

# EXPLORING BARRIERS AND ENABLERS TO ARV TREATMENT ADHERENCE FOR MEN WHO HAVE SEX WITH MEN

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## DECLARATION

I declare that this thesis 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 the university.

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Stephen Laverack

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Date

## **DEDICATION**

I dedicate this work to those who have succumbed to HIV/Aids and to the many millions whose stories remain untold.

## **ACKNOWLEDGEMENTS**

A very special thank you must go to the facilitator of Positively Alive for allowing me the opportunity to meet the group. I also want to thank the nine participants who were interviewed and shared their stories so articulately. Without you, this research would not have been possible.

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## ABSTRACT

The amount of research that examines adherence to antiretroviral treatment is now immeasurable. However, research on understanding the subjective experiences of men who have sex with men (MSM) and living with HIV while taking antiretroviral therapy remains limited.

This research uses a qualitative methodology, using semi-structured interviews, carried out on nine participants who frequently use a Johannesburg support group aimed at MSM living with HIV. The time period of these men living with HIV and taking antiretroviral therapy varied from a number of months to many years. The interviews were audio-recorded and transcribed. In terms of analysis, thematic content analysis was used identified the enablers and barriers to treatment adherence. These were broken into biopsychosocial factors with the main outcomes of this research suggesting that adherence is complex and influences are far beyond just biological. The majority of the elements raised by the participants indicate the significance of psychological and social factors. This makes the development of adherence interventions aimed at MSMs more detailed than simply following medical provider directions. There appeared to be consensus that although some participants of this research would prefer to not take antiretroviral therapy because of the side-effects, the alternative for them was something that they wanted to consider, such as illness and death. The belief that the medication is keeping them healthy, improving quality of life and allowing them to focus on day-to-day living seemed to dominate over the psychological effects of the condition or the medication in terms of adherence. Because of the way that HIV is perceived within society, the threat of discrimination is real and for many of the participants shape the way they see themselves, the world and this in turn guides their thinking when it comes to issues, especially with disclosure. Above all, this research explores the antiretroviral adherence factors specifically associated to MSM.

*Key Words: Adherence, MSM, Antiretroviral Therapy, Barriers, Enablers, South Africa*

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## ABBREVIATIONS

|                 |   |   |
|-----------------|---|---|
| AIDS            | - | Acquired Immunodeficiency Syndrome              |
| ART             | - | Antiretroviral Therapy                          |
| ARV             | - | Antiretroviral Medications                      |
| DOTS            | - | Directly Observed Treatment                     |
| GP              | - | General Practitioner                            |
| HAART           | - | Highly Active Antiretroviral Therapy            |
| HBM             | - | Health Belief Model                             |
| HCT             | - | HIV Counselling & Testing                       |
| HIV             | - | Human Immunodeficiency Virus                    |
| HRQL            | - | Health Related Quality of Life                  |
| IMB             | - | Information-Motivation-Behavioural Skills       |
| MSM             | - | Men who have Sex with Men                       |
| NGO             | - | Non-Government Organisation                     |
| NNRTI           | - | Non-Nucleotide Reverse Transcriptase Inhibitors |
| NRTI            | - | Nucleotide Reverse Transcriptase Inhibitors     |
| NSP (2012-2016) | - | National Strategic Plan (2012-2016)             |
| NtRTI           | - | Nucleotide Reverse Transcriptase Inhibitors     |
| PLWH            | - | People Living With HIV                          |
| PLWA            | - | People Living with Aids                         |
| PI              | - | Protease Inhibitors                             |
| PEP             | - | Post-Exposure Prophylaxis                       |
| PrEP            | - | Pre-Exposure Prophylaxis                        |
| QOL             | - | Quality of Life                                 |
| SCM             | - | Social Cognitive Model                          |
| STD             | - | Sexually Transmitted Disease                    |

|        |   |                                |
|--------|---|--------------------------------|
| STI    | - | Sexually Transmitted Infection |
| TRA    | - | Theory of Reasoned Action      |
| TTM    | - | Trans-Theoretical Model        |
| UNAIDS | - | United Nations AIDS            |
| USA    | - | United States of America       |
| WHO    | - | World Health Organization      |

## CHAPTER ONE: INTRODUCTION

### 1.1 BACKGROUND

Presented in this chapter is the background to this research and the issues around HIV/Aids (Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome), its treatment and its adherence. To put into context, although HIV remains incurable it has become recognised as a treatable and manageable chronic illness which has seen significant developments in relation its treatment through antiretroviral therapy. This chapter will briefly examine why adherence to treatment remains challenging for a number of biological, psychological and social reasons and why this raises specific problems especially among marginalised and discriminated populations, such as MSM. The aim of the research will be detailed followed by the rationale, the structure of the report and lastly, the conclusion.

In the thirty years since HIV/Aids was discovered, it remains a health condition that affects many millions of people (UNAIDS, 2011b). Antiretroviral therapy has been available for a number of years and has turned this deadly condition into a chronic disease which can be managed effectively giving people living with HIV improved health, quality of life and increased survivability (UNAIDS, 2012). Like many chronic diseases, adherence to treatment remains challenging (U.S. Department of Health & Human Services, 2011).

Although this research does not examine adherence rates *per se* one should consider at this point the current issues involving the monitoring and evaluation in South Africa. HIV treatment adherence features in the South African National Strategic Plan 2012–2016 (NSP 2012-2016) whereby the government has set out its aims to have a monitoring and evaluation system rolled out by 2013/2014 (Department of Health, 2011). That is to say, that until this system has been implemented, any understanding of the current ARV treatment adherence rates remains particularly difficult to access and understand. On the other hand, research from the private healthcare sector suggests that the estimated rates of adherence to ARVs are in the range of 50% to 70%. These figures were derived from pharmacy claims submitted by medical scheme members currently registered on various managed care programmes, which largely use medicine couriering companies for the delivery of the medication to places of convenience for members. However, this treatment adherence figure does not actually indicate the physical taking of the medication by the patient (Nachega, Hislop, Dowdy, Chaisson, Regensberg & Maartens, 2007).

A number of studies have examined the factors which make adherence to treatment problematic or what facilitates or makes adherence easier, however these studies have largely focussed on heterosexual populations in other countries. There appears to have been little or no work done examining the enablers and barriers to ARV adherence among MSM in a South African and more specifically in the Johannesburg context where a large number of MSM living with HIV reside.

This is a group that is marginalised and vulnerable not only to the ravages of this infection but also to the social stigma and discrimination associated to HIV which can make access to treatment and the adherence thereof especially challenging (Anova Health Institute, 2010). For this reason, research should focus on giving a voice to MSM with limited influence and interpretations by others who are part of this group (Dilley, 1999). Since HIV/Aids is understood as being more than a biological issue, meaning that people living with HIV experience their condition from a psychological and social context it was imperative to examine this topic broadly (Ghaemi, 2009; Protopopescu et al., 2009). That is to say this research looks at this topic from a biopsychosocial viewpoint, going beyond looking at the biological factors which may hinder treatment adherence by examining the impact of these factors from a psychological and social or structural perspective. Furthermore, since this research examines the topic from a biopsychosocial perspective the terminology used needs to be critically reflected upon. In line with the UNAIDS recommendations, the use of the term 'patient' was only used when considering a person living with HIV (PLWH) in a clinical setting. To reiterate this point, this term also refers to recognising that a PLWH is then understood as a 'patient with HIV-related illness or disease' (UNAIDS, 2011a). Furthermore, in line with the UNAIDS recommendations, when using the term 'vulnerable' this is understood as a key population that is medically vulnerable to HIV infection and for this research this is MSM (UNAIDS, 2011a). Lastly, the term PLWH acknowledges that an infected person may live many healthy and productive years and may not be deemed as sick (UNAIDS, 2011a). With reference to the terminology used for those who were interviewed. As the entry point, the term 'MSM living with HIV and taking ARVs, was adopted by the researcher as the most appropriate, because they collaborated by providing their narratives to refer to them in this report as 'participants' collectively or by the initial of their (pseudonym) name when referred to individually.

## 1.2 RATIONALE

HIV/Aids has had a substantial global impact over the last 30 years with an estimated 34 million adults and children worldwide were living with HIV at the end of 2011 (UNAIDS, 2012). The UNAIDS Global Aids Report (2012) suggests that the number of Aids related deaths has steadily decreased from its peak of 2.4 million people in 2004, to an estimated 1.7 million in 2011. The same report suggests that this decrease is largely due to the availability of ARVs, as well as a shift in the care and support for people living with HIV, especially in middle and low-income countries. The effects of ART are particularly evident in sub-Saharan Africa, where the number of deaths of PLWA that have been prevented has quadrupled over the last four years when ART was rolled out and dramatically expanded (UNAIDS, 2012). According to the UNAIDS (2012), sub-Saharan Africa continues to bear the brunt of the epidemic. Although, the number of people living with HIV around the world continues to climb, the number of new infections in sub-Saharan Africa has decreased by 25% since 2001. However, the region has accounted for 71% of new infections in 2011 of 1.8 million people. In 2011, the number of adults or children living with HIV number reached 23.5 million or 69% of the global total (UNAIDS, 2012). Within this pandemic, in 2010 there were an estimated 5.6 million South Africans living with HIV (UNAIDS, 2011). Whilst two years later more than 60% of those eligible for it were accessing ARVs in South Africa (UNAIDS, 2012).

It is widely accepted that in the years since HIV was first discovered, it has become a treatable chronic condition (Jaffe, Valdiserri, & De Cock, 2007). Essentially, the aim of antiretroviral therapy is to delay the progression of HIV to full blown Aids, and to maintain quality of life and improve the length of life in people living with the virus (Hislop & Regensberg, 2004). Over the years, there have been significant developments in ARVs with current treatment options have become simpler to take and less toxic than earlier ARVs regimes (Hammer et al., 2006). Notwithstanding the pharmacological advances in ARVs, HIV/Aids remain a significant psychosocial issue. What this means is that adherence to ARVs is seen as a complex medical and also a social issue. Research suggests that there are four broad main reasons for non-adherence, these being: psychological, biological or issues associated to the medication and the treatment of the condition, and lastly, ethno-cultural issues (Halkitis & Kirton, 1999). That is to say, people living with HIV may experience many serious psychological and social stressors that complicate the course of the disease, like dealing with isolation, depression and traumatic life events (Gore-Felton & Koopman, 2008)

For this reason, a biological, psychological and social lens has been used by the researcher to explore this issue.

There is an overwhelming amount of literature that explores treatment adherence, covering a magnitude of health conditions including HIV. However, it would seem that much of this is quantitative in nature and seldom is there an understanding of treatment adherence amongst marginalised or vulnerable populations from a qualitative perspective. For this reason, when considering MSM there appears to be minimal information available from a South African context as most research comes from Europe and America. In other words, the lives of HIV-positive MSM when reflecting on their antiretroviral treatment adherence appears to be a grossly under-researched and remains largely unknown, especially when viewed from a South African perspective. Certainly, no research appears to be available which clearly explores the factors that either enable or inhibit treatment adherence amongst MSM in South Africa, let alone Johannesburg. This is something that this research hopes to address.

A recent meta-analysis of low and middle-income countries found that MSM are nearly four times more likely to be infected with HIV than the general population (Baral, Sifakis, Cleghorn, Beyrer, 2007). Furthermore, eight studies conducted between 2005 and 2010 indicated that HIV prevalence among MSM ranged from 10.4% to 43.6% (Burrell, Mark, Grant, Wood, & Bekker, 2010). Although there is further limited research into this population in South Africa, the HIV prevalence in MSM in the 15 to 49 year age-group in the Cape Town area is estimated to be 42%, whilst in the Durban and Pretoria areas it is 25% respectively and 12% in Soweto, Gauteng (UNAIDS, 2011b). Whilst data from the Eastern Cape shows that the likelihood of HIV infection for MSM was 3.6 times higher than for men in the general population. Whilst MSM have been disproportionately affected by HIV since the beginning of the epidemic, research on the epidemiology of this group is in its infancy (Ca'ceres, Konda, Segura, Lyerla, 2008; van Griensven, 2007; Lane, Fisher Raymond, Dladla, Rasethe, Struthers, McFarland, & McIntyre, 2009). Certainly the research is limited when it comes to understanding treatment issues and needs of this group in the South African context and more specifically Johannesburg.

In 1994, homosexuality in South Africa was decriminalized. More recently the country has included MSM in its *HIV and STI National Strategic Plan for 2007-2011* and *HIV, STI and TB National Strategic Plan 2012–2016* (Department of Health, 2011). Thus this acknowledging of the vulnerability of this group to HIV places them within the strategic

priorities of key populations in terms of prevention interventions. This includes interventions such as: peer education, appropriate messaging, condoms, STI management, pre-exposure prophylaxis, HIV HCT and TB Screening within the MSM community (Department of Health, 2011). Nonetheless, even with South Africa's laudable response to HIV, the researcher understands that treatment adherence and the needs of MSM has suffered from limited research with very little being known regarding the treatment and adherence needs of MSM living with HIV who are accessing ARVs in South Africa.

Previous research in the field of ARV treatment adherence has explored the barriers and enablers from a patient and health care provider perspective. However, MSM are a diverse and vulnerable group presenting with specific challenges, additional risk factors and behaviours that alter the management of HIV when compared to the heterosexual population (Anova Health Institute, 2010). There are specific issues to this group, such as its vulnerability to society's discrimination and stigma that may have an impact on their ability and willingness to seek healthcare services (Lane, 2008). This research explores these biopsychosocial factors to understand the extent to which these are a barrier in terms of limiting adherence to treatment and retention into care. Furthermore this research explores the factors which act as enablers to treatment adherence.

Lastly, the participants of this study were drawn from an urban population based in Johannesburg and were members of a support group open to MSMs who are living with HIV. The researcher has worked in the HIV/Aids field for a number of years and had developed a relationship with the group which enabled accessibility to this vulnerable population. In addition, support groups aimed at MSM living with HIV are limited in the local area so using this group also provided a unique opportunity to be able to understand the group itself, its structures and dynamics. Moreover, to gain insight in the ways that a support group such as the one studied may have an impact on treatment adherence.

### **1.3 AIMS OF THE STUDY**

Based on the issues discussed in the rationale, the broad aims of this research are to examine what are the barriers and enablers to ARV adherence that specifically affect MSM in the city of Johannesburg. By using an exploratory qualitative research design, this allowed the researcher to describe and highlight events and experiences from the participant's narratives as closely as possible to the way they were lived. More specifically, this research aims to do this by exploring the biomedical factors that MSM perceive to influence their ARV

adherence. In following a biopsychosocial understanding of the topic, the research also aims to identify, explore and make sense of the psychological factors MSM perceive as influencing their ART adherence. As well as exploring the psychological aspects, it explores the social barriers that MSM perceive to influence their antiretroviral therapy adherence. Lastly, this research aims to examine the participant's thoughts on the support group and other interventions that should be available in order to improve adherence to ART.

#### **1.4 STRUCTURE OF THE RESEARCH REPORT**

The structure of the research report is as follows. Following this initial introductory chapter, Chapter Two examines the literature that was reviewed for this research. This chapter starts by defining MSM, ART, the importance of adherence to the treatment and some of the possible side-effects, which provides an overview of the key concepts of the research. The remainder of this chapter follows a biopsychosocial model when considering ARV treatment adherence. The biological barriers and enablers section examines the complexity of the treatment regime; side effects of the medication; remembering to take the medication, weight, nutrition and adherence; relationship with medical service providers and access to health care facilities. From a psychological perspective when considering the barriers and enablers, the chapter goes on to examine mental health and adherence which includes mood and anxiety disorders; MSM developmental considerations; internalized stigma of Aids; the influence of drugs and alcohol; disclosure of HIV status and how this may influence adherence; beliefs in the effectiveness of ART counselling and adherence needs and the perceived quality of life the medication may bring. This chapter then looks at the social and structural factors that influence treatment adherence. This includes: the medicalization of HIV; stigma and discrimination; support groups and the public face of illness. Lastly, the chapter brings together the key points of the literature that informs this subject, however it also reflects on the gaps in the literature.

Chapter Three provides detail of methodology used for this research, beginning with posing the research questions. The chapter then examines the design of the research. This is followed by a profile of the research participants and how they were selected. The next section details the procedures that were followed during this research. This is followed by the method of data collection and analysis; quality assurance; strengths and weaknesses of the research and researcher reflexivity. The last section of this chapter examines the ethical considerations when working with the participants of this research.



Chapter Four presents the results and discussion that follows the biopsychosocial themes. In addition, there is some discussion on the MSM label and the preference by the participants for the term 'gay men'. This chapter presents the support interventions that the participants felt should be made available to MSM living with HIV to improve adherence. The last section discusses the researcher's experiences when interviewing each participant. Chapter Five is the concluding part of the report and examines the limitations of this study. In addition to this the section ponders on areas for future research.

## **1.5 CONCLUSION**

This chapter introduced the research by highlighting that treatment adherence issues. In the past research when considering MSM has been focussed mostly on quantitative methods and seldom explores this subject using participant's narratives. Furthermore, any research that has been carried out in this area seems to have fixated on MSM in the USA and Europe. This chapter highlighted the need to identify and explore the enablers and facilitators to treatment adherence for MSM by facilitating those who have experience in sharing their experiences. The chapter described the structure of the report which follows the biopsychosocial format. Furthermore, since adherence to treatment is a complex issue, the chapter aimed to motivate why it is vitally important that this research examines this from a biopsychosocial perspective instead of the traditional medical perspective. The chapter also introduced and discussed the terminology which will be used throughout in order to treat this issue in the respectful and sensitive manner that it deserves. The next chapter examines the literature relating to antiretroviral therapy adherence and MSM.

## **CHAPTER TWO: LITERATURE REVIEW**

### **2.1 INTRODUCTION**

HIV and the treatment of the condition appear to feature across three very broad areas: being the medical, psychological and social. When reflecting on the stories of HIV positive MSMs who are taking ARVs, it is especially important to understand these areas and how these may influence adherence to treatment. From a biomedical perspective, this involves examining the complexity of the regime, the side-effects, remembering to take the treatment, nutrition, and the relationship between the medical service provider and the experience of the medical facility. From a psychological perspective, how the PLWH mental health in terms of mood, depression and anxiety affect their ARV adherence, as well as how internalised Aids related stigma, drugs and alcohol use and abuse, disclosure, beliefs surrounding their treatment, counselling and perceptions on quality of life also influence adherence. Lastly, this section reflects on how the various social factors play a role in ARV adherence in the form of the medicalization of HIV, the stigma attached to the virus and the impact that support groups have on treatment adherence.

This chapter will examine the definition MSM. It will then describe what ART is and contextualize importance of adhering to the medication regime. The chapter will then go onto examine the biological, psychological and social factors that have significant influence on ARV adherence.

### **2.2 DEFINING: MEN WHO HAVE SEX WITH MEN (MSM)**

The term MSM is a recent definition for 'gay men' or 'homosexual men' and there appears to be a limited understanding as to the origins of the term (Boellstorff, 2011). Despite its unclear origins, there is consensus that the term started in the mid-1980s in the USA and has been mostly used within English speaking countries of the USA and Europe and since then its use has increased (Boellstorff, 2011). Although the term can largely be understood to originate as a result of HIV/Aids whereby activists set about politicising the condition in the light of its links to discrimination and silencing for two reasons, firstly because there are MSM who do not see themselves as being 'gay' and would perhaps be hostile to this term. Certainly from a local perspective, in Soweto in particular, the understanding of 'gay' differs from a western interpretation of the label whereby it appears associated with effeminate gender identity rather than a man who has sex with other men (Lane et al; 2009). Secondly, HIV prevention and treatment programmes which focus on 'gay men' would to a large degree alienate MSMs

or those who do not identify themselves as 'gay'. As a result, this would mirror inequalities in race and class whereby programmes would be utilised by western, middle-class gay men (Boellstorff, 2011). Thus, these programmes fail to reach many of these 'at risk groups'.

Research is starting to explore the diverse group within the MSM label, many of whom do not consider themselves as gay or homosexual, but have sex with men (Brouard, 2009). This is important because, although the MSM label seems to be rather simplistically used, it needs to be further unpacked, explored and understood especially in a South African context where the labels 'gay' and 'lesbian' are viewed as primarily Western concepts which have limited merit in a local context (Brouard, 2009). In addition, as not all MSMs are identified as discussed as 'gay' or homosexual in the sense that many may be married to or involved with women, have children and have sex with women. Many MSM's identified themselves as 'straight' in order to keep their same sex behaviours hidden from family, friends and female partners (Lane et al., 2009).

For one thing, studies suggest that roughly 50% of MSM have had sex with a woman and in many cases show a low frequency of condom use in sex with both male and female partners. This results in an under-estimation of the rate of HIV transmission from male to female partners (Ca'ceres et al., 2008). All in all, we must take cognizance of the fact that sexual practices do not occur in isolation and are shaped by complex social, cultural, economic and political contexts. This fluid interrelationship between identity and practice provides a deeper understanding that using the term 'gay men' can be challenging and gives reason for the preference of a broader definition of MSM (Brouard, 2009). However, there still appears to be a significant amount of debate by activists around this term. Although discussion on the appropriate use of MSM is not the focus of this research upon reflection and aside from the reasons stated, MSM appears to be palatable and more manageable when examining this heterogeneous group by researchers. The term seems to have made homosexuality appear more clinical, less political, less sexualized, and all in all, it is has become easier to manage by those researching this. In essence, an MSM label may experience less stigmatization in areas outside the USA and Europe than 'western' terms such as 'gay' or 'homosexual', although this has not been extensively researched in South Africa (Boellstorff, 2011).

The aim of this research is to examine the lives and experiences of MSM living with HIV and taking ARVs. Issues of treatment adherence amongst MSM and the debates around the term

MSM are critical as this group is marginalized and is chronically under-researched especially when it comes to treatment issues (Cloete, Simbayi, Kalichman, Strebel, & Henda, 2008).

### **2.3 ANTIRETROVIRAL THERAPY**

Standard ART consists of a combination of at least three ARV drugs to maximally suppress the HIV virus and stop the progression of HIV disease (WHO, 2012). It is important at this point to consider what ARVs do. ARVs aim to block the rather complicated process of the replication of the HI-virus. It aims to do this by impeding three viral enzymes that are known as reverse transcriptase, protease and integrase (Maartens, Cotton, Meintjies, Mendelson & Rabie, 2010). The ARV medications which are known to block the reverse transcriptase process fall into three categories; nucleotide reverse transcriptase inhibitors (NRTIs), Nucleotide reverse transcriptase inhibitors (NtRTIs), Non-nucleotide reverse transcriptase inhibitors (NNRTIs). These medications block the translation of viral RNA into proviral DNA, preventing the generic integration of the virus (Maartens et al., 2010). NRTIs and NtRTIs resemble the natural nucleotide building blocks of DNA so that when the reverse transcriptase tries to add the medication to a developing strand the process cannot be completed. Protease inhibitors (PIs) impede the activity of the HIV protease that cleaves polypeptides into functional virus (Maartens et al., 2010).

The extensive clinical research that has been undertaken over the years suggests that starting antiretroviral therapy with a CD4 count of less than 350 has been shown to have optimal clinical outcomes rather than waiting until severe immune system damage has occurred (Stern et al., 2009). In the last couple of years, many experts have begun endorsing the use of ARVs much earlier with a CD4 count of 500 or more, in order to improve treatment outcomes and maintain undetectable viral loads. The thinking behind this new trend is to try and decrease HIV transmission by using the medication as a form of prevention (Hirschel, 2010). Many medical service providers encourage treatment to commence upon diagnosis regardless of the CD4 count. Despite this new thinking, the authorization of treatment by managed care providers and the public sector remains based on a CD4 count of 350 (Walensky et al., 2009).

Recent developments in the pharmacological treatment of HIV have resulted in the availability of combination medication that can be taken in a 3-in-1 daily tablet format (Nachega, Mugavero, Zeier, Vitoria, & Gallant, 2011). The consequence of this 3-in-1 pill hopefully means that the physical taking of the medication becomes easier because of a one

pill per day format as opposed to multiple pills per day. Furthermore, many low-cost generics are now available, which reduces the financial limitations in terms of accessibility to the medications (Nachega et al., 2011). It is reported that there are less short-term side-effects with more modern drugs, although the long-term side-effects such as fat redistribution and raised cholesterol remains a problem and need to be monitored (Pretorius, Klinker & Rosenkranz, 2011). New generations of existing drug classes such *etravirine* (NNRTI), *darunavir* (PI) have been developed and are becoming more widely available in South Africa (Maartens, et al., 2010). These medications work on other parts of the replication process, in that they focus on new viral targets such as integrase inhibitors, entry inhibitors and receptor blockers (Maartens et al., 2010). In addition to these changes to the nature of treatment, medical providers working in this field now also have a better understanding of sequencing these drugs for best effect, which ones to use in a variety of contexts, the durability of the medication in terms of the circumstances which cause drug resistance, and although these are expensive, these are used in genotyping to test for drug resistance (Dudley, Chin, Bimber, Sanabani, Tarosso, Costa, Sauer, Kallas, & O'Connor, 2012). This knowledge can be used to assist medical providers with making an appropriate drug selection for improved treatment efficacy (Maartens et al., 2010). Notwithstanding the advances in ARVs, adherence still poses a dilemma for a large number of individuals in the treatment of HIV.

#### **2.4 ARV TREATMENT ADHERENCE**

As the focus of this research is on HIV treatment adherence, it is essential at this point to understand this term and the consequences to a PLWH of non-adherence. For the most part, treatment adherence refers to following a treatment regime and taking the correct dose of medication at the right time as prescribed (U.S. Department of Health & Human Services, 2011). When it comes to HIV, this means taking ARVs correctly, as prescribed by the medical service provider in order to prevent the chance of drug resistance. Drug resistance means that the virus may mutate and replicate these mutations in the presence of medication that previously worked (Aidsmap, 2012).

For the most part, studies have suggested that high levels of treatment adherence have been shown to have the best health outcomes for PLWHs, with a marked reduction in response to treatment for adherence lower than 95% (Korb-Savoldelli, Gillaizeau, Caruba, Tauckoor, Prognon, Durieux, & Sabatier, 2012). Adherence also predicts the overall survival of people living with HIV. Maintaining a level of 80% adherence or more has been associated with lower death rates (Chesney, 2000; Maartens et al., 2010). Accordingly, research supports the

positive effects of good treatment adherence in terms of the way the virus responds and thus a PLWH's disease progression. In that way, the medication can keep a PLWH healthy and alive for longer. Whilst on the other hand, the effects of poor treatment adherence include a considerable risk of drug resistance to HIV, as well as the threat that any drug resistance may be passed from one person to another in the same manner as HIV transmission (Chesney, 2000; Maartens et al., 2010).

A consequence of HIV in terms of lower levels of adherence to treatment regimens is that it can lead to increased viral load or the quantity of virus in the body, and a decrease in CD4 count, thereupon a reduction in the overall health of an PLWH resulting in an, increased risk of disease progression (Maartens et al., 2010). In addition, non-adherence to ARVs can increasingly lead to the virus becoming treatment (drug) resistant. By missing doses or taking doses of ARV medication incorrectly, this results in the level of the active ingredients in the blood being too low to stop HIV reproducing when considering the complex process described above (Carter, 2007). This would then result in HIV replicating strains of virus that are now able to reproduce despite the medications' presence in the body and greatly increases the risk of drug resistant strains of HIV emerging (Chesney, 2000; Maartens et al., 2010). This would result in a need to review the treatment regime undertaken using blood tests such as genotyping. Thus, a possible change in medication may be required in order to suppress the virus (Carter, 2007). Such changes in the treatment regime may further limit the future treatment options available for these PLWHs (Maartens et al., 2010).

## **2.5 WORKING DEFINITIONS**

Definitions of key terms used throughout this research are indicated in this section.

*Antiretroviral therapy:* The term 'Antiretroviral therapy' in this context follows the World Health Organization's definition, which simply defines the aim of the medication to maximally suppress the HIV virus and stop the progression of HIV disease (WHO, 2012).

*Treatment adherence:* When 'treatment adherence' is used, in this context it is seen as all of the factors that may influence taking ARV medication, and not only the physical taking of the pills.

*MSM:* The term 'MSM' is used to describe men who have sex with men, including those who self-identify as 'homosexual' or 'gay' as well as those who do not. However, the participants of this research mostly identified themselves as 'gay men' rather than MSM.

*Support group:* The term ‘support group’ was used in its heterogeneous to describe a group of individuals who share a clinical condition, who meet weekly to psychologically support each other and share information, which is facilitated by a subject expert.

*Enablers:* The terms ‘enablers’ of treatment adherence describe those factors that facilitate adherence or make taking ARVs less challenging.

*Barriers:* The term ‘barriers’ was used to describe those factors which make treatment adherence challenging or prevent adherence. The next section examines the factors associated to treatment adherence.

## **2.6 FACTORS ASSOCIATED WITH TREATMENT ADHERENCE**

As we have seen HIV treatment adherence remains vital to impede the progression of the virus, keeping a person healthy and reducing the likelihood of developing drug resistance and succumbing to the virus. However, treatment adherence is complex and work has been carried out to understand the reasons for non-adherence. The biopsychosocial model posits that it is not possible to reduce individuals and their illnesses to one factor, that three areas must be given equal importance. These factors are described as the biological, psychological and social factors and they are relevant in all cases (Ghaemi, 2009). HIV and ARV adherence can be understood in the same way by being reliant on both psychosocial conditions and treatment related characteristics (Protopopescu et al., 2009).

The characteristics that may influence non-adherence can be due to the medicine regime itself. These would include the perceived inconvenience of taking medication on a daily basis. Moreover, the number of pills that a PLWH may have to take at differing times of the day may also influence the taking of the medication (Korb-Savoldelli et al., 2012; Halkitis & Kirton, 1999). Coupled with this, concerns over the resultant dietary restrictions may cause PLWHs to default on taking their treatment (Korb-Savoldelli et al., 2012). In addition, the side effects that a PLWH may experience from the treatment may also make treatment adherence problematic for them (Korb-Savoldelli et al., 2012).

From a psychosocial perspective, several factors have been identified that affect HIV treatment adherence. The patient-provider relationship and system of care plays a crucial role in maintaining treatment adherence (Thom, Hall, & Pawlson, 2004). Psychological conditions such as depression and substance use may also pose a challenge to maintaining treatment adherence because a PLWH’s use of alcohol or other substances may lower treatment

adherence (Chesney, 2000; Halkitis & Kirton, 1999; Halkitis, Parsons, Wolitski, & Remien, 2003).

In addition, a person's response to coping with stress may also affect adherence. In particular, the use of avoidant coping strategies has been implicated in poorer treatment adherence (Halkitis et al., 2003; Martinez et al., 2012). Furthermore, research suggests that disclosure of one's HIV status, particularly sexual partners had a significant influence on treatment adherence (Halkitis et al., 2003). Other areas include what are described as ethno-cultural issues such as medical service providers' lack of cultural understanding and lack of social support (Halkitis & Kirton, 1999). These factors will be dealt with in greater detail later on.

### **2.6.1 Biomedical Enablers and Barriers to Treatment Adherence**

The biomedical aspect of understanding ARV treatment adherence can be described in several areas which include the complexity of the treatment regime, the side-effects of the treatment and in particular how these may affect MSM, forgetting to take the treatment, weight-loss nutrition and adherence and lastly, MSM and their relationship with medical providers and health facilities.

#### ***2.6.1.1 The Complexity of the Medication Regime***

Since HIV is understood as a clinical condition, it is argued that a number of factors that influence adherence are understandably clinical in nature. Although in practice there is inconsistency in terms of the importance placed on the perceived complexity of treatment, the number of pills taken per day and how these may influence adherence. On the one hand, these factors appear to have an influence on the likelihood that a person will take them correctly and maintain treatment adherence in the medium and long term (Protopopescu et al., 2009). In other words, the more pills that are taken at different times and under different circumstances, the greater negative effect it has on treatment adherence. A large number of pills, and a large number of different types of medications each with specific dietary requirements may result in the use of the medication being delayed, being missed altogether, or not taken under the correct circumstances. In addition, a PLWH's ability to maintain a complex regime that is demanding on them, linked to a lack treatment understanding, may be seen as a significant factor that influences non-adherence (Atkinson & Petrozzino, 2009). On the other hand, alternative evidence suggests that adherence is unrelated to the number of different medications that a PLWH is taking, in that adherence rates when comparing those on mono-therapy, to those on dual or triple combination therapies remain similar (Halkitis et



al., 2003). Because, non-adherence is more likely to be as a result of psychological and social issues as opposed to the medications themselves in that avoidant coping strategies, or discomfort in talking to sex partners about HIV and perhaps the use of alcohol and drugs appear to be the overall reasons that make adherence to treatment problematic (Halkitis et al., 2003).

#### **2.6.1.2 Side-effects**

There appears to be consensus that all classes of antiretroviral therapy medications are associated with toxicities (Murphy, 2003). And that the side-effects which come from the toxicity of the medication may vary from mild to severe and from acute to chronic (Maartens et al., 2010; Murphy, 2003). Where side-effects are severe, the medication would need to be stopped and replaced by a new one (Hart, Curtis, Wilkins, & Johnson, 2007). Besides toxicity, changes to regimes occur when it is clear that the viral load is not being suppressed (Maartens et al., 2010). For the most part PLWH's may not have significant adverse side-effects to their antiretroviral therapy, although the effects of the medication on the body need to be monitored. However, because of this there is a potential of those PLWH's reporting symptoms and side-effects may run the risk of having difficulty in maintaining treatment adherence. That is to say the reduction or alleviation of side-effects plays an important role in improving an PLWH's taking the medication regularly and correctly (Ammassari, Murri, Pezzotti, Trotta et al., 2001; Murphy, 2003).

Similarly, because of the potential side-effects of certain classes of antiretroviral therapy medications there are valid concerns that these may be more pronounced for MSM, which could be a barrier to treatment adherence (Anova Health Institute, 2010). For example, the potential of lipodystrophy, flatulence and diarrhea and erectile dysfunction may accordingly mean that adherence to treatment be unappealing (Anova Health Institute, 2010). For instance, lipodystrophy results in changes in fat distribution and can be caused by antiretroviral therapy (Maartens et al., 2010). Chiefly, this would mean that some PLWHs may experience fat loss (Lipotrophy) and some experience fat gain (Lipohyertrophy) and some experience both forms of lipodystrophy. The fat loss is caused by the nucleoside reverse transcriptase inhibitors (NRTIs), and particularly *stavudine* (Maartens et al., 2010). Moreover, the fat accumulation occurs in the abdominal area, in the 'breasts' and chest area and in addition may cause an unsightly 'buffalo' hump between the shoulder blades and this may make PLWH more conspicuous, as this is seen by them and possibly outsiders as

symptomatic of Aids, so they are fearful of being shunned by this side-effect (Leung & Glesby, 2011; Sheth & Larson, 2010).

Generally speaking, some groups within the MSM community place greater importance on physical appearance and sexual desirability compared with their heterosexual counterparts. That is to say, MSM report significantly more unhappiness and distress in many of the psychosocial areas related to 'body dissatisfaction' (Beren, Hayden, Wilfley, & Grilo, 1998). Furthermore, it is recommended that medical providers avoid medication that causes lipodystrophy as this group will not tolerate a visible side-effect such as this (Anova Health Institute, 2010). Correspondingly, certain PIs may cause diarrhea and flatulence and as this may negatively impact anal sexual functioning and the enjoyment of anal sex of MSM which may further have a negative impact on treatment adherence (Anova Health Institute, 2010; Maartens et al., 2010). Conversely, because of the reported increase in sexual dysfunction amongst PLWHs that are taking ARVs, likewise a PLWHs' perceived sexual dysfunction may be associated to defaulted treatment adherence (Trotta, Ammassari, Murri, & Marconi, 2008). Similarly, it was reported that apart from age, a further predictor of erectile dysfunction was the lengthy duration of HIV infection, the use of PIs and lipodystrophy which be a further reason for MSM to have difficulty in maintain treatment adherence (Crum et al., 2005). By and large, MSM who were non-adherent to their treatment cited a greater number and severity of side-effects like gastrointestinal and body changes (Miguez-Burbano, Espinoza, & Lewis, 2007). Specifically, those reporting sexual dysfunction were also less likely to be fully adhering to their medication regime (Miguez-Burbano et al., 2007).

### ***2.6.1.3 The use of reminder tools***

When reflecting upon PLWHs who have been taking ARVs for an extended period, whereby the treatment has become integrated into day-to-day living, studies have shown that forgetfulness is cited as the reason for not taking their medication (Barfod, Sorensen, Nielsen, Rodkjaer, & Obel, 2006; Bartlett, 2002; Chesney, 2000). In other words, not taking treatment may not be as a result of side-effects or the complexity of the treatment but rather the PLWH simply forgetting to take them, or having forgotten whether they have taken them or not.

As a result of this, many interventions have been developed based on tools to remind PLWHs when to take their medication (Maqutu, Zewotir, North, Naidoo, & Grobler, 2010). These are coupled with having a fixed routine, so that medication is taken at the same time of day, such as just before bedtime. Likewise, using reminder tools was most frequently reported as

helping PLWHs adhere by reminding them to take their medication and also prompting them when they had not (Curioso, Kepka, Cabello, Segura, & Kurth, 2010). Here, advances in information and communication technology have proven instrumental. This can be illustrated by cell-phones successfully being used to aid and support medication adherence programmes both in developed and developing countries such as South Africa (Fynn, Jager, Chan, Anand, & Rivett, 2006; Wise, & Operario, 2008). The cell phone alarm acts to prompt an PLWH to self-administer their medication at the appropriate time. One advantage of using a device such as a cell phone is that it is mobile and carried by the PLWH on most occasions. Secondly, it can be hidden away in the sense that when the alarm sounds it can be a reminder for any number of things, and lastly it can be fit unobtrusively into a PLWH's daily routine (Wise, & Operario, 2008). However, the access and availability of such tools may be cost prohibitive to many in the South African context although the number of people with cell-phones continues to grow. In addition, it appears that there has been no research on the use of such reminders by the MSM community and their effectiveness in treatment adherence.

#### ***2.6.1.4 Weight, nutrition and adherence***

For the most part there appears to be little consideration on how nutrition and body weight plays a role in adherence in the MSM community. However, there are several ways in which factors such as these may affect adherence in this group. Generally speaking, in the late stages of the condition, HIV is a protein-wasting illness, and weight loss among infected PLWHs is common. By the same token, there can be a number of other causes of weight loss in people living with HIV which include undiagnosed depression, poor oral health and HIV-associated oral conditions, for example oral thrush which have been understood to cause weight-loss in people living with HIV. Likewise, opportunistic infections, especially those causing prolonged diarrhea and others such as tuberculosis can cause rapid weight loss. Coupled with this ARV medication may cause weight loss in terms of causing diarrhea (Maartens et al., 2010). However, since the taking of antiretroviral therapy is associated with weight gain which may be seen as unappealing to MSM who place significance on body image (Miguez-Burbano et al., 2007). Weight-gain is associated with general well-being and quality of life. Although for PLWHs who have a greater Body Mass Index prior to treatment commencement, and experience further weight-gain may miss doses of their medication in order to counteract the weight gain (Miguez-Burbano et al., 2007) something that may be problematic when it comes to MSM who place significance on body image and any changes to their body.

At the same time, the nutritional requirement for people living with HIV is food that is high in energy. The recommended food intake needs to be increased by 10% over accepted levels in otherwise healthy people and to maintain the body weight in asymptomatic HIV (WHO, 2003). Furthermore, this needs to be increased to 20% or 30% during periods of symptomatic disease or opportunistic infections (WHO, 2003). For the most part, it is acknowledged that although ART is a major aspect of care for people living with HIV, over and above this, more attention needs to be placed on how diet and nutrition may enhance antiretroviral treatment adherence and the effectiveness of the medication (WHO, 2003). For example, dietary counselling, care and support appears to vary for people living with HIV and Aids and may be dependent on individual nutritional challenges or dependent on the stage of the disease a PLWH is in (WHO, 2003). All things considered, in order to maintain good adherence levels, regimes are recommending that PLWHs avoid food restrictions or advisable that certain foods be avoided (Maartens et al., 2010). In other words, to stay away from those that require complex dietary requirements has this been associated to poor treatment adherence (Chesney, 2000).

#### ***2.6.1.5 Medical service providers and facilities***

By the mere nature of being MSM and the stigma often associated with this label, homophobia and the fear of discrimination from health providers has often identified as a barrier to accessing health care and HIV services in this group (Lane, Mogale, Struthers, McIntyre, & Kegeles, 2008). In other words, because of the fear of being discriminated, many MSMs will avoid seeking healthcare assistance and are reluctant to access the essential treatment to keep them alive.

Reports from a number of countries suggest that MSMs in Africa have been refused healthcare due to their sexuality. Therefore MSMs may distrust health care providers to be able to give them the optimal treatment and maintain their confidentiality (Lane et al., 2008). For this reason, MSM are rarely open with their healthcare providers in terms of their health status and would rather not access healthcare due to fear of discrimination (Johnson, 2007).

In order to prevent this scenario from continuing, addressing relational concerns between MSM and healthcare providers, as well as the stigma around HIV/Aids in medical facilities is crucial. Because many MSM regularly access health services from government facilities, there is a strong need to improve the quality of services in government facilities for MSM thus making them more user friendly and accessible (Sheehy, 2011). The aim of the

relationship between the PLWH and their medical service provider should, for the most part be that of providing support, empathy, trust, communication and the provider's knowledge of the PLWH (Forrest, Shi, Von Schrader, & Ng, 2002), so that the PLWH feels safe that they are being listened to, understood, treated with respect in order to gain the best possible clinical care. With this in mind there is a call that more attention to be placed on strengthening the relationship between PLWH and medical service providers (Sixma, Spreeuwenberg, & van der Pasch, 1998). This imperative becomes especially pronounced when working with MSMs as they represent a socially marginalized group. Thus, there is an even stronger need to ensure that the environment is conducive to treating member of this group and that medical service providers are knowledgeable in the specific needs of this community. The focus in the treatment of HIV/Aids should be to the benefit of all PLWHs including those from marginalized communities.

This is a concern when considering the specific needs of the MSM community, as the current practice in mainstream healthcare in South Africa is to render services on the basis of 'sameness', rather than respecting differences or diversity. It is argued that this 'one size fits all' approach is inappropriate and the wrong approach to adopt when being cognizant of the diverse backgrounds that PLWHs have (Nel, 2009). For the most part, healthcare providers tend to blame or judge a PLWH for their HIV status, especially when it is based on their sexual orientation. As MSMs are a diverse group, presenting specific diagnostic and management challenges (Rebe et al., 2011). They also have specific risk factors when it comes to infection and adherence to treatment and behaviours that can change the management of HIV compared to heterosexual population. It is therefore vital that healthcare providers have knowledge of these differences in order to provide appropriate treatment services (Anova Health Institute, 2010) with an attitude of care, understanding and non-judgment. There are many psychosocial and cultural issues that impact on the problems presented by MSM. For example, issues of sex may include loss of libido, self-image, and worries about passing the virus on to sexual partners or the fear of rejection (Bourne, Hickson, Keogh, Reid, & Weatherburn, 2012). From a clinical perspective, these include; aging with HIV, the complications associated to long-term use of ART, co-infection such as STIs and co-morbidities such as various diseases, cancers and mental health problems (Zablotska et al., 2009), which may act as a barrier in terms of their willingness to seek healthcare (Anova Health Institute, 2010), thus placing them at considerable risk from health related problems.

As discussed, distrust in the medical service provider is seen as a barrier to MSM accessing medical care that remains an important factor for those MSM on antiretroviral therapy. Many MSM may feel reluctant to reveal a full sexual history to a medical service provider, for fear of being embarrassed or shamed (Anova Health Institute, 2010). This lack of full disclosure may in turn adversely affect the relationship with their GP in that individuals feel they cannot trust their medical service provider and withdraw vital information. Existing studies suggest that those who have a higher level of trust in their medical service provider show a better adherence levels and were able to deal with the various side effects, and as a result managed to stay longer on their medication (Altice, Mostashari, & Freidland, 2001; Mills et al., 2006). Having a non-judgmental and enabling treatment environment that puts emphasis on a trusting relationship between health care provider and patient is advantageous in promoting optimal for PLWH care (Thom et al., 2004). For the medical service provider, this includes competence, or having the HIV clinical knowledge; comprehensiveness and being holistic with regards to patient care; being consistent with their care; ensuring continuity of care in terms of an PLWH seeing the same medical provider at each visit and lastly being compassionate to the PLWH, their life stage, culture and background (Lewis, Colbert, Erling & Meyers, 2006). So that a PLWH's perception that their experience and satisfaction with their medical service provider is one of 'person-centredness' which may be an important factor for a PLWH remaining a treatment adherent (Thom et al., 2004). This kind of person-centred approach would include having sufficient rapport between the medical providers and patient, where the medical provider at the very least remembers the PLWH's name, listens carefully and shows interest in their lives by asking questions (Beach, Keruly, & Moore, 2006). Because MSMs are marginalized, vulnerable to social discrimination, stigma and prejudice, medical service providers need to create an environment conducive to interacting with MSM and that medical service providers should be aware of their own attitudes towards them as this can affect adherence levels negatively (Anova Health Institute, 2010).

Contrary to these arguments, some studies have shown that satisfaction with the medical provider does not necessarily translate into medication adherence (Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999). However, the literature seems to agree that by maintaining an honest, open and non-paternalistic relationship with those people living with HIV remains crucial and it is a necessary condition to improve adherence (Conway, 2007). On its own, the medical service provider-patient relationship may not be sufficient and other factors play a role. It has been shown that well-intentioned interventions may lead to a

PLWH's dissociation with their treatment and them no longer taking it (Conway, 2007). To illustrate, the admission by a PLWH of poor adherence may lead to the disapproval by the medical provider which may lead to a PLWH not feeling supported and no longer feeling motivated to take their treatment (Conway, 2007). Another example may be that the well-meaning intervention of medical alarms to remind the PLWH that it is time to take their medication may have a negative impact by it being perceived by the PLWH as being discriminatory or patronizing by the suggestion that they somehow lack the agency to remember to take their medication (Mannheimer, Morse, Mats, Andrews, Child, Schemetter, & Friedland, 2006). In terms of the PLWHs relationship with their medical provider and the need for social desirability, to project a positive image which may play a significant role in treatment adherence because it may result in the over-reporting of adherence levels to medical providers (Altice et al., 2001; Murri, Ammassari, Trotta, De Luca, Melzi, Minardi et al., 2004). On the whole, MSM who are taking ARVs need to be supported throughout by their medical service provider and coached that their level of adherence will not hamper the care that they receive in order for them to be retained in that care programme.

### **2.6.2 Psychological Factors which Influence Treatment Adherence amongst MSM**

This section explores some of the psychological factors that may influence treatment adherence. The psychological effects of living with HIV are significant and are implicated in treatment adherence. It would seem that the research on the interrelationship between psychological factors and how they influence behavioral aspects such as treatment adherence resulting in effects on disease progression is limited (Gore-Felton & Koopman, 2008). However, those factors most commonly given include distress, depression, anxiety, stress and coping, substance abuse and the perceptions around the efficacy of the medication (French, Tesoriero & Agins, 2011). For the most part, PLWHs that exhibit emotional distress may do so for many reasons, which may influence their treatment adherence. This may include the fear or anxiety over an uncertain prognosis, the effects of the medication and how they will respond or concerns that it may not work at all. PLWHs display fears for being isolated and abandoned by those around them because of their HIV status, especially partners and loved ones and family. In addition to this, people living with HIV may have an intense fear that they may infect others, which leads to a fear of having sexual relationships with others. Likewise, PLWHs may experience considerable anxiety over the thought of the loss of their health, their independence as they worry about getting sick and finally many years of life lost (Chippindale & French, 2001; Evian, 1997). They may have feelings of guilt due to the belief

that HIV is a punishment for lifestyle choices or being gay whereby HIV's association with deviant and promiscuous sexuality triggers shame and moral censure (Chippindale & French, 2001; Delius & Glaser, 2005).

### ***2.6.2.1 Clinical disorders***

It appears that the prevalence of mental health disorders in PLWH for the most part is reported as being substantially higher than those found in general populations in developing countries and similar to similar groupings in developed countries (Freeman, Nkomo, Kafaar & Kelly, 2007). In particular, depression, post-traumatic stress disorder (PTSD), substance dependence and mood disorders are common conditions reported from people living with HIV/Aids (Herman, Stein, Seedat, Heeringa, Mooma & Williams, 2009). For this reason, studies have highlighted the link between high levels of distress people living with HIV experience and low levels of adherence (Chesney, Ickovics, Chambers, Gifford, Neidig, Zwickl, Wu et al., 2000; Nel & Kagee, 2011). In other words, PLWHs who experience more pronounced emotional reactions to living with HIV are less likely to remain adherent to their treatment. Mood disorders, such as depression, also play an integral part in the progression of HIV and as well as impact on treatment adherence. People who are living with HIV that experience depressive symptoms, even after factoring drug usage and treatment adherence are increasingly at risk of disease progression (Gore-Felton & Koopman, 2008; Komiti, 2003). Generally speaking, the symptoms of depression appear to accelerate the progression of HIV and the development of Aids related symptoms.

Although a number of studies have explored the relationship between poor adherence and depression, the strength of the relationship between the two components has not been understood until recently. Above all, depression has a significant impact on adherence, chiefly in that the relationship between depression and poor adherence has recently been shown to have a strong correlation (Gonzales, Batchelder, Psaros, & Safren, 2011). By the same token, the same relationship is seen in both resource rich and poor settings, in all populations affected by HIV (Peltzer, Friend-du Preez, Ramlagan, & Anderson, 2010). This is further compounded with people living with HIV manifesting symptoms as a result of the side-effects from the antiretroviral therapy medication (Hass et al., 2004) which may make taking the treatment problematic.

When further exploring anxiety and mood disorders and how they play a role in treatment adherence, it needs to be remembered that MSM are a particularly vulnerable group who are



often living in hostile environments. MSM may experience stigma and discrimination in relation to their sexuality and their HIV status. This may culminate in the experiencing of anxiety related disorders like PTSD and mood disorders such as depression (Anova Health Institute, 2010). Correspondingly, there also appears to be a high prevalence of PTSD in people living with HIV which substantially exceeds the rates of the general population often as a result of being diagnosed HIV-positive (Gore-Felton & Koopman, 2008; Martin, Fincham, & Kage, 2009). This is often made more complicated when newly diagnosed PLWHs must commence taking ARVs straightaway due to their stage of disease progression. In contrast, it is suggested that even though PTSD does not impact a PLWH's adherence in the long term, the correlation between PTSD and non-adherence may be driven by the presence of co-morbid depressive symptoms (Kumarasamy, Safren, Raminani, Pickard, James, & Sri-Krishan, 2005; Sledjeski, Delahanty, & Bogart, 2005). That is to say, if a PLWH is newly diagnosed and has to commence therapy straight away, the initial shock and anxiety associated with this may make adherence to therapy challenging. This may mean that individuals may find it difficult to concentrate clearly when it comes to filling prescriptions, remembering to have their medication on their person, remembering to take the medication at the correct time and take the correct number of pills. Lastly, the anxiety and stress may be associated with reduced perceived self-efficacy and more uncertainty (Nel & Kagee, 2011).

### ***2.6.2.3 Stress and coping***

In addition to understanding the effects of mental health on antiretroviral treatment adherence, stress has been seen as playing a role in negatively affecting adherence. Whereby, those that report the highest levels of perceived stress are less likely to be adherent (French, Weiss, Waters, Tesoriero, Finkelstein, & Agins, 2005). This was defined as participants being in control of their lives in that they perceive things in their lives to be working in their favour by their ability to manage personal challenges and the extent to how problems had become overwhelming for them (French et al., 2005). The literature indicated that those who reported a reduction stress being more likely to becoming adherent. Whilst those who experienced an increased perceived level of stress in their lives were more likely to experience difficulty in remaining adherent (French et al., 2011). Moreover, when considering the manner in which individuals coped with living with HIV, there is an inclination to deny or disengage from their status in the presence of a negative or low mood. Furthermore, those individuals with a negative mood face problems with adherence as a result of using avoidant-coping (Weaver et al., 2005).

#### ***2.6.2.4 MSM developmental considerations***

To be able to understand how this affects the MSM community, two complex developmental life stages will often predispose MSMs to exhibit significant levels of stress, anxiety and depression over and above any potential risk from HIV infection (Anova Health Institute, 2010). These are the stage of ‘coming out’ and the later life stage of aging in late adulthood. Firstly, ‘coming out’ is the process whereby a PLWH realized the possibility of his or her sexuality as being homosexual (Cass, 1984). During this stage, a PLWH may experience complex emotional and psychological processes. Feelings of shame, guilt and fear experienced at this stage may be overwhelming to the PLWH that may lead to isolation, withdrawal or depression and also fluctuating with elation and relief when they are able to tell others the truth about themselves (Anova Health Institute, 2010).

The stage of aging in late adulthood may lead to a loss of confidence, self-esteem and the associated depression if PLWHs are no longer perceived as attractive or desirable in a population that places a lot of value on youth, body beauty, fitness, virility and potency (Anova Health Institute, 2010). By and large, those who have a sense of self-worth were seen to have better treatment adherence than those who did not (Mills et al., 2006).

#### ***2.6.2.5 Internalized Aids stigma***

It seems that as a consequence of the negative public opinions towards people living with HIV and the negativity experienced being directed at them being internalized this can result in the development of internalized Aids stigma. That is to say that a PLWH may internalize the socially constructed views of people living with HIV and they begin to see themselves as representing the negative perception and ‘self-abasement’ in relation to being a person living with HIV (Kalichman et al., 2005). For this reason, HIV-positive men in South Africa, irrespective of sexual orientation, experience considerable internalized Aids stigma, emotional distress and discrimination. Similarly, HIV-positive MSM experienced more discrimination relating to their HIV status than their non-MSM counterparts (Cloete et al., 2008). In other words, the fact of being part of the MSM population and living with HIV, in a South African context means that there is a higher experience of internalized Aids stigma. Therefore, the internalized Aids stigma can be understood as resulting in depressive symptoms over and above demographic characteristics, health status, symptoms of grief and various coping responses which may, for the most part, be related to the risk of depressive symptoms (Lee, Kochman, & Sikkema, 2002).

### ***2.6.2.6 The Influence of drugs and alcohol***

From a biological perspective, alcohol consumption has been shown to have strong correlations with not only increased HIV incidence and new infections but also with the deterioration of the condition because of the reduction in the immune system response and the increase in biological susceptibility to HIV (Shuper, Neuman, Kanteres, Baliunas, Joharchi, & Rehm, 2010). There seems to be unanimous agreement when it comes to the ways in which drugs and alcohol are associated with poor antiretroviral treatment adherence (Chesney, 2000; Halkitis et al., 2003; Kekwaletswe, Morojele, & Nkosi, 2011). Whilst in a South African context, alcohol use coupled with depression are variables that predict negative ARV adherence amongst people living with HIV (Kekwaletswe et al., 2011). There appears to be a significant and reliable relationship between alcohol use and medication non-adherence (Hendershot, Stoner, Pantalone, & Simoni, 2009). For the most part, the influence of alcohol and drug use negatively impacts the entry of infected PLWHs into care and support programmes as well as negatively affects their acceptance of and long-term adherence to ART (Lucas, 2010). In other words, the ongoing use of drugs and alcohol seems to be a significant factor when considering long-term treatment adherence.

Almost always the use of drugs and alcohol seem to interfere with treatment adherence. However, as a note of caution this was not the case in all circumstances. Therefore, stereotyping of all drug and alcohol users as non-adherent overemphasizes drug use as a barrier to treatment adherence and under emphasized non-drug related barriers. For this reason there was also a threat of tainting one's assessment of their capacity to adhere to their HIV medication when considering a PLWH's drug and alcohol history over perhaps more significant psychological or social barriers to treatment adherence. By and large, it cannot be automatically assumed that an alcohol or drug-user will be unable to adhere to their HIV treatment (Ware, Wyatt, & Tugenberg, 2005). However, when all things are considered, it would appear that when a PLWH prioritizes their medication following dependency interventions over their substance use, this does appear to facilitate good treatment adherence (Mills et al., 2006).

### ***2.6.2.7 Disclosure of HIV status***

This is perhaps an area that causes the most significant distress for PLWHs living with HIV. Disclosure is an issue that requires considerable reflection lasting many years. There is often an ongoing dilemma surrounding this issue of whom to disclose to, when, for what reason and in anticipating their response. In many cases, the outcome of this debate becomes too

arduous and the outcomes too onerous to contemplate and as a result, PLWHs may choose not to disclose, until a later more opportune time arises.

Disclosure of a PLWH's HIV status to friends, family, and sexual partners has a number of benefits. Firstly, it provides opportunities for accessing social support, as well as improves access to care and treatment including ART. Secondly, disclosure gives a PLWH the opportunity to implement HIV risk reduction with partners in order to prevent the transmission of the virus. Thirdly, disclosure permits greater opportunities for PLWHs to plan for the future. In other words, a PLWH knows fully what they have to contend with and can factor this into future life planning (Maman, & Medley, 2003; Parsons, van Ora, Missildine, Purcell & Gomez, 2004). In addition to those benefits described above, intimacy with partners in terms of sharing important information plus reaffirmation of one's sense of self by factoring a health condition in one's self-knowledge. This brings about the opportunity to share personal experiences and feelings with sexual partners and are some of the other benefits of disclosure (Parsons et al., 2004). Despite the constant internal debate of whether to disclose, who to disclose to and when, those who have disclosed their status to friends and family report a greater level of support and may act as buffer when experiencing emotional distress that a person living with HIV may experience (Kalichmann, DiMarco, Austin, Luke, & DiFonzo, 2003). Perhaps this is as a result of having a support structure around them when problems arise. Living with someone that is actively involved in treatment decision-making and using partners, family and friends as reminders is deemed to have a positive influence on treatment adherence (Mills et al., 2006). In sum, having supportive and open interpersonal relationships may indeed facilitate successful treatment adherence.

On the other hand, there are also potentially negative consequences of disclosure and areas that need to be carefully considered by a PLWH that is considering disclosing to the people in their lives. These can include factoring in the associated stigma that comes attached to HIV, largely due to public misinformation of the virus (USAID, 2006). In addition, PLWHs know that by disclosing they may face rejection by existing and potential sexual partners. This is especially pronounced when individuals openly request to know a person's HIV status before engaging in sex, and rejecting those who are open about the HIV-positive status and reject those who do not know their status (Masten, 2011). Those that have disclosed may have to experience a loss of the closeness and intimacy of friends and family members. In extreme cases, PLWHs who have disclosed may be faced with isolation or threats to their personal well-being and safety (Hardon, et al. 2007; Parsons et al., 2004).

Those who had disclosed their status to a wide range of people, including members of their family and those people close to them, by and large, showed higher rates of HIV treatment adherence (Stirrat, Remien, Smith, Copeland, Krieger et al., 2006). In addition, the same study found that those PLWHs who had not disclosed reported they were non-adherent as a result of hiding their medication because of non-awareness of their HIV status or about taking ARV treatment regime. The rates were the same as those that were none adherent due to recreational drug use or alcohol. However, it would seem that more research has been carried out on the latter to gain a fuller understanding of the effect of disclosure on adherence (Stirrat et al., 2006).

Amongst MSMs, it has been found that discomfort in talking to sex partners about HIV is strongly predicted in treatment adherence. This implies that men who cannot talk openly about their HIV status were less likely to be treatment adherent. To illustrate this, men with partners may have them remind them to take their medication. Although, the converse can happen since being in a relationship *per se* does not have a causal relationship to treatment adherence (Halkitis et al., 2003). In essence, MSM with partners often did not seek support for medication treatment adherence from friends and family, namely because they sought and received informational and emotional support from their partner (Stumbo, Wrubel & Johnson, 2011).

#### ***2.7.2.8 Beliefs in the effectiveness of Antiretroviral Therapy***

For those living with HIV and using ARVs, their thoughts about the effectiveness of their medication is a significant predictor of treatment adherence (Buick, Fisher, Horne, & Leake, 2004). To put it differently, when assessing PLWH's beliefs about the necessity for, and concerns about their ARVs, it was found that PLWHs were more likely to report low adherence rates if their concerns were high in terms of adverse side-effects relative to their perceived need for the medication (Buick et al., 2004). Thus, those that reported high concerns about perceived side-effects relative to their need for the medication experienced lower adherence rates. For this reason, a strong relationship was identified in terms of a PLWH's belief in the effectiveness of the ART and their adherence to it (Johnson et al., 2007). Thus, those PLWHs that believed that their medication would work were more likely to adhere to it. By the same token, PLWH believes in the medication or 'has faith' and seeing the positive results of taking antiretroviral treatment, these are the most common motivators to treatment adherence (Mills et al., 2006). Although a belief that the medication will work influences adherence, there is also a threat that the medication itself may serve as a morbid

constant reminder of their HIV status, which could in turn reverse treatment adherence (Johnston-Roberts, & Mann, 2000). An equally significant aspect is the belief held in the efficacy of the medication comes about because a PLWH holds inaccurate beliefs about the disease and has a poor understanding of the treatment this was also associated with negative treatment adherence and a reduced chance of taking their medication (Atkinson & Petrozzino, 2009). For this reason, it is worth reflecting upon how psychological theories may be applicable to understanding the role of beliefs in treatment adherence.

### **Health Belief Model**

Although the Health Belief Model (HBM) was originally devised in order to understand why people would or would not seek health preventative initiatives, later formulations of the model have been applied to understanding treatment adherence (Becker & Janz, 1985). The HBM is essentially a theoretical model of health-related decision-making that attempts to understand and predict whether or not patients, and in this case, individuals will accept or avoid medical intervention and treatment. In other words, this study looks at this model to propose that individuals who know about and understand their health conditions or perceive them to be serious would accept medical assistance and be more treatment adherent than those that do not (Davies, Hickson, Weatherburn, & Hunt, 1993). In this process, health decision-making and the adoption of health promoting behaviours is improved if the individual desires to avoid illness, or if they are already ill, the desire to get better, is coupled with the belief that by taking a specific action such as taking medication will prevent or improve their health situation. In essence, this would mean that it would be the individual's assessment of the severity of the condition and their evaluation of the chances that they, through certain actions would be able to reduce the threat to their health (Becker & Janz, 1985).

The model further suggests four important components that will predict health outcomes - namely *perceived susceptibility*, *perceived seriousness*, *perceived benefits* and *perceived barriers* (DiMatteo, Haskard, & Williams, 2007). In terms of the *perceived susceptibility* is based on the idea that individuals take the appropriate action to avoid ill-health if they believe that they are personally susceptible to falling ill or becoming well, if they are already sick. In general terms, *perceived susceptibility* is understood as an individual's subjective perception of his/her own health risk. In other words, it can be seen as their emotional response relating to the thoughts around a particular disease and also the kinds of challenges that the individual believes may be created by their condition (Becker & Janz, 1985; Taylor, Bury, Campling, Carter, Garfield, Newbould, & Rennie, 2007). In terms of this model, *perceived severity* is

understood as the individual's subjective assessment of the severity of their health condition. That is to say how an individual understands the clinical, physical and emotional effects of the condition (Taylor et al., 2007). Furthermore, this could perhaps suggest how the condition could affect the individual's work, home and social life (Becker & Janz, 1985). An individual's combined assessment of his/her *perceived susceptibility* and the *perceived severity* of his/her health condition generates the level of motivation that he/she would have in order to avoid a particular health outcome (Taylor et al., 2007).

Furthermore, the belief of the *perceived benefits* of taking a specific action is something that is individually understood to be gaining a positive outcome (Becker & Janz, 1985), in other words, the taking of the health action will offset the threat (Taylor et al., 2007). For example, the benefit of taking an action, such as taking medication far outweighs the assessed threat. Similarly, this assessment would be driven by an individual's overall 'health motivation' and not necessarily by external considerations. Lastly, the perceived barriers are what are to be seen as the aspects that would negatively affect taking the action, such as side-effects or internally held values about HIV and ART coupled with physical barriers such as access to medical service providers or medicine supply and the process of evaluating how to overcome these barriers (Taylor et al., 2007).

On the whole, the combination of perceived susceptibility and severity provide the driving force or the motivation behind health-seeking behaviour, whilst the benefits after considering the barriers provide the way forward or the action to implement the health behavior (Becker & Janz, 1985). In terms of ARV adherence, with this model, a PLWH who has assessed that the benefits of taking their treatment outweighs the barriers and their perceived negative beliefs are low and will be more likely to remain adherent. In other words, when their perceived benefits are high, then the treatment will be taken. However, if the PLWH is not psychologically ready to start treatment as they hold many negative beliefs associated to the treatment then the negative will serve as a barrier and prevent action. Certainly, when looking at perceptions of severity, those PLWHs that perceive the severity of their condition seem more likely to have good adherence because that they understand their condition to be serious and the medication is believed to help them. While on the other hand, non-adherence is significantly higher in those that do not perceive their health condition as severe (DiMatteo et al., 2007).

The HBM is highly regarded in a number of medical fields and used in the field of treatment adherence, such as hypertension, asthma, obesity and other health conditions which involve the taking of medication such as diabetes (Becker & Janz, 1985; Taylor et al., 2007). In that the model, if applied in a systematic has the potential to understand the social, economic and environmental effects on health behavior (Taylor et al., 2007). From an adherence to ARVs perspective an individual's perception of their quality of life, their status itself and health markers such as CD4 count would be seen as their health concern. Their health threat would be the possibility that their health may deteriorate and finally sustains death, whereas the potential to experience stigma as a result of living with HIV may be understood by the individual as a barrier to seeking help (Kagee, 2008). Of interest, is there has been limited investigation internationally, and specifically South Africa when it comes to adherence to ARVs when considering a HBM frame (Kagee, 2008).

### **The Theory of Reasoned Action**

The Theory of Reasoned Action (TRA) model was developed by Martin Fishbein and Icek Azjen in 1975 and posits that individual health behaviour is understood by looking at the individual's intentions, which includes their attitudes, beliefs and behaviours, and the actual acts (Airhihenbuwa & Obregon, 2000). In other words, the individual's behaviour will be driven by their intention to change. In addition this behavior is driven by "their attitude towards the behavior, as well as and the subjective norms associated with the behavior" (Petersen & Govender, 2010, p23). Using HIV adherence as an example, this could mean that PLWH may hold the belief or attitude that by taking the medication it will keep them healthy and productive, thus giving them an improved quality of life. By subjective norms, this means that the opinions and attitudes of the people the PLWH places value on approval and agreement with his assumption, thus he will uphold the behaviour (Petersen & Govender, 2010). This appears to be one of the most popular models with regards to the prediction and explaining health behaviours which resulted in a great deal of research (Azjen, 2012) which has in turn led to a number of additions to this model over the years (Petersen & Govender, 2010).

### **Information-Motivation-Behavioural Skills**

The Information-Motivation-Behavioural Skills (IMB) model appears to incorporate many of the aspects of the previous models. This model aims to understand adherence and its relation to information, motivation and behavioural skills that it sees as being linked as well as the situation and personal factors that a PLWH experiences (Fisher & Fisher, 2006). When it



comes to information, having accurate information about the medication is seen as an essential element in the ongoing and correct use of ARVs. This means that a person who receives accurate and appropriate information about their medication will maintain an appropriate level of adherence (Fisher & Fisher, 2006). Fisher and Fisher (2006) further describe how the PLWH needs to have personal and social motivation to remain adherent. This is achieved by having a positive belief that the medication will work and the effects on health are associated with good adherence. Furthermore, the PLWH perceiving good social support and motivation are associated with good adherence (Fisher & Fisher, 2006). Lastly, this model describes that behavioural skills are of vital importance and includes a PLWH's abilities and self-efficacy regarding their performance with regards to adhering these are described as; adhere to the cues to take the medications as directed whilst incorporating it into day-to-day life; managing the side effects; keep themselves informed of latest developments; remaining in contact with health providers and finally provides reinforcement for maintaining good adherence over a period of time.

### **Trans-Theoretical Model (TTM)**

Although the Trans-Theoretical Model (TMM) was principally developed to understand and promote behaviour change in tobacco smoking, it has experienced varying degrees of success. The model has also been used in other health-related fields, in particular in treatment adherence to dietary change and exercise and activity programmes; STIs and avoiding unwanted pregnancy programmes; breast cancer screening; the control of alcohol use plus generalized treatment adherence interventions (Taylor et al., 2007). Further, it remains unclear whether this model has any advantages or is less effective than other models despite aiming to provide a psychological understanding in terms of health behaviour change (Taylor et al., 2007).

In describing this model, the stages were developed by Prochaska and DiClemente in 1984 and are described as the *pre-contemplation, contemplation, preparation, action and maintenance stages* (Petersen & Govender, 2010; Taylor et al., 2007). During the *pre-contemplation stage* an individual may have no intention of changing their behaviour and may in fact be unaware of the risks on their health that their behaviour has on them. The *contemplation stage* sees the individual becoming aware of the problem and they may explore making changes to their health behaviour, although they do not make any changes at this stage. During the *preparation stage* an individual may take minor steps to change their behavior and they may start planning certain activities in changing behavior. When an

individual makes major changes to their health behavior, this is considered the *action stage*. The *maintenance stage* sees an individual using energy and resources in order to prevent them from relapsing and to ensure that the new behaviour is being sustained (Petersen & Govender, 2010; Taylor et al., 2007). Taylor et al. (2007) describes a final stage, called the *termination stage* where the new behavior has been fully established for a lengthy period. The progression through the stages is not understood as linear, in other words, individuals may move up or down through the stages (Petersen & Govender, 2010; Taylor et al., 2007). This model has been used broadly in terms of health promotion and health behaviour change amongst health education practitioners. However, the model has been criticized by psychologists because it does not factor the social and economic influences of an individual (Taylor et al., 2007).

### **The Social Cognitive Model**

Building on from beliefs, another significant aspect when considering treatment adherence would be self-efficacy which has been added onto the HBM on a number of occasions since the 1970s when Albert Bandura first introduced the idea of act or task specific confidence (Taylor, et al, 2007). In this context, self-efficacy refers to the belief a PLWH holds in being able to carry out a specific behavior (Bandura, 1986).

To be able to understand this approach to health behaviour, for the most part, it broadens from seeing health behavior from a PLWH perspective to understanding it from multilayered structured approach in which self-efficacy, or belief in their own competence operates within goals, expected outcomes and environmental factors that are perceived to act as barriers or enablers to health (Bandura, 1998). What this means is that if a PLWH experiences a sense of control of an outcome, experiences few external barriers and feels a sense of confidence in their own abilities this will drive a behaviour when it comes to health (Armitage & Conner, 2000). When considering social learning, this approach can be understood relationally in terms of the interactions with the environment in that behaviour is learned through the observation and replication of others as well as social reinforcement of perceived desirable behavior by others. In other words, this can be understood through the idea of ‘reciprocal determination’. Reciprocal determinism refers to the way the person, their behavior and their environment relate to one another on an ongoing basis. For example, a person is understood in terms of their personal choices influencing the social environment they find themselves. By the same token, a PLWH learns by observing behaviour and by modelling. Put differently, this means that individual behaviour is learned by observing the behaviour of others.

Simultaneously, reinforcements for maladaptive or desirable behaviours known as ‘vicarious reinforcement’ has the consequence of a PLWH’s behaviour being maintained or eliminated through self-rewarding or positive and negative reinforcements by those around (Bandura, 1986). The model suggests that when PLWHs are able to model good adherence practices and receive praise they are more likely to continue taking their medication.

In addition, this learning would add to a PLWH’s competence in their own behaviour coupled with adding to their confidence in their own abilities to perform a behaviour, or self-efficacy when it comes to their health behaviour (Petersen & Govender, 2010). Thus, when PLWHs have a sense of competence in taking ARVs, they experience and observe the effects the treatment, this will bring about an improved confidence in their abilities to create the desired outcomes and this in itself will drive the continued taking of their treatment. The social cognitive approach addresses social and structural aspects as well as individual determinants of health seeking health behavior. In that way it looks at health behaviour more broadly by seeing a person in their social and individual context (Bandura, 1998). In essence, this means that individual health behaviour and the barriers to healthy living are determined by the interactions between the individual and the health system rather than just limitations in terms of their personal attributes and situation. To illustrate this point: when considering MSM experience of stigma and discrimination in the health care system due to their status and sexual behaviour, this could be understood as a barrier to healthy living as they may not feel able to participate in this system out of fear, clearly negating the possibility of access to treatment. In other words, accessibility to health resources that are perceived to be unavailable, be it from an economic or social perspective, becomes a barrier to individual healthy behaviour (Bandura, 1998).

#### ***2.7.2.9 Counselling and adherence needs***

It is important not to trivialize the importance of HIV and Aids counselling in not only attempting to prevent the transmission of HIV but to also provide support to those infected or affected with HIV. This is chiefly because people living with HIV may suffer from any one of the psychosocial stressors discussed above. This may include having to deal with feelings of fear; loss; grief; guilt; denial; anger; anxiety; low self-esteem; depression; suicidal behavior or ideation; obsessive thoughts; spiritual concerns and socio-economic concerns (van Dyk, 2010). The presence of such stressors may adversely affect treatment adherence and subsequently the efficacy of the ARVs. For this reason, a counselling environment should aim to minimize the morbidity of these stressors and reduce the potential for their

future occurrence. Counselling remains an important tool in not only assessing a PLWHs' adherence to treatment, but simultaneously supporting a PLWH in the routine of taking medication. Likewise, counselling should aim to assist the PLWH in being able master any complex medication regimes and where there are side-effects and by working through what this means to the PLWH in terms of the potential of bearing in mind the regime of taking medication daily of HIV infection (Chippindale & French, 2001).

Although there is limited research into the effects of adherence counselling on treatment adherence, it would seem that rigorous, early adherence counselling at the start of ART was shown to have a continuous and significant impact on adherence and thus the failure of treatment (Chippindale & French, 2001). In essence, this means that adherence during the first month after initiating treatment was significantly higher in those that had received counselling and this remained constant over 18 months (Chippindale & French, 2001). In particular, this meant that counselling, based on the PLWHs needs at the onset of HIV treatment seemed to have long-term benefits. For this reason, the relationship between the healthcare provider and individual patient through communication, education and trust played a significant role (Chung et al., 2011). On the other hand, poor or infrequent counselling can be seen to result by negatively influencing HIV treatment adherence especially when not being able to communicate that the initial side-effects of treatment often goes away (Hardon et al., 2007).

#### ***2.7.2.10 Quality of life***

ART can be understood to prolong life expectancy and to prevent the development of opportunistic infections and other Aids-related conditions, and enable the immune system to rebuild in order to quash viral replication as far as possible for as long as possible (Maartens, et al, 2010). However, beyond its medical effects, the emphasis should be placed on the objective of ART to improve the quality of life for people living with HIV (Maartens et al., 2010).

For this reason, Quality of Life (QOL) forms an important consideration in assessing the benefits and effects of ARV treatment. QOL can be defined as the relationship between an individual's 'dreams, ambitions, hopes for the future, present lifestyle and experiences' (Calman, 1984). When seen in a clinical setting QOL is the aspects of life directly affecting the overall state of health, often referred to as health-related quality of life (HRQL) (Holzemer & Wilson, 1995). This would include are perceptions of health, the status of a

PLWH's symptoms, their ability to function plus other biological and physiological variables, in addition certain individual and environmental characteristics and overall QOL (Wilson, & Cleary, 1995). For the most part, those PLWHs with a lower CD4 count appear to have lower health-related quality of life scores using various measures (Campsmith, Nakashima & Davidson, 2003). This would suggest a correlation between the CD4 count, the overall level of an individual's health and the overall quality of life he/she experience. Although the nature of the relationship between QOL and treatment adherence has not been well studied, although it is known that ART contributes to improved health outcomes. One could hypothesize that this association would result in a better QOL. Thus, QOL may also influence adherence as PLWHs with a better quality of life may have greater ability to adhere to their treatment regimens. Coupled with this, there appears to be a correlation between an individual's QOL and their self-reporting ARV adherence levels. In other words, PLWHs who reported higher levels of adherence also reported higher QOL scores suggesting that this being largely due to the improved clinical results experienced by PLWHs from their medication (Mannheimer, Matts, Telzak, Chesney, Child, Wu, & Friedland, 2005). Although taking ARVs itself was not associated with any differences in HRQL scores, complex regimes did appear to influence quality of life, and thus, adherence (Campsmith, Nakashima, & Davidson, 2003). However, even in PLWHs that are treatment adherent and successful in their clinical outcomes, reported their quality of life as moderate, in a psychological context this was explained by perceived stress, whilst in a physical context it was dependent on the discomfort reported from HIV related symptoms and the treatment itself (Cote, Delmas, Delpierre, Sylvain, Delon, & Rouleau, 2009). In addition to QOL, a correlation exists between health worries, medication worries and financial worries were associated with adherence over time. Specifically, those PLWHs with low adherence were more likely to worry about their health, medication and financial situation than highly adherent PLWHs (Holmes, Bilker, Wang, Chapman, & Gross, 2007). All of these factors could be understood in terms of resilience whereby those people living with HIV presenting greater resilience or hardiness to living with HIV showed lower psychological distress, greater quality of life and greater personal beliefs. Hence, this outcome is significant as psychological distress is associated with risky behaviour and treatment adherence practices (Farber, Schwartz, Schaper, Moonen, & McDaniel, 2000).

### **2.6.3 Social Factors which Influence Treatment Adherence Among MSM**

This section explores some of the social factors that may influence adherence. These include the constructions of masculinity and how this may play a role in males seeking help seeking assistance, medicalization of HIV and the neglect of the social context. Stigma and discrimination that marginalized and vulnerable groups may be exposed to, social support and lastly social media.

#### ***2.6.3.1 Constructions of masculinity and race in health seeking behaviour***

It would seem that there is a substantial amount of literature, mostly from the USA that supports the idea that women are more likely than men to utilize the services of healthcare providers (Galdas, Cheater, & Marshall, 2005). It is until only recently that this perception has started to cause problems. Prior to that, men's behaviour when it came to health were considered normal (Courtenay, 2000), although this appears not to be the case. The literature seems to be inconsistent, in that some research disagrees suggesting that men do use healthcare services which makes a definitive conclusion problematic. Yet other research does strongly indicate that men tend to delay seeking support from a health perspective largely until they become ill (Galdas et al., 2005) as well as engage in more health risk behaviours (Mahalik, Burns, & Syzdek, 2007; Williams, 2003) of which there are a number. And the taking part by men of health promoting activities, the use of health services preventative health visits is lower (Williams, 2003) which is a vital consideration in this research. Furthermore, and of significance to this research, men were also found to have lower levels of adherence to medication regimes than women (Rose, Kim, Dennison, & Hill, 2000). This thinking around health seeking and health risk behaviour amongst men appears to transcend sexual minorities and racial groups in the USA whereby MSM and black males appear to engage on more health risk behaviours than their heterosexual and white counterparts (Dean, Meyer, Robinson, Sell, Sember, Silenzio et al., 2000). By the same token, race, gender and sexual orientation plus experiences of discrimination appear to consistently play a role in treatment adherence in that black MSM who had faced discrimination and stigma based on their status, race or sexuality showed associated lower levels of treatment adherence (Bogart et al., 2010). Yet it seems unclear whether the same patterns emerge locally as this remains an under-researched area.

Simply put, Galdas et al., (2005) argue that in addition to gender difference, economic and occupational statuses seem to be important factors and play a role in explaining the differences on help-seeking behaviour. However, when considering socio-demographic

factors and health behaviour gender differences appear the most consistent (Mahalik, et al., 2007).

In terms of the reasons, because males are a homogeneous group the explanations for this can be multiple (Galdas et al., 2005). Mansfield, Addis and Mahalik (2003) argue that despite the evidence that men are less likely to seek health assistance than women, there has been limited research to explain why this could be, although the reasons could be understood from the gender socialization, social constructionist, and social psychology viewpoints (Addis & Mahalik, 2003). Briefly, this means that from a socialization understanding, our social environment from our culture filters down to family and individual thus teaching us how to express gender specific behaviours and attitudes, including our health behaviour (Mansfield et al., 2003). It would appear that literature abounds with suggestions about 'traditional masculinity' as well as traditional masculinity beliefs when it comes to health are a major factor in health seeking behaviour (Galdas et al., 2005). In that men are not allowed, by society's norms to express their illness (Roberston, 1995) and that their at risk behaviours include an increased alcohol use and smoking and not consulting with medical service providers (Courtenay, 2000) which means that they may put their health at risk (Mahalik et al., 2007).

From a social constructionist view, gender roles are created based on interactions informed from social structures such as race, class, ethnicity, and sexual orientation (Mansfield et al., 2003). Simply put, man may deny illness or sickness in order to reduce the seriousness of the issue in terms of maintain their social status of 'men are strong and women are weak' (Mansfield et al., 2003). In that way, masculinity is seen as a trait of self-reliance in that the man will most likely not seek the advice of a health professional and would be proud of the fact that he had not seen a doctor in many years (Courtenay, 2000). Thus, by denying distress this means that his masculinity remains intact (Mansfield et al., 2003).

From a social psychology perspective, there have been a number of factors that influence help seeking behavior, attitudes and behaviour (Mansfield et al., 2003). These include conformity with group norms and the fear of stigmatization by others for confirming, such as seeking help (Addis & Mahalik, 2003). Being able to maintain control and make decisions, in that when their self-control is jeopardized a man will do what he can to re-establish it, such as being less likely to follow doctor's instructions or seek help (Mansfield et al., 2003). Lastly, from an altruistic perspective, men are more likely to engage in help-seeking behavior if there

is a possibility that they reciprocate the help that they have received such as in a help group setting (Mansfield et al., 2003).

When considering health promotion, Mahalik et al., (2007) argue that any health interventions aimed at men needs to address social norms, men's assumptions about normal health practices. The adoption of these practices in order to reduce health risk seems to support the notion that prevention programmes currently may miss them.

### ***2.6.3.2 Medicalization of HIV and the neglect of the social context***

Like many other illnesses, diseases and syndromes there has been a 'medicalization' of HIV. Medicalization can be understood as the "expansion of medicine as an institution and the use of a medical lens to view human processes and behaviour" (Lantz, Uchtenstein, & Pollack, 2007, p1254). For instance, when making sense of the problems and experiences that people living with HIV experience they are very often interpreted as being medical problems (Conrad & Barker, 2010). This means that the clinical aspects of the issue overshadow the issue and become the focus of intervention without fully comprehending the social context in which the problem lies. However, it is widely accepted that HIV/Aids is not only a medical problem, but also rests within an emotional, psychological and social problem context (Evian, 1997). From the nature of HIV and what the condition represents means that it should be understood more broadly than only from a biomedical perspective. Put another way, the likely outcome of the medicalization of HIV is that interventions are clinically based whilst minimizing or ignoring altogether the social context of the problem, which may in fact be a complicating factor (Lantz et al., 2007). In particular, there should be a shift from tackling illness in a clinical manner solely to exploring the social and cultural situation that creates the problems and negative meanings (Conrad & Barker, 2010).

It may be hypothesized that many individuals do not actively participate with their health condition and its treatment, but are open to allowing the condition, medical service provider or treatments to do what they will to them. However, they can be more active in their condition and its treatment (Conrad & Barker, 2010). For example, often people living with HIV, who have access to information resources increase their knowledge of their condition and play an active role in their overall treatment in conjunction with their medical service provider. They are more involved in the day-to-day realities of managing their condition. Although, as a note of caution, there needs to be a balance whereby they can run the risk of losing their sense of 'self', by becoming immerse in their condition with the added threat of



allowing themselves to be cut off and not looking beyond their illness (Charmaz, 1991). For the most part, when attempting to understand or make sense of their illness, PLWHs will try and give meaning to their condition based on their interpersonal relationships, their employment situation and religious and cultural beliefs and understand the impact of their condition on all facets of their social lives. All things need to be considered in terms of giving optimal treatment and to experience positive health outcomes a PLWH should be actively involved. Furthermore, emphasis should be placed on the meaning and place of medication in a PLWH's life from a social perspective, rather than focus being solely the compliance with the orders of medical providers (Conrad & Barker, 2010).

### ***2.6.3.3 Stigma and discrimination***

The stigma and discrimination surrounding HIV/Aids remains problematic and affects many other aspects of the lives of those PLWHs living with HIV, including MSM. Of concern, in the context of this research is that the stigma associated to HIV/Aids can negatively influence access to treatment, can cause problems in terms of interpersonal relationships and for this reason plays a major role in the formation of a negative self-identity of the person living with the virus (Weitz, 1990). An aspect that can cause considerable reflection is that there is no medical characteristic about HIV that causes it stigmatized but rather it is the way society responds to it, how it is displayed and how society perceived people living with HIV that makes it a stigmatized condition (Conrad & Barker, 2010). Put in a different way, in many cases the suffering that people living with HIV have had to endure has since the discovery of the virus been exacerbated by the stigma and discrimination which surrounds it. This can be illustrated by arguing the case that any disease that is tied to human 'misbehaviour' or deviance means that it will be stigmatized. However, HIV appears to be quite unique because it seems to combine so many of these misdemeanors. In particular, there seems to be no shortage of those who believe HIV's association with deviant and promiscuous sexuality will generate a moral denunciation from religious believers and those with a judgmental or moral leaning (Delius & Glaser, 2005). On the other hand, because it is an incurable condition, HIV often has connotations with death whereby people living with HIV are seen as 'walking dead', this "evokes notions of pollution in African ancestor religions" (Delius & Glaser, 2005, p35). This means that the link to both dying and sex of HIV are perhaps two of the most powerful sources of 'ritual impurity and contagion'. In traditional communities in South Africa, emphasis is placed on pollution and impurity intrinsically being linked to sexual acts and reproduction. This then places the concept of pollution and impurity being used to

explain HIV, for example, these are seen in terms of breaches in 'sexual taboos' cause pollution from HIV being caused by misdemeanors in sexual conduct. This thinking then places the PLWH as responsible for their action, which further contributes to the level of stigma (Delius & Glaser, 2005).

The effect of stigma and discrimination towards MSM in terms of treatment adherence in South Africa has received little attention in research. MSM's experiences of hate speech have been shown to affect their self-esteem or self-regard, which influences vulnerability to depression (Polder, 2006), which in turn plays a role in treatment non-adherence. We could hypothesize that the stigma surrounding conditions such as HIV/Aids can make PLWHs, especially MSMs reluctant to seek treatment for fear that healthcare providers will discriminate them due to them being "publicly associated with a tainted condition" (Conrad & Barker, 2010, p70). By the same token, HIV-positive MSM's have generally experienced more discrimination relating to their HIV status than their HIV positive non-MSM counterparts, meaning that HIV-positive MSMs can suffer from "double or multiple discrimination or super-discrimination" (Cloete et al., 2008, p1110). Furthermore, self-esteem or self-regard, following discriminatory experiences such as hate speech had a significant influence on a PLWH's vulnerability to depression amongst MSM (Polder, 2006). This, in turn, may have a significant influence on ARV treatment adherence (Gonzales et al., 2011).

Stigma has been shown to have significant implications for PLWHs living with HIV, with one example being a PLWH may become isolated from their communities as a result of their status (Hardon et al., 2007). Because of the threat of stigmatization PLWHs may keep their HIV status hidden due to the fear of "rejection, violence or both" (Hardon et al., 2007, p18). Consequently, such efforts to conceal their condition may affect their adherence to treatment by causing them to hide their ARV medications or skip doses when others are present (Nachega, Knowlton et al., 2006b, p131). For this reason, stigmatization for being MSM and fear of being HIV positive presents barriers in making use of available HIV related health services such as HIV Counselling and Testing services aiming to provide health and support to MSM (Lane, McIntyre & Morin, 2006). In response to the effects that stigma poses on treatment adherence, research recommends that interventions be put in place to enable HIV positive MSM to adapt and adjust to their condition and social environment by providing "coping training" aimed at managing social stigma and internalized stigma (Cloete et al., 2008).

#### ***2.6.3.4 Social support***

Social support is seen as one of the most important parts of social relations or the social networks which surrounds an individual (Heaney & Israel, 2002). To further clarify, this social network can be the people an individual depends upon which can include families, friendships, neighbours, work relations, religious groups, help groups and any other voluntary organizations (Brownell & Schumaker, 1984). Research indicates that social support is a means of protection against pathology and is based on significant others who fulfil a number of tasks. These tasks include helping people to access the available psychological tools in order to manage any emotional problems; sharing tasks and lastly, providing individuals with resources such as materials, financing, skills, information and advice in order to manage distressing events they have been exposed to (Brownell & Shumaker, 1984). In addition, social support is understood to be an aspect of social networks and further seen as a realm of relationships. In that way, supportive behaviours include emotional support by the way of empathy, love, trust and caring; instrumental support by the way of physical aid and services that can directly assist; informational support by giving suggests and advise which may assist in managing the problem; and appraisal support which involves giving information that is helpful for self-evaluation such as positive affirmation and constructive input (Heaney & Israel, 2002).

On the whole, there is a great deal of validation of the role that social support plays in the strengthening not only of physical health but also of mental health and is of major significance for MSM living with HIV (Hall, 1999; Petersen & Govender, 2010). The HIV epidemic has meant that MSM's have experienced unimaginable stresses which can include isolation from society; loss of social status; unemployment; reduction of financial resources; changes in physical appearances due to illness or side-effects of the medication; having to change sexual intimacy for fear of infecting; social stigma as a result of living with HIV; abandonment by family and friends; and general prejudice by society (Hall, 1999). Generally speaking, support groups fulfil part of social support function as they aim to create an environment which facilitates the modelling and reinforcement of positive health behaviour which a support group situation may be able to offer. In addition, it may provide an environment that is able to shield the effects of stress on health coupled with having access to resources to manage any stress that may come about from the health condition (Heaney & Israel, 2002). In essence, this could mean having a space where PLWHs can share the emotions and challenges in their life; learn new skills in order to deal with these issues plus

grow personally based on interaction with others. Even though social support can be received in terms of interpersonal relationships, such as a partner, or significant ‘other’, it can also be derived from the realm of group systems which may not include a significant other (Petersen & Govender, 2010). In terms of adherence, this means that having access to support networks and interpersonal relationships that groups provide also plays an important role in treatment adherence (DiMatteo, 2004). The nature of the social support offered can vary and may include giving of emotional care through empathy and caring, providing material forms of support; or the provision of information via advice-givings and constructive feedback which can help in PLWH self-evaluation and enhancement of identity (Heaney & Israel, 2002). And for these reasons, people living with stigmatised conditions such as HIV, would benefit greatly from social support groups (Petersen & Govender 2010). In particular, when the psychosocial needs of PLWHs associated to treatment non-adherence are not being met. In that case, PLWHs who report one or more needs not being met are less likely to take any medication. One of these needs may include the need to access a support group or counselling (Reif, Whetten, Lowe, & Ostermann, 2006). Although when understanding the relationship between depression and perceived social support this may not contribute to improved adherence to HIV medications, so that depressed PLWHs will have lower adherence rates regardless of the social support that they have and that with non-depressed PLWHs, social support was an attributing factor in improving adherence to HIV treatment (Gordillo, del Amo, Soriano, & Gonzalez-Lahoz, 1999).

#### ***2.6.3.5 Social media***

In the past, we held the view that illnesses were seen as something private and that there were almost no illness subcultures (Conrad & Barker, 2010). However, with the emergence of social media there are online groups available for a large magnitude of illnesses with illness becoming an ‘increasingly public experience’, including support groups and social media websites (Conrad & Barker, 2010). For this reason, a number of ‘social movement groups’ have come about relating to specific illnesses or conditions, the members of which exchange information and experiences being one of the new means to expand the knowledge base of illnesses and gain support (Conrad & Stults cited in Conrad & Barker, 2010). Whereas unlike before ‘lay people’, are more increasingly becoming more involved in ‘collective illness behaviour’ which could in turn impact on what illness means to them, service delivery and the sphere of influence and role that medical providers play (Conrad & Barker, 2010). In other words, PLWHs with access to resources are playing an active role in their condition and

its treatment. Part of this includes PLWHs living with HIV having a collective illness identity may be sufficient to create or join illness-based support and social groups, whilst developing new sub-cultures and gaining 'lay' knowledge on their condition based on their 'illness identities' (Brown, Zvestoski, McCormick, Mayer, Morello-Frosch, & Gesior Altman, 2004). In short, this means that by receiving adequate support, whether it is informational or in terms of a strong social network plays a substantial role in the psychological well-being of MSM living with HIV (Hall, 1999).

### **2.3.3 Overview and Gaps in the Literature**

Research is conclusive in arguing that lower levels of adherence to treatment regimens can lead to increased viral load or the quantity of virus in the body, and a decrease in CD4 count, thus, a reduction in the overall health with an increased risk of disease progression (Maartens et al., 2010). There appears to be consensus that as the medication has some toxicity, severe side-effects could make maintaining treatment adherence challenging. And by reducing or alleviating side effects would improve the regular and correct taking of the medication (Ammassari et al., 2001; Murphy, 2003). However, there seems to have been limited research in terms of how side-effects affect MSMs in South Africa and whether they impact treatment adherence.

Although HIV/Aids are seen as a clinical condition, the complex psychological and social factors are significant in its treatment. Research tends to agree that non-adherence is more likely to be as a result of psychological and social issues as opposed to the medication itself. In that although avoidant coping strategies, or discomfort in talking to sex partners about HIV seems to correlate in making adherence to treatment problematic (Halkitis et al., 2003). Of significance here are psychological conditions such as depression and substance use that pose challenges to maintaining treatment adherence (Chesney, 2000; Halkitis et al., 2003). Although it cannot be automatically assumed that an alcoholic or drug user will be unable to adhere to their HIV treatment (Ware et al., 2005). This is an area with little research from a local viewpoint. There also appears to be a causal link between high levels of distress people living with HIV experience and the association to low levels of adherence (Chesney et al., 2000). However, depression was reported in a recent study as having significant impact on adherence (Gonzales et al., 2011). The MSM population living with HIV in a South African context appears to be at a high risk of internalized Aids stigma. Therefore, the internalized AIDS stigma can be understood as resulting in depressive symptoms (Lee et al., 2002), which

may affect adherence. In essence, the relationship between stigma, distress, depression and adherence to ARVs among MSM in South Africa has limited research.

As ART becomes increasingly integrated into day-to-day living, studies have shown that forgetfulness is cited as the reason for not taking their medication (Barfod, et al., 2006; Bartlett, 2002; Chesney, 2000). This has resulted in a number of techniques to remind patients to take the medication such as cell-phones and pill-boxes being developed. Unfortunately, the use of such reminders and the significance MSM place in their use and effectiveness has seen little research both internationally and in South Africa.

The fears of discrimination results in many MSM avoiding seeking assistance and are not accessing the essential treatment to keep them alive which means that the social issues that affect marginalized groups should be actively engaged with and understood by medical providers (Sixma et al., 1998). Because the current practice in mainstream healthcare in South Africa is to render services on the basis of 'sameness', this 'one size fits all' approach has seen limited research on MSM's experience of discrimination in a health care in a South African context and how it may affect their treatment adherence.

In terms of disclosure, this is a complex emotional issue. However, on the whole, having supportive and open interpersonal relationships may facilitate successful treatment adherence. Yet, research in this area is predominantly international which makes it unclear whether MSMs in a South African context share similar experiences as their overseas counterparts.

The research suggests that there is a strong relationship between a PLWH's belief in the effectiveness of the ART and their adherence to ARVs (Johnson et al., 2007). Thus, those PLWHs that believed that their medication would work are more likely to remain adherent to it. In addition, seeing the positive results of taking ARV treatment is also a common motivator to treatment adherence (Mills et al., 2006). However, on the flip side, there is concern that the medication itself may serve as a concrete reminder of their HIV status, which could in turn promote treatment non-adherence (Johnston-Roberts, & Mann, 2000). Research into this has focused on American women, and it seems that no work has been carried out to establish whether this feeling carries across to MSM in South Africa.

The effect of stigma and discrimination towards MSM in terms of treatment adherence in South Africa has received little attention in research. This is surprising as MSM's experiences

of hate speech has been shown to affect their self-esteem increasing vulnerability to depression (Polder, 2006), which can affect treatment adherence.

Lastly, by having a support structure such as a support group means having a space where PLWHs can share the emotions and challenges in their life, learn new skills in order to deal with these issues plus grow personally based on interaction with others. In recent years a number of 'social movement groups' have come about relating to specific illnesses or conditions, the members of which exchange information and experiences being one of the new means to expand the knowledge base of illnesses and gain support (Conrad & Stults cited in Conrad & Barker, 2010). Wherefore 'lay people' are more increasingly becoming more involved in 'collective illness behavior' which could in turn impact on what illness means to them, service delivery and the sphere of influence and role that medical service providers play (Conrad & Barker, 2010). There seems to be a gap in understanding when it comes to the experience participants have and the benefit of support groups for PLWH or MSM taking ARVs in South Africa.

## **2.4 CONCLUSION**

The lives of HIV positive men who have sex with men when reflecting on their antiretroviral treatment adherence experiences and stories appears to be largely under researched and an unknown entity when considering the issue from a South African context. Even to the point of understanding the HIV prevalence and incidence rates amongst this population still remains challenging because of its largely hidden nature. Coupled with this, actual adherence statistics remain challenging to access and understand, hence the grasp of the adherence issues of MSM is largely speculative at best, or more accurately unknown. This chapter reviewed important areas in this research and examined the factors that influence treatment adherence from a clinical, mental health and social perspective because HIV as a chronic health condition that straddles all three areas and in many cases covers many areas within these groupings. HIV still remains a heavily stigmatized and discriminated condition, largely because of its associations to sex and death with the additional labeling and public sentiment towards MSM, leaving this population vulnerable when it comes to health seeking behavior. For the most part, research in this field has focused on the barriers to treatment adherence, however it is important to consider that perhaps there are factors that reduce any demands the good adherence places on a PLWH, be it clinical, psychologically or socially. Hopefully, by exploring all aspects of treatment adherence issues amongst MSM we will gain a clearer picture. However, an important determinant seems to be that a PLWH who understands the

importance of adherence whilst having a good knowledge about their treatment and having faith in its effectiveness have been shown to be facilitators to treatment adherence (Curioso et al., 2010).

This chapter examined the literature pertaining to ARV adherence for MSM from a biopsychosocial perspective. The next chapter examines the methodology used for this research.



## **CHAPTER THREE: METHODOLOGY**

### **3.1 INTRODUCTION**

This chapter discusses the methodology used in the collection and analysis of the data. Included in the methodology are the profile and characteristics and description on the selection of participants. Then procedures used in order to generate the data are discussed and well as the manner in which the data was analyzed. The chapter also discusses the manner in which quality was assured through adhering to validity and reliability measures in put place during the research process. In addition, this chapter reflects on the researcher's experiences of the data collection process. Finally, the chapter highlights the ethical issues that were considered by the research to protect these research participants as vulnerable participants.

### **3.2 RESEARCH QUESTIONS**

The study aimed to explore the following research questions:

- What biomedical factors do MSM perceive to influence ARV treatment adherence?
- What psychological factors do MSM perceive as influencing ARV treatment adherence?
- What structural and social barriers do MSM perceive to influence ARV treatment adherence?
- What support interventions do MSM perceive to be needed to improve ARV treatment adherence?

### **3.3 RESEARCH DESIGN**

The main purpose of this research was to gain insight into the ARV treatment experiences of HIV positive MSM who use a Johannesburg based support group. The research sought to explore and understand the perceived barriers, as well as the enablers to ARV treatment adherence amongst HIV positive MSM, and to elicit the participants' narratives and opinions about adherence.

For this reason, the research used a qualitative and exploratory research design. This methodology was chosen as it is the best methodology suited to this project as it permits the researcher to "describe and interpret people's feelings and experiences in human terms" (Terre Blanche, Kelly, & Durrheim, 2009, p272). Put in another way, this research design allowed the researcher to closely describe and illustrate the events and experiences lived by

the participants, and study these issues in an in-depth, open and detailed manner. Chiefly, this approach enabled the researcher to understand the categories of the information as they emerged from the data. Especially as this study allows the researcher “to study them as they unfold in real world situations” (Terre Blanche et al., 2009, p.47).

For the most part this research was exploratory in nature and used an interpretive phenomenological paradigm as this allows the researcher into the world that connects him to the participants in that this research aims to understand what kind of person the participant is, what is the relationship between the participant and the subject matter and to gain knowledge of the subject matter from the participants perspective. Whilst being mindful that the researcher has feelings and beliefs about the subject matter and being aware of these during the interpretation of the findings (Denzin & Lincoln, 1994).

### **3.4 PARTICIPANTS**

The participants of this research were acquired using a non-probability sampling method, based on their availability and willingness to participate, known as “convenience” or “opportunistic” sampling (Terre Blanche et al., 2009, p. 288). This method of sampling was based on MSMs utilizing the services of a Johannesburg-based support group called Positively Alive. The support group, aimed at MSM, is mainly attended by PLWH who are identified as gay, bi-sexual and transgender living with HIV. However, the researcher learned that the majority of the MSMs using this support group identify themselves as ‘gay men’. Between five and ten PLWH attend the monthly group meetings. The aim of the monthly support group is to enable users to feel comfortable with knowing that everyone utilizing the service is also living with HIV. Then the support group encourages them to share their feelings, emotions, what they are currently dealing with, their concerns and joys in positive and safe contained environment. The sessions have themes, and have a learning component which includes topics such as alternative healing and legal rights. Then the sessions provide an opportunity for support group participants to share their experiences of living with HIV, being on treatment, using nutritional supplement. In addition to this, the support group has a closed membership internet website (by invitation only administered by the group facilitator which has over three hundred participants and enables users to take part in discussion forums, share their concerns and experiences, seek advice and guidance and to make friends.

Incidentally, in August 2011 the researcher spent some time liaising and visiting support organizations designed for MSM living with HIV in order to offer volunteer services. During

this time, the researcher met with the facilitator and support group members of Positively Alive and was impressed by its well-established and clear constitution, the organizations' structure and the encouraging feedback by users. The group holds monthly meetings which are mostly attended by between five to ten participants. This group was targeted as an excellent site for this research, and the facilitator and participants willingly and generously granted this study access. Although Positively Alive was selected for these reasons and despite other support groups offering similar services, mostly based in Pretoria which made access more challenging for the researcher. Therefore for this reason Positively Alive in Johannesburg was selected.

A criterion form of purposive sampling was used, based on the participants possessing personal experience of what was being researched, in other words that they were able to describe in detail their experiences relating to the research topic, and likewise be open to share their experiences with the researcher. Finally, perhaps the most important aspect of this technique was having an interest in taking part, because they envisaged that their input in this research may be of value in the future (Terre Blanche et al., 2009). The participants were all white males living in Johannesburg; all had obtained a matric as a minimum level of education.

**Table 1. Participant Information**

| ID | Age | Occupation             | Commenced ARVs | Adherence (self-reported)                                   |
|----|-----|------------------------|----------------|---|
| A  | 51  | Wellness consultant    | 2004           | Forgotten a couple of times and was late a couple of times. |
| F  | 45  | Occupation undisclosed | 1998           | Has missed doses mainly between 1998 and 2003               |
| H  | 44  | Self employed          | 2011           | Never missed  |
| M  | 43  | Self employed          | 2011           | Never missed  |
| C  | 29  | Graphic design         | 2012 (July*)   | Never missed  |
| N  | 34  | Human resources        | 2012           | Never missed  |
| R  | 24  | Clothing design        | 2012           | Has missed and been late a couple of times                  |
| D  | 62  | Actor & educator       | 2009           | Never missed  |
| G  | 53  | IT specialist          | 2008           | Never missed  |

\* 'C' commenced ART in July 2012, a month before he was interviewed.

### **3.5 PROCEDURES**

The following procedure was utilized to collect the data. First of all, the researcher approached the organization to inform them of the research and request participation of the support group members in this study. This was done in writing (see Appendix A). The facilitator of the organization agreed that the group members could be approached to take part in this research. Next, the researcher attended one of its meetings and carried out a short presentation on the nature of the research, inviting group members to participate whereby an information sheet was handed to each group participant attending that meeting (Appendix C). The information sheet contained information about the nature of the study. Meanwhile, members who agreed to participate were handed a letter (Appendix C) with an informed consent document for signature (Appendix D). All ten participants attending the meeting took information sheets and consent forms. Ten of the informed consent documents were signed at the meeting. Lastly, the researcher contacted each potential participant telephonically to confirm one-on-one interviews based on the criteria above then this was followed up with an email confirming the date, time and venue for the interviews. Out of the ten potential participants, nine were interviewed. One of potential participants was not able to take part in the research due to work commitments.

### **3.6 METHOD OF DATA COLLECTION**

In terms of data collection, the researcher asked the individual participants to take part in semi-structured interviews. With informed consent the interviews were audiotaped. Originally, the interviews were to take place at the at the Emthonjeni Centre at the University of the Witwatersrand, however, it became apparent while making the arrangements that this was problematic due to the participants' work commitments so a more convenient place was selected. This was at the participant's home and on two occasions, at the home of the researcher. The interviews ranged from thirty-five minutes to one hour and twenty minutes in duration with the average length being one hour.

It was vital to create an environment between the researcher and participants that was based on openness and trust where participants could express themselves openly and authentically with the researcher (Terre Blanche et al., 2009). In order to create this environment the researcher used a semi-structured interview technique, namely the researcher had a schedule of key topics that were prepared in advance (See Appendix E), however the structure of the

interview was such that there was the freedom to examine the experiences and emotions further (Terre Blanche et al., 2009).

The researcher was mindful that it was essential to establish trust quickly. Thus, the interview did not start with sensitive questions but rather a summary of the nature of the research and in the early stages involved non-threatening, open-ended questions to put the participant at ease. The researcher attempted to draw the participant into the session by becoming a co-enquirer rather than a research subject; this was accomplished by expressing curiosity about their lives and wanting to learn more about their experiences and feelings (Kelly, 2009). For the most part, the participants were quite relaxed to talk about their experiences with only limited prompting required from the researcher. However during one interview the participant required more prompting than others, the researcher speculated that this is his personality style. By and large, the researcher felt that the interviews were a continuous process of learning more about each other by initially establishing and re-establishing rapport and trust throughout the interview process (Kelly, 2009). With this in mind, the researcher, because of his experience in this area was conscious of not sharing too much of his own experiences, but rather allowing the participant to speak freely with minimal interjection or interpretation, although on one or two occasions this became challenging.

### **3.7 DATA ANALYSIS**

The researcher transcribed the interviews including utterances thought to be ‘fillers’ such as coughs, sighs and laughter this is understood as content that may seem to have little or no value. However these utterances were interpreted in terms of the context of the sentences around it. The accuracy of the transcription was checked by reading it whilst listening to the recording and further gaining a clearer image of the interview as a whole. During the interviews the researcher took note of non-linguistic expressions (sighs, laughs and silences) that may have been missed in the transcription process. Furthermore, discussions at the beginning or end of the interviews when the audio recorder was switched off were also taken note of. This information was added to the researcher’s process notes following the interviews however this data was not transcribed and did not become part of the analysis. During the transcription, there are a number of ways for indicating interruptions, such as speakers talking at the same time, pauses, and raised voices (Terre Blanche et al., 2009), for the purpose of this research bracketed notes was used.

As discussed, qualitative analytical techniques based on the interpretive paradigm were used in order to analyze and interpret the data from an “empathetic understanding” perspective (Terre Blanche et al., 2009, p321). The purpose of interpretive analysis was to provide a

Thorough description of the characteristics, processes, transactions, and contexts that constitute the phenomenon being studied, couched in language not alien to the phenomenon, as well as an account of the researcher’s role in constructing this description (Terre Blanche et al., 2009, p321).

For the most part, there are many qualitative analytical traditions that are part of interpretive analysis; however the procedure followed involved in the evaluation of information from this paradigm using five key steps (Terre Blanche et al., 2009). The first, the researcher familiarized himself with the ideas and theories about the phenomenon being studied, in other words the researcher had a fairly reasonable understanding of the research topic and before setting up the interviews had a preliminary understanding of the data and possible topics that may be raised (Terre Blanche et al., 2009), although he did not try to analyse it too closely but allowed space for the data itself to drive the emergence of themes for later analysis. By the same token, the data provided many interesting features and themes that were coded systematically across the data derived from all participants (Braun & Clarke, 2006).

Secondly, themes, rules or classes were identified through a process of induction (Terre Blanche et al., 2009). In essence, this meant that important points came from the data in line with the research question, which seemed to be similar across all of the transcripts (Braun & Clarke, 2006). So that the “organizing principals” that came through in the material in terms of the ‘language’ used by the participants and “processes, functions, tensions and contradictions” (Terre Blanche et al., 2009, p.323). By and large, during the development of the themes, coding of the data had occurred, whereby different sections of the data were highlighted in terms of “instances of, or relevant to, one or more of your themes” (Terre Blanche et al., 2009, p324).

Later, the themes were further explored through a process of ‘elaboration’, for the most part this meant comparing the themes and subthemes or issues that arose (Terre Blanche et al., 2009). In essence, this was a process of checking the themes against the data and the codes, with the aim of refining the specifics of each theme and the overall story that the data told before moving onto the final stage (Braun & Clarke, 2006). This meant isolating the primary and subthemes that emerged from the data, further checking the appropriateness of the themes against the data. Finally, deciding on a main theme, for example; ‘biological’ and the

subthemes under this such as; ‘experiences of side effects’ or ‘difficulties in taking treatment’.

The final process was interpretation (Terre Blanche et al., 2009). Whereby a written account was created of the researcher’s the interpretation of the phenomenon using the “thematic categories defined in the analysis as sub-headings” (Terre Blanche et al., 2009, p326). This meant that in order to convey the views of the participants adequately by continuously examining the data, the literature to develop an understanding on where they agree or disagree then hypothesizing why this could be.

### **3.8 VALIDITY AND RELIABILITY**

In order for this piece of work to be seen as valid and reliable there seems to be agreement that the manner in which the data has been collected and analysed should be transparent and the researcher should be able to describe how the findings were derived. Therefore, for this research to have credibility, reliability and validity it would need to engage with the subject in many ways to examine areas where there is a clear fit with the participant’s experiences, which may serve as a benchmark, as well as where there are areas that disagree with the participant’s experiences (Lincoln & Guba, 2004). In cross-checking the experiences of ARV adherence amongst MSM from various sources with the data derived with that of the participants would assist in monitoring this (Lincoln & Guba, 2004). In addition to the cross checking the participant’s experiences with the literature to examine whether it fits with other interpretation. It is further recommended that the conclusions should draw agreement between the researcher and his supervisor (Lincoln & Guba, 2004; Terre Blanche et al., 2009). For example, the researcher’s supervisor checked the coding of the transcriptions to confirm what the researcher saw in the data.

In addition to considering the reliability of this research an important aspect is the generalizability of the findings, which means that the findings can be applicable to other PLWHs from similar populations. Further considerations when considering reliability are the transferability and the trustworthiness of the research. This would be based on the amount this research has similarities made by others who wish to apply some of the findings elsewhere (Lincoln & Guba, 2004). For example, where any new or parallel literature was produced on this subject, the findings of which could be integrated with the findings of this research, or if this is not the case, the findings would not undermine the overall research interpretations (Terre Blanche et al., 2009).

The authenticity of the research considers whether the process has been followed fairly meaning that the process was carried out impartially, honestly, respectfully and safely and that the participants were able to tell their stories without favouritism in order to protect the legitimacy of the research. This is defined as “a balanced view that presents all constructions and the values that undergird them” (Lincoln & Guba, 2004, p.79). Meaning that the views, values and belief systems which are different to those held by the researcher and other participants will be presented, and where possible an interpretation of the underlying belief system made (Lincoln & Guba, 2004). Other areas of fairness that were included in this research were gathering informed consent from the participants as well as offering the opportunity to withdraw from the study at any time, plus a check-in after the interview to understand how the participant experienced the process (Lincoln & Guba, 2004). Certainly in line with the principal of fairness, the researcher, at the end of the process will provide a summarized report to the support group gate-keeper in order to enhance his understanding of the group and the phenomenon he represents as part of *educative authentication* (Lincoln & Guba, 2004).

### **3.9 RESEARCHER REFLEXIVITY**

The researcher was the ‘primary instrument’ for both the collection and the analysis of data, because of this it was difficult to be perfectly objective (Terre Blanche et al., 2009). It should be acknowledged that as a white, gay male who has had professional and personal experience with people living with HIV for a number of years, the researcher’s involvement in the phenomenon may influence the way that the data is collected, analyzed and interpreted. However, Terre Blanche et al., (2009) reminds us that “subjectivity is not considered enemy of the truth, but the very thing that makes it possible for us to understand personal and social realities empathetically” (Terre Blanche., et al, 2009, p277). However, in order to understand participant’s world-views and discover their experiences not only is the rapport built between the participant and research key but also the researcher’s relationship with the subject matter (Larkin et al., 2006). Meaning that as a researcher we are a part of the world that we are describing, in this researchers case being actively involved in the HIV/Aids field for many years with professional and personal experience of the subject (Larkin et al., 2006). As a researcher, it should be acknowledged where he used his “subjective capacities” where challenges arose in understanding the issues from the participant’s perspective. For example, making sure the researcher understood the names of the medication the participant was taking in order to have a clearer picture of possible side effects and any challenges in taking the



medication. At other times, using what he had learned from those close to him in terms of the psychological and social challenges of living with HIV and taking ARVs meant that the researcher was able to maintain rapport and 'empathetic attunement' with the participant and their experiences. Because of the researcher's background, the researcher was mindful that the research intended to view the interviews as not for re-confirming pre-existing viewpoints but to rather explore the topic from the perspective of the participant's to interpret their experiences and feelings relating to it. The researcher aimed to create a non-judgmental, trusting, open and positive atmosphere that is conducive for participants to share their experiences and feelings relating to the research topic.

Another significant factor which may have led to some confusion was the aim of the research, in that its objective was introduced as exploring a future programme or intervention aimed at assisting MSM to improve treatment adherence. This may have been interpreted by the participants to mean that their narratives had less significance to the researcher. The researcher reflected upon the possibility of being somewhat divorced from the real world and indicating an ideal world perspective in that during the introduction to the interviews it was suggested that the aim of the research may to drive an intervention. Perhaps this was to create some credibility to the research (Brouard, 2009). Although the aim was to explore the affected lives of the researched, of equal importance was inspiring a sense of empowerment, as this should be the main characteristic of qualitative research (Rappaport, 1994). That is to say there is an appreciation that their experiences and concerns regarding the subject matter will carry on after the research has been completed. For this reason, any questioning of the status quo in terms of what support should be provided can perhaps instill a sense of personal control and empowerment. In that there are ways of affecting and improving the lives of those being researched especially when it comes to trying to understand their needs and the support which should be provided (Dilley, 1999).

### **3.10 ETHICAL CONSIDERATIONS**

As this research involved engaging with an extremely vulnerable group (Cloete et al., 2008) on a complex issue, discretion and confidentiality was guaranteed throughout the process (Punch, 1994). This was to ensure that the interviews were conducted in a manner that that placed no risk in terms of harming the participants' psychological or physical health in any way, and that process was undertaken in a sensitive, constructive and positive way (Punch, 1994).

Approaching the support-group facilitator and the members of the group only commenced upon the university issuing an ethical clearance certificate and written permission was granted to carry out this research.

In order for the members of the group to participate, informed written consent (Punch, 1994) was derived using the letter, information sheet and consent form (Appendix B), which was distributed at the meeting with the group and after completing a short discussion on the exact nature and purpose of the study. This information was also contained in the letter attached to the consent form.

Although anonymity could not be fully guaranteed during the study due to the nature of the data collection method, the participants were advised verbally and in writing that the PLWH interviews would be confidential, that the participant were free to answer only the questions they felt comfortable with, and for any reason and at any time the participant could terminate the interview. None of the participants chose to terminate their interview and all answered the questions fully. Furthermore, the interviews were only audio-recorded with the participant's written consent. During the transcription phase and quoting of the participant's responses in the report, identifying letter was used rather than their name to protect PLWH identity. The participants were informed that for the duration of the research the audio tapes and the transcripts would be locked in a secure place and would be destroyed after 2 years if publications arise from the research and five years should no publications arise from the research. Upon request, feedback on the findings of this research, a one-page summary will be made available to the group facilitator (Lincoln & Guba, 2004).

The participants were made aware that should the interview elicit any strong emotions and that the need for counseling was required; they would be referred to the Health4Men organization or Lifeline. Health4Men is Soweto-based, at the Simon Nkoli Centre for Men's Health at the Baragwanath Hospital. The centre has a team of doctors, nurses, lay counsellors and outreach staff striving to provide comprehensive medical and psychosocial services including telephone counseling to MSM in the Johannesburg area. Health4Men offers free, professional short-term counselling to men on any issue that relates to their sexual and emotional wellbeing.

Finally, should the participants or the facilitator or the support group have any questions about the research, the contact details of the researcher and the supervisor were provided in the information letter.

### **3.11 CONCLUSION**

Previous work in the field of ARV treatment adherence, explored the barriers and facilitators from a patient and healthcare provider perspective. However, men who have sex with men are a diverse and vulnerable group presenting specific challenges that have specific risk factors and behaviours that change the management of HIV compared to the heterosexual population (Anova Health Institute, 2010). There are specific issues to this group such as their vulnerability to social discrimination and stigma that may impact on their ability and willingness to seek health care services. This research hopes to explore these areas and ascertain the extent to which these form a barrier in terms of adherence to treatment and retention into care. This chapter examined the research design; the participants; the procedures that were followed; the method of data collection and analysis; validity and reliability; researcher reflexivity and lastly ethical considerations. The next chapter will focus on the findings and discussion of this research.

## **CHAPTER FOUR: FINDINGS AND DISCUSSION**

### **4.1 INTRODUCTION**

This chapter outlines the findings of this research and presents a discussion of these findings. Quotes from the transcribed data are presented under the various headings. The themes which are presented in this section follow the research questions in that they are broken up into the biomedical, psychological and social or structural factors to explore how each factor had an influence on ARV adherence amongst MSM. The principal theme is further presented along with secondary themes.

Under the biomedical theme, the secondary themes are pre-treatment perceptions; expectations of side-effects prior to treatment commencement; side-effects; difficulties in taking treatment; examples of when treatment was forgotten and finally, what makes it easier to take treatment.

The psychological theme presents the meaning of treatment adherence; participants thoughts about their medication; acceptance of their virus; internal stigma; disclosure; mental health factors; experience of adherence counselling and support groups as secondary themes.

The last principal theme presented in this chapter is the social and structural barriers to treatment adherence. This includes medical facilities; health providers; challenges with medical aid; challenges of medical supply; discrimination and ARV advertising.

The final research question relating to the interventions that the participants would like to see in place to improve adherence, the responses to this have been integrated into the principal and secondary thematic responses.

### **4.2 IDENTITY OF PARTICIPANTS**

Before presenting the findings, it was interesting to note that during the researcher's initial meeting with the group many identified themselves as 'gay men' and found the MSM term cumbersome, a catch-all label and one that does not fully reflect an understanding of their identity or needs, with a fear that they may become absorbed in a wider description for research convenience. This engagement was not reported, however discussions on which label would be appropriate should be the focus of further research. Because the participants for the research were derived from a support group aimed at HIV positive MSM, for the most part this term will be used in this research although all of the participants were identified themselves as gay men.

### 4.3 BIOMEDICAL INFLUENCES OF TREATMENT ADHERENCE

The biomedical influences examined some of the pre-treatment perceptions of ART and their expectations of side-effects. Further discussion went on to explore their actual experiences of the side-effects. The participants shared on the circumstances which had made treatment difficult to take as well as described times when they had forgotten to take their treatment. They further reflected upon the factors which make it easier to take their treatment.

#### 4.3.1 Pre-treatment Perceptions

This section examines the participants' perceptions of ART prior to starting their treatment and their expectations of side-effects; the number medications; the life-long commitment and the sense of medication keeping them alive; the severity of their condition and knowledge of antiretroviral therapy prior to treatment commencement were shared and whether this had influence on the adherence to their treatment. There appears to be a correlation between their beliefs about ARVs before commencing treatment which may have influenced the way they perceived their treatment when they started. Furthermore, the PLWH's perceived sense of severity about their condition may have in turn influenced their on-going adherence to their ARVs. Before commencing ART, N felt that he was going to be unique in taking treatment and that he would perhaps be the only one. In that he thought:

Because when I was diagnosed I also think many people feel at that it was a case of 'I'm the only gay in the village', you think you're the only one and you have that negative perception of that. (N)

In addition to this, 'N' was worried that, in line with a popular mini-series that was shown during the early 2000s called 'Queer as Folk', he understood somewhat humourously that a drug cocktail to mean exactly that, in that he would have to take a cocktail glass of medication each day.

My immediate thought was when I was told that I would have to go on go on the therapy or the treatment was that I was literally going to go on a cocktail glass filled all kind of colourful pills. (N)

He further elaborated on this by describing that he had a picture in his mind from the programme that represented a:

A martini glass filled with pills, that's what I'd imagined, and then my doctor had said no no it's just two so I thought oh well they probably combined it all then well done for medical science and great but I was not aware. (N)

This seemed to suggest that perceptions surrounding ART for N came from watching television. This seems to correspond with the literature in that with the emergence of social media many illnesses, such as HIV/Aids are increasingly becoming public with open discussions and featuring in television and social media websites (Conrad & Barker, 2010). However, it appears that in N's case, relying the information portrayed in television programmes around the taking of ARVs may have created an inaccurate picture. Similarly, when it came to understanding how to take the medication, C described how the first time he and his friends found out that they must take the medication daily at a certain time was when they collected them for the first time. This suggests that during the initial period he was not offered adequate adherence counselling containing information on how and when to take his treatment. This is the first step in the analysis and the researcher will bring in the literature here in order to understand the context. As described, access to adherence counselling whereby issues such as this can be addressed results in treatment adherence during the first month being significantly higher than those that did not, with adherence rates remain constant over an eighteen month period (Chippindale & French, 2001).

Further to this, one of the participants was keen to avoid thinking about starting treatment because of the thought of this routine being a life-long commitment. Thus, the use of avoidant coping strategies has been implicated in poorer treatment adherence (Halkitis et al., 2003; Martinez, et al. 2012).

Initially I didn't want to think about taking it because I kind of think once you start you can't stop and I have now I have to go onto a drug for the rest of my life I didn't like that idea. (H)

By the same token, there was an apprehension about starting treatment for R as:

I've never really wanted to ever rely on something to keep me alive. (R)

His feelings extended to other forms of medications such as headache and painkillers. However, he requested to commence his treatment at an earlier stage when his CD4 was well above 350 in order to prevent disease progression and in order to feel better.

This was contradictory to C's feelings, perhaps as a result of his prior experience of chronic medication and the effects that this medication had had in terms of quality of life, although he knew he would need to start treatment eventually:

It wasn't like I was anxious or eager to start but it was ok...it's like done. (C)

None of the other participants discussed their pre-treatment perceptions regarding ART which was in itself interesting. Perhaps this was due to the questioning not focussing on this issue or whether the participants had no perceptions about their treatment before starting and for them it was simply something they had to do. Those that did convey their pre-treatment perceptions ranged from holding perceptions about what the medication would be like based on media representations; to avoiding the issue altogether; to having concerns around being reliant on medication for the rest of their life. However, all of the participants seemed to appreciate the severity of their condition, and see that the medication provided benefits and were able to assess that the barriers to treatment outweigh the difficulties which the medication may create (Petersen & Govender, 2010).

#### **4.3.2 Expectations of Side-effects Prior to Treatment**

This section examines the participant's pre-treatment expectations of side-effects of ARVs and whether this played a role in starting and adhering to their treatment. Prior to starting ARVs C, who has been living with bi-polar disorder for a number of years and had recently been stabilised on his medication was concerned over the possible interactions that his bipolar medication may have with his ARVs.

I was very worried about it because I didn't want any interactions because after kind of the hell I'd been through before I'd figured this out I didn't want it to interact in any way. (C)

He was also concerned because he had heard other people talking about side effects and he was convinced that he would have the same experience:

At some point of course it's going to have some side effects like that's why people talk about it in such a way. (C)

In addition, one participant, who had been working in the HIV field for a number of years, described how he had come face-to-face with the possible side-effects of ARVs in the early stages of the treatment. In that:

He looked the worst of all of us from the point of view he had wasting. He's alive today still and he looks well now, but back then I almost thought to myself if that's how you look on when you're on ARVs then fuck me, I don't want them. (A)

Similarly, when carrying out this research, prior to starting antiretroviral therapy, there was a sense that information and what was being discussed publically about potential side-effects was not instilling confidence in at least one of the participants:

What I was seeing in terms of stats was not encouraging with the side effects that everybody kept on popping up and showing off in whatever I read I didn't like them. (G)

Some of the participants spoke about their thoughts about side-effects prior to treatment commencement, some based on observations of others, based on personal research, whilst one of the participants it was based on concerns over possible interactions with other chronic medication. However, despite these concerns and contrary to literature suggesting that those who experience side-effects may experience problems in adherence (Ammassari et al., 2001; Murphy, 2003) all the participants started treatment.

### 4.3.3 Side-effects

This section examines whether the participants have experienced difficulty in remaining adherent to their treatment as a result of side effects. In terms of actual experiences of side-effects, there was quite a lot of discussion about their experiences and although in many cases the side-effects experienced were not enough to hinder taking the medication, 'R' had experienced significant side-effects for a prolonged period which had made the taking of his medication challenging. However, there seemed to be some consensus that although there were side-effects, as a result of the toxicities of the medication which can be experienced as mild to severe and from acute to chronic (Murphy, 2003) and those who report side-effects may experience difficulty in remaining treatment adherent (Ammassari et al., 2001; Murphy, 2003). However, for the participants, there appeared to be consensus that although some people would prefer to not take them because of the side-effects, the alternative for them was something that they would not like to consider, in that:

Some people would just prefer not to take a medicine because the side effect might be too difficult to live with without thinking the ultimate side effect which is death or really being very very sick. (F)

The side effect doesn't bother me because I don't think it's really affecting me or that the side effects are going to kill me. (H)

As many of the participants were taking an ARV medication which contains *Efavirenz*, known to cause dizziness and have hallucinogenic qualities (Maartens, et al, 2010) most of the participants had experienced this particular side-effect at various times:

You just have that kind of trippy feeling spaced-out feeling. (H)

For G, his experience was

I'd wake up every morning and I'd literally feel as though an axe was in the middle of my head it was that sore always. (G)

Although for R this particular side-effect was serious, this caused him considerable unhappiness and resulted in him to reflect on his capabilities:



I hate the side-effects I cannot stand them. I hate that drugged feeling I hate not being able to focus whereas before I was able to sit down and focus for hours on end. (R)

In that he:

Gets dizzy, get drugged, battle to talk at times and sometimes paralytic like I just don't want to move I'm lethargic so it's taken some enjoyment out of my life. (R)

These conditions affect his ability to socialise so that he is not able to go out to have a meal after taking his medication because of the 'drugged' feeling in that he feels:

So it's all these like restrictions and like barriers that actually inhibit actually enjoying in some sense. (R)

In essence:

I can't enjoy those kinds of lifestyle any more or I can but then I have to suffer the consequences as a result. (R)

Furthermore, for R one of the side-effects that was extremely disturbing for him were the dreams that at times meant that he becomes disorientated and "unsure of reality", so that he would wake up;

Not sure where you are you're not sure if you're still living in the dream you're not sure if you're back or you're awake again. (R)

For R, he makes sense of these two side-effects by suggesting that they come as a result of being highly stressed and overly tired due to his studies and work responsibilities.

Although some had reported that these side-effects had become less over time, others had tried to identify the circumstances which exacerbated the side effect.

But we've figured out how to treat that and you should practical things eat about half an hour to an hour before you take your ARVs. (H)

Although this can bring about practical problems such as going out socially for dinner, drinking alcohol and how this may bring about this side-effect.

One of the participants, who had started with ARVs in the month prior to the interview, reported that he had noticed that he was finding waking up in the mornings challenging since starting:

Certain things like waking up in the morning are a lot more difficult because I used to be an early riser. (C)

This seemed to be a similar experience for M:

Sometimes in the morning when I get ready I got to work I'll be in the car and I'll think agh god I don't feel so great today I feel a little flu-y but you know It's nothing serious as far as I know energy levels take a dip some days. (M)

However, another participant N described how he experiences a 'warm glow' around the time he takes his medication, and that he had noticed that this had become more pronounced when taking the generic version on his medication.

In some cases, there seemed to be some confusion as to whether what the PLWH was experiencing was a side-effect or another medical condition such as M describing how he had experienced 'trigger finger', 'pins and needles' on his side when lying in bed for long periods, however he was unsure as he had been in a car accident a number of years ago and had suffered with whiplash and some neck problems. His feelings on this were that his ARVs may have exacerbated this condition, although this had been unconfirmed by his doctors.

It seemed that during the initial stages of taking treatment there may be some confusion on what constitutes a side-effect in that there could be a tendency to look for side-effects when in fact the physical symptom may not be related to the treatment at all. As an example of this:

The biggest issue with ARVs is I tended to continuously look for any side effect that, any health issue I would put it down oh my gosh it's probably the pills. (A)

Three of the participants who had been on antiretroviral treatment the longest A, F and G had had some experience of lipodystrophy. In A's case, this was in the chest and 'breast area' and in F's case around the back area. This literature describes how lipodystrophy, along with flatulence and sexual dysfunction are perceived as unappealing and may act as a barrier to treatment adherence amongst MSM (Crum et al., 2005; Miguez-Burbano et al., 2007). Moreover, the literature describes how MSM report higher levels of unhappiness and distress in various psychosocial ways relating to 'body dissatisfaction' (Beren et al., 1998).

Although lipodystrophy had been experienced by these participants, it appears to have not been a deterring factor in their adherence. Although, the effects of lipodystrophy on treatment adherence amongst MSM appears to be under-researched (Anova Health Institute, 2010), as some MSM place significance on external appearance, whether the rest of the participants would concur if they experienced the external effects of the medication on their appearance remains unclear.

I would feel my breast and I had a very sore breast so I thought that's very strange and then I realise that actually my breast was growing. I had a little girl titty on the one side.....when I

got to the HIV specialist she took one look at me and said oh that's lipodystrophy and it's in reversal it hasn't gone far and you can stop it now and its AZT. (A)

For F the lipodystrophy he experienced was:

The buffalo hump which is a little bit more embarrassing. (F)

For R some of the significant side effects of his medication included severe diahorrea and vomiting whereby the result is that he has lost a significant amount of weight. Also described how the medication has affected his metabolism to the extent that he suffers from diahorrea severely after bouts of normal functioning.

It's actually embarrassing at times because you're in the middle of traffic and you're still an hour away from home and you need the bathroom it's happened to me twice already and it's not a very pleasant experience. (R)

F had also experienced similar, whereby:

Nothing else could explain this chronic diarrhoea so I said to my doctor then its ARVs give me a new ARVs because I can't because it was really bad it was very it was it was becoming uncomfortable in the sense that it was because all the time. (F)

However, the constant diahorrea was problematic and embarrassing because of being:

A hindrance to having a normal sex life because you've got constant diarrhoea, so basically it is a problem. (F)

This concurs with the literature in that because certain ARV medication may cause diarrhoea and flatulence these may negatively impacting on anal sex functioning and the enjoyment of anal sex among MSM, resulting in a negative impact on treatment adherence (Anova Health Institute, 2010; Maartens et al., 2010). Furthermore, the reported increase in sexual dysfunction as a result of the medication was associated to PLWHs further defaulting on their antiretroviral treatment (Trotta et al., 2008).

For R, in order to make sense of his treatment, although he has negative thoughts regarding his side effects:

I hate it, I hate feeling that way like that that it makes me feel like it (R).

However, on the other hand and there seems to be consensus with his thinking:

But the positive attributes of being on it is I know the virus is undetectable my CD4 count has risen exponentially and that gives me a positive outlook. (R)

When considering having diahorrea as a side effect or the consequences of not taking his ARVs:

In my case, I refused not to take the ARVs because, I know that if you stop that the consequences of stopping the ARVs are going to be far worse than having a shit sex life for a couple of months it's all a matter of perspective. (F)

Despite the participants indicating that they will take their treatment regardless of the side-effects, it is important to be mindful that the literature describes how the reduction or the alleviation of side-effects altogether plays a significant role in improving the correct and regular taking of the medication (Ammassari et al., 2001). As a rule, despite some of the participants experiencing side-effects, for the most part they remained adherent to the treatment regime because of their belief in the clinical outcomes. This will be discussed in further detail later.

#### **4.3.4 Difficulties in Taking Treatment**

Despite all of the participants' reporting strictness in terms of their adherence the main difficulties the participants experience comes from taking their ARVs in a social context. They felt that they have to be constantly aware of taking their medication when away from home and in a social setting by the way of issues around disclosure. Although there is research that suggests that the number of different medications and the complexity of the treatment impacts treatment adherence. It seems that treatment adherence is more likely unrelated to this when considering that adherence rates for those on mono, dual or triple therapy remain similar. The literature seems to agree that adherence is complex and is more likely to be affected by psychological and social issues rather than the medication itself (Halkitis et al., 2003). For example, in most cases the participants have not disclosed to all of their friends and in some cases to family members which makes adherence to treatment problematic particularly in a social setting. As a result, a number of the participants feel they have to hide their treatment, for example at the allotted time taking their medication in the bathroom and away from friends and family. This behaviour is understood as avoiding the possible threat of stigmatization and therefore they would prefer to keep their HIV status hidden because of the fear of "rejection, violence or both" (Hardon et al., 2007, p. 18). Which means they have to hide the medication or perhaps take medication later than allocated, or not at all if people are present (Nachega et al., 2006). For example:

I have little uncomfortable moments when I'm in a social context and both phones go off and then we visit again two or three days later and the phones again go off at the same time and I'm always sneaking my hand into my bag and trying to be very discreet but we all know that when you are trying to be discreet it is when you are most obvious. (N)

M has similar experiences whereby the alarm signifies that he and his partner should excuse themselves to go to the bathroom in order to take their medication. However, this places them

in a situation whereby their friends making comments about this with M having to justify their behaviour.

We actually laughed the other night because we were at dinner with friends of ours and at 8 o'clock the alarm went off and I said going to the bathroom so he said "Oh, ok" the friends said 'ok' and off we went well off I went and I came back and said are you going to the bathroom now so he said: "Ja" so I said we should have gone together like girls, you know always going to the bathroom together, you know. (M)

Faced with a similar situation R uses the excuse of taking vitamins at an allotted time, although he is fearful that people will enquire about which vitamin he is taking thus placing him in an uncomfortable situation where he has to lie, although he does not want to. This is further compounded by the fears surrounding side-effects whereby he may become drowsy or 'out of sorts' leaving him with often no other choice but to cease going out socially.

I don't go out in the evenings anymore otherwise I'll go out after the effects have worn off or I'll make it before 9 o'clock or make sure that I'm home or in the car before 9 o'clock or on my way home. (R)

He felt this way in the initial stages, whereas A would excuse himself and go to the bathroom to take his medication in a social situation. This has changed over the years in that:

I don't care anymore I just take them in front of everybody, everyone has seen me pop a pill so what it could be Smarties or it could be vitamin pills there are many people on chronic medication how do they know its ARVs I just don't bother about it anymore. (A)

Following on from the social difficulties faced when taking medication it can also effect the working situation. Especially for D, an actor whereby he had to juggle taking his medication and going on stage.

Now you've got your pills with you, you've got to have water with you I've got from the bar or you've got a bottle with you know and you've got to take this into the theatre the curtains going up and you're taking your pills at 8 o'clock. (D)

When considering some of the difficulties in taking treatment, for 'F' he felt that he was not advised adequately about taking the medication and the consequences if this is not followed and a dose is missed. Furthermore he said when he is in a social setting such as at the movies and he cannot hear the alarm on his phone to remind him to take them this can become problematic.

For A, factoring in taking his treatment into his daily routine and being fearful that he might forget was an area of concern. Especially as he travels a lot for business where his routine is disturbed, which makes remembering whether he had taken his medication challenging:

I take mine at 9 o'clock now and at quarter past nine did I take my pill? I've been to the kitchen and taken the pill but I'd forget that I've taken it. (A)

Now that PLWHs have been taking ARV medication for a number of years and that the treatment has been integrated into day-to-day living for many the literature seems to moving towards the idea that forgetfulness is cited as the reason for PLWHs not taking their medication (Bartlett, 2002; Barfod et al., 2006; Chesney, 2000). Certainly, a number of the participants described that they had simply forgotten to take their treatment rather than side-effects or the complexity of treatment regimes.

#### **4.3.5 Examples of times where medication was forgotten**

Despite the participants appearing to be fastidious with adherence there have been times when they have forgotten or taken later than prescribed, usually as a result of being busy or pre-occupied, being faced with a situation whereby they cannot take them or forgetting to pack their medication when going on a trip. For example:

The only way I would forget is if I don't have the thing with me so like going to the movies or going out. (F)

C was in agreement; in that when he first started taking his treatment he had gone to the movies and had forgotten to take his medication with him which resulted in him taking it an hour later. He further described, the next day when going for out for dinner with friends that he realised that he had forgotten his medication and as he was not able to tell the people he was with why he needed to go home. The real reason was to take his medication. This dishonesty made him anxious.

When busy there are times when the medication can be forgotten and they are not taken at the correct time, which means that they may be taken at a later stage. As a result of this the affects can be:

The next day I'm stuffed, I'm really buggered and so it's a bit a bit challenging and it's a bit taxing and it takes its toll on me emotionally, physically. (R)

Even with reminders, R said he may omit taking his medication when busy as he needs to finish a piece of work which may result in him taking a double dose of his medication at a later stage with the same outcome discussed above. R seems to make sense of this by saying:

I get busy like you do forget to take your medication and that happens to everyone whether you take heart medication or whatever. (R)

In other words, R describes how taking the medication:

Goes to the back of my mind. (R)

Similarly, when the medication is not the focus at that moment in time it can be forgotten, which means it may be a delay in being taken, if at all. Watching movies at home or being occupied with work were some of the circumstances described. However, perhaps as an in-built reminder:

I just have this feeling inside, the body thermometer, bio-rhythms tell me “Oo, it must be about 8 o’clock you know”, and it’s either ten-to or ten-past – it’s one of those kinds of things and then we do it. (D)

However, in the early stages when initially starting to take ART forgetting to take the medication may raise concern as to the uncertainty the effects of taking the medication late could have.

I needed to take it like 2 hours later and I had all the collywobbles in the world I thought here I’m stuffing up everything because I haven’t actually kept to my time schedule this is going to put my body totally out. (G)

Other examples of times when medication had been forgotten involved travelling which disrupted the participant’s routine, or that they had forgotten to pack the medication which highlighted how easy it is for medication to be forgotten when travelling away from home and to break a normal routine.

‘J’ was watching me pack he took them and put them back in the cupboard thinking because he saw me with a bottle and he thought I’d put the bottle in some clothes and I hadn’t he put the little container back and I put the bottle back in the cupboard so the only way when we got to the Drakensberg and it got to 8 o’clock at night where’s my pills but there were no pills. (A)

As a result of this experience, A learned to have extra medication at work and in the car, plus always packing one or two pills extra when going away.

Although many of the participants seem to agree that after taking the medication for a period of time, and once it becomes part of routine the challenge is remembering whether the medication has been taken or not, for example:

It’s getting to the point now where ‘Oops, did I take it or not, you know’ and then ‘Oh no, I did’. (C)

Another example was described by F:

You actually forget that you have taken it because it’s such a habit it’s become such an ingrained thing that you like think ‘Shit, did I take it did it not take it? (F)

The research seems to recommend that having a fixed routine so that the medication is taken at the same time each day, plus understanding the importance of their treatment, having faith in its efficacy and good knowledge being shown to be indicators of good adherence (Curioso et al., 2010).

#### **4.3.6 What has made it easier to take treatment?**

Many tools have been developed based on the idea to remind PLWHs when to take their medication (Maqutu et al., 2010). In terms of methods that the participants use to make it easier to take their ARVs, above all the use of cell-phone alarms and pill-boxes seemed to be the most popular. However, two of the participants do not use watches as they believed that their bodies have become attuned to the time in that they instinctively know when it is time to take their medication.

It would seem that because all of the participants have personal cellphones, the use their alarms appeared to be the tool of choice in order to remind them to take their medication. The literature supports the idea that cell-phones have been used successfully in both developed and resource-limited environments to support medication adherence programmes including South Africa (Fynn et al., 2006; Wise & Operario, 2008). The reported advantages of cellphones being used for this purpose because it is mobile, can be hidden and the alarm can be a reminder of many things and it can be incorporated into a PLWH's daily routine (Wise, & Operario, 2008). For example:

Who hasn't got a phone? Do you know there is an alarm clock in your phone can you set it may be and then every time it rings you take your pills what's wrong with that what's so difficult about that? (F)

As discussed, in public situations the alarm can be treated as though it is insignificant thus avoiding disclosure, but not something that can be ignored by the participant:

It doesn't matter if we're with family or out in a restaurant whatever it'll go off I treat it as an SMS, but I cannot ignore it. (H)

In situations where both partners are living with HIV and both are taking treatment, they serve as each other's reminder which was understood to make it easier to take treatment. In other words, the partners sought support for antiretroviral therapy adherence from each other (Stumbo et al., 2011). The participants who are in this situation agree:

You constantly reminding each other at 8 o'clock, we set our phones the phones goes 'Beep beep beep' and that's it. (M)



Furthermore, if they are at a social event and their alarms go off, they will prompt each other to then go to the bathroom one at a time to take their medication as discussed.

The participants appear to be very conscious of the time that the medication must be taken. In order to be reminded that the time is imminent alarms are set ten minutes before, just in case they become busy and forget or that they do not have to hunt around to find the medication:

I know myself my mind is always busy I always have one 10 minutes before and then on the time again just to set my mind to thinking about it so when it happens I don't have to scurry around to find it. (C)

Whilst another will use two cellphones simply because he does not wear a watch or he is not 'time-orientated':

I've got two phones going off so I don't miss it because I'm not a "time-oriented" person I don't wear a watch. (N)

In cases where participants have forgotten whether they have taken their medication the use of pill-boxes appears to serve as a reminder of this, for example:

It's a good idea to put it in those pill things with the day on it, which mine is. So then if I forget that I took it then I just look and I look 'Oh no, and it's Tuesday and I took it'. (F)

Incidentally, the pill-boxes can also be used for convenience so that the bottle of medication does not then need to be carried around. The literature seems to agree that the use of reminder tools being most frequently reported in assisting to PLWHs remain adherent by reminding them to take their medication, but also the use of tools such as pill-boxes to remind them when they had not (Curioso et al., 2010).

One of the participants described how ensuring that he received his medication, delivered to a point of convenience was a means in which it had made it easier for him to take his medication. For example, by being a member of a private managed care programme had ensured a continued supply of medicine so that he would not run out. By way of an example, A was able to describe when medication supplies had been problematic and how difficult this had made in taking the medication, by way of further elaborating on this point during the interview a client telephoned the participant to say that the pharmacist he was using had run out of supply.

You're getting it delivered to you you're getting it before the time you're getting it before the pills are up. (A)

A couple of the participants had given thought to ways in which to make it even easier to take their treatment, suggesting the DOTS (directly observed treatment) process used for tuberculosis and HIV. However, this was rejected due the logistical and resourcing challenges and other methods to make the taking of treatment easier or more convenient could be described.

#### **4.4 PSYCHOLOGICAL INFLUENCES OF TREATMENT ADHERENCE**

The discussions on the psychological influences to treatment adherence could be broken up into what the meaning of treatment adherence was for them and their thoughts about their medication, their feelings towards accepting that they are living with HIV, including any internal stigma they may have towards HIV, whilst further discussions centred on disclosure and mental health.

##### **4.4.1 Meaning of Treatment Adherence**

This section examines what treatment adherence means to the participants and how the importance that they place on their condition and their treatment plays a role in maintaining treatment adherence. Again, this follows a HBM framework that emphasises; firstly, the value that an individual places on trying to avoid illness, or to get well; and secondly the belief that their health action will prevent or improve the illness (Becker & Janz, 1985). As a rule, the participants described the physical taking of the medication as what they understood the meaning of adherence to be.

Making sure you take your medication regularly. (H)

They declared that apart from one or two slips or taking the medication late on occasion that adherence was a priority to them. However, of particular interest was the symbolism that was attached to the taking of the medication, in that they were clear on what the medication did and what it represents for them. In that it becomes a symbol of health and life itself.

The issue of treatment adherence was a non-negotiable in a number of cases and despite the side-effects they would take their medication no matter what as it was the medication that was restraining the virus enabling them to live a healthy life. It seems that they also were confused as to why adherence to ARVs is not priority for others and why others struggle to maintain adherence. Certainly, this seems to correspond with their belief about the need for and their concerns about their treatment indicate their adherence rates.

It's a non-issue for me sometimes a bit arrogantly may be I think that it should also be a non-issue for everybody else but I can see that it's not. (F)

For example, PLWHs are more likely to have low adherence when their concerns about their medication are high in relation to their perceived need to take it (Buick et al., 2004).

By the same token, the confusion of forgetting to take treatment was highlighted in that people can remember other important daily functions yet they do not take their medication, especially when training others on the importance of treatment adherence:

I say 'Who forgot to put their panties on who forgot to brush your teeth?' and then they laugh. (A)

The results of what the medication does and the belief in the efficacy of the medication is often enough for participants to continue taking them and results in them not thinking about or questioning the medication in any other way. This consolidates the finding that there is a strong relationship between the belief in the effectiveness of the antiretroviral therapy and the adherence to it (Johnson et al., 2007). This is in line with the IMB model in that PLWH having personal and social motivation to remain adherent, by having a positive belief that the medication will work and the effects on health are associated with good adherence (Fisher & Fisher, 2006). For example:

I have seen the results the improvement in my blood tests, CD4 rising viral count undetectable Ja, I as I said, I don't really give it much thought I take my medicine and I don't worry about it further. (H)

Put in another way:

It does make me it gives me that confidence, security that I'm on the right path. (H)

This thinking provides an example of a SCT understanding of treatment adherence whereby an individual who experiences a sense of control over the outcome, experiences few external barriers and feels a sense of confidence in their own abilities drives behaviour when it comes to health such as taking their medication (Armitage & Conner, 2000).

For other participants, there was a deep sense of symbolism, in that the medication is keeping them healthy leaving them to function normally, as well as keeping them alive. From this perspective PLWHs who believe that the medication will work are more likely to remain adherent to it. In other words, those who believe in their medication or 'have faith' and see the positive outcomes are understood as significant motivators for on-going treatment adherence (Mills et al., 2006). To illustrate this thinking:

Acknowledging the fact that I have to take it and not only acknowledging it but acting upon it so that I actually have to do it because if I don't I will die. (R)

Put in another way:

Keeping oneself alive, there's the biggest symbol I'm sure we know that it is keeping us alive. (D)

When understanding this from a HBM perspective, it would be seen as the PLWH's need to avoid illness, or if already sick the need to get better. Coupled with this would be the belief that by taking action such as taking medication that this will prevent or improve the health situation. This would be based on the subjective assessment of the severity of the condition and the chance, through certain actions to reduce or improve their situation (Becker & Janz, 1985). This theoretical understanding appears to be significant for D, as he has been diagnosed with terminal lymphatic cancer. There is part of him that wants to stop taking his ARVs in order to speed up the process of dying. However, he was adamant that he will not do this because of the symbolism attached to keeping him and his partner G alive. In addition to this, G sees the meaning of his adherence has symbolised in 'responsibility' in that he has two children and a partner D so he feels that adherence means:

I'm doing my part I'm bring responsible I think that's it's symbol it's showing me a level of responsibility to one's self to life around you. (G)

Two of the participants discussed fear, in terms of the fear of the consequences for not taking the treatment. For one of the participants, it was the fear of drug resistance from the medication not taken correctly so that it would no longer work. For N it was also the consequences of not taking it; however he described how this constant fear of not taking his medication, plus the constant reminder that he does need to take his medication makes him angry because it reminds him of getting infected in the first place something he feels considerably negative about. Moreover he fears not taking his medication because of the threat of illness and death. For the most part, the understanding of consequence of not taking treatment the HBM describes that individuals who perceive the severity of their condition are more likely to have good adherence. This means that non-adherence is significantly higher in those who do not understand the severity of their condition (DiMatteo et al., 2007). This can be seen in N feelings towards the fear of what could happen if he does not take his treatment:

There's an inherent fear that's almost overpowering in that respect and that pisses me off as well and then I'm like you know do I have to and you sort of and then your mind kicks back in and then you're reminded that yes you do have to and the sensibility comes back that that sort of guides you and makes sure that you actually take them. (N)

Likewise, R felt a sense of antagonism between knowing what the consequences of not taking his medication and the frustration by having to take it. On the one hand, for R he feels:

It shouldn't be a problem it shouldn't be an issue for me to do something that's beneficial to me in the long run it shouldn't feel wrong but it does. (R)

And on the other hand:

If I don't I will die, so it's a hard reality but, it's somewhat antagonistic, it antagonises me and it frustrates me. (R)

Furthermore, R sees remaining adherent as an inconvenience and something which interrupts his routine, hence that is why he dislikes his treatment. And it would appear that this sense of antagonism becomes more pronounced for R when it is time to refill his medicine script each month.

On the whole, the participants understand the severity of the condition and the importance of taking their medication in order to prevent them from progressing and falling ill. In a number of cases, they saw their medication as a symbol of remaining healthy and alive. However, on the other hand for a couple of the participants the fear of having to break routines plus the consequences in terms of illness, drug resistance and death from not taking their medication as well as the constant reminder of their condition the medication represents leads to feelings of antagonism and frustration.

#### **4.4.2. Participants Thoughts about their Medication**

Following on from the meaning that the participants placed on treatment adherence, the researcher explored their thoughts towards their medication itself and how they perceive it. There was a lot of discussion on this topic from all of the participants. For the most part, they felt that their medication was comparable to taking chronic medication for other conditions, is keeping the virus under control and similarly to adherence, that it was keeping them healthy and alive. In contrast, although there was an acknowledgement of this by a couple of the participants, they further saw the medication as a constant reminder that they are living with HIV, and perhaps tapping into an internal stigma towards the virus. According to the literature, this could provide a strong indicator for treatment non-adherence (Johnston-Roberts, & Mann, 2000). Furthermore, one of them also saw the medication as a reminder of perceived transgression of getting infected in the first place. It would seem that both participants constantly had internal conflict when trying to grapple with making sense of their feelings towards to medication. One could hypothesize that perhaps this thinking may be due

to both being recently diagnosed and commencing treatment and part of the process of accepting that they are living with HIV.

First of all, a few of the participants likened their ARVs to other chronic medication, and is something they must take:

It's not going to control my life but it's something I must take like I mean I have got [high] cholesterol, so now over the past few weeks, so I take a cholesterol pill. (F)

In a similar way, this medication is understood as taking medication for other chronic conditions and that taking ARVs has become a normal way of life, or is seen as being as normal as taking a multivitamin.

It becomes a way of life and taking chronic medication whether it's for diabetic or for blood pressure it becomes chronic medication so you just take it. (A)

C agrees with this sentiment, perhaps because he has also been taken other chronic medication for a number of years which provide a perceived quality of life and being able to:

Remain in condition and I apply the same kind of thinking to HIV, so as soon as I started treatment it just sort of just slotted in like because it was like another condition I was treating with medication. (C)

Because of the observed effects of the medication, for example whereby CD4 counts had risen, viral loads had dropped to undetectable levels and symptoms has dissipated and the realisation that the medication was working and assisting in managing the condition, this and an extended life expectancy outweighed any issue with side-effects and in many cases resulting in a positive perception of their medication. Therefore, PLWHs with a lower CD4 count appear to have lower health-related quality of life (Campsmith et al., 2003).

To illustrate this:

It's helping, it's helping so and I know its helping, ARVs are going to take care of the virus, however he was quick to add, despite them being potent medications. (F)

Likewise, because of the medication:

... is keeping me well, this thing had changed my life, I was dying again. I think its taking control of my health keeping the virus under control. (A)

In that the medication is controlling the virus and the participants can focus on other parts of their wellness, for example:

I can focus on the rest. I can focus on staying clean on eating healthy on looking after my body and that will take care of that and that's what's been very positive for me. (C)

For this reason, there was a sense from M and F that they see their medication as a ‘friend’ rather than an ‘enemy’. In essence, the medication is achieving the claimed positive outcomes of them; in that they see the benefits of taking an action such as taking the medication far outweighs the assessed threat or *perceived threat* when considering the HBM (Taylor, et al, 2007).

During the initial stages of starting taking ARVs, H saw the medication as a constant reminder that he is living with HIV. Even though he was trying to avoid or deny the issue, the medication was acting contrary to this by reminding him that he is living with HIV and taking antiretroviral therapy. Although, he has moved on as is not bothered anymore with taking the medication. But N and R seem to have some difficulty with the constant reminder of being HIV-positive in that the medication and its regime produces from an emotional response:

Because it’s doing all the work in terms of your health or your physical health but in terms of your mental and emotional health it’s doing the opposite for me. (N)

Because of the reminder, despite the physical outcomes, in that the medication is doing what it is supposed to do, for him it acts as a:

Constant reminder of how you fucked up and now you paying this instalment forever and it’s I take it very heavily, I take it very heavily. So, that is what I find as a negative aspect of the whole scenario. (N)

For N not only the physical taking of the medication is seen in a negative context, causing a gag reflex but also what the medication symbolises is seen with revulsion and a reminder of failure. In a similar manner, the medication represents something that he did not want for himself:

I’m reminded of what I have, I never asked for it and so that constant reminder it’s an emotional draw back and it’s repetitive it’s every single day of my life. (R)

For him, he holds negativity towards the psychological and physiological effects and giving control to the medication that is keeping him alive because he knows that his treatment is doing well by controlling the virus. He reports that this constant inner conflict as being tiring. When considering the consequences of not taking the medication and the possible alternatives:

I have had thoughts about it but then I have to weigh up the pros and the cons at the end of the day and at the moment the pros are outweighing the cons and the major pros being is that it’s keeping me healthy it’s fighting the virus for me and I don’t have to because the minute I stop, yes, the side-effects will go away and I won’t feel so drained and tired but then my body has to work double as hard in order to fight the virus. (R)

Coupled with this, R makes sense of his medication by seeing it as a battle and that the medication is killing the virus, that he has a sense of control over the virus, that his CD4 is high and viral load is undetectable, in that:

Today another 1000 of the buggers are going to be killed; you know it's just like a victory.  
(R)

#### **4.4.3 Acceptance of the Virus**

This section examines the relationship between their personal acceptance of living with HIV and whether this influences their treatment adherence. A couple of the participants spoke on once they had accepted the fact that there were living with HIV, the next stage was to try and remain as healthy as possible, getting access to health care and treatment. However, two of the participants spoke about projecting onto others that they had come to terms with the virus, when in actual fact they had not.

It really is projecting the whole everything is OK.... for me on an emotional level it's not.  
(R)

R agreed, in that although he has come to terms with living with HIV and that he is going to have it for the rest of his life which perhaps taps into the stigma he felt towards himself for being HIV-positive;

There are moments when I cried because I don't want to be HIV-positive and I don't want to take the medication and that's where I've actually refused to take the medication just because I thought you know what the virus is in me to kill me why don't I just let it. ( R)

However, for one participant the initial feelings about living with HIV dissipated to one of life carrying on, whereby he does not feel the need to think about it each day:

Initially for the first 2 or 3 months I think you woke up every day every morning thinking God I've got HIV God I'm going to die and then you get to a point where you go what the fuck get on with your life take your medication. (M)

Similarly, A found that by forgiving himself was a significant way of accepting and healing:

The biggest thing that changed was forgiveness because when I forgave myself I was able to release the path of healing within when I let myself heal within. (A)

During the initial phase of living with HIV, F had difficulty in accepting that he had to take this medication for the rest of his life and had to, that he had to relinquish his sense of control over to the medication. This was an experience that R also experienced. However, for F he rebelled against it by refusing to take the medication:



I rebelled I said I don't want to take pills all of my life; I don't want to be dependent on these things whatever. So a bit of a rebellion sort of rebellious sort of stage but that didn't last very long. (F)

In other words:

This little pill, you know, it's going to dictate you know things, and I and I and I think I had an issue giving it that power. (F)

By rebellion, he spent weekends at nightclubs and took drugs which meant that he omitted to take his medication during these periods. Correspondently, there appears to be no shortage of literature which attests to the relationship between drugs and alcohol and the non-adherence to antiretroviral therapy (Chesney, 2000; Halkitis et al., 2003; Kekwaletswe et al., 2011).

H found the initial stages of taking his treatment extremely difficult, as he was not only newly diagnosed but immediately needed to start antiretroviral therapy:

In the beginning of the treatment, I did feel like that initially after diagnosis I felt contaminated I felt dirty. (H)

This is perhaps tapping into the internalised Aids stigma that H experienced during the early stages of living with HIV.

On the whole, the participants, despite the initial emotions attached to diagnosis had learned to accept that they were living with HIV and had transitioned to focusing on remaining as healthy as possible, getting access to support and treatment. However, a number of the participants felt that although they were projecting this onto the outside world this was very different to how they were feeling internally. Of interest, is that these participants have been diagnosed in the last year and commenced treatment rapidly afterwards, for this reason perhaps, they are experiencing some of the intense emotional affects people living with HIV may experience (van Dyk, 2010).

#### **4.4.4 Internalised Stigma**

From a broad perspective, HIV/Aids have largely been associated to sex and dying, there is a threat that this is projected onto those living with HIV whereby they are perceived negatively by those around them. There is a risk that this negativity is internalised resulting in the creation of negativity about living with HIV. In terms of internal stigma, those who expressed negativity about their status may be as a result of society's perception towards HIV spoke about and how it may play a role in treatment adherence. That is a PLWH may internalize the negatively held views toward people living with HIV and see themselves as representing the

negative ideas held about HIV. Therefore, they may self-abuse themselves because of this (Kalichman, et al. 2005). An illustration of this includes the following:

The worst stigma the most damaging stigma is the one that comes from within. (A)

In other words, because of the way society understands HIV;

You just took on that stigma yourself dirty, vulnerable and stupid; ‘what did you do, didn’t you listen, why didn’t you listen’. All those things came out because the only messages around HIV was HIV/Aids causes death, ABC? I didn’t listen to rules, so wear a jacket and that kind of thing. Which was very helpful when you discovered that you were positive and there was really nothing about living all about dying you’re going to die, so Ja, I think that you focused on dying and it’s your only thing. (A)

Which again corresponds with some of the feelings towards the medication that:

It was a bit of a bind because it was a little bit of a reminder that there something was not quite right. (M)

Although some of the participants that spoke of how they feel negatively about their status, perhaps as a result of society’s perception towards HIV there appeared to be no correlation between the way they feel toward living with HIV and their treatment adherence.

#### **4.4.5 Disclosure**

Disclosure was another topic that generated a significant amount of discussion, with varying levels of disclosure occurring to different groups of people for diverse and personal reasons. In general terms, it seemed that disclosing to family members was problematic and certainly to older parents, due to them not fully understanding what being HIV positive is. This has the potential problem of parents asking awkward questions about how the participant became infected, which may cause embarrassment. Some felt that there would be no benefit in their parents knowing their status, and in fact it may cause them to unduly worry due to the association of HIV/Aids with death. In addition to family, when it came to disclosing to friends, this too produced varied responses; with some choosing not to disclose to anyone while some participants said they have disclosed to a few select friends. As a result, the reasons given centred on the risk of being shunned, stigmatised and judged by their friends. As well as not wanting to unduly concern them in terms of someone close to them living with an incurable chronic disease. The literature describes how those who have disclosed may experience the loss of those close to them particularly friends and family rejecting them. In extreme cases they have faced threats to their personal well-being and isolation (Hardon, et al. 2007; Parsons et al., 2004).

However, those who have disclosed to a wide range of people, including their families showed higher rates of HIV treatment adherence. Those that had not disclosed showed lower rates of adherence due to having to hide their medication (Stirrat et al., 2006).

Also of interest, one participant mentioned that although he disclosed to only a few people it did not affect adherence. However, in social settings the taking of treatment at the correct time became problematic because they were hiding the fact that they were taking ART. R mentioned that he had lost friends because he felt that he could not be open about his status and because he refused social invitations because of his need to take medication at a certain time in the evening, usually at a time when he would be attending a social setting. In order to avoid this, he refused social invitations

### *Family*

Without a doubt, disclosing to friends and family is a complex matter. Despite the unresolved conflict as to whether they should disclose or not, who to disclose to and when the literature reports that those who have disclosed their status to friends and family report having a greater level of support. This may act as a buffer when experiencing emotional distress (Kalichmann et al., 2003) such as finding out that one is living with HIV. However, as discussed above, it is a complex matter and in a number of participants this has been avoided because:

They immediately jump to the conclusion you have AIDS you're going to die. (H)

Furthermore, often the way they have heard family members talk about HIV puts the participants off disclosing to them.

I just think if you've listened we've listened to our relatives talking different times about issues about being HIV-positive, jokes people are making the way people are actually feeling about it. Things they expect from HIV [infected] people and I actually don't want things to change between me and relatives relationship-wise. (H)

M puts it in another way:

You have that burden of wanting to tell them but there's not really the need because they really don't have the tools to handle it, and we don't have the tools to give them the tools to handle it.

Certainly, F describes how he disclosed to his family a number of years ago and the uncle he was close to has since shunned him for many years.

When it comes to disclosing to parents, very often the thought of having to explain the details about the HIV and sparing them the worry of a 'death sentence' are the strong reasons for

keeping it hidden. In addition to this, often parents find it difficult in coming to terms with the sexuality of their child which was perceived to mean that they would have some difficulty accepting them living with HIV and on ART.

N echoes this perception by suggesting that it is not a fear of being disowned or shunned but rather because his mother is conservative she has been exposed to a very specific message when it comes to HIV that may lead her to:

She would now question how did it happen, what happened and when did it happen and why did it happen and have I failed as a parent. (N)

### ***Friends***

Following on from disclosing to family, this section examines in terms of friends the issue of disclosure and its possible effects on adherence. Very often because of the associated stigma or judgements attached to the HIV label prevents disclosure because of:

Fear of losing your friends may be it's a fear of being judged maybe it's a fear of me I have serious issues about people making judgements about gay people. (M)

Likewise, for R he had the same fears:

Quite frankly because I don't want to be looked down upon and shunned because automatically they're going to have this stigmatised image in their mind that I'm a I'm a slut and I sleep around where that's far from it and I don't want that and I don't want to risk it. (R)

And because of there being too much ignorance and stigma, they said they would rather keep it hidden and masked which makes it challenging to take their treatment in a social setting, as discussed.

For 'N' he would rather not deal with his friend's reactions when it comes to his diagnosis:

You don't need to have that upset and aggravation so I avoid the issue. (N)

In any case, when it comes from having support from friends, N felt that because he is the 'go-to-guy' of his friendship group he would not be able to rely on them for support because he thought his friends would have difficulty in him asking for assistance.

As discussed, he mentioned that there is a certain sense of paranoia attached to keeping it hidden, especially when taking his medication in a social setting, which means that he is often left wondering whether everyone knows, if not when 'the bomb's going to explode. He further explains his treatment required planning to hide it from others.

Oh crap, it's 8 and here's everybody and you know I'm not and it's not at my house it's there's always something to sort of make it a little bit more awkward than normal. (N)

In order to further hide his status from his friends, N is holding onto the perceptions that people hold that people living with HIV are sickly and dying. N is transitioning from a stage whereby he became ultra-concerned about living a healthy lifestyle to drinking alcohol, smoking and eating fast food to disguise himself:

It sort helped me rationalise for myself saying well now that I'm drinking socially again and partying and eating burgers and KFC knows who I am again people can't assume and that is something that again I am relying on old stigmas where people assume anyone with HIV whether you are on an undetectable level or at Death's door with Aids, fullblown-Aids assume you with this skeletal person who looks anorexic and has rings under their eyes and really looks bad. So I'm trying so sort of look at me I'm round on every angle so it can't be me even that is sort of a disguise. (N)

He tries to make sense of this by suggesting that as a 'grown person' he should be able to tell the world and if they do not "like it, get lost". However, he feels that society is already only now starting to accept homosexuality, but by being gay and HIV-positive may be too much for many people to endure, in that:

Now you're pushing your luck how much more do you want you know how much sympathy can you demand from us and I just don't see it working. (N)

By the same token, M agrees in that he sees that there is a hypocrisy attached to the association between homosexuality and HIV in that:

"I don't want to turn around to people and say Ok and we're HIV-positive 'well you know all gays get HIV', you know it's that kind of association that kind of fucks me off because I think infections amongst the heterosexual population are far out numbering the ones and I think that gay people are more aware of HIV than heterosexual people. There are guys that get pissed on a Saturday night pick a chick up have got no fucking clue you know and the girl's got no clue." (M)

This position leaves them with what they see as no other choice but to hide their medication and hide their status in general from the outside world.

On the contrary for C, he has found being open about his status has led to some positive experiences:

Most people I've told I've been quite open about it have been very OK about it. (C)

He has been able to use his openness about his status to speak to others who have been positive for a number of years, to share experiences in terms of his treatment and learn from them. He sees this as an opportunity to help others to gain an understanding about HIV, in

terms of breaking the silence around the condition and disclosing that he is living he is living with HIV. In that, by living a healthy lifestyle and speaking openly about it he says he hopes he will then be able to inspire others to do the same. In terms of his family, he described how his family have been positive. His mother and stepfather were described as being very conservative and although they ask how he is managing and responding to his treatment, how he is coping with the side-effects but they seldom talk about his HIV status. Furthermore, C appreciates their concern and effort it is for them to talk about it. He also sees it as his responsibility to maintain a healthy life for his family.

For D, he describes himself as provocative when it comes to his status and treatment. Consequently, he is comfortable enough to raise the subject with strangers when he feels the need and because he is an actor, he incorporates this in to his shows, for example:

I tell them from the stage, you know of course I'm HIV-positive, in fact I've just forgotten to take my pills a little fake number like that you know. (D)

Despite this, he shared that it was challenging telling his father that he was HIV-positive.

For him (D), he described how it is essential to live as transparent as open as possible, and with his HIV status and ARV treatment he feels is no different.

### ***Partners***

The literature argues a strongly that having strong interpersonal relationships plays a significant role in treatment adherence and this section examines whether the participants share the same experiences. There appears to be many examples of those who have disclosed to family, partners and friends having a strong support network which plays a role in positive adherence. In a similar way, living with someone who is actively involved in treatment decision making and the use of partners as reminders is shown to have a positive influence on treatment adherence (Mills et al., 2006). For the most part, partners may remind them to take their medication. However, on the flip side of this thinking, being in a relationship *per se* does not necessarily mean that a PLWH will have better treatment adherence (Halkitis et al., 2003).

When it came to partners, having positive interpersonal relationships F felt that:

I've always been open right from the word go my *modus operandi* was to tell within two weeks if I've met somebody.... (F)

For the most part, the other participants are in relationships, besides C and N, with either their partner also living with HIV and taking ART, or if not being fully aware of their partner living with the virus and assisting with treatment adherence as a support or reminder.

From a partner perspective, G described how his partner D was open and upfront about the ART, in that they use each other as reminders and to motivate each other, which was discussed with their public health medical provider when exploring adherence:

We could go in and let them know that we were monitoring each other that we were boosting each other if one had forgotten the time in terms of adherence. (G)

In this sense, that they were using each other as ‘a treatment buddy’. However, N said he is not in a relationship and felt that when considering this idea that:

I don’t and possibly from my side I won’t allow myself to rely on someone like a sponsor. (N)

When it comes to both partners living with HIV and both taking treatment, although they may act as ‘buddies’ for each other, often knowing that each one is having similar experiences gives each other support. To put in another way:

H going on shortly after me we were sort of going down the same road together kind of holding hands you know so that was very, that was sort of stress off my mind because I knew somebody close to me was going through the same thing. (M)

Although, for R the challenge in terms of his partner, as he is not HIV-positive, centred on having to educate him on what it means to be living with HIV. On the other hand, his partner finding the balance in terms of the level of care R needs, and for him to understand living with HIV from R’s perspective:

I’ve tried to explain it to my partner as well where he doesn’t understand that I have to take my medication at 9 I can’t take it at 11. (R)

Furthermore, explaining to him the consequences of not taking the medication correctly and why R is having the side-effects he is experiencing.

“I don’t want sympathy for my condition I don’t want sympathy for the way I feel as a result for me looking after myself because that’s the same as me saying if he feels full after eating ‘oh are you ok, are you OK’ that kind of thing and it’s somewhat patronising I guess to me or at times so it’s difficult for him to really come to terms with the fact that he will never really be able to see it from my perspective he may be able to understand but never see it from my perspective, so it does it makes it tough.” (R)

In other words, his feelings towards his partner when R feels he has become too concerned:

Stop being so bloody sympathetic’, like I’m not dying, like I’m not sick I’m just, it’s a side-effect it happens to me. (R)

Although on the flip side:

It doesn't mean you have to be malicious about it, because he tried the opposite has well and then I lashed out. (R)

For R, it is finding the balance between having genuine concern and being overbearing:

It's just about knowing what they can do, knowing what I can do, also for them to know what they can do if I'm unable to do it myself. Without having to be all sympathetic and talking down to me like I'm a child. (R)

A described how his family and partner check-up to make sure he has taken his treatment when he is away from home on business and out of his routine when adherence may be problematic and he is using no other form of support.

When it comes to partners, the literature seems to suggest that although being in a relationship *per se* does not result in better adherence, having a partner that is involved in treatment issues is strongly seen as positively influencing adherence. The participants who are in relationships tend to agree in that they remind each other when to take their medication and can provide each other support. If both partners are living with HIV, then their similar experiences can be shared. Although, if a partner is not living with HIV they can still be used as a reminder there may be challenges in terms of their level of knowledge and understanding of the condition which may lead to conflict and the need for on-going psycho-education. All in all, it seems that being transparent and open about their status from the beginning of the relationship is vital in terms of a positive interpersonal relationship. However, a couple of the participants spoke about having psychosocial support interventions made available for family and partners of those living with HIV and taking ARVs, perhaps consisting of a psycho-education element.

#### **4.4.6 Mental Health Factors**

Some of the topics discussed include areas of acceptance that the treatment is taking control of their lives and the feelings of being contaminated. While some participants reflected on their experiences of depression, and how some of the side-effects had in some way exacerbated this, certainly when factoring in fatigue and energy levels; others described how they had experienced a reduced will to live before going onto treatment which improved after starting treatment. While some of the participants said that in order to avoid having to deal with the emotional aspects of living with HIV, they focussed on their work and had not sought psychological support. Lastly, by learning to understand their HIV status as part of their psychological growth in that they had to make alterations to their world-view.



### *Depression and Anxiety*

When it came to depression, it is of significance is that the symptoms of depression have been shown to increase the progression of HIV into the Aids stage (Gore-Felton & Koopman, 2008; Komiti et al., 2003). Furthermore, research has recently indicated that there is a strong link between depression and poor treatment adherence (Gonzales et al., 2011).

A described that he had a history of living with depression and after starting treatment he sank further into depression. Depression plays a significant role in HIV and adherence of antiretroviral medication. For people living with HIV and who are taking antiretroviral therapy, the side-effects of the medication itself may result in depressive symptoms which may make the taking of the treatment more difficult. For A, his experience of depression meant that:

I remember very clearly the more I tried that the less I'd go in fact the deeper I sunk until I admitted I am so depressed I don't want to live anymore and went for help and that's when I got out of it almost immediately it was gone. (A)

For A it was the realisation that the medication was taking was somehow influencing his depression. And he explained that his experiences after initiating his treatment was different, his feelings were 'erratic' whereby he experienced moments where he was fine, and the next he would struggle. In the same way, R had also experienced depressive symptoms as a side-effect of his treatment. He said:

Because I don't want to take antidepressants at all so I do take an anti-anxiety pill which I have been on for the last 3 weeks just to counter-act the feeling of anxiety and anxiousness. (R)

For D, he found that after dealing with his partner's severe long terms illnesses due to Aids-related conditions, that in some way he had neglected himself and that this had manifested in:

Suddenly I lost my will to live, I just like, there was not purpose my job was done you know and there was this depletion of energy and I thought it was really strange. (D)

For D, this was a trigger for him to consult a doctor, have his CD4 and viral load tests. This was carried out in order to find out his CD4 load. He found out that he urgently needed to start antiretroviral therapy and this resulted in a turnaround in what was described above.

For N because of his history of depression, self-esteem and anger issues which were present before he was diagnosed, was compounded when he was diagnosed and further been intensified by his treatment and the reminder that it signifies to him:

I've had issues, problems or self-esteem or anger issues with myself hate the world first but not for this particular issue that I feel I really need the couch and have someone right there you know I feel that need and perhaps once you feel that need and once you have a desire you want to go and do that possibly you do actually need it.

### **Faking everything is OK**

Following on from discussing depression and anxiety for N and C there is a sense of projecting to the world that everything is fine, when in actual fact, this may not be the case.

In particular, this was picked up by N:

I can fake my way through it you know in terms of outward projection and how I appear socially but on my own I'm very negative very sad and miserable and depressed and have been. And it's and it's constant and I brood over it for hours on end sometimes. (N)

By the same token, C uses a Narcotics Anonymous saying, "Fake it until you make it", in order to describe how he feels, whereby a part of him feels strong and able deal with people's negativity and that he is open to talk about his experiences. However, when others reach out to him he feels:

Because they see I'm doing well but I know that I'm not and I point them in the right way but I'd love to help but I'm not in the space where I can give them everything they need at the current time. (C)

### ***Focus on work to avoid***

In order to manage the psychological aspects of living with HIV or antiretroviral treatment when avoidant coping strategies are used this seems to correlate in adherence to treatment being problematic (Halkitis et al., 2003). Interestingly, none of the participants had sought therapy, with only a couple of the participants receiving one or two counselling sessions when initially diagnosed, and perhaps being offered adherence counselling when initiating treatment, with R best encapsulating the sentiment when it comes to this issue:

I just keep it, I throw myself into my work that's the only way to keep my mind occupied the only way that I know how I guess but it's maybe not very constructive it's maybe constructive from a professional point of view but on an emotional level sometimes I don't deal with it. I'm not a fan of voicing my emotions to other people. I haven't seen a therapist or a psychiatrist or psychologist since two weeks after I was diagnosed when I went into hospital for 2 weeks and I said that's enough now I have to face it on my own but since then I haven't I have seen anyone. I will deal with it by myself. (R)

The participants use the support group in order to have their psychological needs met. There was no further discussion on whether this strategy affected treatment adherence as the literature suggests (DiMatteo, 2004).

### ***Psychological growth***

When one considers personal growth in terms of research on resilience in that those people living with HIV/Aids present greater resilience or hardiness to living with HIV. The PLWHs in this study showed lower psychological distress, greater quality of life and greater personal beliefs. Hence, this outcome is significant as psychological distress is associated with risky behavior and treatment adherence practices (Farber et al., 2000). So, for the participants who display resilience when it comes to living with HIV and taking antiretroviral therapy have reduced their distress and can become a useful catalyst for personal growth in that in turn has led to the reflection that:

Psychologically, for me it's been a growth, having to deal with HIV and then particularly ARVs and adherence has been very much an impact to me mentally. I've had to learn to be far more transparent. (G)

In terms of depression and anxiety, the literature seems to indicate a strong correlation with its link with non-adherence (Gonzales et al., 2011). Those that spoke of their experiences of depression whether it is as a result of a side-effect of the medication or a pre-existing condition which was exacerbated by diagnosis or commencing ARVs did not indicate that it negatively affected taking the medication. Once again, the belief that the medication is keeping them healthy, improving quality of life and allowing them to focus on day-to-day living seems to dominate over the psychological effects of the condition or the medication in terms of adherence.

#### **4.4.7 Participants' Experiences of Adherence Counselling**

The literature suggests that poor or infrequent counselling can result in negatively influencing HIV treatment adherence. This is especially the case when discussing the management of side-effects (Hardon et al., 2007). Adherence counselling also aims to work through what the treatment means to the PLWH in terms of the possibility that it serves as a reminder of HIV infection thus tapping into internalized Aids stigma (Chippindale & French, 2001).

This section examines the participant's experiences of support that they have received from various places and whether this has influenced their treatment adherence.

N described how he felt that he received very little support when he was first diagnosed and had to start taking antiretroviral therapy. He explained:

Initially I had sort of zero support you know, I had to boldly go on and pretend like everything was ok and I sort of couldn't take time off work and sort of crawl in a hole and wallow in misery. (N)

He further explained that he experienced very little support after carrying out extensive personal research after he was diagnosed, in other words:

There is no support out there. Not just, you know, for being diagnosed but for the whole scenario. For how taking medication may be or how your dating life will change nothing I found nothing. (N)

Even though R feels that he has the support of his family and the support group he attends to push him 'you know, you can't do that', in order to keep him motivated and fight the virus. He feels somewhat isolated because he does not feel he can ask the questions he has about his virus and treatment.

Like why my CD4 count rose because of my ARV treatment, what's it doing why it is dropping my viral load, why is it able to do that? And I don't, I just feel somewhat isolated in the sense like I don't want to feel like the only one who does it. (R)

The participants seemed to have limited exposure to counselling when initially diagnosed or further counselling when they commenced antiretroviral therapy there seems to be no link between the lack of counselling and treatment adherence in this case. However, despite this they appear to gain support through other means such as support group, Positively Alive, which will be discussed in the next section.

#### **4.4.8 Support Groups**

The literature concurs on the role that social support plays in strengthening mental and physical health which is vitally important when it comes to MSM living with HIV (Petersen & Govender, 2010). When it comes to a support group setting, being given the opportunity to share emotional issues make support groups valuable to its members (Petersen & Govender, 2010). There has been a marked increase in groups available for a large magnitude of illnesses with illness becoming an 'increasingly public experience', including support groups and social media websites (Conrad & Barker, 2010). The literature suggests that receiving adequate support, whether it is informational or in terms of a strong social network plays a substantial role in the psychological well-being of MSM living with HIV (Hall, 1999), and along with social support, having motivation positively influencing treatment adherence (Fisher & Fisher, 2006).

The participants spoke a great deal about what the support group means to them in terms of living with HIV and their ARVs. The following themes appeared to emerge from their discussions that the participants value sharing their stories with others and their experiences of taking their medication in a social context, that they have made friends with members of

the group in that they can ask questions and share each other's experiences such as experiences of side-effects, that they use the group for support, group counselling in order to cope. In other words, so that they can relax PLWHs who are going through similar experiences to their own in a supportive and non-judgemental environment. Lastly, for those that have been attending the group for an extended period the altruistic need to give back to others is something that they value from attending the sessions. Perhaps linking to one of the motivators for help seeking behaviours amongst men, being able to reciprocate the assistance already derived (Mansfield et al., 2003).

### *Sharing*

When it comes to sharing with others, D sees the group as an opportunity to share experiences of taking antiretroviral therapy in that:

...Comparing responses to different ARVs. You know within the group we've got people on different drugs, people on the one a day drug and things like that so those are very interesting and that keeping a transparency flow within our own minds you know, I suppose but you know passing it on to other people. (D)

For N he understands his experience with the group in that, although, he has experienced the awkwardness of seeing people he knows attend the group sessions, he feels relief that he is not alone:

Just it alleviates the pressure I sort of put on myself. (N)

Furthermore, N values the opportunity to be able to proudly take his medication in public with others as opposed to hiding it from those around him in his regular life:

It's really nice at 8 o'clock everybody's phones just about start and that's that you know that's the only time I can laugh at it and put my pills right there with my little glass and very proudly take them and we would talk about who takes what and so on. But when I'm not there it's the exact opposite then it's a very extreme discrete high shame scenario. (N)

This is something that R agrees with having the safe space and camaraderie to take the medication publically, however, for him the issue of his difficulties with side-effects has made it difficult for him to hear that others have not experienced the same, thus making him feel even more isolated:

It's just and you hear other people and it's like they feel nothing, they don't even have dreams 'well F -you' you know 'why me' why does it do it to me and not you.

### ***Friendship***

Many of the participants described how the group had enabled them to make friends often socialising with them outside of the group. For a few of the participants having made ‘gay’ friends beyond their regular social circle, for example:

We have developed a close bond of friendships you know, with couples with PLWHs, which we; it’s new in our gay experience. (D)

### ***Questions and Learning from Others***

For many of the participants, the group gives them the opportunity to ask questions and learn from other people’s experiences, for example:

Well, you hear what other people are experiencing, I can go to a meeting and almost not say a word and still get something out of it there’s always someone asking something that I can learn from. (H)

In addition, N feels that:

I’ve learned there are so many different therapies different medications and people will respond into them differently. (N)

M agreed by suggesting that he learns about how people are coping with their treatment and how they manage day-to-day and about new developments and new treatments by engaging with others in the group.

However, contrary to this R feels that the group can become too “morbid” for him and that he has difficulty listening to other people’s sad stories because:

Then it’s a constant reminder or my own in terms of taking the medication, how the medication feels, the condition itself, the results of the condition and the stigma and the stigma that’s been put around it is what where faced with and sometimes I don’t want to be reminded of that, I get reminded of that enough I don’t need it anymore. (R)

He would prefer his experience to be more social and uplifting which he hope the social event, the first that he would be attending the evening of his interview to be and not a ‘koek en tee’ event.

### ***Relaxing with Similar People***

In terms of therapeutic value, the group was seen as a space to relax with similar people where participants could be themselves in a non-judgemental environment where they can take their medication freely without being stigmatised. Although N felt that he can never really be his true self in a group, he was grateful for the space.

In addition to this, M explained that his counselling and support needs are fulfilled by attending the group sessions in that:

I think we get our counselling in the group you know were picking up on what people are doing and how they're feeling and how and we're kind of mirroring some of those feelings ourselves in how we feel so I think we're getting our counselling pretty much there. (M)

For those who had been attending the group meetings for a number of years, the space provided them a chance to give back to others, for example:

You find yourself really trying to support, you know convince the guy gently that you know everything is going to be OK you know. If an old fart like me can be OK, you are going to be fine right and you'll know the right time and you know your doctors as long as you've got a good doctor and all that sort of stuff. (D)

### ***Improvements to the Support Group and Adherence***

The participants value the support group because it gives them the opportunity to discuss openly and in a non-judgemental environment issues such as sexual health. They saw the value of its expansion further into other areas, perhaps becoming a social group whereby people can get to know each other and share knowledge and experiences in a social manner whilst retaining the 'discussion' group structure. M saw the importance of having cells or networks so that people can be referred depending on their needs be they medical, psychiatric or insurance related, or whether an individual wishes to do outreach work were some of the examples he provided. Further expanding this to include a social aspect in that:

Activities, hiking other than gay related activities bar hopping going out that's there for obviously most guys start on medication HIV positive and want to live a healthier lifestyle, if you can channel that together and like have some get togethers. (C)

He further described how the focus could be on wellness which can give the opportunity to get people together socially in a less threatening context.

In addition, many of the participants saw the importance of coming together to share their experiences and learn for each other in some form of discussion groups created in a non-threatening manner:

Create a forum where you can understand and create that platform where a lot of people can come together and just not share morbid experiences but just to be able to voice your opinion on why you're in that climate and just to be able to see things from others people's perspectives and how they're dealing with it. (R)

C agreed in that very often he has questions that he feels are not answered by the internet or his medical provider and that although he has a basic knowledge about antiretroviral therapy

he would like to know more so that he can feel confident in explaining it to others. Certainly having a forum to discuss latest developments and treatments would be beneficial to them.

New developments, for instance it would be nice to know what's happening because sometimes you don't always you get the information that you're looking for. (R)

He further elaborated that:

I don't know what I'm doing wrong or what I need to do right like to fight the fatigue. Maybe someone's doing something to fight the fatigue or and to fight the stress and not being able to focus. If they're able to do something that's working for them then I may be able to gain some insight of that. (R)

For the participants who had been living with HIV and on treatment for a number of years, felt that they would like to share their experiences with others in this space. Although the use of support groups is invaluable in being able to share emotional and practical experiences, it remains unclear whether this had an impact on treatment adherence within the participants of this research. However, they used the space to be able to share their experiences of the side-effects; used the group for support and group counselling in order to cope. In other words, that they can relax with PLWHs going through similar experiences to their own in a supportive and non-judgemental environment, and lastly, for those that have been attending the group for an extended period the opportunity to exercise their altruistic need to give back to others is something that they value from attending the sessions.

#### **4.5 SOCIAL AND STRUCTURAL BARRIERS TO TREATMENT ADHERENCE**

This section examines the social and structural enablers and the barriers to antiretroviral therapy by exploring the participants' experiences and feelings towards the medical facilities and health providers as well as their experiences of discrimination, public information and support. Incidentally, some of the participants are members of medical schemes, whilst other use the public health service with the majority of those using Health4Men for their medicine supply and support.

##### **4.5.1 Medical Facilities**

The section aims to explore the participants' experiences of the medical facilities they use and whether their experiences played any role in their treatment adherence. D and G shared their experiences of using the public health system, although they now use Health4men. H, M and C use the Health4Men programme based at the Baragwanath Hospital. Health4men is a non-governmental organisation (NGO) providing many services aimed at men including medical screening, access to antiretroviral therapy and adherence counselling. A new clinic



has recently opened in Yeoville. According to SCT, the behaviour of PLWH and the barriers to healthy living are determined by the health system rather than just limitations in terms of their personal situation. When it comes to MSM's, an example of this could be exposure to stigma and discrimination in the health care system due to their status or sexual behaviour. This could be understood as a barrier to healthy living because they may not feel able to participate in the system due to fear, which would then curtail the possibility of accessing treatment. Simply put, this means that the unavailability of access to health resources is due to social or economic reasons which act as a barrier to individual healthy behaviour (Bandura, 1998). The literature informs that the stigma that MSM face, homophobia and the fear of health providers has been understood as a still prevalent barrier to accessing health care and HIV services (Lane et al., 2008).

For the most part, it would seem that the participant's value having organisations such as Health4men, aimed at men and used by men who have sex with men as many receive their medication and gain support through the organisation. Certainly, C who had been referred by a friend reported that "it was great". Likewise, G felt the same way:

There was a lot of experience to be gained from that because likewise they still gave us the counselling, adherence is huge they answered questions and that was good, that I will sing the praises of Health4men. (G)

However, there were a few of the participants who had experienced some negativity around this, centring on the time required to wait for medication, that an PLWH sees a different professional each time and in most cases, not a medical practitioner which caused concern over the level of care they receive and concerns around the cleanliness and level of confidentiality that the facilities provide.

I felt like I shouldn't be sitting there waiting for three hours for my medication this wasn't my choice I didn't want this and now I have to sit in this place and wait and wait and everybody's taking their time. (H)

For H this also tapped into his feelings that he felt that did not deserve to get infected, he did not feel responsible for what happened to him and in some way having to endure the wait he saw as some form of further punishment. All of which is not perhaps helped by the process that is followed which one to the participants described as 'humiliating' whereby their sense of confidentiality, dignity and safety is being compromised:

Walk past like 200 people sitting in chairs you walk in front of them all the way to the end of the room you then produce your urine sample and then walk back past the 200 people taking your urine sample to pour it back down the toilet you know the kind of what's the word the

that kind of medical confidentiality, kind of environment is completely broken. It's like you know you kind of feel like you're standing in a queue for potatoes, it's not a nice feeling. (M)

To further elaborate on this, M described how the plumbing was not working; hence his urine sample had to be disposed of in a basin. Furthermore, because of the structure of the clinic and the process that needs to be followed he had concerns that it would be labelled the 'Aids clinic', which tapped into his feelings towards disclosure.

Furthermore, there was not a sense of safety so that the participants felt that they could ask questions around their condition, or broader health issues and certainly issues specifically to MSM:

They're not always that geared up to give you more information I would like to discuss problems with them. (M)

When it came to the experiences the participants had had in terms of counselling, M reported that he and his partner had one session of counselling when they were diagnosed. However, they felt that counsellor was very young and they understandably questioned him whether he had formal training because of the manner in which it was carried out. For C, the counselling centred on treatment adherence at the start of treatment and there was the scope to discuss certain issues with the counsellor. On-going psychological support was provided out of the Health4men location in Cape Town, however not at the Johannesburg sites. For R, although he does not use Health4men, his experience of HIV counselling was in a hospital setting and resulted in the psychiatrist focussing the session on his experiences of post-exposure prophylaxis and did not deal adequately with R's needs at the time.

From their experiences of the public health system, there were a number of areas which relate to treatment adherence which both D and G experienced, largely around a 'one size fits all' approach and not being tailored for their level of understanding when it came to HIV/Aids. Certainly, the literature suggests that when it comes to the specific needs for the MSM community, the current practice within the health care system is to provide a 'one-size-fits-all' approach rather than being mindful of diversity or difference. However, it has been argued that this approach is inappropriate when working with diverse populations (Nel, 2009). Consequently, programmes, such as Health4Men, is aimed at men living with HIV and mostly MSM attempt to provide services to a diverse population. When considering the public health system, D's experience of the counselling was experienced as "basic", he elaborated:

The process of counselling and whatever and the counselling was minimalistic as far as I was concerned it's not terribly humane. No, but they deal with you rather like a school teacher to student, it's that sort of thing. Very patronising. (D)

During the initial stages of commencing antiretroviral therapy as part of the public health system they had to undergo a strict 'training' on adherence plus a pill count:

Military-style training that I had to adhere to a strict time schedule of ARVs it was drummed in and drummed in and I thought well personally because I'm fortunate to have a level of intelligence and a level of self-discipline and education I felt they really treated me like an idiot. (G)

Despite this, he did acknowledge it was good training. In terms of the pill counting:

...and take whatever was left of your pills they'd count what was left just to prove that you were taking them and after I'd done that about 3 times I said I object to this very strongly, you are undermining my personal you know self-discipline. (D)

At this stage, he argued that he was very aware that the medication was keeping him alive and that was why he was taking them, in other words he understood how:

"...imperative it is to adhere you know so we were being slighted I think we felt 'G' was being slighted on that level and being treated rather inhumanely." (D)

In addition to this, D experienced extremely unpleasant side-effects during the first regime of ARVs, which made taking the treatment challenging. However, when he raised this at the clinic, he was met with opposition to change treatment, perhaps due to the limited scope for flexibility in the treatment algorithms in the public sector:

I went to the clinic I said "You've got to change the regimen" "No, we don't do that" I said "I know you can. My partner had it done" "OK, after 6 weeks." I said "I'm not prepared to go on for 6 weeks. I want to go to the next stage now." "OK". So it was a lot of I had to do this heavy man stuff didn't I? (D)

Certainly, one of the participants described how travelling to the clinic may be problematic and somewhat inconvenient. Since the doctor attends the Health4men clinic on Mondays only, and because he must go regularly for check-ups because of the risk of interaction of his ARVs and his other chronic medications, C in most cases had to take a day's leave from work, requiring sick note, raising questions with his employer. In addition, because he does not own a car had to rely on his scooter or taxis to get to the clinic in Soweto all of which causes him certain amount of anxiety.

On the whole, the participants did not report experiences of discrimination or stigma from the health facilities and clinics that they had attended on the basis of their status or sexual orientation. However, there was some discomfort experienced in terms of the process that had

to be followed in terms of queuing to see the nurse and receive medication, level of counselling, the 'one size fits all approach' and concerns around plumbing and cleanliness. Furthermore, there were concerns on the new Health4men clinic in Yeoville being overtly labelled the 'Aids clinic' which may be problematic as HIV/Aids remain a largely stigmatised condition. Although it seems that this in itself did not deter the participants from collecting their medication. As MSMs regularly access health services from government facilities, there is a strong and continuous need to make these facilities more user-friendly and accessible for this population (Sheehy, 2011).

#### **4.5.2 Health Service Providers**

This section follows on from the participant's experiences of medical facilities and explores their experiences of health service providers and whether that relationship plays a role in the participant's treatment adherence. The literature describes how the relationship between the individual and the medical provider should be, for the most part, is based on support, empathy, trust, communication and the provider demonstrating knowledge of the individual and their situation (Forrest et al., 2002).

By and large, this is described as having competence in terms of HIV clinical knowledge; being comprehensive and holistic when it comes to patient care; being consistent with care; having consistency in seeing the same provider at each visit and being compassionate when it comes to their life stage, culture and background. All of which have been shown to indicate optimal care (Lewis, Colbert, Erling & Meyers 2006). The literature concurs that in situations where a patient has a high level of trust in their medical provider there tends to be a higher level of treatment adherence. This is because they were able to deal with any side-effects, and managed to stay longer on their medication (Altice et al., 2001; Mills et al., 2006). Certainly, to have this kind of relationship, the social issues that affect marginalized groups such as MSM should be understood and engaged with by medical providers (Sixma et al., 1998).

When it came to health providers, various issues were discussed such as not seeing the need to see a HIV specialist and being comfortable with consulting a general practitioner. Issues around the cost of paying specialists fees made it unnecessary. As F had never reached the Aids stage, nor had he been sick, he did not see the need to consult a specialist. Further discussions included becoming an informed patient, in that he was able to pass on his knowledge to his medical service provider about HIV treatment, H and M felt that they can offer their provider information on support groups available or the latest HIV developments.

With more and more people becoming knowledgeable about their health conditions, the literature describes how ‘lay people’ those who are not health professionals who have access to resources are more increasingly playing an active role in controlling their condition and their treatment (Conrad & Barker, 2010). In that:

You would think with something as big as HIV in this country that GPs or most doctors would be clued up but they’re not. Only the basics, Yes, OK, they should have a multivitamin daily and extra Selenium or whatever. (H)

However, in contrast, N often finds that when he consults with his GP he often forgets to ask certain questions about his medication and the conditions in which the medication can be taken, for example:

I’m still with that same GP. She’s actually really nice. It’s maybe more me that has the problem then. But I didn’t think to ask and every time I’d go for my 6-month check-up I’d forget again to ask because I’d sit there and yes everything is lovely and everything is perfect and just sign so I can go you know I didn’t think to ask you know what if I take my pills with a glass of wine. (N)

Despite some of the inconvenience that C experiences in terms of getting to the Health4men facilities, and that he may see a different medical service provider each time. Generally, his experience of the medical providers is:

I must say once I finish being there, I always feel really good because they really take time. I know sometimes it’s a long time to wait but they always over-explain. They’d be, like sorry, the same care given to you is given to everyone else, yes I know that but I didn’t mind. (C)

This is because:

...they spend a lot of time answering every question and make sure you’re OK. ( C)

For R, he is also happy with his general practitioner and if she does not have an answer to one of his questions, she will research and come back to him, for example, when he was suffering from the side-effects from the medication. His frustrations often stem from contradictions in terms of research when it came to treatment, especially when it came to recent investigations into muscle wasting as a result of his ARVs:

My doctor telling me one thing meanwhile there are countless of other doctors who are saying the opposite thing. So even from a medical perspective and scientific perspective there can be a conflict of ideas. So that just blew my mind, so I am so confused. (R)

Although not specific to the medical service provider and perhaps not necessarily relating to treatment adherence, but it is worth noting at this stage that M described how he faces challenges when understanding pathology results, especially from various pathology

laboratories as they appear inconsistent and use terminology aimed at medical professionals. This correlates with the informal discussions the researcher has had with various people outside of this research who face the same challenges.

On the whole, most of the participants consulted with GPs and seem to have a positive and trusting relationship with their providers. The fact that the participants reported that they visit their medical providers regularly, on their treatment programmes seems to contradict the earlier literature which suggests that men are less likely to engage in health-seeking behaviour (Galdas et al., 2005) and were less likely to adhere to medication regimes (Rose et al., 2000). All of which was more pronounced in sexual minority groups than heterosexual men (Dean et al., 2000).

The participants saw that being an ‘informed patient’ means that they often have to give advice to their GPs on support programmes available to PLWH or latest HIV developments. Furthermore, when they have very specific or technical questions their medical service provider may not have the competency to respond which meant they have to research before providing feedback. For example, R experienced confusing and often conflicting information. A further challenge from one of the participants was forgetting to ask certain questions when in consultation which may indicate a need to explore the use of written reminders.

### **4.5.3 Challenges with Medical Aid**

N, R, F and A are members of a medical aid and this section examines any challenges faced by the participants in terms of treatment adherence as a result of their medical aid. Although this appears to be an area that is under-researched, it is suggested that based on courier pharmacy claims, antiretroviral therapy adherence rates in a managed care and private medical aid setting range from between 50 and 70% (Nachega, Hislop et al., 2006). However, it is unclear how the medical aids themselves are the cause of challenges of PLWH adherence amongst those that have poor adherence rates. In terms of challenges with medical aids, for N this centred on antiretroviral therapy being paid out of his savings account and not from their chronic medication benefit and because of this the payment of the account was rejected. As a result of this N had to pay for two weeks supply of medication himself until the situation was resolved. But if he did not have the money this delay would have affected his adherence.

A further challenge for N came about because the medical aid he is a member of is a company sponsored scheme and he is an employee of the company and he was fearful of colleagues finding out and the confidentiality of his status being breached at his workplace:

I was very scared to go onto ARVs because now I'm a [company name] employee and I'm going through [company name] medical aid someone is going to know someone's going to know because I have to activate and request and authorise through chronic and I think someone is going to know so I was petrified of actually starting the whole process but at the same stage I was diagnosed I was in the scenario where I had to go on ARVs. (N)

Again, this is an area that is under-researched; however the threat of accidental or malicious disclosure for PLWH in a workplace setting is a real one as it may lead to stigma and discrimination (Bhagwanjee, Govender, Akintola, Petersen, George, Johnstone & Naidoo, 2011).

#### **4.5.4 Challenges of Medicine Supply**

It is of great importance here to understand whether there have been challenges in the participants receiving their medication and whether this has influenced their treatment adherence. This comes about as a result of the challenges on medicine supply which came about in November 2008 after budget overspending and omitting to apply for emergency funding. This meant that the Free State provincial government was unable to take on new patients onto the antiretroviral treatment programme, this also resulted in an interruption of supply for those already on treatment (Ndluvo, 2009).

It would seem that the risk of potential medicine supply problems is a concern whereby several of the participants have spare medicines, often as a result of over-supply at some stage which is kept for just as an emergency supply, in case the clinic runs out.

Another concern when it came to medicine supply was in the case of medical aid when N needed to be away from home for an extended period. The scheme would not allow the release of an extra supply of medication to cover N during his time away. This brought about challenges for maintaining adherence during this period. N describes this experience:

They don't really release the chronic facility until 25 days or something after you last so you can't stock up or anything like that. I've actually gotten to a point now because I've gone away on business again for 3 weeks to the Cape and it would be over a time period where I need to collect I actually went I got my GP to prescribe a separate prescription and I paid for it on my credit card. (N)

Furthermore, in terms of medicine supply challenges, when comparing participants that are members of a medical scheme to those who are use a public health clinic or Health4men in that they must collect the medication themselves rather than using a courier pharmacy resulting in having to wait a number of hours as discussed. However, at each visit a participant is supplied with two to three months' worth of medication. Although from a logistical perspective, one of the participants recommended improving the Health4men

process so they would not have to queue to collect medicine any longer, or that medication could be dispensed in another manner.

In terms of an intervention programme that should be made available to MSM, in the light of having an over-supply of medication one of the participants felt that an intervention should be implemented that enables those with an oversupply of medication, for example, when they change medications and have a stock at home, the opportunity to return them for re-distribution. Furthermore, for those that have run out or the clinic cannot stock a central 'depot' run by a non-government organisation that could distribute in emergency situations.

This is described as follows:

I know that there is a programme overseas and that is a lot of when you're changing your drugs you might end having 3 months or even 4 or 5 months' supply of drugs in your cupboard then the doctor will say you've got a side-effect we're going to change your drugs you can't give them back they are sealed bottles they've got expiry dates on them and they've got years still to go and I get I keep on getting pills I've a cupboard full and I've got nowhere to go other than to send them to an overseas programme that does take them back and reissues them I think that's something that we can really jump on the band wagon especially your NGO organisations, there should be someone you could send them to. (A)

Although none of the participants reported experiencing challenges with medicine supply, it was certainly something that they were mindful of and had made contingency plans for, in order to maintain their treatment adherence. Certainly, in a private healthcare setting because one of the participants travels and his medical aid is not able to release his medication for his trip he has had to request a separate prescription in order to prevent a break in treatment.

#### **4.5.5 Discrimination**

This section examines how the participant's experiences of discrimination as a result of their status and sexual orientation may have played a role in their treatment adherence. As there is no medical aspect of HIV that makes it stigmatised rather it is the social response to it, how it is displayed and how society understand people living with HIV which makes it a stigmatised condition (Conrad & Barker, 2010). Because of HIV's connotations and its relationship with perceived deviant or promiscuous sexuality leads to PLWH being denounced and judged by many (Delius & Glaser, 2005). The effects of the physical manifestation of discrimination in the form of 'hate-speech' on MSMs can be expressed in their reduced self-esteem or self-regard leading to vulnerability to depression (Polder, 2006), thus having a significant influence on ARV treatment adherence (Gonzales et al., 2011).



From the participants' responses, the threat and the experience of stigma is real and as was seen in the section on disclosure. The stigma that may be associated with disclosure is something that is pervasive and shapes their world-view. Although, A, for example, suggests that:

'Sticks and stones can break your bones but names can never harm you.' You can say whatever you like about me but I don't have to take it on. (A)

In this sense it is something that is external, in other words coming from outside a PLWH and can be experienced when someone looks at him in a certain way.

Both D and F have tried to allay the stigma that surrounds HIV by writing books which detail their life story when it comes to their journey of living with HIV. However, for D in his experiences, he acknowledges that the stigma and discrimination amongst the white population in terms of HIV means that:

There are people that have chosen anonymity and you know non-exposure of it an openness of being HIV being on ARVs. (D)

Although he is quick to point out that he and his partner have not experienced discrimination for living with HIV or taking ARVs:

I don't think we've ever had people throwing words let alone stones or tomatoes at us you know there's never been that feeling. (D)

He described observing the effects of stigma when attending a clinic in Zandspruit and at the Steve Biko Hospital where patients had to hide their medication away as they feared the consequences if people found out what they were. Furthermore, he went on to describe HIV discrimination amongst the 'gay community' in that:

Two strangers about to have sex you know two guys 'are you clean?' you know, what does that mean for God's sake! But it's their euphemistic way of handling you know the threat of Aids presumably. (D)

In contrast, there were a number of the participants who reported experiences of discrimination due to living with HIV, which had made them want to hide their status and their treatment. As discussed earlier, M chooses to keep his status from his family and friends for fear of discrimination, in that he feels strongly:

I feel I get very angry and I do sometimes wish I was in a better place in my social circle where I could say, you know what, guys you've got no fucking idea what you're talking about. (M)

R was able to provide an example of when he faced discrimination and was labelled on the basis of his HIV status which almost affected his access to treatment:

I refuse to go and get my medication now, I've been three times by myself to get it and under someone's breath, the pharmacist, one of the pharmacists for xxxx in xxxx actually, when it was on my way home and I needed to get a refill of my medication, and she was like 'if you weren't such a slut you wouldn't have got it in the first place'. I called the manager and I had her fired because she said she denied saying anything but luckily I had a friend with me and he could vouch for me for what she said. It hurts because you would think you would go to a pharmacist and they would actually help you. No, because not many people know the circumstances so don't judge me and just because I'm willing to actually get help so don't be prejudiced. (R)

As a consequence of this:

I remember bursting into tears and it wasn't fun so I don't get my medication there anymore. My mom gets it delivered for me so I have got an arrangement with the pharmacy to deliver my medication every month so I don't have to go through that again. I refuse to put myself through it I don't have to. (R)

Because of the way that HIV is perceived within society, the threat of discrimination is real and for many of the participants this shapes the way they see themselves, the world and guides their thinking when it comes to issues, such as disclosure. However, there seems to be a refusal to 'take on board' or internalise any negativity they are may be exposed to. However, for those who have experienced stigma and discrimination because of their HIV and treatment status which had an emotional affect, may have had an effect on his access to treatment.

#### **4.5.6 Antiretroviral Therapy Advertising**

At this point, it would be worthwhile to reflect on the way in which ART is advertised on the internet and how this may play a role on the participant's perception and adherence to their treatment. This is of interest since the ways in which the way antiretroviral therapy is 'marketed' was very different to what was being experienced by these participants. The participants' exposure to advertising of ART was based on research before commencing therapy whilst trying to become more 'informed patients'. There appears to be a message conveyed that a person who is taking antiretroviral therapy can have a 'normal' life, however according to G:

It does disappoint me because all of the literature one reads says one ought to be back to an almost normal way of living and to me it hasn't returned to that fully a normal way of living. It's a restricted level. (G)

In that way, G feels that he is not able to do some of the things physically that he was able to do before starting treatment, and that he has seen that his body and strength has changed as a result he believes this was due to his treatment.

By the same token, N sees that advertising of ART, especially on the internet is marketing focussed and tends to paint a very idealistic image of the treatment which in his mind is contrary to his experience, in that:

There's a very generic response when they have testimonials from people who were at the Aids stage or on Death's door with a count of 7 or 3 or 1 and how they've turned it around which yes, it's all great but the way it's told is very, you know, it's marketed almost. And every story has this it's a success story that would almost you know if I think about and look at somebody maybe of lesser social or socio-economic standing would think well if I want to be happy I have to contract this disease because only then when I start taking these meds I'm going to have 2 cars in the garage and a double-storey mansion and a yacht. Because that's what all the stories did and everyone's process of, I was so depressed and then I went on the meds and now everything is 100% I'm happy and I found love and whatever and it's very compact you know. There's no process in between on the journey, there's no discussion of any kind of how people went onto different therapies. (N)

Furthermore, N felt there is no advice, certainly online for those who are not yet ready to see a therapist or has a support group and no talk of the difficulties of getting the medications or the physical reactions and such practical things as travelling overseas with the medication.

Contrary to the positive imagery of ART, M found when looking for information about medication and HIV generally that there was:

...tons of misinformation didn't really help because it as I said you have all this media crap that's dished out to you about how terrible it is and how you're dying and how you know everyone's dying. (M)

And according to F when it came to ART, the information focussed on the toxicity and other negative aspects of the treatment. Although he did not share how this influenced his feelings in any way towards his treatment.

I think it is a matter of information, disseminating the correct information on what actually are ARVs. (F)

Because of the perceived lack of information surrounding antiretroviral therapy, the participants felt that there should be more information made available on antiretroviral therapy aimed at MSMs. Not only to answer the questions that they have, but also the areas of concern that they feel should be tackled in the community as a whole. This corresponds with the IMB model in that adherence is understood by its relationship with information, motivation and behavioural skills which it sees as being linked with the situation and personal

factors that a PLWH experiences (Fisher & Fisher, 2006). When it comes to information, having accurate information about the medication is seen as an essential element in the ongoing and correct use of antiretroviral therapy.

F felt that there was a lack of information aimed at MSM in South Africa living with HIV:

I never realised before but there's nothing, there's nothing specific to South African situation to gay men in South Africa. What is adherence, how do actually become adherent.....you must be 95% adherent that's it and nobody knows that. (F)

The emphasis here is on information being made available to tackle the stigma that surrounds the medication:

Less fear and less stigma attached to you know being on medication. (F)

In addition, information on how recreational drugs and ART medications interact would be useful:

I don't think there's enough targeting them about recreational drug use and ARVs and interactions for instance overdose that it is a critically important thing to be able to be aware. (A)

Plus the importance of conveying the correct messaging about pre-exposure prophylaxis (PrEP) and its relation to 'bareback' sex (anal sex whereby condoms are not used) and the myth that because people are taking antiretroviral therapy they no longer need to use condoms:

I think that the awareness should specifically be for partying and peeing and bare-backing and all these other things that go with it. With the advent of ARVs, what I'm also seeing through my work that I do is there is a growth in because we are undetectable we now go back to bare-backing now I think that's a bit scary as well, there's definitely a growth in that that I've seen over the last few years unbelievable. (A)

D also described, with the advent of antiretroviral therapy there is a misconception that 'safe sex' practices can now be ignored which needs to be corrected:

I mean 'we don't have to wear condoms anymore because you know we just get, we just pop a pill' right I'm thinking you're missing the whole point, alright. Ja so I think the story really needs to be told. (D)

Although A cautions that there has been a certain amount of reluctance by local 'gay' media to cover HIV and treatment related issues:

I think that there needs to be a very in-your-face direct advertising you know we cannot expect that to come from our regular gay MSM publications I mean I write an article for Exit because I fought my way in the door after begging. (A)

He further described how problematic it has been to circulate condoms, lubrication and information about testing and treatment programmes in Johannesburg ‘gay’ nightclubs and sex clubs and that Health4men is dealing with this currently.

M spoke about how he was impressed with how HIV is tackled within the MSM community in Cape Town and felt that a similar model should be used in Johannesburg, in that:

In Cape Town, they are getting into the nightclubs they are getting out putting fliers on people’s cars they are doing great work out there. (M)

He further added that giving out fliers publically about all the resources that are available may help ‘spread the message’:

Get free medication, free testing you can get free counselling you know those it’s not it’s not publicized anywhere where do we see that information you don’t see Health4men on TV saying you know what there is a facility for gay men you can test and get free treatment and medication. Some people never get to find out about that. (M)

A number of the participants felt that the information should be conveyed in a manner which is suitable for local MSMs as most of the information they access is aimed at American or European MSMs:

When you’re reading something you know it’s always like based on the States or something like that you don’t really find as localised or necessarily applied to gay males.

Although not related to treatment and its adherence, a few of the participants felt that further prevention messaging aimed at MSM should be provided for in the public media.

Generally speaking, the participants were exposed to generic information which conveyed a very positive image of ART and in a number of cases ‘misinformation’ which was confusing and unhelpful to their needs. Although their experience of the treatment may be very different from those conveyed in the advertising there was no indication that this contradiction influenced their adherence to their treatment. The participants felt that there needs to be more information available surrounding antiretroviral therapy aimed at MSMs. Not only to answer the questions that they have, but also to address the areas of concern that they feel should be tackled in the community as a whole.

#### **4.6 CONCLUSION**

This chapter presented the findings from this research and discussions. The chapter was presented using the biomedical, psychological and social approach with each principal theme further described using the secondary themes guided from the participant’s interviews.

The next chapter provides a summary of findings, discusses the strengths and limitations of this research, gives recommendations and presents the significance of this research to MSMs living with HIV.

## **CHAPTER FIVE: CONCLUSION**

This chapter describes the findings of this research and will examine the strengths and limitations of this piece of work. The chapter goes on to provide recommendations in terms of an intervention focussing on addressing the challenges in antiretroviral therapy adherence aimed at MSM, based on the findings of this research. This chapter explores the significance of this piece of work whilst being mindful that research understanding the dynamics of treatment adherence of MSM living with HIV in a local context is limited. Lastly, this chapter closes with concluding remarks.

### **5.1 SUMMARY OF THE FINDINGS**

The findings of this research will be presented using the biopsychosocial frame and will be further broken into sub-sections based on the themes emerging from the interviews.

#### **5.1.1 Biomedical Influences of Treatment Adherence**

In terms of pre-treatment perceptions, a PLWH's perceived sense of seriousness of their condition meant that they were more likely to adhere to their treatment (DiMatteo et al., 2007). In terms of their beliefs and feelings they held before starting antiretroviral therapy, which may have influenced the way they perceived their treatment, all of the participants of this research seemed to appreciate the severity of their condition, saw that the medication provided benefits and were able to assess that the barriers to treatment outweigh the costs (Petersen & Govender, 2010). Some of the participants spoke about their thoughts about side-effects prior to treatment commencement, some based on observations of others and on personal research, whilst for one of the participants it was based on concerns over possible interactions with other chronic medications. However, despite these concerns and contrary to literature suggesting that those who experience side-effects may experience problems in adherence (Ammassari et al., 2001; Murphy, 2003) all the participants started ARV therapy.

Although there were side-effects, as a result of the toxicity of the medication (Murphy, 2003) and those who report side-effects may experience difficulty in remaining treatment adherent (Ammassari et al., 2001; Murphy, 2003). Amongst the participants of this research there appeared to be consensus that although some people would prefer to not take them because of the side-effects, the alternative for them was something that they would not like to consider such as illness and death.

When considering difficulties in taking medication many of the participants had not yet disclosed their status to all of their friends and in some cases family members which made

adherence to treatment problematic particularly in a social setting. As a result, a number of the participants felt that they had to hide their treatment. However, a number of the participants described that they had simply forgotten to take their treatment rather than side effects or the complexity of treatment regimens as the treatment had become an intrinsic part of their daily lives. This was particularly pronounced when 'normal' routines were affected by such things as travelling.

The participants described the methods that they used to make it easier to take their ARVs; above all the use of cell-phone alarms and pill-boxes seemed to be the most popular as they could be hidden and were accessible and convenient to carry.

### **5.1.2 Psychological Influences of Treatment Adherence**

The meaning of treatment adherence meant that this was a non-negotiable in a number of cases despite of side-effects and they were confused as to why it is not for other people. This seems to correspond with the idea that an individual belief about the necessity for and the concerns about their treatment drive their adherence. In a number of cases, they saw their medication as a symbol of remaining healthy and alive. On the other hand, for several of the participants, the fear of having to break routines plus the consequences this has in terms of illness, drug resistance and death when not taking their medication as well as the constant reminder of their condition the medication represents leads to personal conflict and frustration. When trying to make sense of this, most of them felt that their medication compared to taking chronic medication for other conditions, as it keeps the virus under control. Similarly, the importance of adherence was apparent to them as it was acknowledged that the medication is keeping them healthy and alive. Although there was the acknowledgement by a few of the participants who saw the medication as a constant reminder that they are living with HIV, and which seemed to tap into an internal stigma towards the virus. On the whole, despite their initial emotions at the time of diagnosed, they had learned to accept that they were living with HIV and had transitioned beyond this initial stage to focusing on remaining as healthy as possible and getting support and treatment. However, a few of the participants felt that although they were projecting this onto the outside world as this was very different to how they said they were feeling internally.

When it came to disclosure to friends and family and how this impacted adherence on the whole, the participants felt that disclosing to family members was problematic with a limited number doing so. Older parents were a concern, due to them not fully understanding what



HIV is and the potential of asking questions about how a participant became infected which may cause embarrassment. Some felt that there would be no benefit in their parents knowing their status, and in fact it may cause them to unduly worry due to the association of death and HIV/Aids. When it came to disclosing to friends, opinions were varied. With some not disclosing to any and some disclosing to a few select friends, the reasons given centred on the risk of being shunned, stigmatised and judged by them. Consequently, this means having to keep medication hidden by sleight of hand and experiencing fear that the truth about being found out thus making taking medication in social settings problematic. With partners, participants in relationships agreed that they remind each other when to take their medication and can provide each other support. If both partners were living with HIV then their similar experiences can be shared. Although, if a partner is not living with HIV, although they can still be used as a reminder there may be challenges in terms of their level of knowledge and understanding of the condition which may lead to conflict and the need for on-going psycho-education. All in all it seems that being transparent and open about their status from the beginning of the relationship is vital in terms of a positive interpersonal relationship.

When it came to mental health issues, the participants discussed areas of accepting the treatment which is simultaneously saving their life and taking control of their life, while on the other hand their feelings of being contaminated. While some reflected on their experiences of depression, and how some of the side-effects had in some way exacerbated this, certainly when factoring in fatigue and energy levels; others described how they had experienced a reduced will to live before going onto the treatment regime which improved the depression after starting treatment. Some participants had coped with the emotional aspects by focusing on their work or had not sought psychological support. Lastly, understanding their HIV status as part of their psychological growth in that they knew they had to have made alterations to their world-view. Although the literature indicates strongly that depression and anxiety correlate with non-adherence those that spoke of their experiences of depression whether it be a side-effect of the medication or a pre-existing condition said it was exacerbated by diagnosis or commencing ARVs did not indicate that it negatively affected taking the medication which contradicts the literature somewhat. Once again, the participant's belief that the medication is keeping them healthy, improving quality of life and allowing them to focus on day-to-day living seems to dominate over psychological effects of the condition or the medication in terms of adherence.

Their experiences of adherence counselling seemed to suggest limited exposure to counselling when initially diagnosed or further counselling when they commenced ARVs. There seemed to be no link between the lack of counselling and treatment adherence in this case. However, despite this they appear to gain support through other means such as the support group, Positively Alive. The participants spoke a great deal about what the support group means to them in terms of living with HIV and their antiretroviral therapy regime. They valued sharing their stories with others and their experiences of taking their medication in a social context, that they have made friends of members of the group that they can ask questions and share each other's experiences such as experiences of side effects. They use this group for support, group counselling in order to cope. In other words that they said can relax with PLWHs going through similar experiences to their own in a supportive and non-judgemental environment and lastly, for those that have been attending the group for an extended period the altruistic need to give back to others is something that they valued from attending the sessions.

### **5.1.3 Social and Structural Barriers to Treatment Adherence**

When discussing the health facilities, the participants did not report any experiences of discrimination or stigma they had attended based on their status or sexual orientation. However, there was some discomfort experienced in the process that had to be followed in terms of queuing to see the nurse and receive medication, level of counselling, the 'one size fits all' approach and concerns around plumbing and cleanliness. Furthermore, there were concerns on the new Health4men clinic in Yeoville being labelled the 'Aids clinic' which may be problematic as HIV/Aids remain a largely stigmatised condition. Although it seems that this in itself would not deter the participants from collecting their medication.

In terms of medical providers, most of the participants are consulting with GPs and seem to have a positive and trusting relationship with their providers. However, being an 'informed patient' means that the participants often have to advise their GPs on support programmes available to PLWH or latest HIV developments. Furthermore, when they have very specific or technical questions their medical provider may not have the competency to respond meaning having to research before providing feedback, with 'R' experiencing confusing and often conflicting information. A further challenge from one of the participants was forgetting to ask certain questions when in consultation which may indicate a need to explore the use of written reminders.

For those participants who are members of a medical aid, there are challenges with medical aids. These challenges are on ARVs being paid out incorrect benefits and because of this the payment of the account was rejected, although this did not affect adherence. A further challenge is with confidentiality because the medical aid is a company sponsored scheme and as an employee of the company there was fear that colleagues may find out and the confidentiality of his status not being maintained. Therefore, running the risk of being discriminated in the workplace as a result of his HIV status becoming known.

Although none of the participants reported experiencing challenges with medicine supply, it was certainly something that they were mindful of and had made contingency plans for, in order to maintain their treatment adherence.

Because of the way that HIV is perceived within society, the threat of discrimination is real for many of the participants and this threat shapes the way they see themselves, the world and guides their thinking when it comes to issues such as disclosure. However, there seems to be a refusal to 'take on board' or internalise any negativity they may be exposed to. However, for those who have experienced stigma and discrimination because of their HIV and treatment status which had an emotional affect, may have had an effect on accessing treatment.

Generally speaking, the participants said that before commencing therapy they tried to become 'informed patients'. The generic information they collected conveyed a very positive image of ART and in a number of cases contained 'misinformation' which was confusing and unhelpful to their needs. Although their experience of the treatment may have been very different from those conveyed in the advertising there was no indication that this contradiction influenced their adherence to their treatment.

Due to the complexity of HIV/Aids, the importance of rigorous adherence to antiretroviral therapy was emphasized. This research further strengthens the understanding of adherence from a bio-psychosocial perspective (Halkitis & Kirton, 1999; Ickovics & Meade, 2002). In that all of the findings of this research could be categorised into the biological, psychological or social factors that influence treatment adherence. This research also correlated with the IMB model in that having accurate information about the medication; having personal and social motivation by holding a positive belief that the medication will work and experiencing positive effects on health; perceiving good social support and motivation; lastly, having behavioural skills all of which positively influenced adherence over a period of time (Fisher

& Fisher, 2006). This is something to take into consideration when considering adherence intervention programmes.

When considering the framework of this research, this study benefited from using the Queer Theory understanding of the participants. In that it examined the ways in which experiences of MSMs are unique and different to those of their heterosexual counterparts; to examine the beliefs as to whether their lives, experiences and the data collected was perhaps outside of any predetermined ideas surrounding treatment adherence issues when it comes to MSM (Dilley, 1999). In order to further achieve this aim further work is needed in determining the differences and uniqueness of the experiences of MSM when compared to heterosexual males and should be an area of future research.

## **5.2 STRENGTHS AND LIMITATIONS OF STUDY**

The use of qualitative methods allowed the researcher to study the issue fully, and in a manner and detail as to identify and attempt to understand the categories of information that emerge from the data. To study a phenomena as they unfold in the real world, from the experience of the participants without manipulation with a Queer Theory understanding of the subject. Reflection of some of the limitations of this research should be acknowledged at this stage. The limited size and nature of the sample, of nine participants and the fact that these MSM live in an urban area, which were white, middle class and identify themselves as gay men may mean that the interpretation of the findings reflects a certain amount of bias which cannot be generalized to apply to all MSM. For this reason, the researcher was mindful that the views provided by the participants can not reflect those of the MSM community living with HIV because they are a diverse group, and as the participants of this research were all high-income earning white males this could not reflect those who are outside the support network and those from different race, income and cultural groups (Brouard, 2009). For example, the findings of this research may not be applicable to black MSM in under-resourced areas. Although this is an under-researched area within the South African context, black men who have sex with men in the United States of America face experiences of discrimination and stigma based on their status, race or sexuality which have showed lower levels of treatment adherence (Bogart et al., 2010). So far, one can only speculate on how the outcomes of this research would have differed were the participants' as different sample of for example, low income earning black MSM who had experienced discrimination and stigma resulting in having to keep their HIV status, medication and sexuality secret and how this influences their treatment adherence. For example, would they be able to use medication

reminder tools such as mobile phone for fear of being found out, or if living in crowded conditions how could this make the taking of medication problematic or would they feel as positive about their medication as their white, higher income earning counterparts? That would be interesting and a source of important information.

By the nature of qualitative research, it is not possible to quantify the findings of this research to test theory derived through developing hypothesis and proposed outcomes. However, this research will contribute in strengthening the argument around the experiences of MSM living with HIV who are taking antiretroviral therapy, perhaps driving future research work.

### **5.2.1 General experience of the interviews**

The researcher's general experiences of the interviews are described in detail in Appendix F. However, for the most part the participants were easy to engage with, willing to share their stories and in most cases there was a mutual connection. However, it should be noted that in several of the interviews the participants were guarded when it came to sharing overtly personal information. This may have been due to sufficient rapport not being developed in a short space of time in that the interviews were on average an hour in duration or that there may have been a sense of concern on how the data would be presented and confidentiality maintained. All of this may have influenced the information derived during the interviews.

In terms of the researcher's contact with Positively Alive, rapport was established quickly bearing in mind that when the research was presented to the group the researcher was known to the facilitator. This meant that the credibility of the researcher and the research topic could be verified and supported by the facilitator.

## **5.3 RECOMMENDATIONS FOR FUTURE RESEARCH**

This research has enabled the researcher to reflect upon areas that require future research attention especially considering MSM in a local context. This is a topic with limited research in a local and international context hence future research could be derived from numerous areas. First and foremost, the researcher would like to extend the number of participants of this research to more widely to incorporate broader groups of MSM from more diverse cultural backgrounds to explore and understand the subject further. The focus of this future research may include an extensive understanding on the biomedical factors and how side-effects may affect adherence; how weight gain plays a role in adherence and how the medication is a reminder of status; the relationship between adherence and medical providers and facilities and how this may affect adherence.

From a mental health perspective, there are many other areas that could be researched. However, when it comes to depression and anxiety, although the literature seems to indicate a strong correlation with its link with non-adherence, this is an issue in which limited research has been done in a South African context and requires attention. This work could also further examine the process and impact of disclosure, drugs and alcohol, attitudes towards medication, internal stigma, the symbolism of the medication the efficacy and being understood to keep PLWH healthy, and acceptance of the virus. Lastly, from a social perspective a lot more work needs to be carried out on the effects of stigma and discrimination and how this impacts adherence amongst MSM specifically examining the experience of black MSM.

Further studies should incorporate medical providers to understand the challenges that MSM are reporting. In addition to this and following a Queer Theory frame, extending this research to include heterosexual participants to explore and understand whether the issues differ from MSM (Dilley, 1999).

Further areas for future research should include the use of treatment reminders such as cell-phones, pill boxes and any other form of reminders. The aim would be to fully explore and understand the extent of their use among PLWH and their success. Many of the participants reported such tools but as this was a small piece of research it would be beneficial to explore this issue more widely.

The aim of this research was not to assess the PLWH rates of treatment adherence but rather to explore barriers and enablers to treatment adherence. However, to further assess a PLWH's clinical vulnerability in terms of treatment non-adherence, consideration of the assessment of adherence and the impact the medication has on the viral load and other clinical measures is reliant on consulting with the medical provider. This means undergoing pathology testing on a regular basis (Maartens et al., 2010). An important aspect of exploring adherence is to view it from a holistic perspective. For the most part, the understanding of what determines adherence, the challenges and what facilitates good adherence should drive interventions to improve adherence which would in turn hopefully play a significant role in PLWH care and support (Maartens et al., 2010). As discussed, the aim of this research is not to assess treatment adherence, it should be reflected on at this point that the self-reporting of adherence to HIV treatment has been shown to overestimate adherence to therapy. This means that PLWHs who report lower treatment adherence tend to be reliable in their assessment of their

adherence rates (Parienti et al., 2004). One could hypothesize that those that report high adherence may not in reality be accurate. However, further study in terms of assessing the rates of self-reported adherence amongst MSM against actual clinical outcomes perhaps should be considered as future research.

Lastly, although the use of support groups is invaluable in being able to share emotional and practical experiences, it still remains unclear as to whether this has an impact on treatment adherence. This could be an area to consider in future research.

#### **5.4 RECOMMENDATIONS FOR INTERVENTIONS WITH MSM**

The participants of this research were asked for their thoughts on the nature of support interventions that they felt should be provided to MSM to improve ARV adherence. Much of the emphases of their discussions were based on the conveying factual information as well as improvements to the support received from the support group. More and more MSMs living with HIV are starting to take ARVs thus there is a strong need for intervention programmes in which psychosocial support is offered. The interventions would need to assist MSM living with HIV to remain adherent based on their specific needs. Although this was a small scale study and for this reason it is not possible to provide the details of a comprehensive programme, the outcome of this research does provide some insight into the needs of MSM living with HIV. Moreover, in an ideal world all of the following components would be incorporated to adherence intervention aimed at MSM perhaps building them into the services already provided by Health4men or Positively Alive.

##### **5.4.1 Adherence Counselling**

It became apparent during this research that the participants had received very limited or no adherence counselling at the onset of their treatment journey, this was concerning. The literature suggests that poor or infrequent counselling can result in negatively influencing HIV treatment adherence. This is especially the case when discussing the management of side effects (Hardon, et al., 2007). Adherence counselling also aims to work through what the treatment means to the PLWH in terms of the possibility that it serves as a reminder of HIV infection thus tapping into any internalized Aids stigma they may have (Chippindale, French, 2001). Any intervention should provide access to ongoing adherence counselling which is aimed to tackle issues which specifically affect MSM.

### **5.4.2 Support for Partners and Families**

A few of the participants spoke about having psychosocial support interventions made available for family and partners of those living with HIV and taking antiretroviral therapy. This should include psycho-education and counselling elements.

### **5.4.3 Health Care Facilities**

As MSM regularly access health services from government facilities and the NGO sector, there is a strong and continuous need to make these facilities more user-friendly and accessible for this population (Sheehy, 2011). For example, from a medicine supply perspective queuing for medication often involved having to take time away from work. It was recommended that this process be improved so that they would not have to queue to collect medicine. Or that medication could be collected in another manner such as from a retail pharmacist which would be more convenient to them. Furthermore, making sure the queuing process is conducive to maintain confidentiality and that the facilities and the staff are aimed treat MSM respectfully and with dignity.

### **5.4.4 Medication Oversupply**

In the event of having an over-supply of medication, one of the participants felt that an intervention should be implemented that enables those with an oversupply of medication when they change medications and have a stock at home to be able to return these for re-distribution. Furthermore, for PLWH who have run out, or when the clinic has low stock to have access to a central 'depot' run by a non-government organisation that could distribute ARVs in emergency situations. Although the legislation surrounding this intervention is unknown by the researcher at this stage, perhaps this is something to consider for the future.

### **5.4.5 Support Group**

The participants valued the support group because it gives the opportunity to discuss openly and in a non-judgemental environment issues such as sexual health. They saw the value of expanding its work into other areas, perhaps with a focus as a social group whereby people can get to know each other and share knowledge and experiences in a social manner as well as retaining the 'discussion' group structure. In addition, having cells or networks which were felt could expand the support group services further, in that way PLWHs can be referred depending on certain needs, for example when they have medical or psychiatric support needs; require insurance assistance or wish to become involved in outreach work.



#### **5.4.6 Information**

When carrying out their research before commencing therapy, in order to become ‘informed patients’ the participants were exposed to generic information which conveyed a very positive image of antiretroviral therapy. In a number of cases, they felt they were exposed to misleading information which was confusing and unhelpful to their needs. In other cases, the lack of information surrounding antiretroviral made the participants feel that there should be more information made available aimed at MSM specifically to answer the questions that they have, but also the areas of concern that they feel should be tackled in the community as a whole.

There were a number of areas that the participants felt were not answered by the internet or their medical provider which would assist them in becoming increasingly confident in taking their treatment. For example, a forum as part of the support group to discuss latest developments and treatment such as the stigma that surrounds the medication; information on how recreational drugs and antiretroviral therapy medications interact; the correct messaging about pre-exposure prophylaxis (PrEP) and its relation to ‘bareback’ sex (anal sex whereby condoms are not used) and the myth that because people are taking antiretroviral therapy they no longer need to use condoms as mentioned earlier.

The implementation of any adherence interventions would need to be to planned and implemented in a way that the outcomes must be monitored and evaluated. So the intervention is continuously being assessed on the basis of clearly defined goals and objectives with the overall aim that it is continuously being improved to meet them.

#### **5.5 SIGNIFICANCE OF THE STUDY**

This seems to have been the first piece of work which explores the ARV adherence issues, enablers and barriers amongst MSM living with HIV in a South African context. The significance of this study is that it examines the experiences of a marginalised and vulnerable group which is often difficult to access, being a group of MSM living with HIV who is taking antiretroviral therapy. This research appears to be one of the first to examine this phenomenon from a local perspective as previous research most originates in Europe and the USA. For this reason it was imperative to explore this subject from an urban South African perspective to fully understand the subject locally and reflect on the areas that compare or contrasts the literature. Hopefully, this research provides a foundation for further work in this important area which will in time drive adherence support interventions aimed at MSM.

## **5.6 CONCLUDING COMMENTS**

One of the participants shared his thoughts about his antiretroviral therapy which the researcher felt also represented those of the other participants:

The ARVs have granted me hope where I was hopeless before I'm hopeful now and it's just it's nice to feel that hope and just to feel that positive energy. (R)

Despite the severe side-effects he experienced through the medication he was able to maintain a sense of hope. Therefore he carried on taking his treatment despite his complications.

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## **APPENDICES**

### **APPENDIX A – FACILITATOR LETTER**

Dear Group Facilitator,

I am currently enrolled as a Masters In Community-Based Counselling Psychology student at the University of the Witwatersrand, and it is required that I conduct research as part of my degree. This research will explore the factors that enable and hinder adherence to HIV treatment regimens among men who have sex with men.

I will be conducting qualitative research which will involve one-on-one interviews and participation in this research is entirely voluntary, members can refuse to participate altogether and you may withdraw the group at any time, and it will not be held against you or the group in any way. Participation by the members of the group is also voluntary and they will have the right to withdraw at any time, as well as the right to not answer any question that they feel uncomfortable answering. The individual confidentiality of the participants will be guaranteed throughout the process, where by the audio recordings, interview transcript and consent forms would be held in a secure place and destroyed after 2 years if publications arise from the research and for six years should no publications arise from the research. At no time will unique identifying information be reported in the transcripts or in the final report submission and pseudonyms will be used to protect individual identity. I would welcome the opportunity to meet with the group, to discuss the exact nature of the research and gain participant consent. Written consent will be gathered from each participant before the interviews are carried out. Should you request feedback on the findings of this research, a one-page summary will be made available to you.

Your permission to participate in the study can be granted by signing the attached consent form and returning to me.

If you have any questions or further enquiries, please feel free to contact me, or my supervisor.

Stephen Laverack

Tanya Graham (Supervisor)

Yours sincerely

**APPENDIX B – SUPPORT GROUP FACILITATOR CONSENT FORM**

I have read the information letter and have understood that the research project involves the participation of the support group, Positively Alive. The participants will each be interviewed on a one-on-one basis on a confidential basis. Member participation is voluntary and interviews will commence on the completion of a consent form.

I know that I may withdraw the support group from the study at any time and it will not be held against me or the group in any way. Participation of the group and members is voluntary and no information that may identify members will be included in the research report.

I hereby consent for Positively Alive to participate in this research report.

Name of support group:

Date:

Facilitators name and signature:

## **APPENDIX C – PARTICIPANT’S INFORMATION SHEET**

Dear member of Positively Alive

My name is Stephen Laverack and I am currently studying a Masters of Arts degree in Community-Based Counseling Psychology at the University of the Witwatersrand. As part of my degree, I am conducting research to explore the factors that enable and hinder adherence to HIV treatment regimens among gay men, or men who have sex with men. This study hopes to contribute to knowledge within the field of psychology when it comes to understanding ARV treatment adherence issues amongst men who have sex with men, guiding future support and intervention.

I would like to invite you to participate in this research by taking part in a one-on-one interview to share your experiences, feelings and thoughts relating to this topic. Your input in this regard would be useful in assisting me to understand the factors specifically relating to you that enable and hinder your ARV treatment adherence. Upon signing the attached consent form I will make contact to arrange a suitable date, time and venue for the interview. The duration of the interview will be approximately one hour.

Participation in this study is entirely voluntary, you can refuse to participate altogether, you may withdraw from the study at any time, as well have the right to not answer any question that you feel uncomfortable answering. Your identity will be kept confidential and no personal information will be reflected in the final report submission or research publications. A pseudonym will be used in the study to protect your identity. With your permission, the interview will be audio recorded. My supervisor and I will be the only ones that will listen to and process the recordings. For the duration of the research, the recordings, transcript and signed consent forms will be kept in a secure place with restricted access at the University of the Witwatersrand. Audio-recordings will be destroyed after 2 years if publications arise from the research and for six years should no publications arise from the research.

If participating in this interview evokes any distress, you can contact a counsellor at Health4Men – Simon Nkoli Centre (tel: 011 989 9756/9865) or Lifeline – 011 728 1347 for

free, alternatively I can arrange a counsellor to be made available to you through the Emthonjeni Centre at Wits upon request. The results of the research will be presented in the form of a research report and published research articles. On request, a 1-page summary of the results of this research will be provided to you. This information will also be provided to the facilitator of the Positively Alive group. If you have any questions about the research, you are more than welcome to contact me or my supervisor.

Your permission to participate in the study can be granted by signing the attached interview and audio-recording consent forms and returning to me.

If you have any questions or further enquiries, please feel free to contact me, or my supervisor.

Stephen Laverack

Tanya Graham (Supervisor)

Yours sincerely



**APPENDIX D – CONSENT FORM (INTERVIEW)**

I, \_\_\_\_\_ have read the attached letter and understand the nature, purpose and procedure of this study. I recognize that participation in the study will not advantage or disadvantage me in any way. I understand that confidentiality of personal information is guaranteed and I have the right to not answer any question that I feel uncomfortable with, and to withdraw from the study at any time. I also understand that the researcher can make direct quotes. I would like to participate in this study.

- I acknowledge that the research data will only be processed and seen by the researcher and the researcher's supervisor

- I acknowledge that there are no anticipated risks and benefits involved in the participation in this study, if I am at psychological risk, provisions have been put into place to minimise that risk.

- No information that may identify me will be included in the research report or research publications, and my identity will remain confidential.

- I acknowledge that anonymity cannot be guaranteed in the study because of the face-to-face nature of interviews.

Signed:

Date:

Telephone number:

**APPENDIX E - CONSENT LETTER (AUDIO-RECORDING)**

I \_\_\_\_\_ consent to my interview with \_\_\_\_\_ for his study on \_\_\_\_\_ being tape-recorded. I understand that:

- The tapes and transcripts will not be seen or heard by any person at the University of the Witwatersrand at any time, and will only be processed by the researcher and the researcher's supervisor.
- I will allow for the use of direct quotes.
- All tape recordings will be destroyed after the research has been examined.
- No information that will identify me will be included in the research and my responses will remain confidential.
- I acknowledge that anonymity cannot be guaranteed in the study because of the face-to-face nature of interviews.

Signed \_\_\_\_\_

Date \_\_\_\_\_

## APPENDIX E - INTERVIEW SCHEDULE

- 1) Tell me about your experience of living with HIV in terms of your antiretroviral therapy?

Probe: What was it like when you first started taking antiretroviral therapy, how did it make you feel emotionally/physically when you started your treatment? How have your feelings changed over time towards your treatment?

- 2) How do you experience your medication?

Probe: What positive things can you tell me about your treatment & what are the negative things can you tell me? What sort of side effects have you experienced? How do you manage them from a physical and emotional perspective?

- 3) Help me understand what treatment adherence means to you?

Probe: How important is treatment adherence to you? How do you manage your adherence?

- 4) Tell me about any difficulties you have faced in taking your treatment?

- a) How have you experienced any psychological challenges could be to taking antiretroviral therapy?
- b) What have your experiences of any social challenges with regards to taking antiretroviral been?

Probe: Whether you have experienced anything that has prevented you from taking your treatment or experienced discrimination that has prevented you from taking your treatment

- 5) Tell me about any areas that have made it easier for you to take your treatment?
- 6) Tell me about the support you have in terms of your antiretroviral treatment

Probe: partners, support groups, friends, family health providers and facilities

- 7) What are your thoughts on the support you think should be provided to HIV positive MSM who are taking antiretroviral therapy?

## **APPENDIX F - INTERVIEW REFLECTIONS**

At this point it important to consider the researchers reflections from each interview, this includes some of the discussions both before and after the interview as well as some of the researcher's thoughts and feelings about the interview itself.

### **Interview with 'A'**

The researcher was concerned that the interview with 'A' became academic in places and at times felt like the interview was part of a workshop that he was hosting. The researcher was mindful that 'A' is a corporate consultant, and carries out HIV/AIDS and wellness workshops as part of his business. He did open up and provide personal insight during the middle parts of the interview. However, the sense was that he had difficulty conveying emotional and psychological challenges and gave this information tentatively to start with and only to a point. The researcher reflected as to whether this was due to 'A' and the researcher knowing each other and latent concerns over confidentiality.

After the recording equipment was switched off 'A' spoke about the negative messaging that antiretroviral therapy receives in the media and how this influences people's thoughts and feelings towards treatment especially in the light of negative media on lipodystrophy. This was of interest to the researcher as 'A' had spoken briefly about his experiences of lipodystrophy during the interview.

Furthermore, the issue of antiretroviral treatment and sexual performance was discussed as the researcher was leaving. In short, it had been raised as a concern in the previous support group meeting that some members, since starting to take antiretroviral therapy had no sex drive. The researcher was curious whether this was 'A's' personal experiences by the manner in which it was being raised. Finally, for 'A' he discussed that the reasons he runs Positively Alive is to give back what he's learned to this community, and to socialise.

### **Interview with 'F'**

Similar to 'A' the researcher was concerned that the interview would be academic in nature as 'F' also carries out workshops and talks as part of his work. The researcher was curious to learn, because he had lived with HIV for so long and on treatment for many years whether his issues with treatment would be less or different than someone who had started treatment fairly recently. At this stage, the researcher was mindful about gathering participants who met this criterion in order to test this. Interviewing 'F' was met with a couple of challenges in

terms of language and understanding, that is to say that 'F' was born and lived in France until adulthood which meant that his accent was quite heavy and at times difficult to understand.

### **Interview with 'C'**

'C' was keen to be interviewed, although he was newly diagnosed and on treatment less than a month which the researcher reflecting whether the limited time would affect 'C' being able to provide significant experience. On the contrary this was not the case. The interview with 'C' gained significant data, however at times he tended to speak tangentially which made following the theme of the topic discussed at that point problematic at times.

### **Interviews with 'H' & 'M'**

Although they were not interviewed together, as they are a couple and many of the same themes were raised that the researcher found interesting. Namely, both reported that they were doing well on treatment, have no psychological or social issues to report. However, the researcher was struck that their sexual performance had suffered as a result of living with HIV and being on treatment as this was raised with the researcher separately after the interview, both requesting PLWH therapy to discuss this issue further. The researcher felt that the interview with 'H' was somewhat inhibited, that is to say a flow of conversation was not reached; this resulted in an almost question and answer format. The researcher reflected that this could be because 'H' came across as a reserved PLWH which may have influenced his ability to speak freely on this subject.

### **Interview with 'N'**

The interview with 'N' was carried out quite late in the evening. The researcher found the experience draining and reflected on whether it was because he was tired, after a long day or whether it was because 'N' was experienced as a negative PLWH with a somewhat flat affect. The researcher was also mindful that 'N' seemed to want to use the interview as a space for personal therapy and that the researcher aimed not to respond to 'N' as a therapist and maintain the interview frame.

### **Interview with 'R'**

The researcher found that because he knew the participant on a personal level a number of years ago before he was diagnosed HIV positive, this some influence on the researcher's counter-transference especially when discussion centred on 'R's' feelings towards living with HIV and his treatment. Again, the researcher was mindful to maintain the interview frame in order to gather data and not allow the space to become therapeutic or a personal 'catch-up'.

However, after the interview further discussion 'R's' background to living with the virus was discussed including his emotional response.

### **Interview with 'D' & 'G'**

Although the aim of the interview, despite them being a couple for many years was to interview them separately, however upon arrival they requested that they be interviewed together. 'D' had recently been diagnosed with lymphatic cancer and looked ill, weak and tired and he felt that it would be the only way he could conduct the interview. Although the researcher was deeply empathetic to the situation, he was mindful about the structure of the interview and how this would influence the collection of data, as well as whether the lymphatic cancer would derive priority over their experiences of antiretroviral treatment. Likewise, whether there was a threat of discussion becoming tangential and other issues becoming prioritised. On the other hand, the researcher felt that they would be able to confirm each other's stories.

The researcher was puzzled in the manner in which 'D' avoided discussing emotional and psychological challenges of living with HIV and in particular to his antiretroviral therapy, in contrast 'G' was more comfortable discussing this. The researcher reflected as to whether 'D's' recent diagnosis played a role in this avoidance and that discussing anything too emotional would be difficult.

The researcher was also captivated by how antiretroviral therapy had played a role in 'D' and 'G's' lives in the dramatic migration from severe illness to health.