babbie & Mouton, 2004; Neuman, 1994). In addition, the researcher hoped to uncover deep and meaningful interpretations of the related research questions through in-depth descriptions to capture the understanding of the participants (Babbie & Mouton, 2004; Neuman, 1994).

The qualitative methodology of phenomenology has been utilised in this research to develop insight into the dynamic experiences of PLWHA who are on ARV treatment. According to Babbie & Mouton (2004), phenomenology goes beyond the positivistic paradigm and aspects of causal factors to include reflexivity and the various ways of being in the world. The focus of phenomenology is the rigorous emphasis of the PLWHAs subjective experiences of being HIV-positive and on ARV treatment and the

manner in which the experiences are constructed, co-constructed and de-constructed in socially contrasted contexts

4.3 RESEARCH QUESTIONS

This research sought to explore the various biopsychosocial barriers and facilitators regarding ARV adherence from the perspectives of the health-care providers and the patients. As the themes unfolded four major themes emerged in relation to the main research questions, aims and objectives. The first three themes revealed, individual level barriers and facilitators, secondly interpersonal level barriers and facilitators and thirdly systemic level barriers and facilitators. The fourth theme has been organised around intervention level barriers and facilitators to ARV adherence.

4.4 SETTING

The sample of the present study was primarily drawn from the Themba Lethu Clinic which is based at the Helen Joseph Hospital in Johannesburg. The Themba Lethu Clinic, which means “Our Hope” in isiZulu, is one of the biggest HIV sites in Southern Africa. There are approximately 6200 patients on ARV treatment at the clinic. The clinic has a staff compliment of about 65 and sees approximately 200 patients a day (Health-e, 2008).

The patients who use this facility are mainly from the inner city “townships” that surrounds the Johannesburg area. Many of the patients come from as far as Alexandra and Diepsloot even though there may be ARV treatment points close to their place of living. Majority of the patients face profound difficulties related to poor socioeconomic standards facing unemployment, low education levels and poverty.

In addition to this, a further sample was drawn from the Treatment Action Campaign (TAC). The TAC is a non-governmental organisation which was started in 1998. Its main purpose is to procure treatment for those infected with the virus. Part of the TAC’s initial mission was to put pressure on the African National Congress (ANC) to start a free ARV

programme in state hospitals, and to get pharmaceuticals to drop their ARV drug prices. The TAC is an activist group that grew out of the political belief that PLWHA should be afforded the same dignity, access to healthcare and equality as all other South Africans (Treatment Action Campaign, 2008).

4.5 PARTICIPANTS

In keeping with qualitative principles, the intention of this study has not been to yield generalisable data (Babbie & Mouton, 2004; Neuman, 1994) but rather to gain an in-depth understanding of the participants' perspectives. A non-probability sample was thus used. Due to the nature of non-probability sampling, the criteria for sampling was based on the availability and willingness of people to participate in the study, and participation was completely voluntary (Rosenthall & Rosnow, 1991).

Furthermore, a combination of purposive as well as convenience sampling was used in this study. The purposive sample included those individuals who were able to provide specialist opinion regarding the facilitators and barriers to ARV adherence. The use of purposive sampling did not allow for random sampling, therefore all persons in a given category were not given an equal chance of being sampled. This sample included medical practitioners. The medical doctor heads the HIV-clinical unit at the hospital. Two nursing sisters were interviewed. Both the nursing sisters have a number of years of experience with PLWHA. One of the nursing sisters has also been instrumental in HIV/AIDS activism for a number of years. Two HIV-adherence counsellors were interviewed. The counsellors who do adherence counselling are specifically trained in this area and see patients individually and also run adherence and re-adherence groups for those patients who default on treatment. A nutritionist was interviewed. Initially this was not intended but it became evident during the data collection that valuable information in relation to nutritional and food needs was of crucial importance. Finally, two ARV treatment activists were interviewed. Both of the participants have a number of years of experience as project managers at the TAC. The reason for including these participants in the study

was so that a more holistic understanding of the issue at hand could be gained not so much for an expert point of view but rather from a multidisciplinary perspective.

The sample group also included individuals on ARV treatment as well as caregivers to individuals who are on ARV treatment. This sample group is reflective of convenience sampling and the criterion for participation was based on the availability and willingness to participate. Four patients were included in the study. Two of the patients had defaulted on treatment and had come back to the clinic for treatment. In addition 2 caregivers to HIV-positive patients were interviewed so as to include some of the challenges that they may be facing.

The sample was thus chosen to reflect those who were the most likely to provide the most meaningful information in relation to the aims and objectives specific to this research based on the judgment of the researcher and in consultation with the supervisor (Rosnow & Rosenthal, 1991). By including this range of participants it was hoped that a more holistic and in-depth understanding of the research aims and objectives would be achieved. It should be noted that some of the professional participants were also HIV-positive and on ARV treatment. Their experiences intersect with both having the experience of working with people who are on treatment as well as having a personal experience with treatment. The following is a breakdown of the participants:

Medical doctor	1
Nursing sisters	2
Nutritionist	1
ARV adherence counsellors	2
Treatment activists	2
PLWHA on treatment	4
Caregivers of PLWHA on treatment	2

4.6 PROCEDURE

The Themba Lethu Clinic at the Helen Joseph Hospital was the main site used in this research. All the participants except the two treatment activists were interviewed through this clinic. Ethical clearance was first sought from the University of Witwatersrand - Medical Research Ethics Committee. Once this was obtained **(Appendix 10),** permission to conduct this study was obtained from the Clinical HIV Research Unit, Department of Medicine (**Appendix 4**). After the regulatory manager of this unit had granted permission for the research to be conducted at the clinic **(Appendix 10)**, the researcher was put in touch with the senior social worker.

The purposive sample (doctor, nurses, counsellors, nutritionist) was identified with the assistance of the senior social worker at the clinic. Interviews were set up with these participants by the social worker. Since Themba Lethu is a very busy clinic and the work schedule and work load of these participants is very heavy, the researcher had to often wait for the participants to have a break in their work routine before proceeding with the interviews.

The convenience sample (participants on treatment and caregivers) were identified with the assistance of one of the adherence counsellors as there was already an established relationship of trust with the patients who were receiving their treatment at the hospital. All the participants were informed verbally about the study by the counsellor on the day that they were attending the clinic and a choice was given to the participants to meet with the researcher. The researcher then arranged for a convenient time to meet with the participants whilst they were waiting for their treatment. As this sample was drawn from a hospital in a specific area, it was envisaged that there would be some common characteristics in terms of racial and socio-economic background. It is hoped that this may have assisted in the facilitation of the sharing of common experiences.

Letters explaining the nature of the study were handed out to all the participants (**Appendix 5**). Consent forms requesting permission to conduct the interviews as well as

permission to audiotape the interviews were handed out at the same time (**Appendix 6**). Once the letter of consent had been returned, appropriate arrangements were made for the interviews to be conducted.

Treatment activists were accessed through the Treatment Action Campaign organisation. Information letters explaining the nature of the study were given to potential participants (**Appendix 7**). An appropriate time and place of meeting was arranged with each participant. Before the interviews took place the full nature of the study was explained to the participants and the necessary consent (**Appendix 6**) was obtained.

4.7 DATA COLLECTION

Data was collected using semi-structured, in-depth interviews. All the interviews were audio-recorded. Interview times ranged between 30 minutes and one hour.

According to Marshall and Rossman (1995), an in-depth interview is more like an ordinary conversation than a question-and-answer session. However, unlike a conversation, there was a clear purpose in the interview session (Marshall & Rossman, 1995). This was done by using a semi-structured interview schedule that allowed for a set amount of information to be gained without limiting the sequence and flow of the discussion **(Appendix 8).** Thus the semi-structured, in-depth interviews allowed for greater flexibility in the questioning process. As a result the researcher was able to probe for greater detail and depth, or clarification of opinions, attitudes and beliefs regarding the subject matter (Marshall & Rossman, 1995). This method also allowed the researcher the opportunity to observe non-verbal behaviour.

As a personal interaction is necessary in semi-structured, in-depth interviews, the participant's willingness and co-operation was imperative (Marshall & Rossman, 1995). A weakness of this interviewing method may have been that participants may have at times been unwilling or uncomfortable to share sensitive information. One participant had substantial difficulty in engaging with the researcher. It appeared that some of the

participants feared that they might be disregarded for further treatment based on their responses. In addition, the interviews were in English and it was difficult for some of the participants to understand particular questions posed to them. Finally, this type of interviewing required a certain degree of expertise on the part of the interviewer (Marshall & Rossman, 1995). This can be particularly challenging when working with a highly vulnerable population. The researcher's background in community psychology was helpful in trying to manage and negotiate some of these difficulties.

One of the reasons for choosing to audio-record the interviews was that the key advantage of this method over taking field notes is that it is less prone to the interpretive filtering effect which is more evident in taking field notes (Speer & Hutchby, 2003). In addition, Hammersley and Atkinson (2003) (as cited in Speer & Hutchby, p.316) argue that recording enables the researcher to capture the social process and context in their entirety and that it provides for a more accurate and detailed account of what was said. A distinct disadvantage of audio-taping may include reactivity or reactive affects (Speer & Hutchby, 2003). It is thus possible that the recording device may have made the participants nervous or anxious, affecting their responses. The non-verbal interaction of at least two participants suggested a discomfort with the recording device. The option of conducting the interview by making field notes was given to all participants but they all preferred the interviews to be audio-recorded.

Finally, even though every effort was made to find a private and quiet environment in which to conduct the interviews, this was not always possible. The rooms where counselling takes place at the hospital are very small and the walls are not soundproof. This made it very difficult for the participants to talk in complete privacy. In addition, the interviews were interrupted from time to time as counsellors looked for a free space from which to work from. This may have impacted on the information that was provided by those who were on treatment. A further difficulty was that the data from four of the interviews was lost due to a combination of very loud background noise and some participants talking very softly. However, despite this the semi-structured nature of the interviews ensured that a large amount of data was generated for analysis.

4.8 DATA ANALYSIS

The analysis of data was done by means of the qualitative analytical technique. All the audiotapes were transcribed verbatim. Once the data was transcribed, thematic content analysis was used to analyse the barriers and facilitating factors impacting on the adherence levels of PLWHA on ARV treatment. Thematic content analysis involves thematic coding which is a process of developing initial categories of concepts and themes through in-depth analyses of the data (Marshall & Rossman, 1995). General themes were thus extracted and carefully scrutinised to accurately capture the understanding and perspective provided by the participants. This involved examining the text for the occurrences of selected words, phrases, concepts, themes or sentences in order to draw out meaning of a descriptive nature (Marshall & Rossman, 1995). A thematic content analysis can therefore be defined to be a systematic technique for compressing huge amounts of information into fewer categories (Boyatzis, 1998).

This procedure involved the evaluation of information through five key steps (Marshall & Rossman, 1995). Firstly, the data was organised into key ideas and theories arising from the literature review (Marshall & Rossman, 1995). For the purpose of this research, questions asked during the interview (**Appendix 8**) provided the framework and cornerstone for the organisation of the themes. This assisted in reducing the raw data into a more manageable size. It also allowed for an internalisation of as much data as possible by the researcher (Boyatzis, 1998).

Secondly, key themes were identified through a process of induction (Marshall & Rossman, 1998). During this process the precise description of the themes was not as important as looking for and finding broad patterns across the responses (Boyatzis, 1998). Themes were then developed and categorised deductively (Boyatzis, 1998). Prior research and theory was applied to replicate, extend or refute what was already presented in the literature review (Boyatzis, 1998).

Thirdly, coding of the emerging themes took place by using different colour markers. The aim of this type of clustering was to further break down thematic information (Marshall & Rossman, 1995). Fourthly, the themes were then explored. This was done via elaboration that allowed for a comparison between themes and sub-themes (Marshall & Rossman, 1995). Finally, the data was written up as an interpretation (Marshall & Rossman, 1995). This process involved the process of deciding on the level of analysis that sufficiently captured the views of the participant as well as deciding on the number of concepts to code for the accurate representation of the collected data.

Thematic analysis is a logical way of organising data in relation to the research questions as well as in the interest of the participants. It should be noted that while coding captures the descriptive nature of the data, the process undertaken in this research also provided for latent content. This latent content was examined and the underlying meaning of the data was then discussed (Ritchie, Spencer & O'Connor, 2003).

4.9 VALIDITY OF RESEARCH

A common concern with qualitative research is the way in which the researcher's bias may influence the findings and discussions (Greenstien, 2003). It is thus important that some form of systemic check or cross-check be carried out by the researcher to ensure that the data is plausible. Greenstein (2003) argues that trustworthiness is an important factor for good qualitative research. Furthermore, the four aspects of credibility, transferability, dependability and confirmability were also taken into account

Credibility is the accuracy of the description of the data (Greenstein, 2003). In this the researcher worked closely with her supervisor to ensure that the reconstruction and representation of the respondents' views on the barriers and facilitators to ARV medication were thematically coded and depicted accurately. In addition, although it was not possible to carry out member checks with all the respondents, the researcher cross-checked her understanding of what was reported with some of the participants. The second aspect of transferability ensures that the findings can be applied to other contexts

and to other respondents (Greenstein, 2003). This was done by establishing the degree of similarity in the respondent's views with other research material on the same subject matter. Additionally, differences were explored and alternative explanations were also sought. The third aspect of dependability concerns the stability of qualitative data over time (Greenstein, 2003). This research collaborated with other similar research and even though people's reality changes over time, much of the findings concur with similar themes and observations found in the literature survey. Where the arguments in this research report differ, the researcher has made the data available so that the findings, discussions, conclusions and recommendations can be traced for verification and ensure comparability.

Despite the above checks to control for researcher impartiality, the personal as well as intellectual biases and values of the researcher have to be taken into consideration as this will impact on the nature of the interaction and the quality of the information gained. Seedat (2001) suggests that research cannot be a neutral exercise and that the researcher cannot be independent from the participants. Personal and epistemological reflexivity become necessary as ways to explore the manner in which the researcher engaged with the study and how further meaning is created out of this exercise (Seedat, 2001)

The researcher's personal view in undertaking this research is that the analysis of treatment adherence in PLWHA cannot be limited to the biomedical/positivistic position or the interpretive epistemological perspective. A thorough study of this topic has to include a critical evaluation that extends beyond just understanding phenomena in order to bring about real change through active participation and activism. The researcher's own interest in HIV began almost a decade ago when she first came into contact with HIV-positive babies at the Chris Baragwaneth Hospital. The researcher found it was a travesty that these babies were allowed to suffer and die whilst the government would engage in one debate after another that stopped pregnant mothers and babies from receiving the much needed treatment.

Furthermore, the researcher's interest in medical sociology and her background in community psychology added to her standpoint that whilst biomedicine and traditional psychology may view health behaviour from a micro point of view, this was a further injustice that PLWHA have to endure. The assumption that all people are in control of and responsible for their health and health behaviour fails to take into account the impact of the greater social order.

It is, therefore the opinion of the researcher that to "cut of the hand of those who steal" is an injustice of enormous magnitude if one does not take into account those aspects of society that creates conditions in which harmful activities can flourish. This is not to take away from personal responsibility but it is rather a reflection on how we all contribute to human-rights violations and create human suffering. This is particularly pertinent for those who are HIV-positive. The researcher thus believes that there is collective and universal responsibility that we all share in fighting inequalities in society.

A further aspect that requires some thought is it became clear to the researcher during the interviews that she was constructed as a professional with specialist knowledge. Whilst the researcher made every attempt to establish rapport and to engage in an emphatic manner, the process of this research did not allow for participatory research where time could have been devoted to building relationships and becoming part of the community in order to gain the information. Hence it was felt that a certain distance between the participants and researcher remained, and it may be that as a result some participants would have been hesitant to speak freely. In addition, all the health professionals who were interviewed reported that there was a tendency on the part of those who came to the clinic for treatment to respond to the staff in a pleasing manner. This may have created a false sense of security between the researcher and participant.

Lastly, the research aim and objectives was aimed at exploring the topic of barriers and facilitators of HIV-adherence and participants were chosen to provide the information in keeping with this. Data was collected in a wide range to include as many biological, psychological and social factors that impact on PLWHA who are on treatment and an

analytical trial was not followed until a saturation point was reached. However, for the purpose of this research saturation of data collection was not seen as a possibility from the onset and the data was collected within the limitation of a project of this nature

4.10 ETHICAL CONSIDERATIONS

The aim and objectives of this research involved engaging with an extremely vulnerable part of the population on highly complex issues about themselves. Therefore, discretion was applied on the part of the researcher to ensure that the interviews were conducted in a manner that did not endanger the participants in any physical or psychological way. The following principles of ethics were followed.

Ethical clearance was first sought from the Medical Research Ethics Committee. Once this was obtained (**Appendix 9**), permission to conduct this study was obtained from the Clinical HIV Research Unit, Department of Medicine (**Appendix 10**). The researcher was put in touch with the social worker as well as the counsellor who runs re-adherence counselling groups at the hospital. This ensured that participants were able to decide whether they wanted to take part in the study from an already established relationship of trust.

Informed consent was gained from all the participants and they were assured of their confidentiality and privacy. Their participation was completely voluntary and they were made aware that they were free to withdraw from the study at any point if they wished to do so. They were also informed that they were not obliged to answer any questions if they felt that some of the questions were too personal, and if they felt uncomfortable they had a right not to respond. Participants who had been struggling to adhere to their treatment were informed that the information that they would provide would not affect their relationship with the medical practitioners or the future course of their treatment.

In addition, permission to audio-tape the sessions was gained beforehand. The option of conducting the interview with a reliance on field notes was extended to all participants.

All the participants signed an informed consent for the audio-taping of the interviews. Participants were informed that the tapes would be transcribed verbatim and that at no time would any mark in the transcripts or research report be able to identify the participant. A guarantee was undertaken to destroy all the audiotapes once they had been transcribed. The researcher assured all the participants that no information of a personal or sensitive nature would be used in the report. Lastly, professional counselling was arranged through the counsellors at the unit for those who may have needed it in the event of stress occurring as a result of the interviews.

4.11 CONCLUSION

In this chapter the methodology used in the collection and analysis of data was discussed with special reference to the research paradigm, setting, sample, procedure, data collection, data analysis, validity of the research and ethical considerations.

CHAPTER FIVE

RESULTS AND DISCUSSION

5.1 INTRODUCTION

This chapter outlines the findings of the study and presents a discussion of these findings. Quotes from the transcribed data are presented under primary and secondary headings. Primary themes have been organised under four main sections. The biological, psychological and social factors that impact on adherence levels are organised under individual, interpersonal and systemic level barriers and facilitators to ARV medication. The fourth main theme is organised under the topic of intervention to ARV adherence. Furthermore, secondary themes are organised under the four main topics. The themes that are covered under individual level factors include treatment factors (complexity of treatment and side effects), psychological factors (stress, depression and anxiety, other psychological symptoms and substance abuse/other medical conditions) and personal factors. Interpersonal themes are covered under topics of the patient/practitioner relationship, disclosure, stigma and discrimination and traditional/other belief systems. Systemic themes are organised under the sub-heading of poverty (unemployment, food needs, transport and social grants), the health care system and political contributors. Finally, the section on intervention level barriers and facilitators to ARV adherence includes the themes of counselling, support networks and community organisation. The presentation of the primary and secondary themes has been done in accordance with the research questions and research aims. The themes are considered to be representative of the biological, psychological and social factors that have emerged from the data analyses. As there is considerable overlap between the biopsycosocial factors it was deemed more appropriate to organise the findings in a manner that demonstrated the multiplicity of issues that impact on adherence levels without getting lost in the content but nevertheless remained in keeping with the thematic content analysis.

5.2 INDIVIDUAL LEVEL BARRIERS AND FACILITATORS TO ARV ADHERENCE

5.2.1 Treatment

5.2.1.1 Complexity of Treatment

ARV treatment is a lifelong commitment to a combination of drugs. The regimen is given as a dual or triple therapy and there is often a large amount of medication that the PLWHA has to take (Hart et al. 2006). Health-care providers and patients indicated that ARV treatment is a complex regimen for individuals to follow and complete adherence was not always an easy task due to this complex nature of treatment:

Resp 1: Adherence is about taking your medication properly as you have been instructed by the doctors, at the right time, not taking it late, not skipping doses. It's fairly complex and not easy to do. Well just think about it, the last time you took antibiotics, did you take every single dose? It [is] just so difficult. [*nurse*]

Resp 6: ARVs is a lifelong commitment. Having to pop pills every single day of your life is quite frustrating. I have been on treatment since 2005, it is my third year. Sometimes I do ask myself, "Why am I still taking this thing?". You know, is [there] not another alternative? Something I can do to suppress the virus? It [is] difficult you know. [*treatment activist*]

These responses indicate that due to the chronic nature of ARV treatment there is always a possibility that treatment may be interrupted from time to time (Altice et al., 2001; Hart et al., 2007; Lesho & Gey, 2003, Maneesriwongal et al, 2006 & Seguy et al., 2007). Taking ARV treatment is a lifelong commitment that can be an arduous and difficult task even for those PLWHA who know about and understand their health problems indicating that despite having adequate knowledge and support, those who are on ARV treatment are often left feeling frustrated as was indicated by respondent 6. Even though individual level health models like the HBM put forward that those individuals who are more knowledgeable will have a higher adherence level (Rosensock et al., 1994), the complexity of the treatment may interact with other psychological factors, for example treatment fatigue (as was indicated by respondent 6), to impact on adherence levels.

Treatment complexity in therefore not limited to the quantity of medication, number of doses or the precise times that the medication needs to be taken but must be extended to the manner in which this interacts at an emotional level for the PLWHA. This is pertinent as emotional aspects (like treatment fatigue) can be combated by a higher quality of medical as well as psychological and support (Maneesriwongel et al, 2006).

In addition, due to the PLWHA's compromised immune system they often suffer from many other co-morbid opportunistic illnesses. The complexity of ARV treatment is complicated even further by a combination of other medical treatment that the PLWHA may have to take to treat these ailments (Altice et al., 2001; Lesho & Gey, 2003). The following response indicates the difficulty in managing multiple treatments simultaneously and how this may serve as a barrier to complete adherence levels:

Resp 8: We start the medication three, four months ago. After four months he is still not getting better. We did [not] understand. We did [not] understand between medication [TB and ARV treatments]. All the time he was taking the medication, it was not the right one. We have a card from Soweto Clinic. They give you a card. When they give medication to us, so tick tick tick tick [ticking off medication] everyday. So we coming here and they say to us no, it is not like that. This is for TB and this is for HIV. It is like so and so. Until this time today I understand. [*care-giver*]

The individual who is on treatment or their caregivers may not be in a position to fully understand the instructions of the health professional. This may be due to language difficulties or people may struggle to understand the instructions due to the complex nature of combined treatment. Often those who have come for treatment may be too ill to be able to fully comprehend the treatment instructions that are given to them. ARV therapy may also be compromised if treatment for one condition is received at a local clinic (for example treatment for TB may be localised) and treatment for HIV is carried out at the regional hospital. This can be confusing for patients who may be assuming that they are getting all the medication from one site. This indicates that a two-level process may unfold in certain instances. On the one hand, a lack of knowledge on the part of the individual may contribute to the confusion created by multiple medical regimens. In this situation the PLWHA or their caregivers may benefit from added instruction and knowledge (Rosenstock et al., 1994). However, on the other hand, this situation can be

avoided if the patient is treated at one centre only. This will avoid conflict and confusion that might arise from trying to adhere to different medical regimes from different hospitals or clinics, signifying a systemic level failure on adherence level.

5.2.1.2 Side Effects

Medication side effect symptoms are frequent in people treated with ARV and are one of the most important biological elements associated with non-adherence (Ammassari et al, 2001; Murphy, 2003). Almost all the respondents reported that side effects contributed in a significant way to how they managed their regimen:

Resp 2: People are going to tell you to use herbs [and] to stop taking ARVs, because ARVs there [is] a lot of side effects to them. So most of them fail to start or maybe some they are taking [ARVs] and then they default because of side effects. [*dietician]*

Resp 3: I [am] taking tablets. I [am] feeling all right. After a year I was sore in my breast and stomach……. My breast were swelling. Dr M was telling me that my body was full of acid….and my feet was pain, painful. Sometimes I am feeling hot, sometimes I am feeling cold. [*patient*]

All ARV medication is associated with adverse side effects ranging from mild to severe, and it is crucial for medical practitioners to manage these symptoms (Altice et al.; Murphy, 2003). Respondent 3 indicated she experienced pain throughout her body due to an increase in lactic acid. Side effects can be managed by using medication that counters side effects (Murphy, 2003). However, as has been seen in the discussion on the complexity of treatment, taking extra medication to counter the side effects may add to the pill burden for the PLWHA, placing the PLWHA under further pressure. This is supported by research where it was found that those who were put on mono-therapy instead of dual or triple therapy showed better adherence outcomes (Altice et al, 2001; Lesho & Gey, 2003)

In addition, using other drugs to counter the side effects of ARVs may not be enough as the *subjectively held belief* that the individual has around the experience of side effects may determine what action the individual will take (Rosenstock et al., 1994). Respondent 2, a dietician, indicated that patients may search for alternate treatment because of their

perception of the toxicity of ARV medication. Taking ARV treatment may reduce the threat of getting severely ill or dying. However, at the same time the action of taking the treatment itself can be seen as immediately upsetting, painful or even fatal. This personal evaluation of the biomedical considerations of being infected versus the toxicity of the ARV medication will then serve as a barrier of action and may lead to avoidance of that medication (Rosenstock et al., 1994). Additionally, any attempts at isolating and managing side effects as a biomedical issue is problematic as traditional and cultural beliefs cannot be isolated from the perceptions of ARV treatment. These belief systems intersect with the experience of side effects to determine the manner in which the individual will respond to the treatment.

Furthermore, health-care providers reported that individuals on treatment often have an ***emotional response*** which results from the **real** powerful negative images of the side effects caused by ARV medication and may renege on their treatment or parts of the treatment regimen because of the fear of either the psychiatric or physical symptoms (Altice et al., 2001; Ammassarri et al., 2001; Stone, 2001). In addition, PLWHA who are on treatment may stop taking or miss treatment because of an **imagined perception** of the impact of the medication as is shown by the following responses. Often these individuals will default on treatment due to the perception that the ARVs are causing the symptoms that they are experiencing. Some individuals may fear taking treatment because of a perception that taking ARVs may cause death. It has been found that in some cases death may occur soon after the person starts medication, however this may be due to the individual's immunity level being compromised and illness having reached a stage where the medical intervention may have been too late (Frank, 2006).

Resp 1: We listen to the patients. You will find that if the patient is complaining of sore feet or something that they "think" is related to ARVs, he'll stop taking the medication properly. Very often you will find them complaining of something and the next time they are complaining and slowly the viral load goes up. [*nurse*]

Resp 5: Someone else would say to them "When I was taking ARVs and I stopped them because [I] went crazy. I would wake up in the middle of the night and I would do funny things and stuff". So when a person come here they already have in their minds, so it [is very difficult to change their mind state……..by the time they [the patient] comes here they [have] known of their friend or a neighbour who was taking ARVs and they die[s] because

[even though] they were taking ARVs, so they will think that the ARVs killed them. [*adherence counsellor*]

Despite extensive information being given to the individual on treatment, distorted perceptual responses to such information often continued to interfere with adherence. The medical view is that perception is based on the epistemology of absoluteness that is largely based on the element of knowledge (Rosenstock et al., 1994). However, Rosenstock et al. (1994) points out those perceptions can be real but there are also components of partiality that determine how a person may perceive their reality. It is because of this partiality in perceptual responses that challenging perceptions and changing behaviour around the toxicity of the ARV regimen can be a difficult task and may require extensive and close collaborative work on the part of a multidisciplinary team. Hence any policy around the management of side effects in a clinical setting will require input from an epistemological framework that will consider the manner in which the individual may be constructing their own reality around the experience of adverse symptoms related to ARV drugs (Gergon, 2001).

Resp 5: Side effects are there but it [is] not everyone who experiences them and side effects are a short-term thing. There is always treatment for that. If they say something is not working, you find an alternative treatment for them. So to encourage them [the patients] to carry on coming and then talking with the practitioner or counsellors about the side effects. [*adherence counsellor*]

Resp 1: So I will notice that things [viral load] are climbing. We don't have a policy in place but it is something that we are discussing….If we see it [viral load] climbing should we not do something like telephone counselling with that person? We see it climbing, we are a bit concerned, rather than waiting until it [is] [viral load] is really high. [*nurse*]

The above responses by health-care providers indicate that building trust in the medication's efficaciousness to not cause harm can be an important factor in changing people's perceptions of the toxicity of the drugs so that adherence levels can be improved. This can be done by providing reassurance over medication (Hardon et al., 2007). Often side effects will decrease or disappear over time and this valuable information must be communicated to the PLWHA (Nakiyamba et al., 2007). In addition, extensive information regarding the trade-off of being on treatment can assist in increasing the acceptance of ARVs in individuals who perceive the consequences of

being on treatment as being worse than the progressive deterioration in health caused by HIV (Altice et al., 2001). It was also indicated by the medical practitioners that timely management of the symptoms adds to increased tolerance to side effects and improved adherence levels (Hardon et al., 2007). However, building trust in the medication's efficaciousness by providing extensive information is not a straightforward task that will automatically lead to increased adherence. In resource-poor settings this is often difficult to achieve and people may have to negotiate managing side effects with a multitude of other realities.

Furthermore, although knowledge about side effects is cited as an important aspect of adherence counselling (Hardon et al., 2007; Nakiyamba et al., 2006), how that knowledge about these side effects is imparted may serve as a barrier, as individuals may reject the medication because of the fear of the symptoms before they give themselves a chance to see if the medication works. Fishburn et al. (1994) believe that one must be particularly vigilant in identifying appropriate kinds of information that must be provided. This becomes evident in the following response by respondent 5 who is a counsellor to patients on ARV treatment. Finally, people's perceptions towards the toxicity of the ARV drugs have also been influenced by the political factors which is a systemic level failure. The government's role and the manner in which ARVs have been introduced have had a major impact on the fears and perceptions around the efficacy of treatment (Frank, 2006).

Resp 5: When we do the talk [adherence groups] about side effects, we just generalise, because if you point out and say "This is D [ARV drug], you may experience hallucinations when you start". They decide they going to take E [ARV drug] and leave D out. Only when you pick up that the viral load is not going down then they will tell you, "I was not taking the drug [D] because I was scared of it"….so they [will] take dual therapy [instead of the prescribed triple therapy]on their own, but they collect all the medication. [***adherence counsellor***]

An important aspect to consider is that whilst some individuals may stop taking their medication in response to the experience and perceptions of severe side effects, there are also those who continue to take their medication despite experiencing severe toxic effects. This was reported by both patients as well as health-care providers and it is

important to identify and understand these responses as further facilitators of ARV adherence. These were some of the responses.

Resp 3: I was continuing to eating [taking] tablets because Doctor was saying to me do [not] stop. The time Doctor tell me stop, I stop…..this is because I want to live. [*patient*]

Resp 7: They [patient] go to the doctor. They look for information. [*treatment activist*]

Resp 5: So to encourage them [the patient] to carry[ing] on coming in and then talking with the counselor about side effects. [***adherence counsellor***]

It would appear that those individuals who were able to manage the toxicity of treatment whilst they waited to talk to a health professional about the side effects showed a better level of adherence. In addition, where side effects have been discussed extensively through counselling, adherence levels have had a more positive outcome. This is supported by studies done by Altice, et el (2001), Hardon et al. (2007) and Nakiyamba et al. (2006). Individuals who can better accept the trade-offs between the benefits of the medication in relation to the limitations (for example, keeping the side effects in perspective, understanding that treatment is beneficial to health of self and for survival or the understanding that there are limited treatment options) were able to recognise that adherence to the medication was important. Respondent 3 articulated that it was her desire to live that allowed her to manage her severe side effect symptoms whilst she waited for medical help.

It may also been found that those who have a high level of trust in the medical system may be better able to manage their side effects (Gordillo, 1999). In addition, allowing for the forgiveness of dosing that is delayed or missed is critical and it is important for health care providers to emphasise that if a treatment dose is missed it is always better to take a dose late than not at all (Hardon et al., 2007; Nakiyamba et al., 2006). This discussion is related to and intersects with the patient/practitioner relationship and a more comprehensive discussion on the complexity of practitioner and patient relationship is presented later under interpersonal level factors that impact on adherence levels. This show further that ARV adherence has to be seen from a biopsycosocial perspective.

5.2.2 Psychological Factors

5.2.2.1 Stress, Depression and Anxiety

Emotional difficulties are common in those who are HIV positive. Individuals who have been diagnosed with HIV suffer from high rates of depression and are more vulnerable to anxiety (Kalichman et al., 2003; Simoni et al., 2000), and depression has been found to be a very common mediator of low adherence levels (Boarts et al., 2006; Kalichman et al., 2003; Simoni et al., 2000; Sledjeski et al., 2005). In addition, it has been found that the psychological stress that the PLWHA experiences leads to poor adherence levels (Bottonari et al., 2005). However, psychological issues in PLWHA remain under-diagnosed even though they play a significant role in non-adherence to treatment. Furthermore, it has been found to be an area that is poorly researched (Gordillo et al., 1999).

This remains consistent in these findings, where almost all of the respondents including the patients indicated that the mental health of the PLWHA who is on treatment is an important area. However, despite an acknowledgement of this, many respondents in this research appeared to either diminish their engagement around this topic or acknowledged that it was an area that remained poorly understood. Whilst some of the respondents who were on treatment recognised that they are feeling constantly sad, helpless and hopeless, they did not always recognise their symptoms as psychological difficulties and are subsequently unable to get the correct assistance. In addition, it appeared that whilst many of the medical practitioners where well versed in psychiatric issues relating to non-adherence, they did not have adequate experience in the psychological area and were therefore unable to engage with the PLWHA on psychological issues. It seemed that this was equally true of the counsellors. The following were some of the responses:

Resp 1: We do think that there is a lot of depression in the patients taking ARVs… There is going to be further research on that issue [psychological issues]. We don't know much about it at the moment. [*nurse*]

Resp 7: They do [not] check such things (psychological aspects]. What they are focusing is that you start treatment and then forgetting to check the person like depression. [*treatment activist]*

Resp 6: Depression, I think [it] is something that is there. Even now when I am on drugs, I still get depressed. [treatment *activist*]

According to Botonari et al. (2005), as the number of life stressors increased, adherence levels to ARV treatment decreases. However, it would seem that as a major life stressor was overcome, adherence levels seemed to increase again. Furthermore, previous research has shown that PLWHA may have experienced at least one traumatic event that was severe enough to meet the diagnosis of acute stress or posttraumatic stress disorder Gore-Felton et al., 2001; Gore-Felton & Koopman 2002; Kimmerling et al. 1999b). Although these stress disorders were not spoken about by the respondents in this research, it is important to note that co-morbid depressive symptoms may interact with traumatic symptoms to decrease adherence levels (Safren, Sledjeski et al., 2005). Nakayimba et al. (2006) argue that it is difficult to ascertain a causal effect between poor adherence levels and depression. This is because people who are depressed may be unable to take their medication as is required of them. However, on the other hand it may be that the PLWHA may get depressed when they struggle to take their medication for whatever other reasons. This is further corroborated by Schonnesson et al., (2004), where it was found that medical concerns around non-adherence may become a marker for depression.

5.2.2.2 Other Psychological Symptoms

Those who are on treatment will often face *multiple* psychological stressors. Constant *intrusive thoughts* around the illness and treatment may increase psychological distress for PLWHA. PLWHA may be in *denial* and unable to accept their status. Many face *isolation.* In addition *fear* and *anger* may increase anxiety in PLWHA further complicating their psychological functioning leading to problems in adherence levels as has been indicated as follows:

Constant *intrusive thoughts* around treatment issues:

Resp 6: You know, just the idea of taking treatment every single day, it gets hectic…..it does have an effect on you as a person. Just thinking you are not normal like everyone else. [treatment *activist*]

Denial of being infected was reported to lead to poor adherence. PLWHA who cannot accept their HIV status will often struggle with treatment as well:

Resp 7: A person does [not] want to take the tablets but [they] can see "But I [am] sick. It [is] not an easy thing to convince a person of that, even to admit that he or she is [HIV] positive. [*treatment activist*]

Resp 1: The patient is not necessarily ready [for treatment] if they have [not] accepted the fact that they [have] got HIV. *[nurse*]

Fear around being ostracised or feelings of *shame and guilt* around being infected:

Resp 1: He was hiding his medication [same patient that was adherent for a number of years]. He was taking his medication but he was hiding the fact that he was HIV positive…and the family was quite supportive. So, often it is very sad….Very often the family actually come in and say – but we could have helped them. We could have got you to give us somebody that would have made him want to come here. We could have done something for the patient. So very often it is the patient rather than the families who think that they should hide their status. [*nurse*]

Fear around death and dying:

Resp 6: Once you are diagnosed with any chronic condition you have a fear of death because death becomes a reality for you, because you are constantly looking death in the face every single day. [*treatment activist*]

Resp 2: before… every time…. Night and day….and I don't eat…I don't sleep….I don't watch my body…because my heart is telling me I am going to die. [*patient*]

A sense of hopelessness and helplessness:

Resp 7: They give up hope. We normally see that in squatter camps, the majority of them lose hope. If you [say] something about HIV/AIDS they will say, "Agh, what is it, we are all going to die." [*treatment activist*]

Resp 8: He was having stress. He did [not] want to talk. Sometimes he did [not] want to hear nothing. He was always wanting to be alone. [*care-giver*]

Self-blame and anger at becoming infected with the virus:

Resp 6: I was angry. It took me a long time to accept that it [is] not my fault that I got infected. After that I went through a period where I started healing gradually. But at the same time I faced stigma in a way I decided to disclose to a friend of mine just after I got tested. I told him in confidence and by the end of the week everybody who knows me knew that I am HIV positive. So it was anger. I was angry with myself. Angry with my ex-partner and also angry with my friend. Angry with the community. [*treatment activist*]

Often PLWHA have to deal with anger that results from being infected and of the fear of the future (Shisana & Simbayi, 2002). Fear of dying (Van Dyk, 1993) is also very prevalent in PLWHA. Respondents in this study indicated that these psychological factors remained ubiquitous in their lives and it also gets extended to issues around treatment. Even though many were aware that ARVs would give them the opportunity to live a long and healthy life, death remained a constant and intrusive companion for those on treatment. It seems that the anger and fear response may affect those who are both educated as well as those who are less educated in similar ways.

In addition, the issue of disclosure is very intimately linked to psychological responses (Siegel & Schrimshaw, 2006). PLWHA show an intense fear around being stigmatised and discriminated against. The process of stigma is both psychological as well as social and continues to have an impact on those who are better educated as well on as those who are less educated, indicating that the level of education does not necessarily increase adherence levels.

However, some patients and care-givers reported that despite having these intensely negative emotional responses, they were able to stay on medication. It would seem that those who were better at understanding and expressing their emotions were able to increase their adherence levels. This observation concurred with other studies (Frank, 2006). The individual's self-efficacy as a psychological resource may assist in increasing adherence to ARV treatment. According to Bandura (1994), those who are able to exercise personal control over their behaviour will show good health outcomes. Respondents who were able to believe in their own ability to manage their treatment and illness and to achieve some kind of self-directed behaviour responded in a much more

favourable manner towards their medication. However, once again it must be noted that Bandura (1994) found that a psychological resource like self-efficacy is only one aspect, and environmental dynamics have to be taken into account to get a better understanding of treatment failures (Bandura, 1994).

Furthermore, ARV treatment is a lifelong commitment and the manner in which the individual experiences and makes meaning of being on treatment thus becomes significant. How individuals comprehend, find meaning and manage their illness may lead to better coping capacity (Cederfall et al., 2002; Siegal & Schrimshaw, 2007). However, findings from this research has indicated that even those individuals who have accepted and made meaning out of the illness for themselves may need ongoing psychological support in order to manage their treatment regimen. Of particular concern, as discussed earlier, is the inability of many medical practitioners and adherence counsellors to provide the appropriate psychological assistance. This will be covered in more detail in the discussion of the counselling needs of those who are on treatment.

5.2.2.3 Substance Abuse and Other Medical Conditions

In addition to stress, depression and anxiety symptoms that the PLWHA may experience, other medical or psychological conditions may add to non-adherence indicating that some individuals may need additional and special care. Alcohol use and abuse came out as a theme that warrants some discussion. These are some of the responses of the counsellors

Resp 5: Most of the people they are afraid to disclose that they are taking alcohol. It is only when they are defaulting and when we push that they talk. They will [not] disclose such information [alcohol intake] because they think we [are] not going to give them their treatment……We do find such cases that a person would say that on weekends because I drink and I was drunk I forgot my tablets. Or I took my tablets because I was drunk and I am not sure if I took the correct dose or what. [***adherence counsellor***]

Resp 4: You find that they take the treatment and you find their acid is so high in their body and they are trying to do all of these sorts of tests only to find that it shows there is something else that they are taking [referring to alcohol use]. [***adherence counsellor***]

It was with some trepidation that alcohol use was placed under individual level barriers and facilitators. Although alcohol use appears across all socio-economic classes, alcohol abuse is inextricably linked to South Africa's historical past. Alcohol use and its interference with ARV treatment in resource-poor settings must take into account the systemic level factors like poverty, unemployment and lack of education. Psychologically, alcohol use may have an impact on the individual's cognitive functioning, impacting on memory and thus a PLWHA may easily forget to either taking their medication in the correct doses or omit to take the medication completely (Frank, 2000). Alcohol use is problematic as patients often do not immediately disclose the level of their alcohol intake for fear of not getting the much needed treatment as was reported by responded 5.

In addition to alcohol use, a further theme that needs consideration is the impact of other medical conditions for example, epilepsy, on adherence levels. Respondent 5 and 10 reported that conditions like epilepsy requires special attention as often people who are have these conditions are overlooked as the underlying assumption is that they are able to take care of all their medical needs.

Resp 5: We have got people who have fits [epilepsy]. So a person would be okay for a few days and then the other days they no longer care. The family assume because they were okay last week, it [is] okay. They will be willing to take their treatment on their own and they [are] okay, but they still need support. [***adherence counsellor***]

Resp 10: For almost two years I am giving him[referring to patient] his tablets, then I see maybe he is okay. He see the tablets, he knows the tablets. SO I do [not]know what changed. The doctor say something changed…but my brother, he is fitting [referring to epilepsy]..so I do[not] know. [*care-giver*]

Respondent 10 articulated that it was difficult for her to take care of her brother who was on ARV treatment as her work often took her away from home. It was during these times that it was found that her brother could not manage his treatment on his own, despite a belief that he could

5.2.3 Personal Factors

PLWHA may miss treatment due to their own forgetfulness, being busy or being away from home (Conway, 2007).

Resp 1: Often you have to give yourself physical reminders. So it may be a cell phone or an alarm or something. But it is so easy to forget and if you don't have yourself organised and have your doses laid out or have a physical reminder to may be thinking -Well did I actually take it? I think I did. Yes, you know I always take at that time. I am sure I did take it. You could be taking double doses or skipping doses, it [is] very easy. [*nurse*]

As taking ARVs is a long-term commitment, tailoring the regimen to suit the needs of the patients so that they are better able to incorporate their medication regimen into their lifestyle using strategies which include habit development and choosing a regimen that matches a particular lifestyle, may increase adherence levels (Conway, 2007). For individuals who manage to stay on their medication over a long period of time, the behaviour of consistently taking the medication at the same time may become a habit with little conscious effort. However, Fishbein et al. (1994) argues that habits may only form under stable conditions but may prove to be difficult in unstable environments. South Africa has a large mobile population and the constant movement between the rural and urban areas as well as between neighbouring countries can be disruptive in the formation of habits like taking medication at set times and thus the factor of population mobility may present an obstacle in maintaining a good adherence level.

Patients and health-care providers both reported that using technology like alarms on cellular phones assisted greatly in managing the regimen. Electronic systems like *A Little Reminder* (ALR) have been known to improve adherence levels (Mannheimer et al., 2006). However, once again this is not always appropriate and it may be that individuals would have difficulty in managing their treatment in public areas. The ringing of the alarm may make others aware of the person's status leading to a fear of stigma and discrimination for the PLWHA.

5.3 INTERPERSONAL & COMMUNITY LEVEL BARRIERS AND FACILITATORS TO ARV ADHERENCE

5.3.1 Patient Practitioner Relationship

Frank (2006) found that the relationship that the PLWHA has with the medical system is important as it contributes to the person's perception of illness and medication. The health system is the first point of entry for diagnoses and treatment and often this is the first time that the PLWHA may come to receive information (Frank, 2006). It is argued that it is this interaction that will impact on the persons future decision-making processes around how they manage their illness (Frank, 2006). This concurs with other literature which shows that the manner in which the health care providers interact with patients and the time that is taken to understand the patient's difficulties is important as it helps to develop trust in the physician and leads to PLWHA feeling satisfied with their health care providers (Leopold et al., 1996; Forest et al., 2002). As a result of such good relationships, patients may be more willing to seek out assistance when needed and leading to better adherence levels (Altice et al., 2002). The level of trust that the individual has in the medical system and the practitioners also overlaps with the experience of side affects and the level of adherence (Altice et al., 2001; Lesho & Gey, 2003). Individuals who had more trust in the medical system and the practitioners were better able to talk about their symptoms and deal with the various side effects, thereby staying longer on the medication until they could access the appropriate help. The following responses show the perceived patient/practitioner relationship and its impact on ARV adherence. It would seem that often those who come for treatment will tend to look for those medical practitioners who they perceive as being helpful, open and trustworthy. Unsympathetic, hostile or unhelpful behaviour on the part of the medical staff will lead to unfavourable treatment outcomes as is very strongly illustrated by the following responses by health-care practitioners:

Resp 1: I think that it [patient/practitioner relationship] is important. You [will] get patients who will come and tell you if your relationship is good. They [will] come and say – This is what is happening with me. Whereas if you do [not] have a good relationship they will hide things from you. [*nurse*]

Resp 5: Some of the things we find out when we do re-adherence [counselling for those who default treatment] is that maybe one of the staff members in the clinic said that if you are not taking your treatment and if you miss your appointment do [not] bother to come back. So they are afraid that if I [they] come back they [medical staff] will shout at me [patient]. [***adherence counsellor***]

According to respondent 1 who is a medical practitioner it was important to build a relationship of trust with patients. This is imperative as often people may experience a host of side effects and this information will not be communicated to medical practitioners for various reasons. One reason that often came up in the interviews was that patients often did not reveal to medical practitioners that they were taking alternate medication with ARV treatment. In addition, patients often become intimidated by adverse behaviour by medical staff. Respondent 5 indicated that some patients would stop coming for refills because they may have become fearful of staff reactions.

The physician is not a neutral entity in the health process but becomes a participant observer who, in the process of attending to the patient, is doing so through his own personal viewing system (Engel (1978) (as cited in Puustinen et al., 2003). The practitioner is both the initiator and the collaborator in the process of medical treatment and therefore, medical practitioners who are better able to understand the individual from different levels of reality including their own will be able to assist their patients in adhering to their regimen (Sixma & Spreeuwenberg, 1998).

However, despite efforts by medical practitioners to understand the psychosocial reality of PLWHA, it was reported be respondent 1 who is a medical practitioner that the focus in the medical treatment of HIV/AIDS remains on the level of the individual patient with an intention to change the patient's behaviour patterns rather than on the wider issues that may be impacting on such behaviour (Hillier, 2002). Adherence counselling in the clinical setting continues to centre around the individual's attitude and behaviours towards their treatment. Re-adherence counselling is therefore focused on education that

is aimed at changing individual behaviour. However, more attention needs to be paid to the interaction process between patients and medical staff. Too often the general practitioner's role in the provision of health care overlooks the social and cultural issues that has an impact on attitudes and behaviours that lead to lowered adherence levels.

Resp 1: It is interesting to see how they [doctors] have changed…They see the patient more as a person in a social environment whereas other units see the [patient] in front of them…because the adherence issue is so important they actually see the patient in a social setting. I [have] noticed it over the years. Is something they develop, even before ARVs the doctors who were interested in HIV became very much a patient's doctor. [*nurse*]

Furthermore, even though there is a concerted effort on the part of both the practitioners and the patients to foster and develop relationships of trust, the medicalisation processes entrench medical social control (Hillier**,** 2002). One example can be found in the manner in which the discourse around medicine and alternate healing systems still includes language that constructs medical reality as superior. Part of the medicalisation process is that medical personnel, and more particularly medical doctors, are often constructed as more powerful and knowledgeable by the patients themselves (Hillier, 2002). Individuals may have a strong desire to please the practitioner and as a consequence may not give an accurate report of the reasons why they may be struggling to adhere to their treatment as indicated by medical practitioners in the quotes below. This power differential may be as a result of a belief that the doctor's ability to define what is right and what is wrong does not match their own experiences. Patients may come into the system with the notion that they do not share the knowledge and skills of doctors and respond to this by surrendering themselves to the expert or professional (Hillier**,** 2002). However, it must also be noted that what may come across as pleasing behaviour may be a rejection of western understanding of their illness by patients. This may be because the treatment option may not fit into the person's cultural and traditional understanding of their illness, further highlighting the responsibility that the medical practitioners have to better understand their patients' cultural belief systems as this may assist in improving treatment adherence.

Resp 5: They trust the doctors more then everyone else. They think that everything that is said by the doctor is okay. So some patients, you try and talk to them and they say "I do [not] want to talk to you. I want to talk to the doctor". [***adherence counsellor***]

Resp 1: One of the big thing is, [some] patients, they want to please, Whatever you say they will say "Yes" because they want to give you the answer that you want. Not necessarily the answer that is truthful. Like they don't want to disappoint you…cultural issues play a part. [*nurse*]

The above discussions on the patient and practitioner relationship are particularly pertinent in demonstrating the importance of deconstructing adherence levels with regard to ARVs. It is simplistic to reduce HIV treatment to biomedicine under the assumption that a trusting relationship with medical caregivers that includes competence, comprehensiveness, consistency of care and compassion (Laince et al., 1996; Kaplan & Rogers, 1993) may be sufficient in getting patients to adhere to their treatment. Whilst this is a very important aspect of care for those who are HIV-positive, the power relationship and dynamics between the two have to be considered as well. The powerlessness that the patient may feel in their relationship with the medical professional thus requires a critical examination. Medical practitioners need to understand their patients' social and cultural realities so that PLWHA may be empowered to take control of their own reality through a process of conscientisation (Rappaport**,** 1981).

5.3.2 Disclosure

All of the respondents reported that disclosure of a person's HIV status was a significant factor impacting on adherence to ARV medication. The following responses capture some of the complexity of disclosure for those who are on treatment. The participants reported that disclosure is not an easy task for PLWHA:

Resp 1: They have been stable. Fantastic. On ARVs. Then suddenly they crashed, They stopped coming. They started being non-adherent and it seemed to be that it was something around disclosure, to the extent that one of them had to be admitted to a hospice. He was so sick…and that's when he disclosed to the family. [*nurse*]

Resp 4: Let's take disclosure. For most people it [is] not easy. We think it [is] easy to disclose. Others disclose, others do [not] want to disclose. [***adherence counsellor***]

Resp 5: They test when they [are] sick and they start treatment because they want to get well. As soon as they get well, it becomes a problem again because you find the issue of disclosure. [***adherence counsellor***]

Resp 6: I [am] very open about my status, my friends know about my treatment but there are other sections, lets say I [am] at a party or any other social setting and at eight o'clock my alarm goes off and I know that I have to take the treatment. The kind of reaction that people give. Like 'oh he is taking his pills now, which means he [is] HIV-positive'. It does have some kind of an effect on you. [activist]

This finding is supported by the study conducted by Frank (2006) where it was found that the main reason disclosure was such a problem was because PLWHA feared the negative responses from others. Mass testing and disclosure has been a major drive of HIV-related campaigns. However, despite massive efforts to help people understand the benefits of disclosure, including the ability to increase adherence levels if the medication is not taken in secret and the accompanying support from their environment, people continue to suffer in silence. Lack of disclosure continues to form a large part of the isolatory nature of PLWHA due to a lack of support from others around them (Hardon et al., 2007, Kumarasamy et al., 2005, Nachega et al., 2006). As a result these individuals do not get adequate encouragement and support from others to take their medication. People who hide their status also have to keep the treatment that they are receiving hidden and this has various consequences on adherence, and taking medication in secret often leads to irregularity (Hardon et al., 2007, Kumarasamy et al., 2005, Nachega et al., 2006). This is confirmed by the following responses.

Resp 1: Your patient should preferably be beyond that [referring to fearing stigma and discrimination] when they start ARVs. That is not easy though. The patients will tell you what you want to hear. [*nurse*]

Resp 4: If you ask them if you [the patient] have a problem [relating to disclosure] he says "I do [no] have a person who [is] taking care of me. Nobody at home knows that I am ill. So if I [am] sick nobody knows that I am taking ARVs, and if I forget sometimes to take my ARVs, then I do [not] take them." …….It [is] easy to ask them "have you disclosed?" They say "yes", but when it comes to treatment it [is] not easy because you can see that the patient is having a problem. Each and every time when he [is] sick, he is coming alone. [***adherence counsellor***]

Disclosure is not a straightforward process and is very intimately linked to the processes of stigma and discrimination. In assessing how one may assist those who have difficulty with disclosure (so that adherence may improve) the individual's perception of their environment and their perceived role in their environment becomes crucial (Bandura**,** 1994). Hence, both the environmental factors that are external to the individual that stops them from disclosing their status, as well as the mental representations of the individuals (real or imagined views of themselves) (Baranowski et al., 2002) need to be taken into account. These concepts are intimately linked to the constructs of stigma and discrimination and are explained in more depth in the section below.

5.3.3 Stigma and Discrimination

Disclosure of a person's HIV status is intimately linked to the construct of stigma and the consequences of stigmatising behaviour, i.e. discrimination (Deacon et al., 2005). PLWHA often struggle with disclosing their status because of an intense fear of being victimised (Deacon et al, 2005). HIV-related stigma is a well documented phenomenon and is arguable one of the most important factors impacting on the lives of PLWHA and it is a significant barrier to testing, care and quality of life in those who are HIV-positive (Aggleton et al., 2003; Deacon et al., 2005, Kelly et al., 2003; Niyonzima, 2003; Parker et al., 2002). Stigma is thus a significant factor that needs to be considered in the treatment of PLWHA since stigma and the resultant discrimination lowers adherence to ARV medication (Hardon et al., 2007; Kumarasamy, et al, 2005).

Patients as well as health-care providers reported that HIV-related stigma and the resultant discrimination of those who are infected continues to play an important role in their lives. Stigma is a process of devaluation of the individual and aspects of this devaluation is related to the individual character that implies a religious, moral or ethical judgment Goffman (1963). Subsequent discriminating attitudes revolve around the perception that the PLWHA are to be blamed, punished, that they bring shame on the family and community or that they are deviant and responsible for contracting the disease in some way (Deacon et al., 2005). The response to those who are HIV-positive is one of

disrespect and degradation and people are often isolated and victimised in very violent ways (Deacon et al., 2005) as is shown in the following responses:

Resp 1: We have seen discrimination many times. We would get a wife coming down from KwaZulu-Natal and chasing the girlfriend around with an axe because she thought the girlfriend had given HIV, patients being locked in their house, being fed through windows……We had one patient where they found out in a block of flats that the one couple had HIV. So they threw blood on the door. They did all sorts of funny things, stole their things and expected not to be held accountable for. Really strange things. [*nurse*]

As a result of the widespread stigma attached to PLWHA, it stands to reason that PLWHA fear disclosing their status since they cannot be sure how others will respond to their news. There appears to be a persistent fear of being victimised or ostracised by family and community members as illustrated in the response below. This will often lead to people taking their treatment in secret as was indicated by respondent 4, or they may even stop taking ARV treatment completely as is articulated by respondent 5:

Resp 4: He was staying with his mom. So his mom passed away…But when the mom passed away he had to go and stay with his grandmother and the grandmother did not know that her grandchild was taking ARVs. [S]he was afraid to tell her grandmother. She would [not] know how the grandmother would respond. So the child just kept quiet…… They say when you are HIV positive they think you are sleeping around. It may be that it is not easy for those women to explain to their husbands. Maybe they are from KwaZulu-Natal to they must vacate their place and go back there. [*adherence counsellor*]

Resp 5: They are sick and they started treatment and now they have to go back to their families or partners. It [is] very difficult for them to disclose. Specially women because you find that they are dependent on their partners so if they tell them about ARVs it [is] like "You come with the issue of HIV in the house, you brought the HIV". So it becomes difficult and in the end they end up defaulting the treatment. [*adherence counsellor*]

Resp 1: The family would lose respect for him…you must be bad to get it. Very often with the older women as well…They feel they have done something wrong and they say "Ek is nie stout nie [I am not naughty"], but here I have got this thing. [*nurse*]

The above responses show that the experience of stigma is both a psychological as well as a social process. PLWHA will often fear being rejected by others in their environment. They may also feel ashamed or guilty about contracting the illness through a psychological process of internalisation of how others have socially constructed them (Patel**,** 2005). This will hinder PLWHA from getting the appropriate treatment or in adhering to their medical regimen. However, the above responses also direct us to the

social processes that are inherent in the analysis of stigma. PLWHA are often stigmatised for being part of a specific group that is defined negatively (Aggleton, et al, 2003). Racism and sexism are used as markers of differences in this process of othering people and constructing them as deviant (Aggleton, et al., 2003). It has been postulated that stigma is a process used by society to perpetuate and legitimise social inequalities, to legitimise social hierarchies and to reinforce pre-existing economic, educational and cultural disadvantages (Aggleton et al., 2003). As a result of this, certain race groups may be more affected by the stigmatising process. In addition, women are also more vulnerable to being blamed and ostracised for having contracted the illness. The combination of the psychological as well as social impact of stigma means that certain groups of people will thus be more vulnerable to non-adherence.

Respondents reported that some patients expressed fear of a lack of confidentiality regarding treatment delivery. PLWHA feared that their status would be divulged to others in their communities and as a result of this fear there is the possibility that they will not return for medication refills. Or in some cases some individuals travelled long distances so that they could obtain treatment further away from home in an attempt to hide their status. This further complicated cost and put an extra financial burden on them.

Resp 1: If somebody [staff member at the clinic] comes to me and says "My neighbour come to the clinic". I say we actually need to sit down with the neighbour and tell them that you are bound [by confidentiality]. You are not allowed to tell anybody. The secrecy is important but it happens. We have had some discrimination issues where X has said something on the taxi……Ideally we get our patients to go to the closest clinic but some patients do [not] want to go to the closest clinic because they do [not] want their communities to find out that they [are] going to the clinic and they are scared that if they are waiting in queues the people are going to find out. [*nurse*]

These responses by the medical practitioner show that there are significant real barriers to adherence levels in situations that have arisen as a result of stigmatising behaviour. This finding is supported by other research that has found confidentiality (Laniece et al., 2003; Nachega et al., 2006) and travelling long distances (Rief et al., 2006) as barriers to treatment adherence. However, in addition to the real experience of being stigmatised, a further significant theme that has to be considered is perceptual stigma. HIV-related stigma has become intensely entrenched and synonymous with the illness and PLWHA

may default on treatment due to the fears associated with being positive. Often those who are on treatment will hide their medication from others with very tragic consequences as reported by respondent 1 and 4. In many instances the families of PLWHA have displayed very supportive attitudes and are surprised at the level of fear, shame and guilt that the person may have experienced. Perceived stigma is often more dangerous as it is the silent aspect of the stigma process (Patel, 2005).

Resp 1: He was hiding his medication. He was taking his medication and he was hiding the fact that he has HIV. But you know the families come in and say, "but we could have helped him….we could have done something for the patient". Very often it is the patient rather then the families who think they should hide their status. [*nurse*]

Resp 4: She would [not] know how the grandmother would respond. So she kept quiet….The granny is so supportive and she was so worried how come she could [not] disclose to her, and how her mother [daughter] could keep this a secret all the time. How they do that alone. [***adherence counsellor***]

One way that one can explain and understand aspects of perceptual stigma is through symbolic interactionism (Desmond**,** 1970). According to Mead (1934) the construction of the self is not a personal experience but arises out of social processes. These social processes interact on a symbolic level on self development and people come to take on the attitude and behaviours of others (Mead**,** 1934). In other words, the way that others behave may be taken on by PLWHA and this process of symbolic internalisation may become a frame of reference from which they acquire meaning of themselves. HIV-related stigmatising behaviour of others can become a focal point of self-perception of constructing negative self-concepts about themselves and engaging in self-depreciating behaviours. The perception of how others may respond to them then becomes a part of the HIV-positive identity and a way of relating to the environment as was reported by the above respondents. HIV-related stigma has become intensely synonymous with the illness that it is no longer necessary for the person to experience it on an individual level to fear it. Hence, both the real act of stigmatisation and discrimination as well as the internalised perception and resultant fear have a very substantial impact on adherence levels (Patel, 2005).

Despite the severe impact of stigma and discrimination, particularly on aspects of disclosure and important theme that emerged is the development of a resistance identity by PLWHA towards this kind of victimisation. The following response by a patient sheds some light on the development of a resistance identity by PLWHA.

Resp 3: If I [am] travelling, I [will] take this plastic, I [will] take these tablets, carry [them] in my bag and a little bottle of water. I [will] drink it. Do [not] worry, because HIV, maybe you have it too, maybe you too [are] positive. [*patient*]

This patient articulated that it was more important for her to take her medication as people who may discriminate against her may also be HIV-positive. Assisting people challenge the responses of others may lead to the PLWHA becoming more open about their status and their medication. The development of a resistance identity does not have to be limited to the individual but can be actively encouraged through the concept of community connectedness and empowerment (Rappaport**,** 1981).

5.4 SYSTEMIC LEVEL BARRIERS AND FACILITATORS TO ARV ADHERENCE

5.4.1 Poverty

The impact of social inequalities on health is well researched and documented (Nettleton, 2002) and poverty is an important consideration in ARV treatment. Although some research has indicated that poverty does not necessarily impact on adherence levels (Frank, 2006), other research has shown that people who live in impoverished circumstances find it more difficult to maintain their ARV regimen than those who have higher income levels (Nakiyamba et al., 2006). Participants in this study reported that unemployment, food needs and transport problems are some of the poverty-related difficulties they have experienced in trying to adhere to the treatment regimen.

5.4.1.1. Unemployment

The following quotes from the respondents highlight the huge challenges faced by PLWHA around unemployment. Individuals who are unemployed will have difficulties in meeting their food needs and in facing challenges of getting to and from health care facilities which are often not in the immediate vicinity.

Resp 4: Most of them are saying that I [am] unemployed and I do [not] have work. [*adherence counsellor*]

Resp 7: There is no one who can hire a person like maybe at the age of fifty. You are not even at the age of getting pension, but over fifty, you know, it is not easy to get a job. [*treatment activist*]

Unemployment has been quoted as one of the biggest markers of poverty and is a critical factor that contributes to social problems in South Africa. The current unemployment rate in South Africa stands between 36 and 42% (Naledi, 2006). Unemployment in South Africa is heavily marked by race, gender and skills level (Naledi, 2006). For those who are employed, earnings have fallen significantly over the past ten years and the population groups that have been most affected by this are those in the lowest income bracket, whose real earnings have almost halved (Naledi, 2006). The ravages of HIV have further complicated the issue of unemployment in the country.

5.4.1.2 Hunger and Food Needs

Nutritional and food needs are a critical component to those who are on ARVs. Proper nutrition is needed to strengthen the immune system and to slow down the progress of the illness (Castleman et al., 2003 Nakiyamba et al., 2006). Furthermore, proper nutrition is required to increase the efficacy of the ARV medication (Castleman et al., 2003). However, even though the South African constitution guarantees sufficient food for all its citizens as a basic human right, all the respondents indicated that meeting food needs is a major challenge many had to face

Resp 4: Our people, they do [not] eat. They are unemployed, nobody can afford food. So it becomes a problem because a person will say, "I can [not] take my medication if I have [not] eaten". Others are saying, "These pills are making me hungry more and more". [***adherence counsellor***]

Resp 5: Sometimes they do [not] have food at all at home, so they will [not] be taking their medication because they will be hungry. [***adherence counsellor***]

From the above responses it becomes clear that it is difficult for PLWHA to take their ARV medication when they are hungry. PLWHA who are on treatment have reported that treatment increases their appetite and this puts a strain on already meagre resources. Some PLWHA may stop taking their treatment altogether because of a lack of food. In some instances patients may not adhere strictly to the treatment, often reducing intake of medication. This concurs with research which indicates that poverty-related lack of food complicates adherence levels (Nachega et al., 2006, Hardon et al., 2007). Although some research has indicated that socio-economic differences do not appear to have an impact on adherence levels, the findings of this research suggest differently. For the struggling classes it becomes a much more difficult task to meet their nutritional requirements. Often, in order for PLWHA to meet their required food needs they may have to find alternate ways of procuring funds. This is often an arduous and difficult task that reduces people to begging or borrowing funds. The following patient articulated the challenges that she has to face in meeting her food needs.

Resp 3: I [am] telling friends give me five rand or ten rand to buy a cabbage or a beetroot or fruits. I am worried. I [am] going to borrow money [from] a friend or neighbour. I [am] going somewhere. My husband if he [is] paid he [is] giving me some money. [*patient*]

This concurs with findings where it has been found that some individuals may have to rely on other employed family members to provide the necessary financial support so that they can maintain their treatment regimen, including the provision of food (Nachega et al., 2006, Kumarasamy et al., 2005; Hardon et al., 2007). Borrowing funds from alternate sources may often place the individual in further debt and push them into further poverty. Nutritional supplementation, food donations via the Social Welfare Department and Non Governmental Organisations (NGOs) food programmes provide some relief for those taking treatment as is indicated by the following response.

Resp 1: At one stage we researched e-pap. We managed to get donations for e-pap for our patients when they were really very, very sick and even without ARVs the pap lifted them up. [*nurse*]

Resp 5: In other communities there are projects where people would engage themselves in like food gardening, they would go and help in a church somewhere where they would give them food parcels. [***adherence counsellor***]

However, providing additional nutrition and food for the individual on treatment fails to take the complexity of poverty into account. The food that is provided through the government and donor systems does not sufficiently address the food needs of the person who is on treatment as the rations will often be used for the needs of the entire family. In many other instances these rations are also used to sustain extended family or community members. Those who are on treatment may compromise themselves so that others in the family system may gain access to the food as mentioned by respondent 4 who is an adherence counsellor.

Resp 4: How do you deal with a person when they say, "I don't have food"? How you going to deal with it because we give them e-pap. It [is] not for the whole month. The social workers try to give them food parcels but we don't even know how many of them they in that house. Because most of the people, it [is] not only one, maybe it [is] eight or nine persons to a house. [***adherence counsellor***]

5.4.1.3 Transport

A further significant theme linked to poverty is transport costs. Travelling to and from ARV sites remains one of the most problematic and challenging issues for many PLWHA and it was a frequently discussed theme by both the patients or their care-givers as well as an often discussed factor that impinges on adherence levels by the medical care-providers..

Resp 3: I come once a month. When Dr M stopped my treatment I come once a week. Eleven rand to Diepsloot, Joburg six rand. Joburg to [HJ] hospital. Joburg to hospital is R32… and I am going to borrow [money]. Last year I am going to Rissik Street to want a grant. After two months was coming a letter to tell me [they] are not giving me the grant. [*patient*]

Resp 4: In first time counselling [adherence counselling] we explain to our patient that it [is] not going to be a once-off visit. You ask them of their financial status…Most people who come this side it is double transport. It can cost R50, R60 just to come here from one of the townships. [***adherence counsellor***]

Resp 5: Most of them are complaining about transport money. There is no one to give them money for transport to come to the hospital. [***adherence counsellor***]

Resp 6: Many people in our country, they can only access their treatment from the public sector and usually this is the provincial or regional hospitals, which are very far for them. As you know we have a high rate of unemployment and poverty, many people actually can [not] afford to have the money to get into the taxi every single month and to go and get their treatment. [*treatment activist*]

Like nutritional and food needs, transport was another factor that forced people to resort to drastic measures to meet the need (Kumarasamy, 2005). This is not only a critical issue for individuals who live in rural areas (Hardon et al., 2007) where HIV treatment points are difficult to access. The high level of unemployment and the increasing cost of transport place an added financial burden on those needing to access treatment. It may also possibly remain a major reason why some individuals may not be able to come to the health facility for re-fills of their medication (Hardon et al., 2007). Increasing localised roll- out sites may be one way that the health system can be organised to manage problems such as the difficulty that PLWHA face in getting to regional hospitals. However, this cannot be managed in isolation and aspects like the severe implications of stigma and discrimination need to be taken into account.

While short-term solutions are important, Van der Vliet (1996) believes that to limit HIV-related strategies to social and economic contexts would be to deprive people control over their lives. It becomes imperative to engage with systemic level conditions like poverty as an empowering exercise (Rappaort, 1981). This would require an engagement with the communities at a level that would allow for active participation to take place. Hence, poverty-related issues that impact on ARV treatment indicate that free treatment in itself is not sufficient (Kumarasamy, 2005), and systemic level solutions have to be found around issues like meeting people's food and transport needs.

5.4.2.4 Social Grants

A significant theme linked to poverty that was frequently discussed by the all the respondents was the issue of the government social grant. The above discussions demonstrate that the link between HIV and poverty is not limited to the rate of HIV infection (Barnett & Whiteside, 2002; Kalichman Et al, 2003; Kalichman, 2005, Shishana & Simbayi, 2002) but extends to ARV treatment where various factors like unemployment, lack of food and high travel costs impact on adherence levels. The government social grant is one of the ways that poverty is being addressed. Research has found that social grants significantly assist towards the alleviation of poverty and it is are often the only financial resources available to PLWHA and their families (Booysens, 2004) as is indicated by the following response.

Resp 1: If they [the patients] take all their ARVs and they get better, then they do [not] qualify for the grant. And often the grant is not only feeding them but it [is] supporting the whole family. [*nurse*]

Resp 2: Last year, I [am] going to Rissik [street] to [get] a grant. After two months was coming the letter to tell me the reason which they do[not] give me a grant.

Having access to the grant is a significant concern for many PLWHA as has been found in other research (Hardon et al., 2006; Kumarasamy et al., 2005) and it has become a very significant theme that needs further investigation as many individuals make use of the grant as a way to control and manage their socio-economic situation with serious implications for adherence levels. PLWHA usually qualify for the grant in the initial phases of the illness when they are too ill to work. However, once ARV treatment restores the PLWHA to health, they are deregistered from the grant system.

Health-care workers (as is indicated by the above response by respondent 1) reported that patients may be motivated to default on their treatment because they want to qualify for a grant. In some instances patients would go through great lengths to avoid taking treatment so that they may be able to access the grant. Respondent 7 an activist, articulated that often patients may manage their treatment in a manner that keeps them just ill enough to access the grant. Both the respondents noted that PLWHA would often

face a great deal of physical pain and suffering in an attempt to manage their CD4 count in this manner. It was indicated that even when patients are given information on the damage that this does to their bodies and to their immune systems, the desperation created by poverty is so great that people will be motivated to remain ill. The social grant has to be evaluated against the conditions of poverty levels experienced by PLWHA, as often this is the only income available to the person and it becomes their only means of survival, with serious consequences to ARV treatment adherence

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Resp 1: He [the patient] did not qualify for a grant. He was stage 1 and he was angry with us because he was not getting his grant. He actually went to the newspapers and then he got opinions from people who said he should be on treatment but he is actually a big problem because I do [not] think he [is] going to be compliant either because his motivation is not right either. His motivation is that he can [not] pay his flat rent. We started to work him up for ARVs because his count had come down and he said to me, "What about the grant?". His motivation is purely and simply the grant. [*nurse*]

Resp 7: People tend to not adhere because their is this social grant. If somebody is taking the medication then the doctor makes a note that this person qualifies to get a grant. Then when you start taking the ARVs then your CD4 count goes up and you get well. Then you fit to work, and this person thinks they [social services] will cut my grant, then how am I going to live without that. So they tell themselves As long as I live I [will drink them [ARVs] and sometimes I will [not] drink them [ARVs]. The doctor is saying you are not good and the money is not cutting off…….Instead of taking their medication they staying with pain. But there is medication here that can help you and it [is] for free. The problem is the grant You take your medication today, you do [not] take your medication tomorrow, it does resistance in your body and by the time you start another [treatment] then it does [not] work and people they have passed away. [*treatment activist*]

In resource-poor settings free treatment is clearly not enough and social grants have become an important factor. However, despite the much needed relief that the social grant provides it also creates a paradoxical situation for many. According to the Health Belief Model, it would be logical and rational for those who are on treatment to respond to their illness by taking care of their health and not willingly risk putting themselves in any kind of danger (Rosenstock et al., 1994). According to this theory, given the serious consequence of not taking ARV treatment, PLWHA will make every attempt to take the medication exactly as prescribed. It would appear that the negative aspects of suffering and even facing death would be seen as strong motivating factor to get well.

However, Lupton (1999) argues that the manner in which the individual identifies risk is never an objective factor. Thus, the way in which the PLWHA construct their illness and the reality of their existence is constructed, deconstructed and reconstructed through their various experiences (Gergen, 2001). In order to assess the dynamics that are created around the social grant, it is imperative to understand that for those who are struggling with their day-to-day existence it may make more sense to negotiate their daily poverty-related difficulties rather than focus on the illness. Even though individuals may have the required information and knowledge about the consequences of non-adherence, for some individuals the option of immediate poverty relief is more important than facing pain and eventual death some time in the future. Therefore, in order to understand the process that is unfolding, one needs to look through the eyes of those who are trying to exist in and through poverty (Gergen, 2001).

5.4.2 The Health Care System

The South African health care system is overburdened with reports by the Human Research Council of South Africa (Ncayiya, 2004) suggesting that the country's supply of health care workers is on the decrease. This, together with the manner in which the health care system is organised can have an impact on PLWHA who are on treatment (Hardon et al., 2007). The following responses by HIV/AIDS activists strongly indicated the impact that the health care system has on adherence levels.

Resp 6: We are also not seeing any political leadership from our political leaders. As far as our health services are concerned here in South Africa it is a shambles. Health professionals are leaving for other countries. Hospitals are there but the services are not good. If you go to some of our hospitals you can [not] believe that this is actually where you treat people. So health is not our governments priority, which is something totally opposite to what our constitution says, that everybody has a right to access quality healthcare. Some times when you go to a hospital you end up having to spend the whole day there, sometimes you get turned away, you do [not] get any services and the human resource factor is really one of the things the government is not doing anything about. Other hospitals they experience stop-outs, you find that a certain drug is not there...sitting in the queues in the clinic or hospital waiting to be served and even the doctors, there are not enough doctors in [on] the site. Sometimes you might be experiencing side-effects which you are told once you start experiencing such and such [side-effects] you have to see a doctor. You have to consult and you can [not] afford to go to a private practitioner. [*treatment activist*]

Resp 7: There are long queues in the clinics and slowness and some of the hospitals cut of the queue and say we are taking 60 people, you are too late. *[treatment activist*]

Medical facilities are often under resourced and the lack of staff leads to an increased workload, leading to burnout, absenteeism and low staff moral (Hardon et al., 2007). This can lead to decreased quality of care for the PLWHA. This, coupled with difficult administrative procedures, means that that people on treatment often have to wait in long queues to be seen (Hardon et al, 2007. The time that the individual spends at the health care facility often leads to frustration for the person and which can impact negatively on adherence levels as been reported by the patients in this study. Those who are employed lose at least one working day when they go to the clinic or hospital. The extra time that is needed for routine check-ups and getting medication refills places an additional burden on those who have not disclosed their status to others and on those who may not have adequate support from those around them. Requests are often made for three to four prescription refills, however, paradoxically, one month refills are needed to monitor adherence levels and extended time periods may only serve to impose constraints on the monitoring of adherence levels in PLWHA. Furthermore, whilst side effects may be understood as an individual level problem that has been managed primarily through educative means firmly entrenched in a biomedical worldview, systemic level difficulties add to this burden. As has been indicated by respondent 6, it is often a frustrating task for individuals to negotiate the health system and it may be more useful and beneficial for PLWHA if alternative ways can be found to manage their illness.

5.4.3 Political Contributors

The South African government was slow to respond to the HIV crisis and remained complacent around acknowledging the full impact of the illness. Early political responses to the HIV pandemic were caught up in a quagmire of controversy and confusing messages (Barnett & Whiteside**,** 2002). The political leadership's early attitude towards the pandemic centred around preventative programme implementation. In addition, the government questioned whether HIV actually even existed and if it indeed was the cause of AIDS (Barnett & Whiteside, 2002). The lack of political commitment and willingness

to mobilise adequate resources led to the subsequent ARV roll-out being a long and drawn-out process (Schneider, 1996). However, these early responses by the political leadership not only impacted on the ability of people to access ARV treatment but it has also impacted on issues around adherence to treatment. The following are some of the responses by HIV/AIDS activists that capture the attitude and stance of the political leadership in this country and the role that the government has played in contributing to the systemic difficulties around adherence to ARV treatment. These include the perpetuation of stigma and the stand that the Health Ministry has taken over the toxicity and benefits of ARV treatment.

Perception of Government Response

Resp 6: Our government is not prioritising the lives of the people of our country. Like if you are investing in the lives of people in our country, it [is] like investing in the economy. If you have access to treatment, you can live a healthy, a long and productive life. [*treatment activist*]

Resp 7: Government, the thing is [they] are slow. They do hear what people are asking but they are slowly to reply. Like prevention from mother to child, it [is] not implemented in all hospitals and certain hospitals you will find that you can already find that you stay far from there. [*treatment activist*]

Stigma

Resp 6: I can say our government played a great role in perpetuating stigma. Our president is quoted as having said that he [has] never seen someone with AIDS. So there is mixed messages it also helps to perpetuate the situation that we find ourselves in. People can [not] accept that HIV is there. [*treatment activist*]

Nutrition versus ARV treatment

Resp 6: The Minister of Health, she [is] always talking about nutrition, saying nutrition can help you not go to the stages of AIDS, always highlighting the negatives of taking drugs. She is always talking about garlic and lemon and all that. [*treatment activist*]

The government's role and the manner in which ARVs have been introduced in the country has generated much fear that has impacted on people's perceptions of HIV as well as the efficacy of treatment (Frank, 2006). In this regard Frank (2006) believes that people's perception of the efficacy of the drug will determine how well they adhere to the

treatment. This argument may be particularly pertinent in this situation and may throw some light on how PLWHA deal with their perceptions around the toxicity of ARV medication and the experience of side effects. It may be that some individuals may stop taking the medication without consulting appropriate medical staff in favour of garlic, african potato, lemon and beetroot which are very rigorously promoted by the Health Department. In addition, the conflicting messages also appear to impact on adherence levels as patients turn increasingly to alternative and traditional healing systems as a way of managing their perceptions of ARV treatment (Frank, 2006). In addition, Frank (2006) also points out that people who come from the poorer socio-economic levels may adhere more closely to the government's directives due to their loyalty to the government. However, one would need to take into account that the government is in a position of authority and power and thus information coming from these political structures would be more trusted by those needing medical attention.

In addition to the early responses that have pointed to a distorted consciousness around the perception of ARV treatment, a further political failure that has been reported is the lack of adequate drug supplies and the procurement of improved treatment.

Resp 6: When our government started to roll out ARVs, they never anticipated that many people would take drugs. So there is never enough supply of ARVs. More and more people know there is treatment available and the demand far outweighs the supply…Other hospitals experience stop-outs. You find that a certain drug is not there. You have to take your drugs in combination and once you do [not] take your medication in combination it can cause problems. Like you may develop resistance. Other people end up not taking the whole course of their medication because a certain drug is not available……I do [not] think that the government is doing enough in terms of procuring tenders from [drug] suppliers. Because even the drugs that we are using are the same that was introduced in 1994. We have [not] had an improvement in as far as treatment is concerned. Whereas in other countries they have even better [treatment] choices then ours and their choices are better than ours in that they have less side effects. [*treatment activist*]

It would seem that often the problem of drug shortages at the ARV roll-out sites are linked to administrative problems where demand for treatment outweighs the clinics' anticipated need for treatment. This oversight on the part of the medical health system has very serious consequences for those who are on treatment. In addition, respondent 6 also indicated that much of the treatment used in the public health system has serious side

effects. The more recent ARV medication has reduced toxicity, but these are not available in public hospitals. This shows a lack of political commitment and a failure on the part of the Health Department to PLWHA and it is a direct infringement of basic human rights that demand adequate medical care for all.

5.4.4 Traditional and Other Belief Systems

All the respondents emphasised the importance of educating those who are HIV-positive. Knowledge about the virus itself and the treatment is a critical step towards empowering patients to take care of themselves. Educating people around the importance of taking the medication exactly as is prescribed, toxicity of the medication, the benefits of treatment, better nutrition, maintaining a positive attitudes and developing support systems are imperative determinants in increasing adherence levels (Stemson et al., 2005).

Resp 1: We have started the Wellness Centre in 2000. We are saying to them [patients] this is HIV. This is what it does to your immune system. These are the bad effects on your immune system. These are the good things for your immune system. Looking at diet. Looking at disclosure. Even before they [the patient] goes to adherence [counselling], they go to the Wellness Centre. [*nurse*]

Resp 6: By turning to people and educating them I [have] realised that with education, you give someone enough education on drugs; they will change their minds before treatment. So we can teach people by speaking in their own language, trying to simplify things, they tend to get an understanding and see why the benefits far outweighs the negatives and more and more people actually do want to go on ARVs. [*treatment activist*]

Resp 3: [in response to benefit of adherence counselling] they tell me if I take my medication, after a time the viral load is up. If I am staying two days, one week, one month without medication, the sick is coming back. The time is coming maybe I [am] going to die...[so] every time I am remembering to take my medication, eating. [*patient*]

Models of individual health behaviour are useful in developing interventions that use knowledge as a way of getting people to understand their susceptibility to getting very ill and dying if ARV treatment is not taken exactly as has been prescribed. Benefits and barriers can be explained to the individual, added control (Rosenstock et al., 1994) and mastery over their illness can be evaluated with the patient (Fishbein et al., 1994). However, educating people around HIV and its treatment in a top-down process remains

problematic and cultural practises have to be taken into account. Lupton (1999**)** puts forward the compelling argument that giving people knowledge around their illness is not enough, but knowledge has to be managed through the reproduction of meaning that the individual constructs through their social interactions. The different socio-cultural matrices and competing views have to be taken into account when analysing what it means for the PLWHA to be on ARV treatment. For many South Africans, traditional healing systems are an established form of health care in their communities (Pretorius, 1996). It has been estimated that between 60 to 80% of the South African population makes use of traditional healing systems (Pretorius, 1996). Many South Africans also make use of both the traditional healing systems as well as western medicine (Pretorius, 1996). However, there appears to be a dichotomy and schism between the two healing systems that has become a barrier for people adhering to ARV treatment (Owen Smith et al., 2007; Wong at al. 2006). Health care providers as is indicated by respondent 1 in the quote below reported that often patients are conflicted around the two treatment systems. Patients may often favour traditional healing and this will impact on ARV treatment adherence. Respondent 5 reported that many patients would seek out both treatments but would often hide the fact that they are also on taking traditional treatment.

Resp 1: Sometimes the family will tell them [patients], "You [have] been to the clinic, you [have] got them [ARVs] but first do the traditional medicine. First you must be stronger because the ARVs have side effects, because they are so toxic. You must get stronger first. So take some other medication and boost your immune system first….The family does not believe in ARVs and believe that they should take traditional medicines…we do [no]t advise our patients to take traditional medicine together with ARVs because of possible interactions. [*nurse*]

Resp 5: They [are] afraid to disclose [traditional treatment] because when you do education you say it is important that you do [not eat [take] ARVs with other things [traditional medication], and then because they still believe that maybe whatever that I [am going to be doing is going to "cure" HIV. So they think, "If I mix the two it might cure the HIV". So they do not disclose such things until they see it becomes a problem. It makes them sick. That is when they will say, "I was also taking this". [***adherence counsellor***]

The toxicity of ARV medication is particularly problematic (Owen Smith et al., 2007) and this together with the mixed messages that have been sent from the South African political structures(Barnett & Whiteside, 2002) have had a major influence on PLWHA who appear to be relying increasingly on alternative healing systems (Frank, 2006).

PLWHA may hide alternative medication from medical practitioners in the mistaken belief that taking the two together may be more beneficial. PLWHA who are using other treatments may be significantly more likely to miss doses of ARV, suggesting that they are using these as an alternative to ARV treatment rather then complementing treatment (Owen-Smith et al., 2007, Wong et al., 2006), often with serious consequences for the PLWHA, as is suggested by the following statement.

Resp 1: They are so sick, they were desperate, they were trying anything, without having necessarily going through all of the issues [ARVs vs. traditional medicine]. Then a year, two years later when they [are] really feeling well, then they start thinking, well maybe they can just go back to traditional medication……The main thing is that if they [are] going to stop taking ARVs then they must stop taking ARVs. One time, not partially take them because they half believe in the. They must stop taking them, try their traditional medicine so we can take a viral load and see whether the ARVs are working at this stage. If they start taking them less and less then we have a problem when viral load resistance starts. [*nurse*]

The two systems of traditional healing and western medicine are set up as a dichotomy and it has been argued that in this dualism, traditional indigenous knowledge has been treated with disdain and arrogance by a western worldview (Muller & Steyn, 1996). It is further postulated by Muller and Steyn (1996) that medical pluralism can exist side by side. Understanding and incorporating the value of traditional medicine and alternative healing systems into the biomedical model appears to be imperative in the management of PLWHA who are on ARVs. It is a futile exercise to exclude these alternate ways of being and there is a benefit to be derived by being more inclusive. A combination of the two healing systems can help PLWHA to improve their adherence levels. The following responses indicate the benefits of working with alternate healing systems:

Resp 1: I think it is useful to work with them [referring to working with traditional healers]. Because especially with patients who are more with the traditional healing and the ancestors [belief]. If they are told by the traditional healer that, "This treatment is okay, go and get this treatment". We educating the traditional healers and they do refer patients in… they are referring for HIV testing, and they will tell the patient, "you must finish this course of medicine before you start on ARVs". [*nurse]*

Resp 7: With HIV you experience a lot of things, you can get peripheral sores, etc. so you can go for treatment, the western treatment. I think if we can train traditional healers, to make them understand, here I can help you, now I can [not] help you. I [am] working with doctor, I can transfer you to doctor... Working with traditional healers, you [are] not telling people we [are] against what you are doing...there [is] one woman in our location. She [is] a

sangoma, when you go to her she tell that person she is working with a doctor. She is doing good work. She [the sangoma][will] tell you, "You can come back to me, come show me your tablets so that I can see which medication from me will go together with this one [ARVs]. So I believe that she has got an understanding. [Treatment activist]

However, a major issue that arises from the responses and from literature (Muller & Steyn, 1996) is the feasibility of such a partnership. The new health care system in South Africa is based on the principle of primary health care that allows for PLWHA to have their needs met at a local level where communities can participate and be more in control of their health needs. There is an opportunity for a partnership to develop between western and traditional healing in the health system (Pretorius, 1996). As has been argued, (Pretorius, 1996) one of the main constraints to such a partnership is one of cultural systemic differences. Around HIV/AIDS in particular there is much debate (Pretorius, 1996) of unhealthy and dangerous practices by traditional healers that can lead to PLWHA suffering unduly and dying as a consequence (Rissik, 1996).

In addition, it is often feared that a status quo may be created by the professionalisation of traditional healers in that it will give the government an excuse not to provide adequate health care facilities to under resourced areas (Muller & Steyn, 1996). Certainly one can argue that the government's conflicting messages around ARV treatment and their focus on nutrition and immune boosters seems to point to the fact that they may be back stepping from political responsibilities with regard to PLWHA. Yet, it is important to note that traditional healers are physically, socially and culturally more available and accessible to masses of people (Muller & Steyn, 1996). It might be a dangerous practise to exclude different forms of healing systems and initiatives must be put in place within the health care system as well as from outside the public health care system to include traditional systems.

Furthermore, although there is much focus on traditional belief systems, organised religious systems play an equally important function in people's lives. The following statements reflect the importance of religious beliefs in terms of adherence levels regarding ARV treatment.

Resp 5: Some people would say [that] at my church they have services for, they pray for people who are HIV-positive and after they pray they [will] be cured from HIV. So they come here and they want HIV tests every now and then, and when it [they] continues to be HIV-positive they become depressed and they want to stop treatment because they lose faith in everything. There is this one lady, she always comes and she would look for a person who she has never seen before. She would pretend to be a new patient and do HIV- test until we noticed. I called her and she came in and we spoke about it. She said that she believes that the prayer service that they have at the church, they [are] going to help her cure HIV. So she was thinking if she takes the medication it would be like she does not believe in God. So she stopped the medication and only believed in prayer. [***adherence counsellor***]

This concurs with Frank's (2006) findings in which she argued that people are often desperate and will turn to religious practices to find a cure for their illness. Furthermore, many South Africans have a dual belief system that incorporates traditional healing systems and organised monotheistic religious beliefs like Christianity. Although it is understood that religion may impact on adherence levels, very little research has been found in this respect with regard to the PLWHA point of view. However, Respondent 5 articulated that it was important to understand and to work with individuals in their respective systems of belief. This can lead to an acceptance of ARV treatment that will increase adherence levels as PLWHA. The statement by Respondent 5 highlights the argument by Airhihenbuwa (1995) that culture can be used as an ally in the deconstruction of health issues. Even if great sensitivity is shown towards alternate belief systems, it would seem to be a pointless and meaningless exercise to change people's belief systems to fit in with western medical ways of thinking (Airhihenbuwa. 1995). This would only serve to strengthen the arrogance of traditional western medicine whilst creating a further stoic resistance to ARV treatment by PLWHA. Tapping into the strengths and attributes that are helpful in promoting better adherence may prove to be a more successful way of engaging with different religious beliefs (Airhehenbuwa, 1995).

Gramsci (1971) argues that social structures like religion can be seen as a hegemony based on persuasion and consent. According to Gramsci (1971), religious leaders as functionaries of the hegemony use systems of religious ideological knowledge to legitimise and maintain power. One way of challenging this power around certain convictions may be from the religious system itself. This argument is poignantly brought to life by the following response:

Resp 5: I spoke to her about curing and healing and God loves everyone so if there was a cure He would bring it to everyone else, not only to one person. So because doctors are also created by God, people who are making the medication are also created by God. So it s one way that God is giving support by making people create treatment. At first she was reluctant but I had an ongoing conversation until she realised that it was important for her to take the medication and still continue praying. You must believe in your ARVs. Everything comes with belief. If you believe that prayer is healing, you must believe that ARVs are going to keep the virus away and you will live healthy like everyone else. [*adherence counsellor*]

Respondent 5 reported that one way that she managed religious issues during counselling with her patients was not to create a dichotomy between religious beliefs and traditional western medication. However, she draws on religious beliefs through a process of dialogue or an ongoing conversation where she parallels healing through ARV treatment as part of a religious belief. Apart from being inclusive of the religious belief, this way of engaging is also tantamount to a challenge on the power of religious leaders who promotes religious believe over ARV medication

5.5 INTERVENTION LEVEL BARRIERS AND FACILITATORS TO TREATMENT

5.5.1 Counselling

PLWHA often experience a disproportional amount of emotional difficulty in relation to their diagnosis as they struggle to cope with the demands of the situation as well as the limited resources that may be available to them (Kalichman et al., 2003; Simoni et al., 2000). These emotional difficulties extend to the treatment regimen and the research indicates that the level of adherence to ARV treatment may depend on the person's ability to adapt to and manage their illness (Cederfall et al., 2002; Siegel & Schrimshaw, 2007). Counselling plays a vital role in the provision of care and support for those who are HIV-positive. The following response by a patient illustrates how crucial counselling is in assisting those who are diagnosed as HIV-positive:

Resp 3: I [am] feeling my heart is so painful because my heart was telling me to die. The time…come to hospital and I get counselling. I [am] feeling alright. Because my heart is telling me I [am still here a long long time. [patient]

Significantly, the care and support that the PLWHA receives in understanding and managing their illness has to be extended to ARV treatment. Although medical practitioners are more involved in the treatment and management of the illness, counsellors often spend a greater time in covering HIV-related issues in more detail (Safren et al., 2005). Counsellors are also in a better position to try and understand the person's background information in order to help them manage their adherence levels better (see respondent 4 below). Respondent 5 also reported that counsellors would often spend more time discussing perceptions around stigma, issues around disclosure, fears around dying, complexity of treatment and effects of the toxicity of the medication in more detail. This is supported by other research where it has been found that counsellors spend more time with those who are on treatment (Safren et al, 2005).

Resp 4: I go back to their history. Is he married, having children, is he employed, is he working, going to church. I find out these things. I find out their history when they start ARVs. What were some of the difficulties when he started. So if you find out these things you can pick up the problems...because once he starts telling you his stories then he starts opening up and the problems…what makes him not take the ARVs. [***adherence counsellor***]

Resp 5: You [will] find that in a counselling session, re-adherence session, the person will mention the issues with disclosure, their fears around death, the side effects and things like that. Once they see the doctor and they do [not] see the counsellor, so they do [no]t get that support. It [is] best if, let's say every time they come for their appointments, you sit down with them and find out, "How are you now doing with the issue that you are afraid of, the side effects, are you dealing with the issue of disclosure?". [***adherence counsellor***]

Counsellors can assist PLWHA with cognitive coping strategies that help the individual to adjust to their stressful life situation (Sarafino, 2002). In other words, those who are on ARV treatment may be able to increase their adherence levels as their coping abilities increase (Sarafino, 2002; Siegel & Schrimshaw, 2007). One way that cognitive coping can be increased in PLWHA is through the provision of information and education around the illness as well as the treatment of HIV (Rosenstock et al., 1994). Knowledge around the biomedical components of ARV medication can help the person to understand what is happening in their bodies. Information can assist the PLWHA to look out for certain symptoms and side effects, get the correct assistance from the practitioners and

manage their nutritional need. Educative endeavours around treatment may also help to reduce confusing biological messages and perceptions around treatment, thereby allowing for more empowered and informed choices around the management of the illness.

Evidence suggests that individual level models of health behaviour which use education and the dissemination of information as a way of targeting certain health belief variables can improve adherence levels (Janz et al, 2002). In situations where those who are on treatment have a larger degree of control of their behaviour and environment, distorted beliefs around treatment can be identified and changed (Fishbein et al., 1994). In addition, the HBM which is based on the premise that those who have a better understanding of their health issues will perform better than those who are less knowledgeable (Rosenstock et al, 1994), offers a way of identifying and changing certain distorted beliefs around ARV treatment. Counselling at the individual level may also help in assisting patients to develop a sense of increased self-efficacy that will help patients to question their health and see the point of changing certain behaviours to increase adherence (Bandura, 1994). For example, if people are given information that gives them an increased sense of mastery over managing their relationship with the practitioner, they will be able to better manage any adverse side effects and they will be able to negotiate this relationship in a more constructive way.

There is therefore a twofold process with regard to adherence counselling. On the one hand it serves a very important function in the provision of emotional and psychological support. On the other hand, counselling also serves an educative purpose that allows the person to become more informed about the important issues around ARV treatment and adherence. However, a significant theme that requires discussion is the many challenges that the counsellors experiences as well as the shortfall of counsellors in the public health system that prevents people from accessing appropriate levels of care and support. The following are some of the responses that demonstrate the difficulties experienced by counsellors who work in the public health system:

Resp 4: Most of the time you feel hopeless. If the social service gives them money they come back next time but sometimes social service will [not] because they keep records. [***adherence counsellor***]

Resp 5: Sometimes you feel so discouraged. Like after giving all the information using education and trying to get all the support for the person it still happens. You really get discouraged. You [are] really not sure whether you [are] winning the situation or you [are] just going backwards. [***adherence counsellor***]

Resp 7: It [is] hurting sometimes. It [is] no good because you come across a lot of people and their problems and it ends up affecting you…how can we help that person. [*treatment activist*]

In resource-poor setting, training and using lay counsellors takes the burden off the medical system (Hardon et al., 2007. Counselling also for the PLWHA to gain the much needed information as well as support with their treatment (Hardon et al., 2007). In the South African health facilities, many counsellors may be volunteers recruited through NGO services. They have to face large volumes of people wanting to access their services. As a result counsellors struggle with low motivation and work fatigue that may leave them with a sense of hopelessness and helplessness. Other problems include staff shortages and the lack of adequate facilities at the ARV roll-out site that would be conducive to meeting the counselling needs of the person as is articulated in the following response:

Resp 5: On our side, counselling side, the problem comes with the issue of the counselling rooms. Because these are the only counselling rooms we have. So there is a lot of people standing outside, you feel pressures that you give all your time to one person and people end up waiting. So counsellors end up giving less time for counselling [per patient]. It really impacts very badly because you do [not] give yourself enough time to attend to all the issues that the person might want to discuss with the counsellor because you are rushing for the queue outside. Also when you start taking ARVs it [is] always a rush. There [is] a line of people who want to see the same counsellor. So it [is] more about getting there, being told you have to take this treatment for life, This is the kind of treatment you will be taking. The possible side effects that you will get. There is no psychological support. [***adherence counsellor***]

It would seem that only a small number of ARV users may be able to make use of the counselling service at each visit even though monitoring adherence requires regular contact and support and a need for ongoing counselling. Quality of care becomes severely

compromised. This is supported by other research (Hardon et al., 2007). A further major difficulty experienced in the counselling situation is that counsellors are often trained in dealing with the biomedical aspects of treatment and adherence. The focus on adherence counselling is on the educative component around managing the benefits of ARV treatment, managing side effects and the complexity of the treatment and talking to patients about the benefits of developing good practitioner relationships. In addition, social aspects like the importance of disclosure, stigma and discrimination are discussed in adherence counselling. However, whilst counsellors understand the impact that these issues have on adherence levels, this information is imparted in a top-down manner rather than in a way that will allow the PLWHA to engage with the issues on a more personal level. Furthermore, counsellors do not receive adequate training in identifying and integrating psychological issues, and as a consequence patients often do not get the psychological help that is much needed and which may be contributing to low adherence levels. Therefore, while the educative component to adherence counselling may be adequate, there are two important components that appear to be missing that may increase adherence levels. The first is the inadequate psychological assistance. More importantly, the educative component of ARV adherence does not necessarily take the person's needs and own solutions into account.

5.5.2 Social Support and Support Groups

In addition to counselling for PLWHA, support networks and social support outside of the counselling situation are critical important in assisting those who are HIV-positive deal with their emotional and social challenges, and they can be a very powerful force that can be a rich source of empowerment for those living with HIV/AIDS (Heaney & Israel, 2002; Walch et al., 2006). Respondents three and four articulated the importance of social support with regard to treatment and adherence. Being open about their status and knowing that they are accepted by others allows for a space where individuals may be able to express their feelings. This reduces the shame attached to being HIV-positive allowing the person to be more open about their treatment. In addition, those who are on treatment can often find very valuable and powerful support from other people who are

on treatment as has been indicated by respondent 1. In a clinical environment where people have to often wait for long hours for their medical check-ups and treatment refills the sharing of common experiences often develops a sense of camaraderie between people who are on ARV treatment. These informal support networks become very useful in assisting people to understand each other and manage their treatment.

Resp 3: [in response to what makes taking the treatment easier] If I [am] going out, talking with my friends, my sister, my husband. My friends, tell me they like me. My sister tells me she likes me. My husband tells me I love you. I [am] feeling all right… If I cry my friends is here. [*patient*]

Resp 4: She would [not] know how the grandmother would respond. So she kept quiet...The granny is so supportive …and the child is so happy because [s]he is coping again. [S]he is going back to school. And the grandmother each and every time she is bringing him to the clinic...[referring to further example] [S]he was staying with his [sic] mom…the mom use to remind her [to] take the treatment], she used to take her to the clinic. The mom use to do everything with the patient. [***adherence counsellor***]

Resp 1: They [will] talk to them [other patients] and they [will] say, "Don't worry, as long as she takes the treatment, as long as keeps her appointments, she will get well". So there is that support. Very often they come the same day each month so they become little cliques and they are a support system for each other. [*nurse*]

These findings are supported by Heaney and Israel (2002) where it has been found that social support and networks have a very significant influence on health outcomes. Studies have indicated that people who are on ARV treatment and who receive adequate emotional support and the correct affirmations (Siegel & Schrimshaw, 2007) are better able to adhere to their medication regimens. Support systems can also help reduce the impact of stigma and discrimination (Kumarasamy et al., 2005) that the person may fear thus allowing for a more open attitude towards taking medication in public. In addition to the emotional support, social support networks are also a site of educational interventions where people can be assisted with information that can lead to increased adherence. In resource-poor settings where counselling is problematic and fraught with difficulties, social support networks can serve to assist those who are struggling with various issues around the illness and its treatment to find a space that can reduce the emotional burden like fear, anger and guilt (Kalichman, et al., 2003; Simoni et al., 2000). Finally support networks can be a powerful place for empowerment and mobilisation (Rappaport, 1981)

for PLWHA and this will be discussed more fully under the community level intervention section.

In addition, home-based care-giving and support is an area that has been found to provide much needed assistance to PLWHA (Gupta & Santos da Silva, 2006) and this can be extended to include assistance around ARV treatment. Family members like siblings and children have been found to be useful as facilitators to ARV adherence (Hardon et al., 2007) . Both respondents 8 and 10 reported that they played a vital role in facilitating treatment adherence for their family members who were ill and could not manage to take their medication without assistance. This is supported by research done by Hardon et al. (2007) who found that children can be an important source of support when it comes to collecting medication for their parents or in contributing towards their food needs. Furthermore, they can also play a role in assisting those family members who are too ill to understand treatment instructions or who are too weak to be able to take their medication without assistance. However, taking care of PLWHA places a huge responsibility on family members and it is thus not only the infected people who are in need of support. Those who are affected by the illness need appropriate support structures as was reported by respondent 8. People who are primary caregivers to PLWHA are also in need of appropriate levels of care and support.

Resp 8: I run a business with my father, so we will be together, so I [am] going to give him the medication. When I am go[ing] [on business trip], I will go with this medication…The way we are close, me and my father. When I say to him "eat this" [referring to ARVs] he is going to eat this. He will [not] say no. I will try my level best to give him the medication….We [have] got one of our cousins, he [is] helping me maar[but] I know sometimes he [will] be far. Because Baba [referring to father] even he has things coming to him [and] it [is] going to hit me, ya wabona [you understand]. If there are support groups there I can take further steps, but I do [not] have support groups like this, what can I do but I do [not] mind to go there. [*care-giver*]

Despite the many benefits of social networks and support groups, family and community members may prove to be a hindrance to PLWHA who are on treatment and this has the potential in reducing adherence levels (Nakiyamba et al., 2006; Wagner, 2002). Finding the appropriate support even for those who have disclosed their status to other family and

community members can be an arduous and difficult task. Often people in the immediate environment may be preoccupied with other commitments as was reported by respondent 5. Furthermore, as has been discussed extensively under culture and traditional beliefs, members of the family or wider community may have differing and often conflicting belief systems around ARV treatment. Respondent 1 highlighted the duality that may arise in such situations where the person who is on treatment may not want to take ARV treatment due to alternate belief systems but may be forced to do so by the family. Alternatively, it may be that the family may put pressure on the person to seek alternative cures and this may clash with the treatment regimen.

Resp 5: Even when they [patients] disclose to their family it [is] very difficult for them [the family] to monitor the people [patient] that is being treated for HIV because maybe they [the family member] have to go to work and there [is] no person who can say, "I am going to stay at home and make sure they are taking their treatment". [[***adherence counsellor***]**

Resp 1: Family problems sometimes. Either the patient does [not] believe that in their ARVs but they are coming because the family is pushing them or the family does [not] believe in ARVs and believes that they should take traditional medicine or immune boosters before they go on ARVs. [*nurse***]**

Resp 4: Sometimes it [is] just the family. How family talks make you stop taking the ARVs because most of the time people do [not] understand why people have to take these tablets. Especially when it comes to HIV. [***adherence counsellor***]**

In addition, for groups to be sustainable as a support system they need to be convenient to access as is reported by respondent 5. A problem that arises in this respect is that due to the perceptions around stigma and discrimination, PLWHA may continue to fear being victimised or ostracised by their communities and are therefore reluctant to access these facilities.

Resp 5: We had support groups but the problem was that most of the people who come here are from townships, Soweto, Alexandra, Witkoppen. So we would rather refer them to support groups near their place instead of coming here always. They may not have transport money and we do [not] have money to give them for transport……Some of them [patients], they do come and report back that I am going to a support group and it [is] very beneficial. But some of them feel that "no". "I felt that because my neighbour is also going there or I felt that the support group is near where I stay. So people are going to see me coming there and it becomes a problem. [***adherence counsellor***]**

From the information that was provided by the participants it would seem that treatment intervention is primarily provided through treatment and adherence counselling. In addition, social support level intervention is available to people who are on treatment, however, they are largely in informal settings. Both counselling and social support networks as methods of interventions have huge benefits in increasing people's adherence levels. However, as interventions they also serve as significant barriers to ARV treatment as has been argued in the above two sections. These intervention modalities also remain severely limited. It would seem that this is particularly so in addressing systemic level issues that impact on ARV adherence, however, the interventions are also severely limited in addressing individual and interpersonal level issues. Visnergarwala and colleagues (2006), in their study of ARV adherence, proposes the de-institutionalising the approach to ARV adherence. It is recommended by Vinesgarwala et al. (2006) is an area that requires further investigation.

Significantly, none of respondents made any reference to organisational and community level intervention that proposes a model in which people can take control over their lives and their environment to ensure better health outcomes through empowerment, a critical consciousness and social action (Rappaport, 1981). However, one respondent made reference to notions of empowerment. Respondent 6 who is a treatment activist reported that empowering people was a crucial element in addressing systemic level barriers to adherence like poverty that leads to decreased adherence levels. Although this was only reported by one respondent the information has none the less been included so that this crucial area may at least be identified for further research purposes. There is a possibility that this topic was not engaged with by more of the participants not because it is of little significance but it may be that it has not reached a point of critical consciousness yet. Initially this section was constructed under the sub-theme of community level intervention but methodological restrictions imposed on data received from just one participant has led to the placement of this argument as an extension under the sub-theme of social intervention.

As a activist, Respondent 6 believed that those who are HIV-positive may be empowered through the development of skills that would allow them to take better charge of their environment and their lives. The same respondent also expressed that it was important for people to stop seeing themselves as victims of their circumstances.

Resp 6: If we can empower our people as a community. Empowering the people to learn, to start doing things for themselves. Like having their own food gardens, like finding ways of making money, opening your own small business even though it [may] not be a formal business. Find something to sell in order for you to have money...If you empower someone you give them skills and the ability to do things for themselves. To think for themselves instead of having to depend on the government or having to depend on other people in order to make sure your quality of life impoverished…..Especially with HIV, once they are diagnosed, people will like start wanting to access disability grants. So, we need to come out of that mindset. Being HIV-positive does not mean that you cannot do things for yourself; you can still do things for yourself. [*treatment activist*]

The notion of empowerment can be seen on two levels. Firstly, at the level of the individual those who are on treatment can be empowered to take charge of their wellbeing. This may increase the ability to engage with their illness with increased confidence as well as increased self-esteem (Perkins & Zimmerman, 1995). Individual level empowerment may assist those who are on ARV treatment to better understand and negotiate the relationship between them and the health care professional, be more active rather than passive in negotiating medication and side effects, take charge of their psychological wellbeing, deal with stigma and discrimination and seek out the appropriate support networks (Perkins & Zimmerman, 1995). Respondent 6 expressed the need for a sense of empowerment:

Resp 6: We do [not] have to always be putting the blame on other people. On the external factors. On the services you get from the health facility or the service you get from the health workers or even what the government is doing. At the end of the day, the only person who will determine how you adhere to your treatment, how you deal with your psychological issues is you, yourself. If you within yourself because we all have the power to overcome. [*treatment activist*]

However, this kind of response once again limits intervention to individual psychological reactions. Empowering individual should also include self-determination with an emphasis on collective initiatives that will enable groups of people to take charge of their

lives (Perkins & Zimmerman, 1995). Hence it is argued that macro-level policy changes need to be implemented in order to address the systemic level barriers and facilitators to ARV adherence (Frank, 2006). The argument that is proposed is that any macro-level systemic changes can only happen if PLWHA gain an awareness of the cultural as well as socio-political factors (Freier as cited in Hope & Timmel, 2003) that impact deeply on their ability to manage their illness and treatment thereof. It is crucial for the communities on the whole to be able to identify, mobilise and address social and public health issues through active participation (Freier as cited in Hope & Timmel, 2003) and a critical awareness of the various contexts that impinge on their ability to maintain adequate ARV adherence levels. People and communities can become vehicles of power (Foucault, 1998) and move away from being mere passive objects and bystanders in their experience of being HIV-positive and the treatment. The response that follows captures most poignantly this gap in addressing the needs of those who on ARV treatment:

Resp 6: You never see these projects happening [referring to community empowerment projects]. In most cases it is more about talking instead of actually doing. Like it [is] no action. We really do [not] have a policy around that. [*treatment activist*]

This study concurs with Frank (2006) where it was reported that HIV-adherence requires a micro as well as a macro level understanding. By dividing the themes into individual, interpersonal and systemic level factors, this study has also added meso level factors. Individual level factors like treatment complexity and side effects would require a continued intervention that is based on education and training as a way of containing and managing these difficulties. Similarly, psychological difficulties experienced by PLWHA would require counselling as well as psychological services that are individual in nature. Meso level factors like the patient/practitioner relationship, disclosure and stigma would benefit from continued social network and support group interventions

Of greatest concern and a major factor that requires some discussion is that many of the difficulties faced by PLWHA on ARV treatment may initially appear to be located at the individual level; where it is spoken by patients as well as some health-care providers as if these are the aspects that PLWHA may have power over and difficulties can be changed through ARV adherence counselling or through the support group assistance. However,

as one begins to deconstruct some of the narratives from both the patients as well as the health care provider's perspectives it becomes more clear that many issues are systemic in nature. This is supported by Franks (2006) study where it was reported that micro level issues are impacted by macro level factors and these are difficult to separate.

Furthermore, whilst many of the healthcare-providers understood that the challenges faced by the patients are systemic in nature, many expressed frustration and exasperation at not being able to engage with or assist their patients adequately with these difficulties. Whilst this is also true of medical health in general in South Africa, these systemic problems become even more difficult for those who are HIV- positive as they have to deal with added complications like the experience of stigma and discrimination or political driven mixed messages around HIV-treatment. It is with this in mind that community empowerment, activism and concientisation is highlighted as a critical area of mass mobilisation and social change that require further investigation that may assist and benefit future policy drives that will assist PLWHA.

5.6 CONCLUSION

This chapter has presented the results and the discussions obtained from the study. The chapter has been thematically organised to answer the research aims and questions. The major topics covered have been individual level, interpersonal level, systemic level and intervention level barriers and facilitators to ARV adherence levels.

CHAPTER SIX

CONCLUSION

6.1 SUMMARY AND CONCLUSION OF STUDY

HIV/AIDS is a global pandemic with statistics showing that South Africa remains one of the countries with the highest prevalence rates (UNAIDS, 2007). Advances in ART have meant that while HIV remains an incurable illness, it has been turned into a chronic condition (Avert, 2008b; Barnett & Whiteside, 2002). However, the South African government has been slow in responding to the provision of adequate treatment to PLWHA, and access to ART remains problematic (Department of Health, 2000). A further issue that remains a challenge is the difficulty experienced with the level of adherence to ART (Department of Health, 2000). It is possible for those who are HIV-positive to live stable and productive lives for as long as they continue to take ARV treatment exactly as has been prescribed to them by the medical practitioners. However, a 95% adherence level is necessary for the treatment to be of optimal benefit (Low-Beer et al., 2002; Shutner et al., 2007).

Adhering to ART is complex and requires more than a mere conforming to a set of medical standards and instructions. This study has made use of the biopsychosocial model in an attempt to bring medical theory and clinical work in line with the many psychosocial realties faced by PLWHA who are on treatment (Engel, 1978 as cited in Puustinen et al., 2003). The aim of this study was to explore the various biological, psychological and social factors that impact on adherence levels and as a consequence lead to increased HIV-related morbidity and mortality rates. In order to gain a deep and rich understanding of this topic, the qualitative method of research was deemed to be the most appropriate for this study. The sample was drawn from a variety of situations, including medical practitioners, counsellors, HIV activists as well as those who are currently on ARV treatment. The vast amount of data that was generated through the

semi-structured interviews was thematically organised to reflect the biological, psychological and social factors that impact on ARV treatment.

Four main clusters of information emerged. These are individual, interpersonal and community, systemic and intervention levels of barriers and facilitators to ARV adherence. On the first level, treatment factors like the complexity of treatment and the toxicity of the medical regimen appeared to be impacted by the individual level factors like the ability to understand and manage the illness and medical regimen. In addition, psychological factors were also conceptualised as an individual level theme. On the other hand, the patient/practitioner relationship, issues around disclosure, stigma and traditional healing/belief systems are more related to interpersonal barriers and facilitators in ARV adherence. Significantly, a further theme that emerged was around those barriers and facilitators that are systemic in nature. These included poverty-related issues like transport and food needs, problems within the health care system and political contributors

However, despite this categorisation, the main findings in this study suggest that none of the factors identified and discussed by the participants as having some kind of impact on adherence levels, be they positive or negative, can be seen in isolation. There is thus in actual fact a web of interlinked reasons why those who are on ARV treatment may struggle to take their medication exactly as prescribed. Thus, for example, while complexity of treatment and side effects may be biological in nature, a more favourable and committed response by the Health Department in the procurement of newer treatment options would reduce these factors significantly, making it easier for PLWHA to adhere to a less complicated and less toxic medication regimen. A further example is that while stigma and discrimination operate on an interpersonal and community level, the government's role around the perceptions of HIV and ARV treatment continues to contribute to the perpetuation of stigma. Furthermore, aspects like food needs and transport issues are traditionally seen as individual level factors but they are also poverty-related systemic level failures that stop people from accessing and adhering to ART. Of particular significance is that systemic level factors remain particular pertinent, as has

been consistently found in this research, and appear to have a pervasive impact on both the individual level and interpersonal level factors.

In addition, although most of the findings in this study support the findings of other research conducted in this field, there is also significant additional information that has come to light. Complexity and toxicity of treatment, the patient/practitioner relationship, stigma and discrimination, the role of traditional belief systems, transport and food needs all remain primary issues for those on ARV treatment. However, a new important theme that has emerged is that of the social grant. The social grant has become a major concern for many PLWHA and has been identified as an area that is complicating ARV treatment.

Furthermore, in the course of exploring the various biopsychosocial factors at these three levels, a particularly pertinent fourth theme started to emerge. This is the manner in which ARV treatment intervention comes to impinge on ARV adherence levels. Lay counselling and informal support systems are the predominant methods of intervention. It is critical to our understanding to note that the traditional intervention methods that have been constructed to assist people in understanding their illness and the treatment are based on looking at individual behaviour from a point of view that takes into account the person's knowledge, attitudes, behavioural intention and behavioural practices (Fishbein et al., 1994; Rosenstock et al., 1994). Traditionally, gaps in the above factors are then targeted for change.

However, if we take into account the many systemic level factors that are woven into people's daily experiences around HIV, then it becomes obvious why we need to understand how PLWHA construct and deconstruct their contextual matrices that give meaning to being HIV-positive and as a consequence what it means to be on treatment (Gergen, 2001; Lupton, 1999). Thus, for example, the paradoxical nature of social grants has to be deconstructed through an epistemological framework that takes this into account. In this research paper it is therefore argued that it is essential to provide individual level intervention, like counselling, or interpersonal level intervention, like social support, to those who are on ARV treatment in order to improve adherence levels.

However, at the same time it is also crucially important to empower PLWHA through concientisation and activism.

6.2 LIMITATION OF THE STUDY

Being a qualitative research study, this research has been limited by the restricted sample size. As a consequence, one limitation is the inability to provide generalisible data. The views and opinions are therefore a reflection of a specific group of participants. This affects the external validity of the study (Greenstein, 2003). However, as the main purpose of this study has been to gain an in-depth understanding that will add to the existing body of knowledge and generate future research in this area, the criteria of credibility, transferability, dependability and conformability were adhered to in order to ensure soundness of the study (Rosenthal & Rosnow, 1991).

A further limitation to be taken into account is the voluntary basis of participation. This means that the volunteers could have provided information that was socially desirable or that was not in accordance with their true experience (Rosenthal & Rosnow, 1991). It may therefore be possible that the information presented may be biased and not completely reflective of the group (Rosenthal & Rosnow, 1991).

In addition, some participants had difficulty in verbalising and expressing their thoughts and feelings. This may have been due to a difficulty with the medium of language used in the interviews. There were instances when it seemed that some participants did not understand the questions asked and there is the possibility that by rephrasing the questions some leading questions might have been asked.

A significant strength of the sample was that some of the participants included people who had defaulted on their treatment and were at the clinic for re-adherence counselling. This allowed for the participants to be more open and forthcoming about some of the issues that had impacted on their adherence levels. However, despite assurances of complete confidentiality by the researcher, there is also a possibility that participants may

have been hesitant to be completely honest about their experiences as they might have been afraid that such information might impact on their chances of going back on ARV treatment.

6.3 RECOMMENDATIONS

6.3.1 Recommendations regarding adherence to treatment

Biomedical

As the clinical setting is the first place of contact for those who require ARV treatment, it is the first point of discussion under recommendations.

The patient/practitioner relationship is an important one. In this study, practitioners displayed a warm and open attitude towards their patients. Many of the practitioners have also become activists and have dedicated their time in lobbying for treatment for their patients. This kind of activism needs to be continued so that better treatment options may be procured and offered to patients.

Many patients continue to see medical doctors as having expert knowledge and insight into their problems. A challenge for practitioners is to remain engaged around these issues with their patients. Working in a multidisciplinary team can help the medical practitioners to assist their patients with both psychological and social difficulties.

Psychological

Patients who enter the system for treatment are often first referred to counsellors who will deal with adherence issues. Most counsellors are trained in the biomedical understanding of HIV and ARV treatment. Knowledge around the illness and aspects like complexity of treatment and side effects are communicated very proficiently. However, counsellors are not trained to engage with psychological issues. As PLWHA suffer from a disproportional amount of emotional difficulties, this area needs to be researched and adequate psychological care and service need to be offered to the patients.

The role of community psychology needs some exploration as this modality of intervention will focus on the extended notion of community empowerment through collective initiatives. In this way, PLWHA may become more engaged with the systemic level challenges.

Socio-cultural

The traditional healing systems are an established form of health care in the South African society. Understanding and incorporating these systems into the western medical modality is thus necessary and will allow for medical pluralism and inclusivity.

Stigma continues to be a huge predictor of lowered adherence levels. Continued support around this issue is necessary.

Social support networks are a valuable source of empowerment for PLWHA. Support structures can help to reduce emotional difficulties like shame and guilt that the patient may be experiencing. These networks are also platforms where the PLWHA may obtain information regarding their treatment. The combined emotional and practical support can assist in increased in adherence.

Continued activism from multiple forums (medical practitioners, counsellors, social workers, HIV activists and PLWHA) must continue to take on and challenge systemic level barriers to ARV adherence.

Political

The stance taken by the political leadership and the role of the government continues to add to the many systemic level difficulties experienced by PLWHA who are on treatment. A greater commitment is required by our political structures. It is recommended that the Department of Health make a greater effort to commit to:

- Work towards eliminating the many mixed messages that are communicated to the public, particularly around the toxicity of treatment and the benefits of ARV treatment.
- This will also assist in eliminating the perpetuation of systemic level stigma around HIV.
- To engage traditional healing systems and to allow for medical pluralism in the treatment of PLWHA.
- Make provision for better psychological services in the clinical setting
- Continue working towards increasing ARV sites that will make access to treatment easier for PLWHA.
- Make greater efforts to procure newer drugs that will decrease the complexity as well as the many side effects currently experienced by PLWHA who are taking older drug regimens.

6.3.2 Recommendation for future research

Based on the results of this study, it is recommended that future research be conducted in the area of the effectiveness of ARV adherence counselling. The shortfalls in ARV counselling and gaps in theoretical knowledge around this area need further investigation.

The government social grant has been identified as an element that is increasingly complicating ARV treatment adherence, and thus this area requires further research.

Finally, there are many predictors that impacts on ARV adherence levels and much research has been done to uncover these variables. However, there is a lacuna in a theoretical understanding around how these factors come to interact with health believes and behaviours. This research has made a tentative attempt at bringing together the various biopsychosocial factors that contribute to varying adherence levels to ARV treatment together with some theoretical understanding using various health models. However, future research is needed in uncovering aspects like how PLWHA conceptualise and construct themselves, the manner in which risk is understood and power differentials that impacts on how PLWHA constructs their illness and how this may impact on future treatment.

REFERENCES

Abah, S.J., Addo, E., Adjei, P.C., Arhin, P., Barami, A.A.S., Byarugaba, M.A., et al. (2006). *There's hope – early observations of ARV treatment rollout in South Africa.* Retrieved March 19, 2006, from http://mednet3.who.int/PRDUC/Data_ins/MastersheetsARVTreatment/ConsolidatedCompleteHIVReport

Aggleton, P., Parker, R., & Maluwa, M. (2003). *Stigma, discrimination and HIV/AIDS in Latin America and Caribbean.* Retrieved February 27, 2004, from http://www/iadb.or/sds/publications

Aids South Africa. (2006). *Antiretroviral drug resistance to HIV.* Retrieved February 15, 2008, from http://www.niv.ac.za

Airhihenbuwa, C.O. (1995). *Health and culture: Beyond Western paradigm.* London: Sage.

Altice, F L. ; Mostashari, F., & Friedland, G. H. (2001). Trust and the acceptance of and adherence to antiretroviral therapy. *Journal of Acquired Immune Deficiency Syndromes,* 28(1), 47-58.

Ammassari, A., Murri, R., Pezzotti, P., Trotta, M.P., Ravasio, L., De Longis, P., et al. (2001). Self-reported symptoms and medication side effects influence adherence to highly active antiretroviral therapy in persons with HIV Infection. *Journal of Acquired Immune Deficiency Syndromes,* 28(5), 445-449.

Ammassari, A., Trotta, M.P., Murri, R., Castelli, F., Narciso, P., Noto, P., Vecchiet, J., Monforte, A., Wu, A.W., & Antinori, A. (2002). Correlates and predictors of adherence to highly active antiretroviral therapy: Overview of published literature. *Journal of Acquired Immune Deficiency Syndromes,* 31 (Supp 3), S123-S127.

Astin, J.A., Sierpina, V.S., Forys, K., & Clarridge, B. (2008). Integration of the biopsychosocial model: perspectives of medical students and residents. *Academic Medicine*, 83(1), 20-27.

Au, J. T., Kayitenkore, K., Shutes, E., Karita, E., Peters, P. J., Tichacek, A., & Allen, S.A. (2006). Access to adequate nutrition is a major potential obstacle to antiretroviral adherence among HIV-infected individuals in Rwanda. *AIDS,* 20(16), 2116-2118.

Avert. (2008a). *Southern African Aids Statistics*. Retrieved March 11, 2008, from http://www.avert.org

Avert. (2008b). *Introduction to HIV/AIDS Treatment*. Retrieved March 11, 2008, from http://www.avert.org

Babbie, E., & Mouton, J. (2004). *The practice of social research*. Cape Town: Oxford University Press Southern Africa.

Bandura, A. (1994). 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.* New York: Plenum Press. 25-57

Bangsberg, D.R., Perry, S., Charlebois, E.D., Clark, R.A., Roberston, M., Zolopa, A.R.,& Moss, A. (2001). Non-adherence to highly active antiretroviral therapy predicts progression to AIDS. *AIDS*, 15(9), 1181-1183.

Barnett, T., & Whiteside, A. (2002). *Aids in the twenty-first century: Disease and globalization.* New York: Palgrave Macmillan.

Batohi, S. (2004). An assessment of counselling needs of adolescents and youth living with HIV/AIDS in Lusikisiki in the Eastern Cape. Unpublished master's dissertation, University of the Witwatersrand, Johannesburg, South Africa.

Boarts, J.M., Sledjeski, E.M., Bogart, L.M., & Delahanty, D.L. (2006). The differential impact of PTSD and depression on HIV disease markers and adherence to Haart in people living with HIV. *AIDS and Behaviour*, 10(3), 253-261.

Booysens, F. (2004). Social Grants as a Safety Net for HIV/AIDS affected households in South Africa, *Journal of Social Aspects HIV/AIDS Research Alliance,* 1(1), 1-11

Bottonari, K.A., Roberts, J.E., Ciesla, J.A., & Hewitt, R.G. (2005). Life stress and adherence to antiretroviral therapy among HIV-positive individuals: A preliminary investigation. *Aids Patient Care*, 19(11), 719-727.

Boyatzis, R.E. (1998). *Transforming qualitative information: thematic analysis and code development.* London: Sage.

Bury, M. (1997). *Health, illness & a changing society.* London: Routledge.

Castleman, T., Seumo, E., & Cogill, B. (2003). Food and nutrition: Implications for antiretroviral therapy in resource limited settings. *Food and Nutrition Technical Assistance Project – Washington.* Retrieved January 3, 2006, from http://www.fantaproject.org/downloads/pdfs/nutARV

Cederfall, C., Languis-Eklof, R.N., Lidman, K., & Wredling R. (2002). Self-reported adherence to antiretroviral treatment and degree of sense of coherence in a group of HIV-infected patients. *Aids Patient Care,*16 (12), 609-616.

Cohen, J., Krackov, S.K., Black, E.R., & Holyst, M. (2000). Introduction to human health and illness: a series of patient centered conferences based on the biopsychosocial model. *Academic Medicine,* 75(4), 390-395.

Coleman, J.C. (1988). Social capital and the creation of human capital. *American Journal of Sociology,* 94, S95-S120.

Connolly, R. (1980). Freire, praxis and education. In R. Mackie (Ed.), *Literacy and Revolution: The Pedagogy of Paulo Freire.* London: Pluto.

Conway, B. (2007). The role of adherence to antiretroviral therapy in the management of HIV Infection. *Journal of Acquired Immune Deficiency Syndromes,* 45(Supp 1), S14-S18.

Crothers, C. (2001) Social factors and HIV/AIDS in South Africa: A framework and summary. *Society in Transition,* 32(1), 5-20.

Cullen, M., & Whiteford, H. (2001). The interrelations of social capital with health and mental health. A national mental health strategy – Australia. Retrieved 20th February 2008 from http://www/mentalhealth.gov.au

Curtis, S., & Taket, A. (1996). *Health and societies: changing perspectives*. London: Arnold Publications.

Deacon, H., Sthephney, I., & Prosalendis, S. (2005). *Understanding HIV/AIDS stigma: theoretical and methodological analyses.* HSRC Research Monograph.

De Bruin, M., Hospers, H.J., Van Den Borne, H.W. Kok, G., & Prins, J.M. (2005). Theory and evidence based intervention to improve adherence to antiretrovial therapy among HIV infected patients in the Netherlands: A Pilot study. *AIDS Patient Care, 19(6),* 384-394.

Delius, P., & Glaser, C. (2005). Sex, disease and stigma in South Africa: a historical perspective. *African Journal of Aids Research,* 4(1),1-9.

Department of Health. (2000). *HIV/AIDS/STD – Strategic Plan for S.A. (2000-2005).*

Desmond, W.H. (1970). Position of G.H. Mead. In H. Stone, & H. Faberman (Eds.), *Social Psychology: Theory and Symbolic Interactionism.* New York: Ginn & Company.

Diabate, S., Alary, M., & Koffi, C.K. (2007). Determinants of adherence to highly active antiretroviral therapy among HIV-1-infected patients in Cote d'Ivoire. *AIDS,* 21(13), 1799-1803.

DiClemente, J. & Peterson, J.L. (1994). Changing HIV/AIDS risk behaviour. In R. J. DiClemente, & J.L. Peterson (Eds.), *Preventing AIDS: Theories and Methods of Behavioural Interventions*. New York: Plenum Press.5-22

Fishbein, M., Middlestadt, S.E., & Hitchcock, P.J. (1994). Using information to change sexually transmitted disease-related behaviours: an analysis based on the theory of reasoned action. In R. J. DiClemente & J.L. Peterson (Eds.), *Preventing AIDS: Theories and Methods of Behavioural Interventions.* New York: Plenum Press. 61-78

Fisher, J., Cornman, D., Wynne, N., & Fisher, W. (2006). Involving behavioural scientists, health care providers and HIV-infected patients as collaborators in theory based HIV prevention and antiretroviral adherence intervention. *Journal of Acquired Immune Deficiency Syndromes,* 43(Supp 1), S10-S17.

Forrest, C., Shi, L., Von Schrader, S., & Ng. J. (2002). Managed care, primary care, and the health practitioner relationship. *JGIM,* 17, 270-277.

Foucault, M. (1994). *The birth of the clinic: an archeology of medical perspective*. New York: Vintage Books.

Frank (2006). *Exploring expert and patient opinions and recommendations regarding antiretroviral treatment compliance*. Unpublished Masters Research, University of the Witwatersrand, Johannesburg, South Africa.

Friedland, G. (2006). HIV medication adherence: the intersection of biomedical, behavioral, and social science research and clinical practice. *Journal of Acquired Immune Deficiency Syndromes,* 43 (Supp 1), S3-S39.

Garcia, R., Schooley, R.T., & Badaro, R. (2003). An adherence essential for long-term HAART success. *BJID,* 7(307), 313-320.

Gergen, K.J. (2001). *An invitation to social construction*. London: Sage.

Gilbert, L., Selikow, T.A., & Walker, L. (2002). Social behavioral sciences in training health professionals: an introduction to a different perspective. In L. Gilbert, T.A. Selikow, & L. Walker (Eds.), *Society, Health and Disease: An Introduction Reader for Health Professionals.* Braamfontein: Ravan. 3-8

Goffman, E. (1963). *Stigma: notes on management of a spoiled identity.* Oxford: Blackwell Publishers.

Gordillo, V., del Amo, J., Soriano, V., & Gonzalez-Lahoz, J.C. (1999). Socio-demographic and psychological variables influencing adherence to antiretroviral therapy. *AIDS,* 13(13), 1763-1769.

Gore-Felton, C., Butler, L.D., & Koopman, C. (2001). HIV disease, violence and posttraumatic stress. *Focus*, 16, 5-7.

Gore-Felton, C., & Koopman, C. (2002). Traumatic experiences: harbinger of risk behavior among HIV-positive adults. *Journal of Trauma and Dissociation*, 3, 121-135.

Gramsci, A. (1971). *Selections from a Prisons Notebooks.* London: Lawrence and Wishart.

Greenstein, R. (2003). Researching social life. *Research Methods Manual,* University of the Witwatersrand, Johannesburg, South Africa.

Gupta, N., & Santos da Silva A.C. (2006). The role of integrated home-based care in patients adherence to antiretroviral therapy. Retrieved 19th March 2006 from http://www.pubpol.duke.edu.researchpaper

Hardon, A.P., Akurut, D., Comoro, C., Ekezie, C., Irunde, H.F., Gerrits, T., et al. (2007). Hunger, waiting time and transport cost: time to confront challenges to ART adherence in Africa. *AIDS,* 19(5), 658-665.

Hart, E., Curtis, H., Wilkins, E., & Johnson, M. (2007). National review of first treatment change after starting highly active antiretroviral therapy in antiretroviral-naive patients. *HIV Medicine,* 8(3), 186-191.

Heaney, C.A., & Israel, B.A. (2002). Social networks & social support. In K. Glanz, B.K. Rimmer, & F.M. Lewis (Eds.), *Health Behaviour & Health Education: Theory Research and Practice.* San Francisco: John Wiley.

Hillier, S.M. (2002). Medicine and social control. In L. Gilbert, T.A. Selikow, & L. Walker (Eds.), *Society, Health and Disease: An Introduction Reader for Health Professionals.* Braamfontein: Ravan. 24-28

Hogg, R., Yipp, B., Chan, K. O'Shaughnessy, M., & Montaner, J. (2000). *Non-adherence to triple combination ART is predictive of AIDS progression and death in HIV positive men and women.* Paper presented at the XIIIth International AIDS conference, Durban.

Holmes, W.C., Bilker, Warren B., Wang, H., Chapman, J., & Gross, R. (2007). HIV/AIDS-specific quality of life and adherence to antiretroviral therapy over time. *Journal of Acquired Immune Deficiency Syndromes,* 46(3), 323-327.

Hope, A., & Timmel, S. (2003). *Training for transformation: a handbook for community workers.* London: ITDG.

Jackson, H. (2002). *AIDS Africa: continent in crises*. Harare: SafAIDS.

Janz, N.K., Champion, V.L. & Strecher, V.J. (2002). The health belief model. In K. Glanz, B.K. Rimmer, & F.M. Lewis (Eds.), *Health Behaviour & Health Education: Theory Research and Practice.* San Francisco: John Wiley.45-66

Jimenez-Exposito, M.J., Garcia-Lorda, P., Alonso-Villaverde, C., de Virgala, C., Sola, R., Masana, L., et al. (1998). Effect of mal-absorption on nutritional status and resting energy expenditure in HIV-infected patients. *AIDS*, 12(15), 1965-1972.

Joint Working Party of the Welsh Council of the Royal College of General Practitioners and the Welsh General Medical Service Committee (1994). Education and debate: patient care and the general practitioner. *BMJ*, 309, 1144-1146.

Kaiser H.J. Family Foundation. (2005). *HIV-AIDS policy fact sheet.* Retrieved March 11, 2008, from http://www.kff.org

Kalichman, S.C., DiMarco, M., Austin, J., Luke, W., & Di Fonzo, K. (2003). Stress, social support and HIV-status disclosure to family and friends among HIV-positive men & women. *Journal of Behavioral Medicine*, 26(4), 315-332.

Kalichman, S.C., Simbayi, C., & Jooste, S. (2005). Poverty related stressors and HIV/AIDS transmission risks in two South African communities. *Journal of Urban Health*, 82(2), 237-249.

Kaplan, S., & Rogers, W.H. (1993). Physicians characteristics influence patients adherence to medical treatment: results from the medical outcome study. *Health Psychology*, 12, 93-102.

Kelly, K., Ntlabati, P., Oyosi, S., Van der Riet, M., & Parker, W. (2002). *Making HIV our problem: young people and developmental challenges in South Africa.* South Africa: Save our Children Program.

Kelly, K., Parker, W., & Oyoshi S. (2002). *Pathways to action: HIV/AIDS prevention, children and young people in South Africa.* South Africa: Save our Children Program.

Kidder, D.P. , Wolitski, R. J., Campsmith, M. L., & Nakamura, G. V. (2007). Health care use, medication use, and medication adherence among homeless and housed people living with HIV/AIDS. *American Journal of Public Health Status,* 97(12), 2238-2245.

Kimerling, R., Armistead, L., & Forehand R. (1999a). Victimisation experiences with HIV infection in women: associations with serostatus, psychological symptoms and health status. *Journal of Traumatic Stress,* 12, 41-58.

Kimerling, R., Calhoun, K.S., Forehand, R., Armistead, L., Morse, E., & Morse, P. (1999b). Traumatic stress in HIV-infected women. *AIDS Education and Prevention*, 11, 321-330.

Kleeberger, C.A., Phair, J.P., Strathdee, S.A., Detels, R., Kingsley, L., & Jacobson, L.P. (2001). Determinants of heterogeneous adherence to HIV-antiretroviral therapies in the multicenter AIDS cohort study. *Journal of Acquired Immune Deficiency Syndromes*, 26(1), 82-92.

Kotler, D. P. (2000). Nutritional alterations associated with HIV Infection. *Journal of Acquired Immune Deficiency Syndromes,* 25 (Supp 1), S81-S87.

Kumarasamy, N., Safren, S., Raminani, S.R., Pickard, R., James, R., Sri-Krishnan, A.K., et al. (2005). Barriers and facilitators to antiretroviral medication adherence among patients with HIV in Chennai, India: A qualitative study. *Aids Patient Care,*19 (8), 526-537.

Laince, C., & Davidhoff, F. (1996). Important elements of outpatient care: A comparison of patients and physicians opinions. *Annual Internal Medicine,* 125, 640-645.

Laniece, I.,Ciss, M., Desclaux, A., Diop, K., Mbodj, F., Ndiaye, B., et al. (2003). Adherence to HAART and its principal determinants in a cohort of Senegalese adults. *AIDS,* 17 (Supp 3), S103-S108.

Leopold, N., Cooper, J., & Clancey C. (1996). Sustained partnership in primary care. *Journal of Family Practise,* 42,129-137.

Lesho, E.P., & Gey D.A. (2003). Managing issues related to antiretroviral therapy. *American Family Physician,* 68(4), 1-15.

Lewis, M.P., Colbert, A., Erlin, J., & Meyers, M. (2006). A qualitative study of persons who are 100% adherent to antiretroviral therapy. *Aids Care,* 18(2), 140-148.

Lindau, S.T., Laumann, E.O., Levinson, W., & Waite, L.J. (2003). Synthesis of scientific disciplines in pursuit of health. *Perspective in Biology and Health,* 46(3), 74-86.

Low-Beer, S., Yip, B., O'Shaughnessy, M.V., Hogg, R.S., & Montana, J.S. (2000). Adherence to triple therapy and viral load response. *Journal of Acquired Immune Defeciency Syndrome,* 23(4), 360-361.

Lupton, D. (1999). *Theorising risk*. London: Routledge.

Maiman, L.A., & Becker, M.H. (1974). The health belief model: origins and correlates in psychological theory. In M.H. Becker (Ed), *The Health Belief Model and Personal Health Behaviour.* New Jersey: Charles B. Slack.

Maneesriwongul, W.L., Tulathong, S., Fennie, K., & Williams, A. (2006). Adherence to antiretroviral medication among HIV-positive patients in Thailand. *Journal of Acquired Immune Deficiency Syndromes,* 43 (Supp 1), S119-S129

Mann, P.A. (1978). *Community psychology: concepts and applications*. London: The Free Press.

Mannheimer, S, B., Morse, E., Matts, John P., Andrews, L., Child, C., Schmetter, B., et al. (2006). Sustained benefit from a long-term antiretroviral adherence intervention: results of a large randomized clinical trial. *Journal of Acquired Immune Deficiency Syndromes,* 43 (Supp 1), S41-S47.

Margalit, A.P.A., Glick, S.M., Benbassat, J., & Cohen, A. (2004). Effects of a biopsychosocial approach on patient satisfaction and patterns of care. *JGIM,* 19 (part 2), 485-491.

Marshall, C., & Rossman, G.B. (1995). *Designing qualitative research (2nd ed*.). London: Sage.

McHoul, A., & Grace, W. (1998). *A Foucault primer: discourse power and the subject*. Victoria: Melbourne University Press.

Mead, G.H. (1934). *Mind self and society*. Chicago: Chicago University Press.

Mehta, S., Moore, R.D., & Graham, N.M.H. (1997). Potential factors affecting adherence with HIV therapy. *AIDS,* 11 (14),1665-1670.

Mellins, C.A., Kang, E., Leu, C., Havens, J.F., & Chesney, M.A. (2003). Longitudinal study of mental health and psychological predictors of medical treatment adherence in mothers living with HIV disease. *AIDS Patient Care & STDs,* 17, 407-416.

Mills, E.J., Nachega, J.B., Buchan, I., Orbinski, J., Attaran, A. Singh, S. et al. (2006). Adherence to antiretroviral therapy in Sub-Saharan Africa and North Africa. *JAMA,* 296(6), 679-690.

Minkler, M., & Wallerstein, N.B. (2002). Improving health through community organisation and community building. In K. Glanz, B.K. Rimmer, & F.M. Lewis (Eds.), *Health Behaviour & Health Education: Theory Research and Practice*. San Francisco: John Wiley. 279-311

Mosley, A. (2004). Does HIV or poverty cause AIDS? Biomedical and epidemiological perspectives. *Theoretical Medicine*, 25, 399-421.

Muller, A., & Steyn, M. (2002). Culture and the feasibility of a partnership between westernised practitioners and traditional healers. In L. Gilbert, T.A. Selikow, & L. Walker (Eds.), *Society, Health and Disease: An Introduction Reader for Health Professionals.* Braamfontein: Ravan. 79-87

Murphy, D.A., Greenwill, L., & Hoffman, D. (2002). Factors associated with antiretroviral adherence among HIV-infected women with children. *Women Health*, 36, 97-111.

Murphy, R.L. (2003). Defining the toxicity profile of nevirapine and other antiretroviral drugs. *Journal of Acquired Immune Deficiency Syndromes,* 34 (Supp 1), S15-S20.

Murri, R., Ammassari, A., Trotta, M.P., De Luca, A., Melzi, S., Minardi, C., et al. (2004). Patient-reported and physician estimated adherence to HAART. *JGIM,* 19,1104-1110.

Nachega, J. B., Lehman, D.A., Hlatshwayo, D., Mothopeng, R., Chaisson, R. E., & Karstaedt, A.S. (2005). Antiretroviral treatment knowledge, attitudes, beliefs, and practices in HIV-infected adults in Soweto, South Africa. *Journal of Acquired Immune Deficiency Syndromes,* 38(2),196-201.

Nachega, J.B., Knowlton, A.R., Deluca, A., Schoeman, J.H., Watkinson, L., Efron, A., et al. (2006). Treatment supporter to improve adherence to antiretroviral therapy in HIV-infected South African adults: a qualitative study. *Journal of Acquired Immune Deficiency Syndromes*, 43 (Supp 1), S127-S133.

Nakiyemba, A., Kwasa, R., & Akurut, D. (2006). Barriers to antiretroviral adherence for patients living with HIV infection and Aids in Uganda. Retrieved March 19, 2006, from http://mednet3.who.int/PRDUC/Resource_Mats/UG2_proposalOnAdherenceToARVs.pdf

Naledi, I.F. (2006). Poverty and Unemployment in South Africa. Retrieved 20th April 2008, from http://www.naledi.org.za

Ncayiyana, D.J. (2004). Doctors and Burses with HIV/AIDS in Sub-Saharan Africa. *BMJ.* 329(7466), 518-585

Nelson, G., & Prelliltensky, I. (2005). *Community psychology: in pursuit of liberation and wellbeing. London*: Pallgrave Macmillan.

Nettleton, S. (2002). Introduction: the changing domains of sociology of health and illness, In L. Gilbert, T.A. Selikow, & L. Walker (Eds.), *Society, Health and Disease: An Introduction Reader for Health Professionals.* Braamfontein: Ravan. 19-23

Nettleton, S. (2002). *Sociology of health & illness*. Cape Town: Polity Press.

Neuman, W.L. (1994). *Social research methods: Qualitative and quantitative approaches.* Boston: Allyn and Bacon.

Nguyen, V.K., Ako, C.Y., Niamba, P., Sylla, A., & Tiendrebeogo, I. (2007). Adherence as therapeutic citizenship: impact of the history of access to antiretroviral drugs on adherence to treatment. *AIDS*, 21 (Supp 5), S31-S35.

Niyonzima, S. (2003). *Understanding HIV-related stigma*. Retrieved February 27, 2004, from http://wwwdevelopmentgateway.org

Owen-Smith, A., DiClemente, R., & Wingwood, G. (2007). Complimentary and alternative medicine use decreases adherence to HAART in HIV-positive women. *AIDS Care*, 19(5), 589-593

Parker, R., Aggleton, P., Howell, K., Polarity, J., & Brown, L. (2002). *HIV-related stigma and discrimination: A conceptual framework for agenda for action.* Retrieved March 4, 2004, from http://www.popcpuncil.org

Patel, R. (2005) *The impact of stigma on adolescents living with HIV/AIDS*. Unpublished honours research paper, University of the Witwatersrand, Johannesburg, South Africa.

Perkins, D.D., & Zimmerman, M.A. (1995). Empowerment theory research & application. *American Journal of Community Psychology*, 19(1), 1-16
Pretorius, E. (2002). Traditional healers. In L. Gilbert, T.A. Selikow, & L. Walker (Eds.), *Society, Health and Disease: An Introduction Reader for Health Professionals.* Braamfontein: Ravan. 88-92

Puustinen, R., Leiman, M., & Viljanen, A.M. (2003) and Medicine humanities – theoretical and methodological issues. *Journal of Medical Ethics*, 29(2), 77-80.

Radley, A. (1995). M*aking sense of illness: The social psychology of health and disease.* London: Sage.

Rappaport, J. (1981). In praise of paradox: a social policy of empowerment over prevention. *American Journal of Psychology*, 9(1), 176-196.

Reif, S., Whetten, K., Lowe, K., & Osterman, J. (2006). Association on unmet needs for support services with medication use and adherence among HIV-infected individuals in the Southeastern United States. *AIDS Care*, 18(4), 277-293.

Richter, D. (1999). Chronic mental illness and the limits of the biopsychosocial model. *Medicine, Health Care and Philosophy*, 2, 21-30.

Rimmer, B.K. (2002). Perspectives on intrapersonal theory of health behaviour. In K. Glanz, B.K. Rimmer, & F.M. Lewis (Eds.), *Health Behaviour & Health Education: Theory Research and Practice*. San Francisco: John Wiley. 144-158

Rissik, D. (2002). Bones of Contention. In L. Gilbert, T.A. Selikow & L. Walker (Eds.), *Society, health and disease: an introduction reader for health professionals.* Braamfontein: Ravan. 76-78

Ritchie, J., Spencer, L., & O'Connor, W. (2003). Carrying out qualitative analysis. In J. Ritchie and J. Lewis (Eds.), *Qualitative Research Practice: A Guide for Social Science Students and Researchers.* London: Sage.

Robins, S. (2004). ARVs and the passage from "near death" to "new life": AIDS activism and "responsibilised" citizens in South Africa. Paper presented at the WISER & CRESP Symposium on Life and Death in the Time of Aids: The Southern African Experience. 14th – 16th October 2004.

Rosenstock, I.M. (1974). Historical origins of the health belief model. In M.H. Becker (Ed), *The Health Belief Model and Personal Health Behaviour*. New Jersey: Charles B. Slack.

Rosenstock, I.M., Strecher, V., & Becker, M.H. (1994). The health belief model and HIV risk behaviour change. In R. J. DiClemente, & J.L. Peterson (Eds.), *Preventing AIDS: Theories and Methods of Behavioural Interventions*. New York: Plenum Press.5-22

Rosenthal, R., & Rosnow, R.L. (1991). *Essentials of behavioural research: methods and data analyses.* New York: McGraw Hill.

Safren, S.A., Kumarasamy, N., James, R., Raminani, S., Solomon, S., & Mayer, K.J. (2005). ART adherence, demographic variables and CD4 outcome among HIV-positive patients on antiretroviral therapy in Chennai, India. *Aids Care,* 17 (7). 853-862.

Sarafino, P. (2002). *Health psychology: A biopsychosocial interaction.* New Jersey: John Wiley.

Seedat, M., Duncan, N., & Lazarus, S. (2003). Community psychology, theory, method and practice. In M. Seedat (Ed.), N. Duncan & S. Lazarus (Cons Ed.), *Community Psychology: Theory, Method and Practice*. Cape Town: Oxford University Press.

Seoane-Vazquez, E., & Rodriguez-Monguio, R. (2007). Negotiating antiretroviral drug prices: the experience of the Andean countries. *Health Policy and Planning*, 22(2), 63-72.

Schneider, H. (2002). The politics behind AIDS. In L. Gilbert, T.A. Selikow, & L. Walker (Eds.), *Society, Health and Disease: An Introductory Reader for Health Professionals.* Braamfontein: Ravan. 183-199

Schonnesson, L.N., Ross. M.W., & Williams, M. (2004). The HIV medication self-reported non-adherence reasons (SNAR) index and its underlying psychological dimensions. *AIDS and Behavior*, 8(3), 293-301.

Shingal, A., & Rogers, E.M. (2003). *Combating AIDS: strategies in action*. London: Sage.

.

Shuter, J., Sarlo, J., Kanmaz, T., Rhode, R., & Zingman, B. (2007). HIV-infected patients receiving Lopinavir/Ritonavir-based antiretroviral therapy achieve high rates of virologic

suppression despite adherence rates less than 95%. *Journal of Acquired Immune Deficiency Syndrome,* 45(1), 4-8.

Seguy, N., Diaz, T., Pereira-Campos, D., Veloso, V.G., Grinsztejin, B., Teixeira, L. et al. (2007). Evaluation of the consistency of refills for antiretroviral medications in two hospitals in the state of Rio de Janeiro, Brazil. *AIDS Care,* 19(5), 617-625.

Seone-Vazquez, E., & Rodriguez-Monguio, R. (2007). Negotiating antiretroviral drug prices: the experience of Andean countries. *Health Policy and Planning,* 22(2), 63-72.

Sharpstone, D., Murray, C., Ross, H., Phelan, M., et al. (1999). The influence of nutritional and metabolic status on progression from asymptomatic HIV infection to AIDS-defining diagnosis. *AIDS,* 13(10), 1221-1226.

Shishana, O., & Simbayi, L. (2002). *Nelson Mandela/HSRC study of HIV/AIDS: South African National HIV prevalence, behavioral risks and mass media survey*. Cape Town: Human Research Council.

Siegel, K., & Schrimshaw, E.W. (2007). The stress moderating role of benefit finding on psychological distress and well-being among women living with HIV/AIDS. *AIDS Behavior,* 11, 421-433.

Simoni, J.M., Demas, P., Mason, H.R.C., Drossman, J.A., & Davis, M.L. (2000). HIV disclosure among women of African descent: Associations with coping, social support and psychological adaptation. *AIDS and Behavior,* 4(2), 147-158.

Sixma, H.J., Spreeuwenberg, P., & Van der Pasch, M. (1998). Patient satisfaction with the general practitioner: A two level analysis. *Journal of Medical Care,* 36(2), 212-229.

Sledjeski, E.M., Delahanty, D.L., & Bogart, L.M. (2005). Incidence and impact of posttraumatic stress disorder and co morbid depression on adherence to HAART and CD4 count in people with HIV. *AIDS Patient Care,* 19, 728-736.

Speer, S.A., & Hutchby, I. (2003). From ethics to analytics: Aspects of participant's orientation to the presence and relevance of recording devices. *Sociology,* 37(2), 315-337.

Stenson. A.L., Charalambous, S., Dwadwa. T., Pemba, L., Du Toit, J.D., Baggaley, R., et al. (2005). Evaluation of antiretroviral therapy related counseling in a workplace-based ART implementation program, South Africa. *AIDS Care,* 17(8), 949-957.

Stone, V.E., Hogan, J.W., Schuman, P., Rompalo, A. M., Howard, A., Korkontzelou, C., et al. (2001). Antiretroviral regimen complexity, self-reported adherence, and HIV patients: Understanding of their regimens: Survey of women in the HER study. *Journal of Acquired Immune Deficiency Syndromes,* 28(2), 124-131.

Suls, J., & Rothman, A. (2004). Evolution of the biopsychosocial model: Prospects and challenges. *Health Psychology,* 23(2), 119-125.

Strode, A., & Grant, K.B. (2001). *The role of stigma and discrimination in increasing vulnerability of children and youth infected with and affected by HIV/AIDS.* South Africa: Save our Children Program.

Tauber, A.I. (2005). Medicine and the call for moral epistemology. *Perspectives in Biology and Medicine,* 48(1), 42-54.

Treatment Action Campaign, Campaigning for the rights of people with HIV/AIDS. Retrieved July 30, 2008, from http://www.tac.org

United Nations Aids (UNAIDS) & World Health Organisation (WHO). (2007). *Aids Epidemic Update.* Retrieved March 11, 2008, from http://www.unaids.org

Van der Vliet, V. (1996). *The politics of AIDS.* London: Bowerdean Publishing Company.

Van der Walt, G., & & McKay, R. (1991). Living with AIDS. In J. de Jonge van Arkel. *Living in the AIDS Culture*. Pretoria: University of South Africa.

Van Dyk, A. (2001). *HIV/AIDS care and counseling: A multidisciplinary approach.* Cape Town: Pearson Education South Africa.

Van Dyk, A., & Van Dyk P.J. (2003). "What is the point of knowing?": Psychological barriers to HIV/AIDS, voluntary counseling and testing program in South Africa. *South African Journal of Psychology,* 33, 118-125.

Visnegalwala, F., Rodriquez-Baaradass, M.C., Graviss, E.A., Caprio, M., Nykyforchym, M., & Laufman, L. (2006). Community outreach with weekly delivery of anti-retroviral drugs compared to cognitive-behavioral health care team-based approach to improve adherence among indigent women newly starting HAART. *AIDS Care,* 18(4), 332-338.

Wagner, G.J. (2002). Predictor of antiretroviral adherence as measured by self-report, electronic monitoring and medication diaries. *AIDS Patient Care and STDs,* 16(12), 500-608.

Walch, S.E., Roetzer, M., & Minnett, T.A. (2006). Support group participation among persons with HIV: Demographic characteristics and perceived barriers. *AIDS Care,* 18(4), 284-289.

Webster, R.D., & Barr, D. (1999). Adherence to highly active antiretroviral therapy. *Centre for Health Policy Research – George Washington University Medical Centre.* Retrieved December 8, 2005, from http://www/hivforum.org

Weiser, S., Wolfe, W., Bangsberg, D., Thior, I., Gilbert, P., Makhema, J., et al. (2003). Barriers to antiretroviral adherence for patients living with HIV infection and AIDS in Botswana. *Journal of Acquired Immune Deficiency Syndrome*, 34(3), 281-288.

Whiteside, A., & Sunter, C. (2000). *AIDS: The challenge for South Africa.* Cape Town: Human Rousseau & Tafelberg.

Wong, I.Y., Lawrence, N., Struthers, H., McIntyre, J., & Friedland, G. (2006). Development and assessment of an innovative culturally sensitive educational videotape to improve adherence to highly active antiretroviral therapy in Soweto, South Africa. *Journal of Acquired Immune Deficiency Syndromes*, 43 (Supp 1), S142-S148.

Appendix 4

PERMISSION TO CONDUCT RESEARCH – DEPT OF HEALTH/HEAD OF HIV UNIT

Dear Sir/Madam

My name is Rabia Patel and I am currently registered for the Masters degree in Community and Counselling Psychology at the University of Witwatersrand, Johannesburg. As part of my degree I am required to undertake a research project. My research would be looking at and understanding possible barriers and facilitators to ART adherence. I would hereby like to request permission to be able to conduct my research at the Helen Joseph and/or the Johannesburg Hospital.

Adherence to antiretroviral medication is essential for the successful treatment and sustained viral control in individuals who are HIV-positive. However, adherence to medication can be a complex interaction of emotional, cognitive, behavioural, social and medical factors. The focus of my research is to better understand the biomedical, psychological and social barriers as well as facilitators to antiretroviral therapy (ART). It is envisaged that this research will possibly be able to add some value to both theoretical as well as practical aspects in the overall outcome of adherence to ART.

In undertaking this research, I will make an attempt to understand the viewpoint of medical practitioners as well as patients on ART. My intention is to conduct semi structured, in-depth interviews in order to get a qualitative understanding of their experiences of the barriers and facilitators to adherence to ART. Furthermore, I will need to interview a minimum of six medical practitioners (3 medical doctors and 3 nurses) and five patients. **It is envisaged that the interviews will last for approximately an hour**. I will tape the interviews and take some notes during the interviews. This will help me to gather the required information. All information I receive will be confidential. The audiotapes will be destroyed as soon as they have been transcribed. No identifying details will be included on any transcribed material or in the research report.

I include herewith my research proposal for further information. Either my supervisor or I can be reached at the numbers provided below for any further questions.

Thanking You

Rabia Patel
(Researcher)
(011) 615-1771
0824498386

Malose Langa
(Research Supervisor)
(011) 717-4536

Appendix 5

Participants Information Sheet

Hello,

My name is Rabia Patel, and I am conducting research for the purposes of obtaining a Masters in Community and Counselling psychology at the University of the Witwatersrand. The focus of my research is to better understand what makes it easier or more difficult to take antiretroviral medication. It is hoped that this research will be able to assist in improving the overall outcome of adherence to ART.

We would like to invite you to participate in this study. Participation in this research will entail being interviewed by me, at a time and place that is convenient for you. **The interview will last for approximately one hour**. With your permission this interview will be recorded in order to ensure accuracy. Participation is voluntary, and no person will be advantaged or disadvantaged in any way for choosing to participate or not participate in the study. All of your responses will be kept confidential, and no information that could identify you would be included in the research report. The interview material (tapes and transcripts) will not be seen or heard by any person in this organisation at any time, and will only be processed by myself. You may refuse to answer any questions you would prefer not to, and you may choose to withdraw from the study at any point without any negative consequence to you or the treatment that you receive.

In the event of stress occurring as a result of participation in this study, you will be provided with details of available psychological services at the hospital. If you choose to participate in the study please fill in your details on the form below and place it in the sealed box that is provided. You may find this box in the reception area of the hospital where you are receiving the treatment. I will empty the box at regular intervals, and will contact you within two weeks in order to discuss your participation.

In taking part in this research I hope to bring awareness of the needs of HIV- positive people who are on antiretroviral treatment and to help equip health professionals to make the appropriate responses in dealing with non-adherence to treatment. It is also hoped that this research will contribute both to a larger body of knowledge on adherence to ARV. If you have any questions I can be reached at the following telephone numbers.

Thanking You

Rabia Patel
(Researcher)

(011) 615-1771
0824498386

Malose Langa
(Research Supervisor)

Appendix 6

CONSENT FORM - PARTICIPANT

I _____ consent to being interviewed by Rabia Patel for her study on HIV/AIDS – Living with Chronic Medication: Barriers and Facilitators to Antiretroviral Therapy Adherence. I understand that:

- Participation in this interview is voluntary.
- That I may refuse to answer any questions I would prefer not to.
- I may withdraw from the study at any time.
- No information that may identify me will be included in the research report, and my responses will remain confidential.

Signed _____

CONSENT FORM – AUDIOTAPE

I _____ consent to my interview with Rabia Patel for her study on HIV/AIDS – Living with Chronic Medication: Barriers and Facilitators to Antiretroviral Therapy Adherence being tape-recorded. I understand that:

- The tapes and transcripts will not be seen or heard by any person in this organisation at any time, and will only be processed by the researcher.
- All tape recordings will be destroyed after the research is complete.
- No identifying information will be used in the transcripts or the research report.

Signed _____

Appendix 7

PERMISSION TO CONDUCT RESEARCH – TAC/AIDS CONSORTIUM

Dear Sir/Madam

My name is Rabia Patel and I am currently completing my Masters degree in Community and Counselling Psychology at the University of Witwatersrand, Johannesburg. As part of my degree I am required to undertake a research project. My research would be looking at and understanding possible barriers and facilitators to ART adherence. I would hereby like to request permission to be able to conduct my research at your organisation.

Adherence to antiretroviral medication is essential for the successful treatment and sustained viral control in individuals who are HIV-positive. However, adherence to medication can be a complex interaction of emotional, cognitive, behavioural, social and medical factors. The focus of my research is to better understand the biomedical, psychological and social barriers as well as facilitators to antiretroviral therapy (ART). It is envisaged that this research will possibly be able to add some value to both theoretical as well as practical aspects in the overall outcome of adherence to ART.

In undertaking this research, I will make an attempt to understand the viewpoint of HIV/AIDS activist. My intention is to conduct in-depth interviews in order to get a qualitative understanding of their experiences of the barriers and facilitators to adherence to ART. Furthermore, I will need to interview a minimum of 3 members from your organisation**. It is envisaged that the interviews will last for approximately an hour**. I will tape the interviews and take some notes during the interviews. This will help me to gather the required information. All information I receive will be confidential. The audiotapes will be destroyed as soon as they have been transcribed. No identifying details will be included on any transcribed material or in the research report.

I include herewith my research proposal for further information. Either my supervisor or I can be reached at the numbers provided below for any further questions.

Thanking You

Rabia Patel
(Researcher)
(011) 615-1771
0824498386

Malose Langa
(Research Supervisor)
(011) 717-4536

Appendix 08

Interview Schedule – Participants on ART

Introduction
How long have you been on treatment?
What treatment are you on?
What are your experiences of receiving the treatment at the hospital?
What do you think makes it difficult for you to take your medication?
What are some of the things that makes it easier for you to stay on your medication?
What can be done to help you with the difficulties that you may be experiencing in taking your treatment?
Is there anything more you would like to add?

Please note that the above are the core questions. These questions are meant to get the participant to share the possible barriers and facilitators to adherence to ARV's. As this study wishes to capture the experiences of the participants and build up to a theoretical formulation, the original interview schedule was meant to be a thematic guide to ensure that important areas that may be impacting on adherence is noted when conducting the interviews.

1) What makes the treatment difficult?
Draw out *Biomedical Factors*

- How complicated is the treatment
- How is this experienced
- Are they experiencing any side effects
- How do they deal with this
- How expensive is it to get the treatment
- Is the hospital facilities difficult to access
- How is their experience of the medical personnel

2) What are some of the things that makes treatment easier?

- Did they receive any pre treatment counselling
- Are they receiving any counselling presently
- What type of counselling are they receiving

3) Do the way you feel have an impact on your treatment?
Draw out psychological factors

- Explore pre medication psychological factors
- How did they experience being HIV-positive
- Depression
- Stress
- Coping styles
- Self esteem
- Anger
- Fear
- Guilt

- Blame
- Was any of this was explored before the start of treatment (via counselling or medical practitioners)
- Post medication psychological factors
- Has any of this changed
- Positive responses (look for support etc)
- Negative Responses (withdrawal, self blame etc)

4) Draw out *social factors*
- Financial situation
- Material support
- Does the way others behave towards you impact on your treatment
- Is it easy or difficult to take the medication around others
- Stigma
- What kind of social support are you getting?
- How do the above two impact on adherence

Closing Interview
5)What are some of your concerns?
6)What can be done to make the process of taking medication easier for you?
7)Is there anything more you would like to add?

Interview Schedule – Others
Medical Personnel

1) Can you tell me about the ARV treatment plan?
2) How do you determine who qualifies for the programme?
3)Adherence is vital in ARV treatment plan. Can you define adherence?
4)What are some of the problems that impact on adherence to treatment?
5)How is this managed?
6)What are some of the aspects that lead to increased adherence?
7)What can be done to improve adherence to ART?

HIV/AIDS Activist/Counsellors

1)Adherence is cited as one of the major aspect that impacts on effective viral load treatment on those who are HIV- positive. Can you tell me what is understood by adherence?
2)How does differ from the concept of compliance?
3)What are some of the biomedical factors that have an impact on adherence?
4)What in your experience are the psychological factors that impact on adherence?
5)How do these impact on adherence to ART?
6)Can you tell me how socio-economic factors impact on adherence to ART?
7)What other factors in your opinion makes it difficult for patients to adhere to medication?
8)What can be done to improve adherence?