ADHERENCE TO ANTI-RETROVIRAL TREATMENT AMONGST HIV POSITIVE GAY MEN AND OTHER MEN WHO HAVE SEX WITH MEN IN TSHWANE

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ABSTRACT

Gay men and other men who have sex with men (MSM) and a subset within this group who are people who inject drugs (PWID) face difficulties when trying to access human-immune deficiency virus (HIV)/ anti-retroviral treatment (ART) services and adhere to ART, due to the intersecting forms of oppression they face. Current interventions to address adherence to ART are mostly bio-medical in nature, and support the presumption that individual-level factors are the most pertinent barriers to adherence to ART. This mini-thesis presents findings from a qualitative study that explored individual, health systems and structural factors that shape experiences of adherence to ART amongst gay men and other MSM and a subset within this group who are PWID.

Using purposive sampling and drawing study participants from among attendees enrolled in the ART programme at the OUT 1081 Clinic in Tshwane, 6 PLHIV men who identified as gay or MSM and 3 PLHIV who identified as gay or MSM and as injecting drug users were recruited. In-depth interviews were conducted with these 9 men. In addition, 3 key informant interviews were conducted, 2 with nurses (a resident nurse at facility and an outreach nurse), and one with the PWID programme manager at the clinic. The interviews were transcribed verbatim, and a thematic analysis was used to analyze the data.

An analysis of the interview data revealed that factors affecting adherence to ART among the participants were shaped more by health systems and structural barriers than by individual-level factors. Also, having an additional marginal identity to being gay or MSM (that is, also being a PWID) did not significantly affect adherence to ART. Health systems and structural factors that affected adherence to ART were categorised into 5 thematic areas: (1) service integrity; (2) service standards; (3) process of de-humanisation; (4) imagining re-humanisation; and (5) differentiated service modelling and delivery. The data reveals that structural inequalities that gay men and other MSM and PWID face put them at the margins of society and in a position of exclusion and devaluation. Their experiences of adherence to ART are experiences of resilience in the face of difficult structural and health systems barriers.

Based on the study findings, it is recommended that government should invest in scaling-up dedicated “one stop shop” clinics with presence of a multidisciplinary sensitized and competently trained health staff, to deliver ethical affirming services to gay men and other MSM and a subset within this group who are PWID. Further, a differentiated model of service and service delivery that is grounded in an understanding of the substance use sub-culture of PWID must be co-designed with PWID, in other to deliver services that speaks to their needs and is supportive of adherence to ART. Additionally, it would be in the government’s public health and human rights interests to decriminalize injecting drug use and invest in drug dependence treatment and harm reduction for PWID.

DECLARATION

I declare that this mini-thesis, “Adherence to anti-retroviral drugs amongst gay men and other men who have sex with men in Tshwane”, is my own work and has not been submitted for any degree or examination in another university. All the sources I have used or quoted have been indicated or acknowledged by way of complete references.

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Date: 14 November 2019

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ABBREVIATIONS AND ACRONYMS

ART	anti-retroviral treatment
DHHS	Department of Health and Human Services
DOH	Department of Health
GDP	gross domestic product
HCT	HIV counselling and testing
LGBTQI	lesbian, gay, bisexual transgender, queer and intersex
MEMS	medication event monitoring systems
METH	methamphetamine
MSM	men who have sex with men
NI-MART	Nurse Initiated Management of Anti-Retroviral Treatment
NRTI	nucleoside reverse transcriptase inhibitors
NNRTI	non-nucleoside reverse transcriptase inhibitors
PEPFAR	United States President's Emergency Plan for AIDS Relief
PLHIV	people living with HIV
PWID	people who inject drugs
NDOH	National Department of Health
NGO	non-governmental organization
NSP	needle exchange programme
OST	opioid substitution therapy
PI	protease inhibitors
PREP	pre-exposure prophylaxis
HAART	highly active antiretroviral drugs
HIV	human immune deficiency virus
FDC	fixed dose combination
SANAC	South African National Aids Council
SES	socio-economic status
STATS SA	Statistics South Africa
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

CHAPTER 1: DESCRIPTION OF STUDY

1.1 BACKGROUND

1.1.1 HIV prevalence

According to UNAIDS (2016), 37 million people are infected by HIV worldwide. Sub-Saharan Africa remains the worst affected by HIV, accounting for about 70% of total worldwide HIV cases (UNAIDS, 2016). South Africa is the country worst affected by the HIV epidemic in population numbers, with over 7.1 million persons living with HIV (UNAIDS, 2017). This represents a fifth of the total number of people living with HIV (PLHIV) globally (UNAIDS, 2017). The epidemic is generalised, meaning that at least over 1% of the general population have been infected, and transmission is still predominantly heterosexual, with wide variations across age, sex, class, race and geographical location (Shisana et al., 2014). The national prevalence of HIV in 2017 was 12,6% (STATS SA, 2017). The incidence has shown a sharp decline from a high of 1.74% amongst 15-49-year olds in 2007, to 0.91% in 2017 (STATS SA, 2017). At the provincial level, the HIV prevalence in Gauteng stood at 12.4%, 5% for the Western Cape and 16.4% for KwaZulu-Natal Province (Shisana et al., 2014).

Given the heavy burden of HIV in South Africa and the current HIV response by the government of South Africa, and despite the epidemic in the country being considered as generalized, South Africa has identified 5 specific groups as key populations: sex workers, men who have sex with men, transgender persons, people who use drugs, and inmates (SANAC, 2017). A particular emphasis for HIV prevention and treatment is placed on these groups. Key populations, also referred to as most-at-risk populations, are those segments of the population at the highest risk of HIV infection. They exhibit a disproportionately high HIV infection rate compared to the general population. This may be because of increased behavioural, socio-economic or health service risks for HIV. The specific risks include unprotected anal sex, and lack of adequate access to services (because of structural stigma and discrimination)). Amongst these groups are gay men and other men who have sex with men (MSM), and people who inject drugs (PWID) (SANAC, 2017).

1.1.2 Treatment access

Anti-retroviral treatment (ART) reduces progression of HIV to AIDS by sustaining virologic and immunologic responses, thereby preventing AIDS related illness and deaths and significantly reducing the risk of transmission of the HIV virus (UNAIDS, 2014; Nachega et al., 2009). Against this background, bilateral and multilateral donors like the United States President's Emergency Plan for AIDS Relief (PEPFAR) and the Global Fund to fight AIDS, Malaria and TB, started heavily investing in an HIV/AIDS response in low- and middle-income countries (UNAIDS, 2016). However, in 2011, UNAIDS called for a shared responsibility and country ownership and accountability towards the fight against HIV/AIDS (UNAIDS, 2011)

Assessing the advances in commitment by the government of countries, 5 years since the call by UNAIDS in 2011, shows a marked improvement in investment by low- and middle-income countries of over 46% in that period – from US$5 billion to US$10.8 billion (UNAIDS, 2016). This commitment and ownership of their HIV/AIDS response has brought about significant increases in access and coverage rates for ART. In 2002, just 300,000 persons had access to ART in low- and middle-income countries; of this number, only a sixth (50,000 persons) were from sub-Saharan Africa (WHO, 2002). A decade later, over 9.7 million people were on ART globally and 7.5 million persons of that number were sub-Saharan Africans (WHO, 2013). The total number of persons on ART has doubled in just 5 years globally, to over 20 million with coverage rates in sub-Saharan Africa at close to 14 million (11.7 million in East and Southern Africa alone) (UNAIDS, 2017). This has halved the number of HIV-related deaths from a high of over 2 million in 2005 to 1.1 million a decade later (UNAIDS, 2016). South Africa has the largest ART programme in the world with a national coverage of over 3.7 million persons initiated on ART (SANAC, 2017). Against this background, South Africa keeps seeing dramatic increases in life expectancy. More PLHIV on ART, are living longer lives. Life expectancy for males at birth stands at 61.7 years; and for females, at 66.7 years. The country average sits at 65 years in 2017, from 58.7 years in 2011 (STATS SA, 2017; SANAC 2017).

1.1.3 Drug resistance

Despite the important advances in the number of PLHIV initiated on ART, drug resistance is a major concern amongst PLHIV who are on long-term ART. It is not clear if resistance is a consequence of long-term use of ART. There is well-established evidence that inconsistent or non-adherence brings about drug resistance. As long ago as 1999, Friedland and Williams (1999) proposed a bell-shaped relationship between drug resistance and non-adherence, with complete non-adherence on the one side and total adherence on the other side of the spectrum, with the latter associated with a lower propensity for drug resistance. Conversely, the level of non-adherence to ART determines the risk of drug resistance. Sub-optimal levels of adherence markedly increase the risk of drug resistance and treatment failure (Walsh et al., 2002). The question of what level of adherence is sufficient to fend off drug resistance and treatment failure will always be a contentious. In the past the scientific and lay community were given the figure ≥95% based on studies done on nucleoside reverse transcriptase inhibitors (NRTI) along with unboosted protease inhibitors (PI). Patterson et al., 2000, for example, proposed an adherence rate of 95% to ensure virological suppression, but the class of drugs used in their research were un-boosted protease inhibitors (PI) regimens. With the advent of the newer antiretroviral drugs, evidence from adherence studies has shown that a much lower percentage of ART adherence can ensure virological suppression. For example, Bangsberg's (2006) study found that patients on non-nucleoside reverse transcriptase inhibitors (NNRTI) achieved virological suppression, with a mean adherence level of 54-100%. In the same vein, data from Maggiolo et al., (2005) study showed that patients with adherence rates of 85% on PI based regimens had failure rates of >20%, while patients on NNRTIs with adherence rates of ≤ 75% had failure rates of only >10%. However, individuals on NNRTI's with moderate levels of adherence, will have better viral suppression outcomes if they adhered more (Bangsberg et al., 2006; Nachega et al., 2007). Several studies now show that boosted PI based regimens (boosted with ritonavir) are maybe more forgiving of missed doses and sub-optimal adherence. A key challenge is still retention in care and adherence to ART, as a significant proportion of those living with HIV have been initiated on ART.

1.1.4 Treatment as prevention

Against this background, the "HIV treatment as prevention approach" has been advocated and proposed as the new intervention strategy to combat HIV incidence. The logic behind this is that, if many more people are on ART, there is greater viral suppression and a lower propensity to transmit infections (WHO, 2015). The “treatment as prevention” approach is part of the post-2015 UNAIDS Global Fast Track strategy to ends AIDS as a public health problem by 2030. In the short term, the strategy proposes a 90-90-90 treatment target for 2020, which means that 90 percent of persons with HIV must be diagnosed; 90% of those diagnosed must be on treatment; and 90% of those on treatment must attain viral suppression (UNAIDS, 2014). This means that the world is steadily adopting a “test and treat” approach to HIV, rather than using CD4 count values as prerequisite to start ART. While this is an important advance in approaches to ART, the enormous demands of greater and faster scale up and coverage, through increased initiation of those on ART, bring even more concerns and questions about whether initiating PLHIV early on treatment (when they are newly diagnosed with HIV) and mostly have not yet begun to feel any illness effect, may lead to increased levels of non-adherence to ART.

1.1.5 Adherence

As the world continues its fight against HIV by scaling up ART coverage to outpace the transmission of new HIV infections, new concerns about socio-behavioural factors that may act as barriers to adherence become pertinent (Sahay, Reddy & Dhayarkar 2011). Research that compares adherence in resource poor settings like sub-Saharan Africa to that in western countries have shown similar levels of adherence and specific studies have been undertaken amongst the general population of PLHIV to determine the barriers to adherence (Mills et al., 2006). However, there is a dearth of studies into barriers to adherence amongst key populations including among gay men and other MSM in countries in sub-Saharan Africa. This is problematic, especially given the overwhelming scientific evidence that puts HIV prevalence of MSM and PWID at 24 times greater than the general population, globally (UNAIDS, 2016). Further, stigma and prejudice associated with the mode of HIV transmission amongst gay men and MSM, which includes multiple and concurrent partnerships, anal sex between men, structural stigma and injectable drug use (Alonzo & Reynolds, 1995; Sonya Areola et al., 2014; Levy et al., 2014; Krusi et al., 2010), bring a new dimension to managing HIV in this population. These factors differentiate HIV amongst gay men and MSM from experiences of other diseases (Remien & Rabkin, 2001), and play a distinct potential role in interfering with access to and uptake of services, as well as adherence to ART (Chesney & Smith, 1999; Arreola et al., 2014).

It is important to research barriers to adherence, specifically among gay and MSM populations in countries in sub-Saharan Africa, with the heaviest HIV burden, as findings from the vantage point of the general population cannot necessarily be transferable to gay and MSM populations in these settings. There are clearly articulated challenges of key populations and specifically gay men and other MSM in respect of adherence to ART in other settings, internationally. A study by Reback, Larkins & Shoptaw (2003), examined adherence amongst gay Caucasian middle class Americans who are methamphetamine (METH) users. In this study the participants were divided into two groups, based on the nature of METH (sex drug) use in the community. One group deliberately did not adhere to ART around the period they wanted to use the drug and in the other, ART was interrupted as result of being under the influence of the drug (that is in this instance non-adherence was not planned in advance). The conclusion from this study was that METH usage may lead to non-adherence. Other studies have proposed associations between substance abuse and non-adherence to include: the lifestyle associated with drug use, cognitive impairment and an exacerbation of psychiatric issues

(Hinkin et al., 2007; Rendell, Mazur & Henry, 2009; Parsons, Rosof & Mustanski, 2008). Another study found an association between internalized stigma, combined with the negative effects of drugs use and non-adherence to ART (Johnson et al., 2008). It is methodologically difficult to conduct research on MSM and other gay men in many African countries because of the difficult legal and policy environment, stigma and discrimination, the hidden nature of the population and limited access to funding (Beyrer et al., 2011). It would be of great value to research these issues in these populations in a country such as South Africa, where same-sex relationships are legal, but where people in same-sex relationships still face stigma and discrimination. This would provide a feasible context in which to explore issues related to ART adherence, considering the specific vulnerabilities in this regard, of a population of gay men and MSM and gay men and other MSM with other marginal identities. The evidence and information derived from such research will deepen our understanding of these populations and serve as a springboard to design tailor-made interventions to address possible problems in PLHIV in this population's adherence to ART.

1.2 COUNTRY SETTING

South Africa is a middle-income country with one of the highest Gini coefficients in the world, with a very wide disparity between the rich and poor. The Gini coefficient is a measure of income inequality documented as between 0 and 1, with 0 denoting a totally equal society and 1 a completely unequal society (World Bank, 2016). This kind of deep inequality existent in South Africa makes it important for there to be free medical services for life-threatening illnesses like HIV/AIDS. Taking into cognisance the "quadruple" burden of disease in South Africa, due largely to HIV/AIDS; the Tuberculosis burden; high levels of infant and maternal mortality, and the rise of non-communicable diseases and injuries (NDOH, 2016), the >8% of South Africa's gross domestic product (GDP) allocated to financing health services is justifiable (World Bank, 2016; DOH, 2015). This is even though the quality of public sector services needs improvement and South African's health status falls short of what it should be with this level of public sector health expenditure (Ataguba et al., 2011).

The South African health system consists of a large public health sector, a rapidly growing private health sector and a non-governmental sector (NGO), which relies on donor funding (National Health Act, 2004). Only 16% of the South African population accesses medical care through close to 100 private medical schemes (STATSA, 2019). These private medical schemes fund health services for mostly formal sector workers and their dependents (DOH, 2015). The remainder of the population (close to 84%) use public sector health services that are tax funded, in a system whereby the rich subsidise the poor. Those benefiting from public sector health services include informal workers, unemployed and the poor (DOH, 2015).

South Africa intends to provide future health care for all through its proposed National Health Insurance Scheme (NHI, 2017). The Department of Health published a White Paper in 1997, which the government is using as a document to help guide the transformation of the health system for all people of South Africa. The document lays the foundation of the devolution of control of health care in South Africa to lower levels of authority, with decentralization of health care provision to the provincial and municipal governments. It uses a district health care system as a vehicle to implement a strategic Comprehensive Primary Health Care approach. The logic behind this is to create a unifying way of providing healthcare access and ensuring equitable health for all. Further, Comprehensive Primary Health Care would be the strategic approach and vehicle to deliver equitable quality health care (NDOH, 1997). The NHI Bill was finally announced and released in August 2019 and it is currently being debated at the level of Parliament. The core of the Bill is about devolution of care to Primary Health Care are as the main health cover (Malan, 2019).

One of the proposals and policies of the proposed NHI, is a minimum package of services which will be offered to all citizens of South Africa (NDOH, 1997). Considering the huge burden of HIV in South Africa and the unprecedented government commitment to the ART programme, it is unsurprising that over 7.9% of public sector healthcare expenditure presently goes to the HIV care allocations of provincial and national health government. The South African Government currently provides over 80% of the country's HIV funding in the 2018/2019 fiscal year (SANAC, 2017).

The South African HIV/AIDS ART programme that was rolled out a decade ago has changed the face of the HIV/AIDS epidemic in South Africa. Life expectancy has increased from 53.8 in the male population in 2002 to 61.1 years in 2018, and amongst females 57.6 in 2002 to 67.3 in 2018 (STATS SA, 2019). While many populations have benefited from the programme, especially women, who account for over two thirds of the population reached by the ART programme, men have been underserved (Cornell, 2013). More so, gay men and MSM who are one of the key populations at increased risk of HIV infection. A variety of reasons for suboptimal services for gay men and other MSM have been provided in studies. More detail will be provided in the literature review chapter.

HIV/AIDS services in South Africa are provided as part of a package of services outlined in the most recent National Strategic Plan on HIV/AIDS (SANAC, 2017), with a preventive arm and a treatment arm. There are different health actors offering full services and partial services. For example, at public and some private clinics, a full package of services is offered, in which some NGOs with clinical services offer prevention messaging, HIV testing and counselling services and referrals to public hospitals and clinics if necessary; other NGOs offer outreach services to communities that are underserved, providing behavioural messaging and HTC and referrals, but no clinical services of their own. The government and NGOs have used task shifting of services in a variety of ways to increase ART access. For example, in the past, this system was used to integrate services in primary healthcare clinics.

The government is currently using Nurse Initiated Management of Anti-Retroviral Treatment (NI-MART) as a task-shifting method to increase access to ART (Nyasulu et al., 2013; Georgeu, Colvin & Lewin, 2012; Fairall, Bachmann & Lombard, 2012). Additionally, the provincial governments of the Western Cape and Gauteng have partnered with NGO clinics run by *Anova* health to create "Centres of excellence" where large groups of gay men and other MSM are offered equitable and acceptable, high quality services to address their specific needs and mitigate the effects of HIV infections and transmission (Rebe & Mcintyre, 2014). Other kinds of collaboration between provincial governments and NGOs are also taking place. For example, the TEN81 clinic ran by OUT LGBT Wellbeing in Tshwane represents the first integrated clinic that offers services to key populations (gay men and other MSM, and PWID). Collaborations like these are provincial government innovations directed at providing targeted services for key populations and increasing coverage of gay men and MSM living with HIV (Aidsfonds, 2015).

The estimated HIV prevalence amongst MSM in South Africa ranges from 13 to 49% (NSP, 2017). The second and third component in the 90-90-90 strategy involves the following: 90% of persons who know their HIV status should be on ART and 90% of persons on ART should have viral suppression by the year 2020 (UNAIDS, 2015). This means that as the population of persons on ART increases more effort will need to be made to facilitate optimal ART adherence, to ensure viral suppression. The 2017-2022 NSP's strategic objective 4 proposes several strategies to mitigate anticipated ART adherence problems. These include having adherence supporters, adherence clubs, SMS contact reminders, 'return to care' programmes for those who have interrupted treatment, and interventions to limit ART drug resistance (SANAC, 2017). The NSP 2017-2022 recognizes the need to understand the individual and social ART adherence challenges that clients experience and tailor-make support strategies to address adherence challenges.

1.3 PROBLEM STATEMENT

The purpose of running an ART programme is to ensure a high level of adherence among the targeted group and strengthen ways to retain them in the treatment programme. Adherence challenges cut across a wide spectrum of issues, ranging from co-morbidities to spirituality and beliefs as determinants. People may struggle to adhere to treatment regimens, which, in turn, brings about poor treatment and health outcomes. Globally, there is a relative paucity of research on ART adherence among gay men and other MSM, particularly in high burden HIV countries in sub-Saharan Africa. There is some literature on adherence among PWID from the Global North. The intersectionality and interrelatedness of gay men and MSM who also have other marginal identities, (in particular, MSM and gay men who are also injecting drug users) and their experiences of ART adherence remain unexplored in this setting. The societal stigma and discrimination associated with their sexual orientations, anal sex and injectable drug use, the criminalization of injectable drug use, the ostracization of PWID from all spheres of dignified life on account of these intersecting factors and the reactions of others and how these impact on adherence, have received scant research attention (Pachankis, Hatzenbuehler & Starks, 2013). This study aims to explore the lived personal experiences of HIV positive gay men and other MSM and gay men and MSM who are also injecting drug users and to investigate how this may impact on their adherence to ART

1.4 RATIONALE

The first aspect of the rationale of this study relates to its knowledge aspect. The study aims to complement the relatively scant existing literature on adherence to ART in population groups in which HIV prevalence is disproportionately high, such as gay men and MSM, and PWID. The study sets out to achieve this aim by exploring the meaning these key population groups give to situations in which they find themselves and how these situations affect their adherence to ART. In the process, the study is an attempt to arrive at a better understanding of the factors affecting the level of adherence to ART among these groups.

The second aspect of the study's rationale speaks to its practical implications and applications. Access and adherence to ART by marginalised groups is a key issue that needs to be addressed by government, if there is to be a real commitment to fighting the HIV epidemic. However, at present it is unclear whether the initiation and follow up of clients in ART services by healthcare workers adequately take into account the real-life realities and struggles of these targeted key populations. By focusing on the realities and struggles as well as the coping mechanisms of members of these groups, this study aims to reach a holistic understanding of what the ART adherence issues and needs of the investigated population groups are. Based on these identified needs, new ways of thinking about improving HIV services, including ART adherence, can be developed. This new thinking will serve as the building block for developing tailor-made services and strategies addressing the specific and contextualised needs of these population groups.

1.5 OUTLINE OF THE MINI-THESIS

Chapter 1 introduces the study and includes the formulation of the problem statement and rationale for the research study. Chapter 2 focuses on reviewing the relevant literature on barriers to adherence by gay men and MSM living with HIV and gay men and other MSM who have other marginal identities, specifically injecting drug use. Chapter 3 describes the aims and objectives of the study and explains it research design and methodology.

While Chapter 4 presents the study findings, Chapter 5 discusses and interprets these findings. Chapter 6 draws conclusions and makes recommendations for improvements in addressing ART adherence challenges for gay men and MSM living with HIV, as well as a subset within this group who are also PWID.

CHAPTER 2: LITERATURE REVIEW

2.1 INTRODUCTION

This Chapter introduces the key concepts of this study: adherence, sub-optimal adherence and compliance. Thereafter, it reviews the relevant literature pertaining to the factors that have been found to affect adherence. These are first presented for the general population, and then specifically for gay men and other men who have sex with men (MSM), and for a specific subset within this group, namely, gay men and other MSM who are also people who inject drugs (PWID).

2.2 DEFINITIONS OF ADHERENCE, SUB-OPTIMAL ADHERENCE AND COMPLIANCE

2.2.1 Adherence

The WHO Adherence Project 2003 defines adherence, with reference to persons with chronic diseases, as the "extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes – corresponds with agreed recommendations from a health care provider" (WHO, 2003: 18). In the construction of this definition, it was important for WHO to present the patient as an active participant in the process of adherence and as "owning" the process. Strong emphasis is placed on the patient agreeing with the health care provider. Ministerio de Saúde Brazil (2007 and 2008) define adherence as a *collaborative* process that involves the acceptance and integration of certain therapeutic regimes into the daily lives of clients who are in treatment, by obtaining their consent and commitment to participate in decisions about the regimen. Further, it involves a process of negotiation aimed at understanding the clients' habits and how the regimen can fit into their habits and individualized needs, with the aim of strengthening their autonomy to self-care, thus transcending the simple ingestion of drugs. This definition emphasizes the self-efficacy and agency of the client, placing it above just taking the medication and the expectation of the medical practitioner. Adherence on its own is a lifelong event in chronic disease management, and it is not linear. Most patients will go through periods of individual strife or stress that may enhance or constrain adherence.

Specifically, in respect of adherence to anti-retroviral treatment (ART), there is a strict recommendation for 90-95% adherence in respect of virologic and immunologic health. This is important from an individual perspective, in that adherence to medication at that level leads to an increased CD4 count, thus enhancing individual health. From a public health perspective, it is important that adherence at that level renders viral load undetectable, and thus, minimises the risk of HIV transmission by clients of their partners. Adherence to ART cannot be properly defined without being cognisant of control of HIV replication and improved immunologic function along with agreeing to follow up prescribed combination dose regimens, meal plans and executing lifestyle changes.

The Panel on Clinical Practices for Treatment of HIV Infection, convened by the Department of Health and Human Services (DHHS) and the Henry J. Kaiser Family Foundation in the United States, also proposed a biomedical based definition of adherence, termed "adherence to treatment", which describes adherence as a three-part process involving linkages to care, regularly attending appointments, and adherence to treatment. It emphasizes the 'continuum of care' (USDHHS, 2002).

However, this definition seems to place the patient outside the decision-making process and seems to emphasize a strictly biomedical understanding of adherence, thereby making secondary the social determinants of a person's adherence to ART. That having been said, adherence involves several subunits: adherence to dosage means the number of pills taken as prescribed; adherence to schedule means pills taken consistently and on time; and adherence to meal plans means pills taken with, before or after meals.

2.2.2 Sub-optimal adherence

Sub-optimal adherence is understood as constituting a deviation from agreed and negotiated recommendations from a health care provider in regard to taking medication, following prescribed diet and executing lifestyle changes (WHO, 2003). With the advent of the newer classes of antiretroviral drugs, the definition of sub-optimal adherence to antiretrovirals has however become more contentious. Adherence studies that established the >90 or 95% rule of adherence for viral suppression were based on un-boosted protease inhibitors (PI) (Oh et al., 2009; Chesney, 2000). In respect of newer ART regimens, for example boosted PI and non-nucleoside reverse transcriptase inhibitors (NNRTI), viral suppression has been shown to be achieved at around just 60% adherence. In his study on adherence, Bangsberg (2006) found that the 95% recommendation for adherence, which is based on the cut off of 400 copies/ml viral load, was not applicable to boosted PI and NNRTI regimens. In fact, his data showed that while un-boosted PI regimen clients had to achieve adherence of 95-100% to achieve viral load counts of 400 copies/ml, for boosted PI and NNRTI based regimen clients, the required adherence rates to achieve adherence ranged between 54 and 100%. The fact that viral load can become undetectable at a much lower adherence rate calls into question what "sub-optimal adherence" in fact entails.

2.2.3 Compliance

Compliance has often been used interchangeably with adherence, but compliance suggests a passive process as opposed to adherence, which places emphasis on the agency, autonomy and active participation of the patient in agreeing to the regimen. According to WHO (2003), compliance suggests the extent to which instructions given by the clinician on taking medication are followed. This takes away the powers of decision-making from the patient and presents a potential danger to the patient-clinician relationship (Chakrabarti, 2014). Doctors and medical practitioners prefer to use the term "adherence" or even "concordance" because of the inclusion of the patients in decision-making.

2.3 ASSESSMENT AND INDICATORS FOR ADHERENCE

2.3.1 Overview

A variety of methods have been used to assess adherence. There is no clear cut "gold standard" for measuring adherence. Methods used in assessment should take into cognisance the type of resource setting and should take into account what is available, affordable, accessible and convenient for the patient and health care provider. WHO (2003) groups measurement of adherence are categorised into subjective and objective measures.

Subjective measures, on the one hand, involve the patient and the provider assessing the patient's medication taking behaviour (Lam & Fresco, 2015). The most commonly used subjective measures are self-reporting and healthcare provider assessment of clients' medication use. The problem with these measures is over reporting, which is linked to the client's anxiety of disapproval by the health care provider about medication usage (Vik, Maxwell & Hogan, 2004). Objective measures, on the other hand, involve tools and methods to assess medication usage of clients outside and beyond their own assessment or the provider's assessment. These include pill counts, medication event monitoring systems (MEMS), and biological markers such as viral load and CD4 counts. They are thought to be an improvement over subjective measures and have often been suggested to improve the validity of subjective measures. It follows that if a subjective measure is used, it should ideally be combined with an objective measure.

In what follows, MEMS, pill counting, self-reporting, biological markers and electronic prescription services and pharmacy refill claims are discussed, before some remarks are made as to the most suitable adherence measure to adopt in this study.

2.3.2 Medication event monitoring systems

Much of the literature views medication event monitoring systems (MEMS) as of superior reliability and validity compared to the other methods (Riekert & Rand, 2002; Neu, 2006). MEMS are meant to track adherence as it occurs, although this is still an indirect method. MEMS rely on caps with chips embedded in them, which track activity on the caps by electronically recording them as they are opened to dispense drugs (Shellmer & Zelikovsky, 2007). MEMS provide critical information to healthcare providers that include daily dosing, inter-dose intervals and drug holidays. In its initial testing and piloting, when it was used for persons with chronic illnesses, including HIV, some challenges were brought to light. Practical problems, including multiple dosing on single opening and opening of the caps without taking the drugs, have raised questions about the reliability of MEMS (Bova et al., 2005; Wendel et al., 2001). Notwithstanding, MEMS is still regarded highly in linking adherence with the medical management of HIV.

2.3.3 Pill counting

Using pill counts to assess adherence involves the healthcare provider manually counting pills that remain between two clinic visits. The number of pills left is then offset against the number of pills dispensed to arrive at the adherence ratio (Farmer, 1999). This is the easiest and most-often used method, especially in resource poor settings. However, it does have some significant drawbacks. It does not, for example, help to track re-fill adherence behaviour and patterns of clients, when these patients have had their medication dispensed to them months before the new refill. It does not help the healthcare provider to discern a pattern of pill taking between hospital refill appointments. Further, some patients present early to pick up their pills even if they still have some left over from previous hospital visit and combine the new refill in one bottle with the old leftovers (Vik, Maxwell & Hogan, 2004). This poses a significant difficulty in assessing their adherence correctly, since pill counting as an adherence-tracking method is based on pills dispensed versus pills used (Farmer, 1999). There is also a significant risk of straining the crucial client-doctor trust building process, as patients may feel their word is not being trusted. Pill counting is based on the same assumption as the MEMS method, namely, that if medication is taken out of the bottle, it is regarded as taken. However, MEMS help to give a more accurate assessment of adherence patterns. Since pill counting does not give an indication of adherence patterns, the causes of adherence cannot be ascertained.

2.3.4 Self-reporting

Self-reporting (in some instances called “patient interviews”) involves the healthcare provider asking patients to report on their own impression of their adherence to the medication regimen. They could ask specific questions, such as how many missed doses they have had in a certain time span. Other follow-up questions can also be asked, like drug names, schedule and indications. Based on the answers, the healthcare provider can estimate the patient’s adherence to the regimen (Lam & Fresco, 2015). This is a subjective method of assessment, and it has several drawbacks, for example, there is a limitation of how far back the patient can give an impression on their medication taking patterns. Further, it also tends to overestimate adherence (Noto et al., 2002). This method requires skilled healthcare personnel to get the right balance to not make the client feel victimized for not taking their medication. If this happens it will potentially bias the responses given by the clients (Farmer, 1999).

2.3.5 Biological markers

In recent times undetectable viral load has come to be regarded as the best measurement of adherence for patients on ART. However, it is important to note that viral load measurements are still unavailable in most HIV health centres in resource-constrained settings. Another form of biological marker involves the measurement of the concentration of the drug or its metabolite in body fluids (blood or urine) and evaluating the presence of the biological marker taken with the drug (Lam & Fresco, 2015). While this is hailed as the most accurate assessment of whether a client is taking a drug or not, it too has its shortcomings. Body metabolisms vary from one patient to the other, and it cannot measure a pattern of adherence, since it can only tell if a drug is taken or not (Farmer, 1999), yielding only a Yes/No answer. It is also regarded as intrusive and a source of anxiety for the client.

2.3.6 Electronic prescription service and pharmacy refill claim

These methods operate from the assumption that a client’s commitment to refilling his or her medication regimen corresponds to that person’s medication taking patterns. It also assumes that medication is taken as prescribed (Steiner & Prochaska, 1997). Not turning up for refills is regarded as non-adherence. The disadvantage of this method is that it does not measure actual medication intake, but merely assumes medication intake based on refills.

2.3.7 Choosing a suitable medication adherence measure

A suitable medication adherence measure should be cost effective, flexible, easy to use, easy to administer, reliable and practical (Vermiere et al., 2001). Clearly, the suitability of a method of assessment is dependent on the setting. Subjective or objective measures are chosen depending on the clinical and research settings.

In settings where they are routinely accessible, viral load measurements remains the most accurate measure of virological suppression and, by extension, of ART adherence. Routine assessment of adherence in combination with viral load measurements remains advised in settings where both are available (Kapaimba, Masango & Mphuthi, 2016).

In most of sub-Saharan Africa, however, there are still huge challenges in providing viral load and CD4 services at health centres available to gay men and other MSM who are on the margins. Viral load measurements are still regarded as too costly and may not acceptable to be used by clients or researchers because of their intrusive nature (Lam & Fresco, 2015). As a result, routine assessment by medical practitioners remains the most relevant in these settings. Self-reporting might be preferable in resource-poor settings with low literacy levels, because it is a quick way to assess medication adherence. Pill counting is more suitable in clinic settings than other service-based methods because of the limited staff and time available to execute, compared to higher resources in research settings. MEMS are not suitable for research settings because of the considerable costs for large research. Pharmacy refill claims are more suitable in this instance.

2.4 FACTORS AFFECTING ADHERENCE TO ANTI-RETROVIRALS

Adherence to ART is a complex and dynamic process. Adherence is not linear, since people living with HIV (PLHIV) often go through periods of adherence interpolated with periods of sub-optimal adherence. The extent of adherence depends on various factors that play an important role in the life of the client. Adherent behaviour is therefore determined by a nexus of interrelated factors that change over time, depending on the changing conditions of the client (Bourdages et al., 2001; Spire et al., 2002). Many studies have been done in both developing and developed countries to establish the barriers to adherence to ART (Golin et al., 2002; MacDonell et al., 2010; Rudy et al., 2009; Jensen-Fangel et al., 2002; Rosen et al., 2007). It is important to note that a significant amount of research available on adherence predates the era of single dose regimen of ART or “treatment as prevention” (Chesney, 2000; Oh et al., 2009). “Treatment as prevention” is a methodology that involves immediately placing HIV positive persons when they test positive on ART, to drastically reduce their viral load, so they cannot infect other persons (Cohen, McCauley & Gamble, 2012). Ickovics & Miesler (1997) categorise factors influencing adherence to ART into patient-related factors, socio-economic variables, the nature of the treatment regimen, the disease characteristics, the patient-provider relationship and the clinical setting. Inspired particularly by the Ickovics & Miesler (1997) study, the present study divides the factors potentially affecting adherence to ART into five main categories: patient-related, socio-economic, health system-related, treatment (medication)-related and family and community-related factors.

2.4.1 Patient-related factors

Patient-related factors are factors directly affecting a patient on ART. These include socio-demographic factors such as age, sex, ethnicity, race, and psycho-social factors such as the degree of social support, psychiatric illness, as well as drug or alcohol use (Ickovics & Meisler, 1997; Ickovics & Meade, 2002; Di Matteo, 2004; Ammassari et al., 2002). In the review below, the following patient-related aspects are covered: socio-demographic factors; psychosocial factors; drug and substance use; disruptions in daily routine; and patients’ beliefs about HIV disease and ART medication. Although they are directly affecting the patient, these factors are influenced by other factors such as socio-economic factors and health system-related factors (discussed in 2.4.2 and 2.4.3 below).

Socio-demographic factors

Socio-demographic factors such as race and ethnic minority status have inconsistently been linked to adherence, with studies reporting divergent results. Some studies have found that the association between race or ethnic status and adherence disappears when stronger factors or key predictors of adherence to ART, such as drug literacy level, drug and substance abuse and depression, are adjusted for (Golin et al., 2002; Paterson et al., 2000; Thrasher et al., 2008). In other studies, the association was found to persist even after these key predictors had been adjusted (Golin et al., 2002; MacDonell et al., 2010; Rudy et al., 2009). Further, stark differences have been observed when comparing black

African migrants in European studies (Jensen-Fangel et al., 2002), with similar studies from the United States. The former does not suggest an association between racial ethnicity and minority status and adherence, whereas cases from the United States often do show associations with race, ethnicity and adherence. South Africa is a similar country with similar adherence issues among black persons as those in the United States. However, in the United States black people have a minority status while black South Africans enjoy majority status (Rosen et al., 2007). It should be noted that it is not race or ethnicity in and of itself, but some social conditions or cultural beliefs, for which it is a proxy, that affects adherence.

Some studies have shown an association between the combination of Hispanic and black American ethnicity, lower income, female sex and younger age, on the one hand, and sub-optimal adherence, on the other (Golin et al., 2002; Murphy et al., 2005; Thrasher et al., 2008; Ickovics & Meade, 2002). Some studies suggest an association, in combination, between age, gender and adherence (Paterson et al., 2000), while others have not found this association (Golin et al., 2002; Diabate et al., 2007; Mouala et al., 2006; Weiser et al., 2003. Some studies like the Wutoh et al. (2001) study found optimal adherence in older MSM. Different studies have shown the association between literacy, level of education and optimal adherence (Hegazi et al., 2010; Catz, Hechman & Kochman, 1999). Other studies have found inconclusive evidence that there is an association between literacy level and adherence (Watt et al., 2009).

Psychosocial factors

A meta-analysis done across low, middle- and high-income countries found a clear association of depression and sub-optimal adherence, with decreased adherence common among clients in low-income countries eliciting depressive symptoms as compared to clients in middle and high-income countries (Uthman et al., 2014). A study conducted in South Africa's Limpopo and Western Cape provinces respectively by Thom & Brandt (2009 as cited by Kheswa, 2014), found that patients with sub-optimal adherence were more likely to elicit depressive symptoms

Research among racial minority youth, majorly black with 36% identifying as gay youth showed that youth with more psychological problems adhered less to ART, exhibited less self-efficacy, and had less social support. This is in consonance with other research done among youth generally (Hosek, Harper & Domanico, 2005; Murphy et al., 2001; Reisner et al., 2009). Gordillo et al. (1999), Rabkin & Ferrando (1997) and Mehta, Moor & Graham (1997) found a clear association between psychological issues and sub-optimal adherence.

Martin, Pryce & Leeper (2005); Mills et al. (2004); Stall et al. (2001) brought to the fore the link between psychosocial problems like depression and sub-optimal adherence and suggested further that this could be worse amongst gay men and other MSM. Du Bois & McKirnan (2012) in their study posit that substance use amongst MSM mediates the effect of depression on health behaviour (increases depression) and leading to cognitive escape and may lead to sub-optimal adherence. This finding is supported by Halkitis & Palamar (2008); Marks, Bingman, & Duval (1998) and Piasecki et al. (1997), who in theory agree that depression can induce substance use as an escapist method of avoidance of positive health seeking behaviour and adherence to ART. Further, sexual minorities, in this instance gay men and other MSM, may deal with minority stress, for example homophobia by engaging in substance use which is associated with psychological problems and in turn often leads to poor health outcomes (Meyer, 1985). Against this background, gay men and other MSM coping with their marginal identity and who also happen to have substance abuse issues or are injecting drug users, are more likely to be depressed and adhere less to ART (Halkitis & Palmar, 2008; Du Bois & McKirnan, 2012).

Drug and substance use

There has been strong evidence of a linkage between drug use and sub-optimal adherence, with injecting drug use leading to worse adherence (Marquez et al., 2009; Gordillo et al., 1999; Knobel et al., 1997). Friedman et al.'s (2010) study among homeless PLHIV found a link between substance use and sub-optimal adherence among heterosexual, homeless PLHIV. However, they also found that substance use was linked with being more sexually active among gay men, which over time brings about sub-optimal adherence. Kalichman et al. (2009); and Reimen et al. (2007) had similar findings between substance use and non-adherence among heterosexual men living with HIV, but linked substance use with sexual risk amongst gay men living with HIV, with the substance use progressively leading to sub-optimal adherence.

Among gay men and other MSM, there has been an increased use of "club drugs" (methamphetamine, ketamine and gamma-hydroxybutyrate, cocaine and sexual aids like sildenafil citrate). Several studies have linked these drugs to increased sexual risk taking and as a risk factor for HIV transmission among gay men and other MSM (Gorman & Halkitis, 2003; Romanelli et al., 2003; Slavin, 2004). "Club drugs" in its modern use are drugs used by gay men and other MSM in "chem-sex parties" that could run through several days, typically starting on a Friday and ending on a Monday. This causes disruptions in ART adherence that involves well "thought through" deliberate routines. These drugs are used in combination with one another (poly-drug use). They are meant to reduce inhibition, alter mental states or lead to loss of muscle control e.g Katemine (Freese et al., 2002 and GHB (Teter & Guthrie, 2001) and enhance sexual competence, as in the case of methamphetamine (Drumright, Patterson & Strathdee 2006; Kurtz, 2005). Methamphetamine also reportedly increases confidence and reduces pain (Green, 2003). Methamphetamine in particular has been enshrined in gay male culture as the "gold standard" or 'go-to' drug because of the effects mentioned above (increased confidence to initiate sexual encounters, reduced pain, reduced inhibition, increased sexual appetite and sexual competence) (Freese et al., 2002; Halkitis et al., 2001; Semple et al., 2002). This drug is also linked to periods of disruptions to the user, because of alteration in mental states and the patient from time to time loosing track of time. This is problematic for adherence that needs well thought through deliberate routines and hence this leads to poorer adherence.

Semple et al. (2002) conducted a qualitative study, which identified motivations for methamphetamine use and self-medicating on methamphetamine among MSM as enhanced sexual experience, coping with the reality of being HIV positive, dealing with negative self-perceptions and social rejection as a result of HIV serostatus. The implications on HIV treatment include poorer adherence and virological and immunological failure as a result of poor adherence to ART. This is consistent with a study by Mckirnan et al. (2001) and supports the theory of self-medication proposed by Khantzian (1985), which posits that people do not just get addicted to particular drugs by chance but deliberately choose them for their psychotherapeutic effects. Reback, Larkins & Shoptaw (2003) in their study found two distinct types of adherence patterns among HIV positive gay and bisexual men: planned non-adherence and unplanned non-adherence. Planned non-adherence results from a deliberate decision made by the person who uses drugs to either skip ART doses, increase the length of time between doses or choosing what doses to omit. Since methamphetamine use among gay men and other MSM is linked to a growing culture of “chem sex”, ART drugs are deliberately skipped for reasons like avoidance of “drug mixing”, the duration of these “chem sex” parties, loss of time due to the psychotherapeutic effects of the drugs and also a deliberate escapist route the drug offers (Reback, Larkins & Shoptaw, 2003; Drumright, Patterson & Strathdee 2006). Unplanned non-adherence is mostly linked to the spontaneity of methamphetamine use and how this interferes with the deliberate routine of adhering to ART. Participants in the study by Reback, Larkins & Shoptaw (2003) linked non-adherence to disruptions in cues linked to taking their ART medications such as “time to eat”, sleeping time or waking up time.

Disruptions in daily routine

Watt et al. (2009) and WHO (2006a) have established that persons with more organised daily routines and who institute cues such as reminders in their routines to facilitate their ART pill taking, are more adherent to ART. A study done in Kadutu Clinic in the Democratic Republic of the Congo among PLHIV found that a barrier to adherence was forgetfulness and inability to arrange a schedule around pill taking (Mupendwa & Ntokamunda, 2009). The Dowshen & D’Angelo (2011) and Reynolds (2004) studies linked unintentional non-adherence to issues like forgetfulness, complicated regimens, substance use and substance use toxicity.

Among gay men and other MSM who also are PWID, as mentioned, several studies have established the disruptions caused by “club drugs” in established routines and cues linked to adherence pill taking behaviours (Rajasingham et al., 2012). Another study linked methamphetamine use on a daily aggregate rate to non-adherence on that day (Parsons et al., 2013). There have been studies showing methamphetamine use and its effect on the limbic system in the brain, causing mood disorders (London et al., 2004). Additional frequent stimulant use has been linked to negative affect and in turn lower adherence in PLHIV stimulant users (Carrico et al., 2010; Carrico et al., 2007). Some studies have suggested getting good results with improved adherence, with cognitive behavioural therapy, contingency management, motivational and skills development among methamphetamine users (Parsons et al., 2013).

Patients’ belief about HIV disease and ART medication

A study in PLHIV in St Petersburg, Russia, found that their personal beliefs about HIV disease and ART affected their adherence to ART. A percentage of them believed that HIV disease was a punishment and taking ART medication was a punishment and shameful (Pecoraro et al., 2015). Musheke, Bond & Merten (2013) study established that an individual’s negative experience of their own state of health was a deterrent to initiating ART and continuation after initiation of ART. In the same study, some participants viewed ART medication as poisonous and harmful and attributed the death of persons on ART to the drug itself. An absence of symptoms was linked to doubts of actually having HIV (Beer et al., 2009). Studies from the United States show that the popularity of prevalent conspiracy theories amongst African-American persons, such as the belief that persons who take new ART medications are just government guinea pigs, was associated with non-adherence even after controlling for other barriers to care such as a lack of medical insurance or transportation (Bogart, 2010). These beliefs are linked to a collective social group and not individual based beliefs. A study among rural and urban

Zambians found that persons opted for faith healing and herbal remedies not due to ignorance of the efficacy and benefits of ART medication, but because of a loss of faith in the health system, doubts about their own personal efficacy to be on life-long treatment, and personal beliefs about the toxicity of treatment (Fox et al., 2010; Musheke, Bond & Merten, 2013).

The study findings by Schonnesson et al. (2007) among gay and bisexual Caucasian Swedes found an association between side effects of ART medication and sub-optimal adherence. In this study, medication adherence was linked to beliefs about treatment and the experience of illness and self-efficacy. For example, the study found that the less the illness or side effects, the more adherent the patient will be. These findings are supported by other studies by Ammassari et al. (2001); Gonzalez et al. (2007) and Holzemer et al. (1999). In another study among gay men, an association was found to exist between sexual risk and the belief that ART reduces transmission, and that this association was moderated by medication taking behaviour, with poor adherers taking more sexual risks (Joseph et al., 2009).

2.4.2 Socio-economic factors

Lack of social support, poverty, unemployment, financial status and transportation costs have been identified as barriers to adherence (WHO, 2006). Research done in resource rich countries of the Global North typically cite patient and treatment related factors such as substance and alcohol abuse, complexity of dosing regimen and pill burden as deterring factors (DiMatteo, 2004; Chesney, 2000; American Public Health Association, 2004; WHO, 2004). By contrast, studies in resource poor countries often point to different deterring factors that are more socio-economic in nature (Hardon, Hodgkin & Fresle, 2004), even though substance and alcohol misuse in higher-income countries could be related to socio-economic and political factors.

Socio-economic status

Although "socio-economic status" (SES) is a commonly used term, it is quite difficult to define and measure. According to the Oxford Reference Dictionary (2018), SES is defined as a person's position in society as a result of a mix of occupational, economic and educational criteria, usually grouped into stratified categories. At times these categories are defined simply, like occupational status, which is linked to education and income or further broken down into, for example, level of education, whether the persons resides in a rented apartment or is a property owner. Further, the new dictionary of cultural literacy (2002), as cited by Falagas et al. (2008), portends that SES is a combination of variables that include occupation, income, education, type of accommodation and the specific locality of accommodation (neighbourhood). Literature consistently supports an association between elevated SES and higher adherence to medication in most chronic diseases like asthma, diabetes and survival from myocardial infarction (Ickovics & Meade, 2002; Di Matteo, 2004; Sonia et al., 2005; Hsi, Chen & Lee, 1990). It is not clear if an association between higher SES and better adherence to ART consistently applies to PLHIV, even though adherence levels are higher amongst PLHIV generally compared to other chronic disease (Golin et al., 2002). The suggested pathways through which the three main components of SES (education, income and occupation) may facilitate increased adherence are as follows: Education places the client in a favourable position to have better opportunities and a secure future, access health information and resources. Income influences access to medication and treatment facilities. Occupation may determine adherence through parameters of workload, stress and type of work. For example, the experience of men engaged in mining in South Africa, who are exposed to damaging environmental conditions can deter adherence. These circumstances could serve as a determinant of lower on the SES scale and could be a predictor of poorer adherence (Adler & Newman, 2002).

That having been said, evidence from literature on PLHIV does not seem to establish a direct link between SES and adherence. A systemic review by Falagas et al. (2008) could not establish a consistent association between SES and adherence to ART. The review looked at the separate components of SES (education, income and occupation) and tried to find a statistically significant links with adherence in PLHIV. In 14 reviewed studies, only 7 found a statistically significant link between SES and adherence. Out of these 7, four identified the cost of ART and living conditions as factors preventing clients from adhering. In the studies that found a significantly positive link, an increase in income level was associated with improvement in adherence (Laniece et al., 2003; Perretti-Wattel et al., 2005; Kalichman, Ramancandran & Catz, 1999; Weiser et al., 2003). In the other three studies in persons with a higher SES, a link was found between adherence and higher yearly income.

In a study by Morse et al. (1991) in which 13 studies were examined, education was found to be statistically associated with adherence in only 4 of them (Golin et al., 2002; Goldman & Smith, 2002; Kalichman, Ramancandran & Catz, 1999). In one of the studies in which there was a positive link, health literacy among persons with a higher SES was associated with better adherence, although health literacy was also associated with health care providers' supportive manner in giving instructions. However, health literacy may also be present in those with lower SES. Employment on the other hand was not associated with better adherence in the reviewed studies. This study aligns with some of the findings by Peltzer & Pengpid (2013), who performed a systemic review of the association between SES and adherence to ART in low- and middle-income countries. This study also showed an inconsistent association between the SES and adherence, although it did show a positive trend in the association between the different components of SES (income, education, employment/occupation) and adherence to ART. Hence the evidence is conflicting and ambiguous on SES and ART adherence.

Financial problems

A study on PLHIV in Ethiopia found that 48% of the study participants attribute non-adherence to financial problems. It also found that middle to higher income families manifested higher adherence in PLHIV than lower income family groups (Tiyou et al., 2010). A study conducted by Traeger et al. (2012) among African-American gay men and other MSM found that non-adherence was associated with an annual income lower than $20 000. This tends to place those with a lower SES in terms of economic status, on a deprivation slope and supports the link between income stratification and the ability to adhere. A study by Micheni et al. (2017) in Kenyan MSM linked financial problems to access and lower adherence to ARV treatment, and further linked continuous societal ostracization of gay men and other MSM with worse access to financial means.

Food security and dietary habits

Food security, which is a structural level factor, was associated with sub-optimal adherence in several studies (Unge et al., 2008; Musheke, Bond & Merten, 2013; Kalichman et al., 2012). Further, it has been linked with poorer health choices, including lower medication adherence and more sexual risk-taking behaviours (Anema et al., 2009; Singer, Weiser & McCoy, 2015). Participants in the Kenyan and Zambian study cited fear of adhering to ART medication on an empty stomach, taking cognisance of the dietary requirements, as associated with lower ART medication adherence (Unge et.al, 2008; Musheke, Bond & Merten, 2013). This fear is linked to adherence advice received from health care practitioners on initiating ART, which emphasises the importance of a good diet to support the efficacy of the drug. This holds true for PLHIV, because as there is already a case for suppressed immune systems. Hence inadequate diet will be an additional burden on an already suppressed immune system (Pellowski, Huedo-Medina & Kalichman, 2018; Kalichman et al., 2012). Food insecurity is linked with poverty and availability of resources. "Resources" are material and tangible, taking the form of transport to clinics, to grocery stores to get food, and the means to purchase groceries; but are also mental or psychological, such as an individual's innate resources to deal with mental health-depression, to cope, and act with self-efficacy. There are clear pathways in which tangible resources can deplete mental resources. For example, a lack of food can lead to the depletion of mental resources, through depression, stress or lack of social support. This can affect the ability to make good health choices such as those related to adhering to ART (Pellowski, Huedo-Medina & Kalichman, 2018).

Among gay men, body-image satisfaction is an interesting angle from which to view dietary choices. Body-image dissatisfaction has been linked to issues like over exercising, feeding disorders, over-eating and dietary restraints (McFarland & Kaminski, 2009; Olivardia et al., 2004; Feldman, Torino & Swift, 2011). In PLHIV who used the first-generation medication (stavudine, zidovudine) HAART regimens, lipodystrophy was a common side effect. It is a syndrome that presents with unequal distribution of fat across extremities like the face, abdomen or breasts. This can result in dissatisfaction with body image and affect dietary habits that can lead to ART non-adherence (McFarland & Kaminski, 2009; Olivardia et al., 2004; Feldman, Torino & Swift, 2011).

Social support

Social support has been associated with improved adherence to ART (Morse et al., 1991). Social support refers to receiving emotional support (positive assurance), informational support (counselling and guidance about HIV) and instrumental help (giving goods or tangible commodities) from persons who have intimate relationships with the client. This latter includes relatives, partners, children and friends with whom the client enjoys satisfaction, a positive mind-set and assurances from this supportive arrangement (Schulz & Schwarzer, 2004). It is thought that since social support is about positive affirmation, it might enhance self-efficacy (Bandura, 1997). This holds true, as a client must navigate a complex continuum of care, with different stages, from diagnosis of HIV to linkage to care, ART initiation, retention in care and adherence to ART. It is not clear if social support facilitates all these stages and if a direct link between social support or if links with all the HIV care stages are just hypothetical. Nonetheless, there are clear linkages between lack of social support and lower level of adherence to ART (Atkinson et al., 2008; Catz et al., 2000; Murphy et al., 2004). Further, there is evidence to support, for example, someone providing concrete support such as helping a client collect medical refills from the clinic and adherence to ART (Ulett et al., 2009; Vyavaharkar et al., 2007; Gonzalez et al., 2004; Kelly et al., 2014). McCoy et al. (2009), Kelly et al. (2014) and Gardener et al. (2004) found a link between social support and linkage to care in PLHIV.

A study done amongst African-American and Latino gay men and other MSM found that the nature of support networks was important. If African-American gay considered satisfactory and positive support from friends, HIV specific health care provider support and other HIV positive networks (Galvan et al., 2008; Tobin & Latkin, 2008; Wohl et al., 2010; McCoy et al., 2009) had a positive impact on adherence to ART. This is in sharp contrast to other studies that found emotional support and HIV specific support less significant to adherence, compared to more tangible forms of support like a friend collecting medication or reminding a person to take medication (Gonzalez et al., 2004; Kelly et al., 2014; Taylor et al., 2010). Among Latino gay men, family networks were found to be very important, but are also associated with stigma and discrimination. In Latino MSM, family networks and HIV-specific health care provider support was more important than other forms of support and adherence to ART (Wohl et al., 2010). Another study conducted with African-American and Latino gay men and other MSM shows a link between social support and accessing HIV care only when there is disclosure of status to a significant number of their social networks (Wohl et al., 2010; Waddell & Messeri, 2006). It is thought that HIV disclosure brings about stigma reduction and facilitates the client pursuing HIV care and hence facilitates ART adherence without fear and shame (Wohl et al., 2010). The study by Wohl et al. (2010) found that disclosure to social networks was associated with retention in care and adherence to ART and not necessarily the support acquired from the social network. The lack of disclosure of HIV status to social networks supports the literature on high levels of stigma and discrimination in the MSM communities and the importance of addressing stigma and discrimination to improve adherence to ART and retention in care.

In PLHIV who are injecting drug users, a study found that female support and emotional support was associated with more outpatient visits to receive HIV care and adherence to ART. Further, the Knowlton study (2005) also suggests that social support may be associated with better adherence to ART in PWID (Knowlton, Hua & Latkin, 2005). The Lancaster et al. (2019) study explored tailoring service to PWID based on their individual perceptions of what system and structural barriers exist in their navigation of HIV/ART care. It confirmed the relevance of social support in adherence to ART.

Transport costs

Studies conducted in developing countries in Asia and sub-Saharan Africa point to other factors like transport costs, diagnostic costs and travel costs to access treatment (Wasti et al., 2011). Multiple studies have shown the importance of proximity of ART clinics to clients to reduce other cost burdens like transport costs (Kagee et al., 2011). A Ugandan study found that giving PLHIV transport vouchers significantly improved adherence (Emenyonu et al., 2012). Kempf et al. (2010) and Boehme et al. (2014) cited lack of transport fare support as a hindrance to optimal adherence. The Magesa et al.

(2014) study in Tanzania with MSM identified the financial hardships of gay men and other MSM in having to travel long distances to access “MSM-friendly clinics” for services. This finding was similar to that of a South African study by Rispel et al. (2012) with gay men and other MSM who had difficulty in accessing HIV treatment care services. This was because of the need to attend MSM friendly clinics for ART services, which are scarce.

Homelessness and unstable living conditions

Several studies have found the interconnectedness of homelessness, substance use, HIV risk taking behaviours and sub-optimal adherence. There are several studies that found that homeless people are more likely to sell sex or engage in survival sex (Greene, Ennett & Ringwalt, 1999; Surratt et al., 2004), have substance use problems (O’Toole et al., 2004), become infected with HIV; and less likely to adhere to ART medication (Culhane et al., 2001; Estebanez et al., 2000; Aidala et al., 2007; and Kidder et al., 2007a).

A study among bisexual men living with HIV in the United States associated periods of homelessness and unstable housing with sub-optimal adherence (Arnold et al., 2017). Miloy et al. (2012) explored the health outcomes of PLHIV who are also PWID and homeless but had access to universal free healthcare. The study results found a clear link between homelessness and sub-optimal adherence. This was in keeping with another study that explored homelessness in PWID who did not have free universal health care access (Berg et al., 2004). The difference between these two studies is that the Berg et al. (2004) study may not have been able to distinguish the effect of homelessness on adherence, without cofounding with financial constraint in its analysis.

Unstable livings conditions in PWID often involve arbitrary arrests, detention and incarceration. Studies from the United States, which display a punitive approach towards drug use, show that the retribution, rehabilitation, reduction in crime and corrective intent of criminalising drug use has not delivered the intended results (Clark, Dolan & Farabee, 2017). As a matter of fact, drug dependent offenders are more likely to return to prison than other prisoners Columbia University (2010, as cited by Clark, Dolan & Farabee, 2017). Public health interventions that have yielded positive results in countries like Portugal could be emulated. Public health interventions include (1) decriminalising illicit personal use of drugs, (2) ensuring access to ART drugs and drug dependence treatment (in case of detention and incarceration), and (3) more focus on the demand-side and harm reduction, as opposed to on the supply side (Clark, Dolan & Farabee, 2017). The Lancaster et al. (2019) study stresses the importance of designing evidence-informed programmes in conjunction with PWID, drug control sectors and law enforcement in order to secure successful programme implementation tailored to the needs of the PWID.

2.4.3 Health system-related factors

One of the most important determinants of effective engagement with health services and optimal adherence to ART is access to a functional good quality health care system (Merten et al., 2010; Mannheim et al., 2005; Micheni et al., 2017). Access to a functional good quality health care system is related to non-judgemental attitudes and competence of healthcare system staff. Gay men and other MSM, PWID, are particularly disadvantaged in this regard, as they experience difficult challenges in access, often related to repressive legal environments and related stigmatisation. Against this background, WHO along with UNAIDS in their guidelines, adopted a rights-based approach to treatment and care for gay men and other MSM (UNAIDS, 2015).

Patient-health provider relationship

A study in Botswana (Wesier et. al., 2003) associated optimal adherence with patients' perceptions of being treated with respect and dignity. Van Loggerenberg et al. (2015) and Treves-Kagan et al. (2016) in South Africa found stigmatization attitudes by healthcare providers as a deterrent to initiate and adhere to ART. Lyons et al. (2016) reached similar conclusions in Mozambique. Several studies profiling the experiences of racial and ethnic minorities in the United States found that racial or ethnic minorities were more likely to have negative experiences and unfair treatment in health service, compared to white patients, and as a result are less likely to register trust in healthcare providers (Piette et al., 2006; Trivedi & Ayanian, 2006; Doescher et al., 2000).

The Arnold et al. (2017) study with bisexual men associated a trusting relationship with a clinic, which gave access to clinical trials to test compatible drugs to their strain of HIV, with adherence. In countries with a stifling legal and policy environment, which brings about heightened stigma and community ostracization of gay men and other MSM, the importance of a trusting patient-provider relationship has been associated with optimal adherence among gay men and other MSM (Cloete et al., 2008; Fay et al., 2011; Graham et al., 2013). The Rispel et al. (2011) study, which looked at health service utilization by MSM in South African cities, found that key barriers to adherence included personal perceptions of competence of healthcare providers in attending to their needs; issues of compassion and stigma reduction which has an additional dimension in the case of bisexual, gay and MSM; and trust and confidentiality. This is corroborated by another study in the United States by Mimiaga et al. (2007), which found that MSM refused to seek adherence services due to lack of confidentiality, as well as stigma and discrimination they experienced at the hands of healthcare providers. Lane et al. (2008) and Magesa et al. (2014) both found that issues of confidentiality weighed significantly on MSM's attitudes towards adherence. For example, gay men who were a part of the study in Tanzania by Magesa et al. (2014) revealed situations of open rebuke by healthcare providers, finger pointing and sharing information in clinical settings as factors inducing non-adhering to ART. These men were terrified of returning to those clinics – which were often the only clinics available to them – for refills. Further, issues of lack of competency and culturally sensitive interventions tailored to gay men and other MSM were clear concerns hampering adherence among study participants from a United States study (Beckermann & Fontana, 2009).

Lack of friendly and competent health care service providers

Gay men and other MSM in sub-Saharan Africa bear the brunt of being on the margins, being the "other", a process that is facilitated by prevailing legal and policy environments. As a result, gay men and other MSM are more likely to have negative health seeking behaviour and present late for ART care (Micheni et al., 2017; Baral et al., 2009; Risher et al., 2013). In countries where homosexuality is illegal, the prevailing legal and policy environment leaves healthcare providers in a difficult situation of choosing between their ethical duties as medical practitioners and breaking the law. Against this background, healthcare workers by association are also secondarily stigmatized, especially if they have undergone sensitization training and are seen to be supportive of gay men and other MSM who access healthcare. Notwithstanding this, healthcare worker training was associated with improved attitudes towards gay men and other MSM, which in turn led to more trusting patient-provider relationships and improved ART adherence (Van der Elst et al., 2015). Competency and sensitization training related to gender non-conforming people, which is embedded in curricular of pre-service and in-service healthcare providers is thought to probably improve secondary stigma (Micheni et al., 2017). Physician reports of attending continuing education update courses on HIV treatment and care, awareness of the United States Department of Health and Human Services Panel on Antiretroviral Guidelines for Adults and Adolescents (DHHSS ART guidelines) and implementation of these guidelines were associated with more patients enrolling for ART services by these healthcare workers and subsequent adherence (Bogart et al., 2000). Some studies have also raised the issue of cultural competency of healthcare providers, associating cultural and ethnic commonalities with more trusting relationships between patient and providers (Arnold, Weeks & Benjamin, 2017). This is ideally integrated with other commonalities such as sexual orientation.

Health system settings and structures

South Africa and North America have interesting parallels in the way the health system is structured. Whilst the North American system historically excluded black persons who are racial/ ethnic minorities, the South African apartheid system excluded black persons who are racial /ethnic majorities. The commonalities between the two situations are disempowerment and disenfranchisement. An institute of medicine study from the United states tasked with addressing racial and ethnic disparities in access to health care identified: health insurance status, state of health systems, patient and health provider attitudes and behaviour and expectation as contributors to challenges in access (The National Academic Press, 2008). These have clear parallels to the South African reality. Access to healthcare and adherence to ART in South Africa is a factor of socio-economic status, education, cultural gaps with a close relationship between class and race and white persons having more means to resolve the personal costs involved.

Further the importance of setting up integrated services or integrated models of care and ART clinics being a one stop shop where all tests, consultations and a multidisciplinary team (inclusive of peer educators, laboratory scientists, adherence counsellors, nurses and medical doctors) are available to the clients cannot be overemphasized (WHO 2006a; Beane et al., 2014; Carhill, Mayer & Boswell, 2015). The data from medical schemes in South Africa tell a different story, with a prevalence of fragmented care and availability of services in different disparate locations. This creates an additional level of difficulty for gay men and other MSM who already exist on the margins of society with poorer access to good, tailored healthcare. Further, there is data from care and treatment of other diseases within South Africa that paints a picture that care was tailored in medical schemes to white persons and were exclusionary for black patients (Rothberg & Mcloed, 2008; Mathabathe, 2002). It is not established whether the private health sector is currently arranged along the lines of paying power, cultural disposition or provider attitudes. More studies will have to be conducted to establish this.

There is lack of literature on modelling HIV/ ART service within health systems and structures. Most HIV/ART service delivery is modelled with the “one size fits all” thinking. The understanding of HIV/ART service modelling being tailored in such a way that it takes into account the cultural nuances of the target group has not yet been achieved, hence the failure of many HIV/ART retention services. An interesting study amongst PWID in Ukraine, Thailand and Vietnam looked at structural and systems factors outside individual level factors that are barriers to adherence from the vantage point of PWID themselves (Lancaster et al., 2019). This resulted in an HIV/ART service being modelled based on what they identified. Each country and site reports different barriers at the health system level. Vietnam requires a social support person, to register along with the PWID PLHIV, to access services, Thailand, has issues of accessibility to care because of a bad transport system and Ukraine has separate places for HIV testing and HIV initiation, creating an access bureaucracy and loss of clients to the system. These findings generated from the vantage point of PWID helped model the programme (Lancaster et al., 2019) and yielded improved adherence amongst PWID. This poses profound questions about our present HIV/ART service models.

2.4.4 Treatment-related factors

Treatment related factors concern circumstances and dynamics that influence adherence as a result of ART treatment initiation. ART therapy involves taking a combination of drugs for life. This section describes treatment related factors, which include co-morbidity factors, drug stock outs and drug formulations and how this affect adherence to ART. I also highlight their relevance specifically to MSM and gay men.

Co-morbidities

Co-morbidities such as hypertension, diabetes, tuberculosis and mental-health issues make the treatment of HIV and adhering to ART more complex. PLHIV have cited the need to take other medications for other chronic diseases in conjunction with their ART as causing unpleasant side-effects like depression and fatigue (WHO 2003, WHO 2006a; Arnold et al., 2017). Although there is a paucity of research on how co-morbidities and chronic illness impact on adherence to ART, available research suggests that co-morbidities may delay ART initiation (Abara et al., 2014). More research needs to be carried out to specifically link how co-morbidities affect adherence to ART among gay men and other MSM and how they affect gay men and other MSM who are also injecting drug users.

Drug stock outs

Supply chain reliability of clinics and a system that ensures uninterrupted ART supplies were associated with increased adherence in some South African studies (Brennan et al., 2017; Bekker et al., 2014). In South Africa, the roll out of the fixed dose combination (FDC) comprising tenofovir (TDF), emtricitabine (FTC) and efavirenz (EFV) (Davies, 2013) should ease some of the previous problems with taking multiple regimens, which gave patients the opportunity to discontinue one pill out of three taken, due to side effects. Optimizing supply chain management especially in resource- limited settings has been associated with improved adherence in PLHIV (WHO, 2015). A study in Côte d’Ivoire found that drug stock outs led to a significant number of PLHIV discontinuing their ART medication or looking for other available medication combination alternatives (Pasquet, Metou & Gabillard, 2010). With specific reference to gay men and other MSM, more research needs to be done to ascertain how drug stock outs specifically affect their adherence to ART.

Drug formulations

Previously HIV drug formulations involved usage of multiple pills, in different shapes, sizes and tastes and this was associated with sub-optimal adherence Nieuwkert & Gisolf (2000, as cited by Olabanji, 2014). With the emergence of single pill formulations and the introduction of the fixed dose combination (FDC) comprising tenofovir (TDF), emtricitabine (FTC) and efavirenz (EFV) in South Africa, new challenges emerged (Davies, 2013). HIV has moved from an acute illness with mortality within a decade to a chronic disease. This means that the demographic profile of PLHIV is shifting from a disease of the youth, to a more aging population, with co-morbidities such as hypertension, and diabetes and an increased propensity for hospitalizations. This raises issues of correct drug prescriptions and watching out for drug interactions. In a study by Heelon et al. (2007), examining ART prescription and administration errors among hospitalised PLHIV, common errors included: incomplete regimens, incorrect dosages, incorrect schedules, medication-disease interactions, incorrect formulations, incorrect antiretroviral drugs, duplication of therapy, and prescription of drugs with drug-drug interactions. All these impact on PLHIV's adherence and should be taken into cognisance. In South Africa, the roll out of the FDC should ease some of the previous problems with multiple regimens. There is scant research on drug formulations, specifically for MSM and other gay men and injecting drug users, and how this affects their adherence to ART, which calls for more research in this area.

2.4.5 Family and community-related factors

Several studies have associated familial support and support from close friendships to improved ART adherence.

Stigma and discrimination

Stigma can be defined as a "badge of disgrace' associated with a person, consequent on the person's real or perceived deviation from certain cultural standards and norms. This sets them aside from what is regarded as "typical". Discrimination is the behaviour of persons towards the stigmatized persons as a result of the perceived or real deviation from what is considered typical. Stigma is a social process that is installed to enact and re-enact relations along intersecting spaces of social inequality (Parker et al., 2017). To understand societal stigma, we must understand three concepts: (1) social vulnerability, (2) social risk, and (3) social production of space and how these concepts help reinforce stigma and in turn affect adherence to ART.

Social vulnerability explains a departure from some HIV traditions that uses individual level risk to explain social distribution of HIV (Mann & Tarantola, 1996). Social vulnerability describes the position individuals occupy within a social structure and how that position determines their vulnerability to illness. Social risk which has been confused with social vulnerability is quite different but since it references health related behaviour and decisions. It could be a lens through which to understand how social vulnerability mould behaviour in health relevant ways for example adherence to ART. Social risk can be described as detrimental to culturally valued traditions, linked to decisions and behaviour that has severe health consequences that can pose a threat to present or future relations (Hirsch et al., 2009). Social production of space ties all these concepts together when trying to understand barriers to ART adherence. Social production of space explains how occupation of a space is not static and how a space provides an avenue for spatial distribution of persons along lines of social inequalities. As a result, it determines who is included in that space and who is excluded. Gay men and other MSM and a subset of this group who are PWID must constantly navigate stigmatizing spaces that continuously reject, ostracise and devalue them. This constant process of devaluation and exclusion is a hindrance to adherence to ART.

Understanding these concepts and how space helps reinforce stigma, helps to relate to persons who experience high levels of stigma and the discomfort they may find in taking medications in public. As a result, they may skip doses or hospital appointments (Ware et al., 2006; Monjok et al., 2010). In the Western Cape Province of South Africa, HIV is referred to as *ulwazi (that thing – that is known).* As people do not want to be identified with the word connotations, they may default from appointment adherence visits (Cloete et al., 2010). Patients tend to adopt a cost-benefit approach to initiating or adhering to ART medication. If taking ART will cost them their social image, social aspirations, social and economic networks, they will likely opt not to initiate or adhere to treatment (Skovdal et al., 2011; Barton et al., 2000).

Gay men and other MSM who are PLHIV deal with multiple layers of stigma because of possessing multiple marginal identities. Besides the stigma of being PLHlV, they also have to navigate stigma attached to their sexual orientation and sexual behaviour (Crowell et al., 2017; Rodriguez-Hart, Nowak & Musci, 2017). In many studies, stigma has been associated with sub-optimal adherence to ART and bad health outcomes (Schwartz et al., 2015; Risher at al., 2013).

2.5 SUMMARY

Since the advent of firstly, highly active antiretroviral drugs (HAART) and then even more potent single pill medication, called fixed dose combination (FDC) regimens of ART, there has been increases in the life expectancy of PLHIV, including specifically gay men and other MSM. There have been challenges in access and adherence to treatment particularly for gay men and other MSM due to various institutional, social and structural factors as highlighted in the literature review. The issue of adherence to ART is of even more concern for gay men and MSM who are also PWID, due to the criminalization of drug use, the particular disruptions that drug use causes in developing and maintaining daily routines and cues associated with adherent behaviour and the resistance to harm reduction methods. In the joint quest to end HIV/AIDS, a holistic package of care and wellbeing that involves mental health care and addressing social, legal and structural issues will go a long way to improving adherence.

CHAPTER 3: METHODOLOGY

3.1 INTRODUCTION

This Chapter details the aims and objectives of the study, the study design, a description of study sampling methods, data collection and analysis, and the steps taken to ensure the rigour and ethical conformity of study.

3.2 AIMS AND OBJECTIVES OF THE STUDY

The aim of this study was to explore experiences and challenges of adherence to anti-retroviral treatment (ART) by HIV positive gay men and men who have sex with men (MSM) and a subset within this group who are injecting drug users, in a clinic in Tshwane. The study's objectives were to describe and better understand the following:

- the lived personal experiences of gay men and MSM living with HIV on ART;
- the challenges gay men and other MSM living with HIV face on ART;
- the lived personal experience of adherence amongst gay men and MSM and gay men and MSM living with HIV who are also people who inject drugs (PWID); and
- .how the interplay of having different marginal identities – being simultaneously gay or MSM, and a PWID – affect adherence to ART.

3.3 STUDY DESIGN AND RATIONALE FOR CHOICE OF QUALITATIVE RESEARCH

In keeping with the nature of the research problem, as well as the study's aims and objectives, I adopted an exploratory qualitative study design, situated in a phenomenological epistemology. Qualitative studies aim to understand attitudes, perceptions, experiences and how life circumstances affect phenomena. They explore the meaning people give to situations in which they find themselves and how these situations affect their decisions (Robson, 2011). In this vein, this study explores the choices and experiences of adherence to ART of gay men and MSM and gay men and MSM living with HIV, who also inject drugs. This study considers the societal challenges they face and the facilitators in accessing health services and adhering to ART, resulting from their identities and struggles, and of being gay men and MSM living with HIV. For the purposes of grounding this study, as well as the findings and subsequent discussions, I introduce two concepts: (1) "passing", and (2) "congruence". This is in order to better understand the intersecting oppressions these men face.

Being "passable" stems from the process through which sexual and gender minorities negotiate spaces in their daily lives and refers to how efficiently they can do it, without being scarred by stigma, discrimination, violations and violence. "Congruence" is similar to "passing", but "congruence" addresses harmony or a harmoniously consistent presentation of self, across all spaces, in order to "pass" in all these spaces and escape stigma, violence and violations.

This study uses an experiential narrative lens provided by qualitative research methods, in answering the research questions. The key research questions are: What meaning do the study subjects give to the situations in which they find themselves, and how do these situations affect their adherence to ART? Linked to these questions, is a third question: What are the ART adherence issues and needs of the investigated population groups? By answering these questions, the facilitators and barriers to adherence peculiar to these groups will be revealed, and the effect of having multiple marginal identities on ART adherence will be better understood.

Schwandt (2007) theorizes that constructionist approaches, utilized in qualitative research, stress the experiential world as it is lived, felt and experienced by people in a social space. The constructionist ontology in which qualitative research is situated, can therefore help illuminate for the researcher the everyday reality and struggles of gay men and other MSM with ART adherence, from their own perspective, especially taking into account the context in which they exist. Firestone (1987) suggests that qualitative research overcomes the abstraction evident in quantitative research through rich depiction and strategic comparison across cases. By using a qualitative approach, this study seeks to contribute to a deeper and richer understanding of the underlying issues and needs of gay men and other MSM living with HIV with respect to ART adherence. Based on these identified needs, new ways of thinking about improving HIV services, including those aimed at improving ART adherence, can be developed. This new thinking could serve as the building block for developing tailor-made services and strategies addressing the specific and contextualised needs of gay men and other MSM on ART.

3.4 STUDY POPULATION AND SAMPLE PROCESS

Study population: The study population consisted of gay men and other MSM living with HIV, who were enrolled in the ART programme at a clinic in Tshwane.

Sampling process: A purposive sampling method was used. Sample size in qualitative research depends on motivation for a specific enquiry (Holloway & Wheeler, 2013). Therefore, situations, people and events most likely to reveal information-rich data about the problems being studied are selectively chosen. Hence, participants most likely to provide depth and richness of information were selected for this study. (See Appendix 1 for the information sheet shared with clients.) The researcher presented the study topic, inclusion criteria for recruitment and the objectives of the study to the 2 nurses and PWID programme manager. This helped the only 2 nurses and the PWID manager who provide services to the gay and other MSM, in the recruitment process of study participants.

The two nurses were selected for interview, using the ART case register of the clinic. This was based on them having knowledge and insights into the target group, identified HIV positive gay men and other MSM who provided rich stories on issues of adherence to ART. They served as key informants for interview because of their close relationship with the target groups and insights into the study topic. A PWID manager was additionally selected for interview. No sampling was required, since only one person held this position. (See Appendix 2 for the information sheet shared with clinic staff.) The PWID manager along with the two nurses helped identify PWID for the study.

Inclusion criteria: The inclusion criteria for sample in this study, sourced from a study population of HIV positive gay men and other MSM, all enrolled at the antiretroviral treatment (ART) programme at the OUT LGBT Wellbeing (OUT) 1081 Clinic, are listed below: (OUT is a registered non-profit organisation, based in Tshwane, aimed at providing direct health services to the lesbian, gay, bisexual and transgender (LGBT) community, MSM, sex workers, and injecting drug users, including HIV testing, counselling, treatment and general lifestyle advice and support.) Further, OUT'S mandate of offering professional competent health and psychosocial services to the LGBT and drug use community, is funded partly by international donors and to a small extent the Tshwane and Gauteng Department of Health. As a result of this, all OUT clients are offered free services, as this is covered under the funding and partnerships they have established over the years.

- Language: Participants must speak English or Afrikaans.
- Typicality: Participants typical of the black and white racial categories in the South African population. This is important especially taking into cognizance the history of South Africa, the persisting state of segregation among race groups and the different ways in which HIV affects the various race groups based on the history of apartheid and the draconian policies that followed during the AIDS denial years. Scrubb (2011) argues that the notions of white supremacy and the continuous lack of integration of society are continuing barriers restricting efforts of the South African government to transform its health care system.
- Duration of ART: Participants must have been on treatment for at least 6 months, because I aimed to understand if differences in the adherence journey of participants who have recently initiated ART therapy differed from those who have been on long term ART therapy.

Inclusion criteria for health care workers were:

- The nurses must have worked at the Clinic for at least 6 months.
- The nurses must be responsible for case management and treatment of gay men and other MSM enrolled at the OUT 1081 Clinic.

Identification and selection of participants was carried out with the assistance of the two nurses at the OUT 1081 Clinic. Among the gay men and other MSM, a number who formed a sub-sample of those who also inject drugs were identified for interview by the PWID manager and the 2 case nurses.

Sample size: I recruited 6 gay or other MSM living with HIV and on ART for in-depth interviews, 3 gay men and other MSM living with HIV and on ART, who are also injecting drug users and as key informants: 2 nurses and the manager of the PWID programme. I interviewed participants until saturation of data was reached.

3.5 DATA COLLECTION

Existing qualitative studies exploring ART adherence have made use of a number of methodologies, including the following: (i) focus group discussions; (ii) in-depth interviews; (iii) participant observations; and (iv) diaries being kept by participants. The choice of in-depth interviews in this study was informed by the sensitivities linked to ART adherence among gay men and MSM and in particular, injecting drug users in the group. There are still alarming levels of stigma and discrimination targeted at gay men, MSM and as well as and criminalization of those who inject drugs.

According to DiCicco-Bloom & Crabtree (2006), in-depth interviews help both the interviewer and respondent through the interview process, to reinvent meaning by re-enacting perceptions of events and experiences related to health and health care delivery. Further, in-depth interviews explore phenomena in greater individual detail (Britten, 1995) and allow for greater privacy than would focus group discussions. The study topic of this mini-thesis plays itself out in spheres of privacy – everyone’s experience of ART adherence is a private issue and a personal lived reality. Adherence is a very complex and personal issue, reflecting a lifelong struggle that may fluctuate over time, along the contours of a person’s life. To grasp these complexities, in-depth interviews supported by key informant views are most appropriate to obtain rich life descriptions.

All Interviews were conducted in English with an average duration of 45 minutes per interview. In addition, healthcare professional key informants at the clinic were individually interviewed. In consultation with my supervisor, I developed interview guides for the in-depth interviews with participants. (See Appendix 5 for the interview guide with healthcare professionals; Appendix 6 for the interview guide with clients; and Appendix 7 for the interview guide with the PWID manager.) I carried out the interviews in an office, located in a private section at the clinic premises. This was important to allay any fears on the part of participants concerning confidentiality. Face-to-face interviews were audio-taped, with consent from participants. The recruitment process took 2 months. because of work commitments and waiting for approval from the ethics committee (approval came in May/June2019). Recruitment started in July 2019 and I had identified all my participants by August. The field study took place from July until middle September 2019. In the previous year I had done some interviews but decided not to use them and started afresh.

3.6 DATA ANALYSIS

I started the analysis process by carefully listening to tapes and comparing them to field notes which I had kept. Taped interviews were transcribed verbatim. I then analysed the data after transcription into codes and then themes (Thematic Coding Analysis (TCA)), within 10 days of the interviews. Robson (2011) describes TCA as a generic data analysis approach with no theoretical perspective. It involves coding of all parts of data. I grouped together codes with the same label and themes occurring in the data were determined inductively by reviewing the data. The themes then served as a platform for further data analysis and interpretation. Data analysis was done *manually* following the key steps of the TCA. These steps are: familiarization with data set; coding; identifying themes; naming and defining themes; reviewing themes; and the integration and interpretation of themes.

3.6.1 Familiarization with data set

Ritchie & Spencer (2002) define familiarization as a process that involves the researcher becoming acquainted with the transcribed data and gaining an overview of the collected data. The process of verbatim transcription of the data began the process of familiarization with the data. I then read the text of the interviews for illumination and generation of meaning. Extensive notes were taken and read and juxtaposed with the raw data from the transcription, in order to elucidate a sense of meaning to the data. The summary of the preliminary meanings was kept in a journal before coding.

3.6.2 Coding

Gibbs (2007: 38) defines coding as a method of assigning labels to data being analysed to understand what they mean. Pope, Ziebland & Mays (2000) explain "coding" by using a different term. They describe preservation of data in a textual form, which are "indexed" to spawn either analytical categories or theoretical explanations. Against this background, after familiarization with the data set, I scrutinized the textual data for interesting features, behaviour, events and strategies (Gibbs, 2007). Then, I inductively coded them, accordingly. Only actual sentences, phrases and paragraphs were coded from the text. Through a process of constant comparison (Pope, Ziebland & Mays, 2000), textual data was checked against existing codes to see where they fitted in; and another code was formed if the data did not fit anywhere. The next step in the coding process involved closer scrutiny of the data for similar codes within the text, which I gathered under already-identified codes in preparation for identifying emerging themes. A combination of colour coding and cut-and-pasting was employed to cluster the codes.

3.6.3 Identifying and naming and themes

In this key step, I drew themes from clustered codes to decipher meaning from the data. At this stage I analysed the information from the data in a broad and deep way. Relationships and possible linkages between codes, possible themes and different levels of themes were interrogated. For this purpose, I operated in consultation with a researcher from the Centre for Human Rights (CHR), University of Pretoria. This was done iteratively with an extra eye to jointly looking at how the themes capture the meaning of the data. If any possible textual data were missed these could be coded within particular themes.

3.6.4 Reviewing themes

This part of the analysis was concerned with pulling themes into maps or networks on the basis of content or on emerging theory frameworks (Robson, 2011: 483). The themes were arranged in a singular network if they had similar issues but was broken up into separate groupings if issues did not align with the network's overriding main theme. Further, I employed the Attride-Stirling method (2001), which suggests using three levels of themes: global, organizing and basic. The global theme represents the overall impression of the researcher on what the sub-themes represent (organizing and basic) (Robson, 2011: 483). This stage was also undertaken in consultation with the researcher from CHR, allowing the researcher's choices on the extracts falling under each theme to be interrogated for coherence. If not coherent, I jointly worked with the researcher from CHR to find out from where the problem emanated. Problems sometimes arose from the extracts being placed under a wrong theme, or the suitability of the theme itself needed to be interrogated. The Braun & Clarke table (2006) was used to provide a visual representation of the codes and themes. Further, the entire data set was interrogated to scrutinize the alignment of the codes, global themes, and subthemes with the meaning of the actual textual data; and it was established if the data supported these themes. Additionally, common themes emerging from target group of study. Themes emerging from the key informant interviews were noted and distinguished. These were used to validate the client interview data set, where appropriate.

3.6.5 Integration and interpretation

I gave final names to the themes and discarded working names. Further, another round of scrutiny between and within themes was undertaken to juxtapose the meaning from the visual charts and networks with the meaning the raw data communicates. At this juncture, I defined the meaning behind the themes. Miles & Huberman (1994: 245) define this process as "generating meaning".

3.7 RIGOUR

I endeavoured to ensure rigour throughout the life of the study, as discussed earlier. In specific relation to data analysis I made use of the following strategies to ensure rigour: reflexivity, source triangulation and triangulation within the data analysis process.

3.7.1 Reflexivity

The data analysis stage of any researcher is a point whereby bias can be introduced into a process that is meant to generate meaning. Shaw (2010) defines reflexivity as a critical evaluation of self. The focus is to search within oneself in a bid to interrogate perceptions, set believes, motivations and personal reality in reference to research study. For the purpose of the study I underwent a reflexive process that involved looking inwards, to identify, personal vested interests held in relation to the study, motivations and pre-suppositions and reflected them back to self. Goicoechea (2006) theorises that the researcher views a study from a critical vantage point and the interpretation of that study is a product of the researcher's presuppositions, predilections and horizons of thought. Reflexivity is a key tool to reduce the influence of the researcher's own personal sense of consciousness of the study, To ensure rigour, I jotted down the findings from my personal introspection in diaries and notes and declared what they are, before the data analysis process began, and also in the final report. The reflexive process not only helped to ensure rigour in this study, but also enhanced the truth value (trustworthiness) of the data analysis process by constantly bringing awareness to me of my personal horizon of understanding of the phenomenon.

I happen to have a personal interest in this research topic as a black, middle class man, and medical doctor. I have worked within the public, private and NGO systems of health provision for over 14 years and have been fascinated by how the physical presentation of men has caused all sorts of abuse, stigma and discrimination from health care workers. In my personal obsession with this phenomenon and in the current HIV space in which I have now worked for 10 years, I have always thought that the main reason for health care workers' negative attitudes towards gay men and other MSM is their apprehensions about femininity in men. This fear is borne out of the socialization of men which puts a burden on an hierarchical hegemony, with the alpha male positioned at the top as the desirable standard. Gay men and other MSM who present in what is regarded as effeminate ways are at the receiving end of hardships, rejection, devaluation, stigma and discrimination. This plays out in the healthcare system and societal spaces. These systems within society exclude and reject overt femininity in men. Taking this back to HIV and the need for optimal adherence, I have always theorized and wondered if my assumptions and biases are a true reflection of the reason for the exclusion that gay men and other MSM face in most spaces and how this could potentially affect or improve their adherence to ART. I have come into this research aware of my assumptions biases, and acknowledged them at every junction of the research process.

3.7.2 Source triangulation

The study involved two separate respondent target groups who were interviewed. A mentioned, the one group consisted of gay men and other MSM, with whom in-depth interviews was held. The other group, including nursing staff and a manager of the PWID programme at OUT, was targeted for the key-informant interviews. I used source triangulation to interrogate information obtained from the two groups. This contributed to study rigour because it brought together data sets from two different vantage points: one from lived experiences (gay men and other MSM); and the other from expert experiential knowledge gained from professional involvement with gay men and other MSM and PWID. The data set credibility was increased because it was obtained from at least two distinct and distinguishable sources. In analyzing the two distinct data sets, common categories, themes and networks, applying to both, provided rich material for analysis and improve rigour. Differences were also noted.

3.7.3 Triangulation within data analysis

Patton (2002) presents triangulation as a strategy to improve rigour because it involves usage of more than one method. Johnson (1997) enumerates different kinds of triangulation that can be used: data triangulation; methodological triangulation; theory triangulation and investigator triangulation. For the purposes of this study, I used triangulation within the data analysis process by employing investigator triangulation. I made use of the expertise of the supervisor of the study, and a researcher at the Centre for Human Rights, University of Pretoria. They separately scrutinized the data set and codes generated and came up with their own themes and networks and charts and the meaning behind the themes. I conducted two separate de-briefing meetings with the two researchers to compare notes and discuss critically their different perspective in relation to the data set and the meanings and sense they make of it. This was done with the intention of challenging the researcher's assumptions, and questioning decisions through the research process, in order to increase the validity of the study.

3.8 ETHICS

Since this study involves human subjects, it was important that it was guided by sound ethical principles of autonomy, non-maleficence, beneficence and justice. The proposal for this study was submitted for ethics clearance to the Biomedical Ethics Committee at the University of the Western Cape and for approval at the University's Higher Degrees Committee. Ethics approval was obtained prior to data collection from the proposed clinic management. (See Appendix 8 for the ethical clearance certificate.)

The study purpose was explained to potential participants through use of a participant information sheet in accessible English, so that they fully understood what their participation involved. Participants were informed that the interview language was English and Afrikaans, according to their preference. As study participants are part of vulnerable populations, the sharing of potentially sensitive information on their lives and ART adherence may put them at risk. I therefore, ensured that the guiding principles of 'do no harm' and justice, were consistently implemented. As consent is a statement of trust, it is often open to renegotiation (Morse & Field, 1995). Hence participants were free to participate or not, and even if participating, to withdraw from the research at any point. In addition, participants had the right to refuse to answer questions that they found uncomfortable. (See consent forms for clients, Appendix 3; and for staff, Appendix 4). Recording interviews was part of the consent process. Participants were given codes rather than their names being used in interview transcription, keeping their views anonymous. The data is stored in a locked cupboard in my house, to which only I have access. The tapes and notes taken will be destroyed 5 years after the completion of the thesis. Taking the issue of justice into account for fairness, equal sharing, respondent vulnerabilities and contributions (Orb et al., 2001), the overall study results will be disseminated to participants Study identification numbers or pseudonyms will be use in dissemination of findings and participants rather than any names used. For participant autonomy, interviews were held in a private office at the NGO clinic, a safe drop-in centre for key populations. Preparation for an in-house psychologist was arranged for and the psychologist was available throughout the process of the interviews, for any envisaged emotional distress caused by the interview process.

CHAPTER 4: FINDINGS

4.1 INTRODUCTION

This Chapter presents the study sample socio-demographic profiles. Thereafter, it presents emerging themes and sub-themes from the in-depth interviews with gay identifying men and other men who have sex with men (MSM), who do not necessarily identify themselves as gay men. They also present themes from a specific sub-group within this group, namely, gay men and other MSM who also inject drugs (PWID); the manager of the PWID programme; a resident nurse at the clinic; and an outreach nurse. The themes that emerged from the 2 nurses and the manager of the PWID programme are also documented. The themes on gay men, MSM and PWID focus on how they hinder or promote ART adherence.

4.2 SOCIO-DEMOGRAPHIC PARTICIPANT PROFILE

A total of 12 participants were interviewed. The socio-demographic profiles of the nurses (*n=2; I resident nurse and 1 outreach nurse*); the programme manager of the PWID programme (*n=1*); gay men and other MSM (*n=6*); gay men and other MSM who are also PWID (*n=3*) are presented in Table 4.1 below.

Table 4.1: Participant socio-demographic profiles

Participant Cadre	Age	Race	Sex	Employment Status	Participant Coding
Resident Clinic Nurse	32	Black	Female	Employed	Resident Clinic Nurse
Outreach Nurse	29	Black	Female	Employed	Outreach Nurse
PWID Programme Manager	36	White	Male	Employed	PWID Programme Manager
Gay Man 1 (Mr C1)	30	Black	Male	Employed	Mr C1
Gay Man 2 (Mr C2)	25	black	Male	Student	Mr C2
Gay Man 3 (Mr C3)	27	Black	Male	Employed	Mr C3

Gay Man 4 (Mr C4)	23	Black	Male	Student	Mr C4
Gay Man 5 (Mr C6)	26	Coloured	Male	Unemployed	Mr C6
MSM 1 (Mr C5)	59	White	Male	Employed at low paying job	Mr C5
PWID 1 (Mr C1.1)	30	Black	Male	Employed as a peer outreach officer on drug programme	Mr C1.1
PWID 2 (Mr C1.2)	46	White	Male	Unemployed	Mr C1.2
PWID 3 (Mr C1.3)	29	Black	Male	Unemployed	Mr C1.3

Explanation of participant coding in Table 4.1: All gay men and other MSM are coded with the letter C. The 3 PWID persons are coded as C1.1; C1.2 and C1.3.

The nurses interviewed work within two-service model types, offered by the clinic: (i) providers resident at the clinic; and (ii) outreach programme in which the provider goes out into the townships to offer services.

There were 5 gay identifying men and 1 MSM interviewed. Their ages ranged from 21-59. As in the Table above, the two nurses were 28 and 31 years old respectively and the programme manager for the PWID programme was 36 years old.

4.3 EMERGING THEMES

My process of data analysis yielded 5 themes and sub-themes. These themes are in line with the study aim and objectives. These were used to describe and understand the lived personal experiences of gay men and MSM living with HIV on ART and those who also inject drugs. They capture their positive experiences that facilitate HIV care and ART adherence and the challenges they face. Each theme incorporates positive lived experiences and challenges in this regard.

During the results reporting, I will also document the emerging themes from the 2 nurses and the programme manager, for their similarity or difference. It is also noted if they add another separate perspective to those of the clients. These were coded and emerging themes generated as part of the 5 themes.

Table 4.2: Themes and sub-themes

Themes	1. Service integrity	2. Service standards	3. Process of dehumanisation	4. Imagining Re-humanisation	5. Differentiated service modelling and delivery
Sub – themes					
	1.1 Preference for critical mass of similar and familiar people to create user-friendly spaces	2.1 Service reach/ accessibility and competent hassle-free service	3.1 Loss of Control	4.1 Power of Information as motivation	5.1 Flexibility within service delivery
	1.2 Preservation of confidentiality	2.2 Humane sensitive service delivery	3.2 Broken ties with family structures	4.2 Support systems	5.2 Limited ART drug side effects
	1.3 Degrading service and 'difference'	2.3 Comfort of space and service provider	3.3 Homelessness, arbitrary arrest and detention	4.3 Self-Efficacy/Determination to succeed/ Longer life/Faith in higher being	5.3 Use of preventive options in discordant couple relationships and bio markers motivating adherence
	1.4 Stigma associated with sexual orientation disclosure		3.4 Negotiating stigma and discrimination in social spaces		5.4 Drug use culture/ Routinization

4.3.1 Theme 1: Service integrity

All the participants in this study were passionate about seeking care from healthcare workers who attached great importance to delivering an ethical, judgement-free service. Different sub-themes underpinned the meanings attached to the theme. These sub-themes are documented in the Table above.

Preference for critical mass of similar people for user-friendly spaces

Mr C1.1 succinctly explained the importance of establishing a critical mass of similar community persons in friendly spaces as a motivation to seek particular HIV adherence services:

> *Last time when I was with some friends of mine, they also told me that they attending in Sunnyside. And I was also like inviting them here … and they told me like no they … are okay with Sunnyside because of proximity.* (Mr C1.1)

Mr C1.2 like Mr C1.1 reflected on how he had moved to this clinic from another to seek the benefits of accessing HIV adherence services in a supportive similar community context. He articulated this as follows: “Like, well all these guys, I know them for a long time. So, they said switch [from one clinic to another], it’s much easier for me as well”.

It was important for some participants to receive services where there was a critical mass of persons with similar marginal identities, however, some specifically wanted to avoid acquaintances from other spheres of the lives: For example, one participant observed that he did not want his “business out there for discussion because some persons working in the clinic are personal friends or friends of friends”:

> *So, I just… Okay. Coming here, I was a bit fearful and a bit sceptical also to come here because there were a lot of people who work here from the same social circle. So, I knew obviously that there’s is huge chance someone will say something, and it made me feel a bit uneasy.* (Mr C6)

Sharing friendly healthcare spaces with persons who have similar life struggles to one’s own seemed to be of importance and fostered a positive community of support. Hence, this contributes to their lived experiences as gay men living with HIV on ART. Not accessing this represented a challenge.

Preservation of confidentiality

Against this background, all clients interviewed voiced the importance of meticulously guarding their information, as they saw anything less as a breach of confidentiality. If a confidentiality breach occurred, this deterred them from attending these services and led to problems in adhering to their treatment. Mr C2 for example articulates a common encounter at public hospitals that concerned himself, as well as some of his friends, where an aspect of their lives was publicly revealed: “But then obviously when you get in there, oh, that person is gay. They’re like, ah.”.

Mr C1.1 presented what he called a typical scene in the public health clinics from personal experience and accounts of friends and colleagues, as follows: “And one thing … it is protocol for them to respect confidentiality, but they won’t. When they have their tea-time, I know they discuss”.

Most of the study participating clients cited confidentiality as a crucial factor that led to retention in an HIV ART programme.

Degrading service due to ‘difference’

In several interviews this study all client participants highlighted what can be seen as a heightened level of degradation they faced in trying to access HIV services. The presence and extent of the degradation experienced, which was due to stigma and discrimination, was identified as a deterrent to accessing HIV ART services, and to ART adherence. Consider, for example, the interview of Mr C3 as an illustration of how demotivating these experiences could be:

> *Yes, we have, and I have experienced some* [discrimination and stigma] *because generally you know as queer people, some are a bit more effeminate that others. So even walking into a healthcare establishment, they will look at you a certain way. They would make certain comments even when you are talking to them. Because I remember I had an incident with a friend. It was in private health care where he tried to commit suicide. So, the reception on its own upon arrival wasn’t a friendly one*. (Mr C3)

Mr C1.1 corroborated what was typical treatment experienced in several clinics:

> *When I take the other drug users … you get other drug users that are probably injured, and they would have to need to be taken to the hospital. So, they* [healthcare providers] *would give attitude because that person is different. He is probably ‘dirt’, and I am ‘clean’ by that time. .Therefore that person.... she will be* [treated] *worse and when I explain: ‘you know madam I can report you for this ..I even had a violation report too that I am going to write everything, every experience’. This is why I am here, that is where they start being quiet … but… people who don’t know about their rights that is why they treat them…*

Mr C1.3 had this to say about a process of degradation at health clinics:

> *No, State hospitals, I don’t say it in a rude way but, for me, they don’t treat people the same like you know people who come from this background of us are in the street. ..Sometimes, you can go there, you’ll find out you are first in the line; they tell you ‘hey you, you are stinking, what-what, go and bath’, but they don’t realise that you are sick…they must at least help you first before they will tell you those such of stories; you stink, things like that.* (Mr C1.3)

He saw the state hospitals as classist spaces that pre-judged people based on their appearance. He emphasised that he had his 'pride' even though he thought they were uninformed.

Participants related that some healthcare providers discriminated against those who they saw as drug users, 'dirty' and homeless. They had an attitude that the person was responsible for their situation and did not deserve to be helped. This was a deterrent to HIV ART care and retention. Further, the constant devaluation and rejection aligns with my central study objective which is to explore the lived experiences and challenges of gay men and other MSM and a subset within this group who are PWID.

Stigma associated with sexual orientation disclosure

Most study participants elucidated the difficultly in disclosure of sexual orientation in public health clinics, when presenting with a sexually related health problem. Stigma and lack of disclosure that results could hinder appropriate treatment and ART adherence. As Mr C1 explained:

> *…some have a little knowledge about our issues that we face. In some cases, you'd show up with a case of maybe some STI…maybe in the anus, and whatsoever, then they'd be surprised; why, why, how did you get it? No, I've been … why do you have to have sex with other men. Like it becomes, it becomes more judgemental than a health service.* (Mr C1)

As a result, they felt more comfortable attending a specialised clinic for gay men and this could promote care and adherence. Mr C1 had this comment:

> *So, I think on the LGTBI clinics, hence there's a few, but they give proper services to the LGTBI communities, other than at the public services like the general hospital where you go there, it's, the treatment, sometimes you even get afraid to disclose one or two, three things, because you're afraid to be judged…you'll be like thinking.. oh, if I tell this person, what will they say? He's just an old man with probably masculinity issues.*

The resident clinic nurse interviewed corroborated this participant view on the difficulty in disclosure of sexual orientation in public health clinics:

> *… but you also have MSM who will say that, you know what, I'm not comfortable going to the …general population clinic… when I'm there I'm not able to actually disclose what's happening with regard to my personal life or how I a normally, especially with regards to sexuality yeah.*

> *And the sexual practices, they can't sort of open up because of, they don't feel comfortable.* (Resident Clinic Nurse)

These participant reports highlight the stigma participants face in the sexual orientation in public sector facilities. Having to negotiate stigma laden spaces to get access to ART and care was a constant predicament for gay men and other MSM in this study. It posed a constant psychological and emotional challenge to them.

4.3.2 Theme 2: Service standards

Service reach/ accessibility and competent hassle- free service

Over half of the participants decried the absence of sufficient stand-alone competent services for gay men, other MSM and a sub-set of the group who are also PWID. Mr C3's words could not be more poignant in articulating this issue:

> *I will say the reach isn't very extensive. Like there isn't a lot of services that we know of where we could necessarily go to find the help…Where can I obtain help regarding such a thing and where can I learn more about my sexual health and so forth. So, it's not easily accessible.*

The outreach nurse concurred that gay/MSM competent services in Tshwane were insufficient:

> *I think people need to be sensitised in understanding issues because there's a lot of discrimination out there and so they struggle a lot because services are there but they are not offered to MSMs and gay men as equivalent to any other heterosexual male. So, more especially the ones who are visible in showing that they are gay and in terms of their femininity. So,... clinics like ours they are very limited and .. they struggle to come through; many of them in terms of finances, in terms of time; in terms of resources that we have as well.* (Outreach Nurse)

Mr C1 had this impression about service accessibility:

> *It has been scarce for like, quite a period of time, but recently it's improving. We're getting there. Because there is more, okay, outreach is done, there's one or two clinics available that deals with the LGTBI communities… So, the services are accessible, but mostly for people who are in the urban areas. Like in the rural areas they are not getting these services that much.*

About half of the participants mentioned bureaucratic processes at state clinics that are hinderances to attending an ART Programme. Mr C1.1 stressed the importance of fast service delivery in services. Mr C5 put it as follows: “Only the waiting time. That’s terrible”. Mr C4, reiterated the problem with waiting times: “I once went to a public hospital, clinic rather in 2016. The service was not quite up to standard, because we had to wait. I got there around 08:00 and then I only got consultation around 15:00 close to the knock-off time”. Having to go through this process in public health care sectors was a lived experience and challenge for participants in this study.

Humane and sensitive service delivery needed

A significant number of the participants noted the importance of humane, “in touch with the issues” kind of service delivery as a preferred way to access HIV services and encourage ART adherence. The outreach nurse had this to say about humane personalised service delivery:

> *I think people need to be sensitised in terms of understanding issues because there’s a lot of discrimination out there and so they struggle a lot because services are there but they are not offered to MSMs and gay men as equivalent to any other heterosexual male.*

As one participant suggested, there needs to be “some kind of bridge” built between sexual minorities and heterosexual persons that can help facilitate a deep understanding of the intersectional oppressions that sexual minorities face.

Mr C1.3’s view was that while some healthcare providers, especially in the public sector, may be technically competent, they lacked compassion and sensitivity.

Comfort of space and service provider

Mr C3 gave a nuanced perspective about why he decided to access HIV services and what he considered as his primary motivations for adherence. Among these, he highlights the comfort and security of the space and the service delivery process:

> *…I know it’s a place where I can go and I can feel comfortable as opposed to going somewhere and being subjected to a whole lot of negativity. So, I make it a point to come all the way. So, I know it’s a safe space and I know that I will get the services and the healthcare that I need.*

Mr C1 was discouraged at an ART clinic from providing details of his sexual life. This could serve as a barrier to appropriate HIV care and ART adherence. This experience struck a chord for him on the difficulties he had faced in his youth in being attracted to a same sex person:

> *He* [the healthcare provider] *was like, don't go too much into details … there are a few who are sensitised about the Lesbian, gay, bisexual, transgender communities. So, most of them, they still have that mentality of a person who is a homosexual, they are.. and you don't choose to be homosexual... You are born like that. Imagine how hard you, when you're growing up, like with some other kids, they're attracted to the opposite sex, and you're like, no. You pray very hard for that demon to stop, but apparently you grow, and it is still there. So, I think some of them, they still need to learn more. Because they have not, they don't have enough information.*

He interpreted the behaviour of the health worker as a lack of sensitization and comfort of the health worker, with persons who do not fit into what is expected as societal ideals of masculinity. This reinforces the aim of this study, gay men and other MSM in some spaces had to deny their nature and essence as gay men and MSM to be able to get service delivery.

4.3.3 Theme3: Process of de-humanisation

Loss of control

The loss of control as a precursor to the process of what I have termed de-humanisation emerged as a prevalent theme at three levels. The participants seemed to demonstrate loss of control at the personal level, community level and structural level (which all are interconnected). The other two sub-themes are: negotiating stigma and discrimination laden social spaces and trauma.

Excerpts from the transcripts of Mr C1.1 evidence how injecting drug use ravaged the client mind and body. In his articulation of his loss of control, he describes a process that seems like a "stream of consciousness" whereby his injecting drug use decides his decision-making process about his life choices and wishes he could train his mind and body to reject the power the drug had over him, so he could have clarity on what steps to take to turn around his life. When living with HIV it can hinder care and treatment.

Mr C1.3 made it clear that drug use controls everything, even when a person did not want to engage in sex, he needed the money to pay for drug use This makes PWID vulnerable to HIV infection:

> *They don't care, because everything's all about money for them… Ja, for the drugs. Some of us, I can say some people, they don't just like to sleep with men; they sleep with men because of money, they want something from them; they want to benefit, you understand, for them to buy drugs.*

The PWID programme manager concurred on the power of drugs over the life of PWID persons in a drive for money for drug use, emphasizing the loss of control of their lives that occurred:

> *… these people are probably the most resourceful and determined individuals you'll meet in your entire life. Especially the people who we work with who are homeless. And the thing is, they wake up every day with nothing, nothing. And they eat and they "use" and they satisfy their needs and they go back to sleep. But they wake up with nothing. But by 10, 11 they have a hundred rand, 12. One. They have another hundred rand.* (PWID programme manager)

Broken ties with family structures

At the community level, participants mentioned broken ties with family structures and social alienation that followed drug addiction. These acted as barriers to HIV care and ART initiation and adherence. Mr C1.3 commented: "…Like, now, I don't have a job, I'm not close to my family, I live with people that I don't even know where they come from, you understand?".

Mr C1.2 describes the effects of drug use on family relations:

> *In my case, okay, I come from a well to-do family, and ja, I never stole from them, just the things I do, my dad can't handle the drugs, and he can't see me coming home in Waterkloof, coming home, seeing a needle in my arm, dead. He'll kill me, he'll rather kill himself. He said I must rather go. So, if he knows that* [if] *I'm off the drugs and, or just on the ARV's, he will support me right, all the way.* (Mr C1.2)

Homelessness, arbitrary arrest and detention

At the structural level, loss of control intersected with another sub-theme: Homelessness, arbitrary arrest by state actors, and detention. This sub-theme is peculiar to a subset of gay and MSM persons who are also PWID. The PWID programme manager explained that arrest and detention often led to poor ART adherence: "That happens often when they get arrested. For us to get their treatment to them is not as simple as it should be is it is challenging...".

Further, following arrests, PWID are frequently detained. Mr C1.1 gives a clear picture of his experiences of ART disruption during short-term detention:

> *They tested me when I was inside* [detained], *then I told them that I am* [HIV] *positive but the six weeks they couldn't just give me the meds I want … somebody has to bring them for you. They will not give it to you unless if you were to stay for a longer period …they have to also take blood and take it there then your meds would come … By probably that time...you are also attending court, then court will release you.*

The PWID programme manager provided this insight on the greater weight PWID organisations had compared with other peer PWID, in securing ART for PWID in detention:

> *Look, if we go there as programmatic staff and we make a bit of a noise and we throw our weight around and you know, this is my client, he needs to get his tablets, then they ... allow it but if it's another homeless community member walking in saying, Hey, these are my friends, pills they, they won't listen.*

Homelessness is challenging. Homeless people are mobile and at times lose their belongings, including their ART medication. Mr C1.2 talked about spontaneous mobility as a barrier to adherence that once again was resolved by a PWID programme manager:

> *Those times, I ran out of* [ART] *… I was once in Durban and I couldn't access in Durban … if you access in Durban you have to wait in Addington Hospital. A long wait. So, then Nelson, his boss* [PWID programme manager], *came up from, came down to Durban. He brought me back up again*.

Mr C1.1 related a lack of communication with providers to make plans for his medication when away. This meant that support could not be offered:

> *So, then I didn't actually tell them that I was going to go away for a certain time. So, I only had the last bottles. So, I couldn't get them by any other clinic. So, when I came back, I started telling them that you know sometimes I were to go away for like quite some time and not knowing and not prepared.*

Lack of own shelter or private accommodation was hinderance to ART adherence for some clients.

Mr C4 lived in a student commune and described difficulty with taking his ART medication due to lack of privacy; "It goes back to when I take my meds, I have to lock myself in the room and take them you know?" Mr C2 shared the following in the same vein, about a desire for privacy and secrecy:

> *At the time when I was still staying at home, right, so I would hide them in one spot where I know that I will find them; only me who knows that; it stays, right under the dresser. When it's 9 o'clock, I'll sneak out.* (Mr C2)

The importance of shelter and privacy continues to be a challenge for gay men and other MSM and a subset who are PWID. Their lived personal experiences in their journey of ART adherence is often coloured by these challenges.

Negotiating stigma and discrimination in social spaces

Social spaces were challenging for participants of this study who are gay, MSM or in the sub-group of PWID, to negotiate, due to heightened stigma, discrimination, violence and fear of violence members of all these groups experience.

Mr C4 described his uneasiness about disclosing sexual orientation at the first clinic of accessing HIV testing:

> *…I only disclosed here* [at the specialised clinic for gay men and MSM] *because they offer services to understand. It was a matter of protecting you know, myself rather …I didn't want to be seen in a different light or judged or something, so did not disclose in the government clinic.*

Mr C1 described his issues with internal stigma and difficult process of adherence even though he was a HIV counsellor:

> *Even if they weren't saying much, but it was a like a sound board, what I'm telling them, it reflects back to me. Like okay, I'm telling this person to take treatment while I'm HIV positive, as well, I have to take it. So, I, there was, at this point in time, I was so sick. I got admitted to hospital like, I think I was paralysed, because I couldn't move. I had kidney failure, whatever, and a lot of that. So, but, with the good professional help that I got, I managed to get back to my feet. Then hence I adhered to my medication.*

Mr C2 too described they difficulties he experienced with his discrimination because of his sexual orientation in public hospitals:

> *Okay, the reason I moved from like public clinic it's just the way treating Lesbian, Gay, Bisexual, Transgender, Queer and Intersex (LGBTQI) people, like, in a right way; as they should be treated. Ja, so like they would call you names, you understand.*

The outreach nurse concurred on the challenges effeminate gay men faced in negotiating clinic spaces and the discrimination experienced:

> *So, more especially the ones who are visible in showing that they are gay and in terms of their femininity. So, it becomes an issue in these clinics and it's like that and clinics like ours, they are very limited, and we've got broad locations in Tshwane as you can see and such they struggle to come through.*

The PWID programme manager reflected:

> *… they've been pushed to really to the fringes of the edges of the system of society and the communities where they come from, they're not welcome…not welcome in the shopping centre you're not welcome in most places. Exactly, you're just not welcome. So..you do internalize that a lot...*

Mr C1.1 described how he picks and chooses how to in his presentation in his community and at home, due to having been met with stigma:

> *…since actually what happened my grandma is the one that made me not to be comfortable.… there was a time when my gay friends would come to my house then she started noticing that, like he has no more being friends with his normal friends he is always with gay friends every day…He is always with them and fashion shows and he is dressing now funny. Then she tried to make it uncomfortable… since from then I just became that person that doesn't hide it when I am around my people* [gay men] *and ..I had to just practice to live two type lives because I had to be who I am for them at home.*

Mr C4 talked about toning down his sexual orientation expression due to fear of violence:

> *I have a friend who has committed suicide, and I stopped going to gay prides because when we get back from the gay prides, there are people waiting for us, you know, to bash us, to attack us. You know to take our belongings… and it's just not nice living in fear of your own life in a free country.*

The PWID programme manager spoke about a lack of "congruence" or "passing", leading sometimes to violence:

> *… he had a couple of hundred bucks on him and they mugged him, and he went to the police station to try and press charges. They literally laughed at him and mainly because of who he was. He is very flamboyant, he's very loud. He likes to make noise, he likes to prove a point and he wasn't going to let down and eventually they went to arrest him for sort of disturbing the peace was the charge… and I always asked myself: was it because he was a homeless drug user? Or was it because he was gay? … So, obviously the social things have a lot of play …, d sometimes it's better to be MSM* [rather than MSM as well as PWID*] because* [if you are MSM alone] *you can go into a pharmacy and buy syringes.*

All these factors can influence accessing HIV care and treatment and adherence to ART. The phenomena of congruence and 'passability' in social spaces form a constant challenge for gay men and gay men who are PWID. There is a deep psychological conversation to this phenomenon that has not been explored. This needs exploration. Having to 'change' oneself constantly to fit into spaces to get treatment and care is a constant lived experience. These phenomena help shed light on the aim and objectives of this study.

4.3.4 Theme 4: Imagining re-humanisation

Participants described processes that have led to them to accepting their status and motivated them to adhere to ART. These can be categorised into three broad sub-themes: power of information as motivation (personal and external); support systems; self-efficacy /determination/faith and intersectional space of acceptance amongst PWID community.

Power of information and information as motivation for ART adherence

Some participants spoke of information acting as a powerful motivation for ART adherence.

Mr C1 gave a personal account of his experience of initially not adhering well to ART:

> *I started with the treatment, then I defaulted… because I started at the local clinic…the first time you go to the check-up, you are very sick... You go, you get your drugs, then you leave. The next time when you come for a follow up check-up, you see someone, you're like, okay, that person must not know that I'm* [gay and PLHIV] *… then you run off…, until you get sick again.*

Mr C6 expressed his initial denial of his HIV status: "Psychologically, I remember when I got the [HIV virus] … you see they give you this certificate. I burned it". He described the later process of coming to terms with his HIV status and taking his ART medication:

> *… obviously coming from the hood, there's so much stigma. But ..even though it wasn't something I was paying attention to, I somehow subconsciously was Googling what it was about, I tried to get more information online more than I would go and ask anybody who had more information about it, personally. And then the more I read about it, the more…I registered it as not a death sentence and I was like "no, let me just do the right thing for myself and my health and take care of myself".* (Mr C6)

Mr C4 saw his nurse's counselling, as having given him confidence and motivated his adherence. The resident nurse emphasised the importance of information for client adherence:

> *Oh, adhere to it? Because they know the benefits for them, mostly because of…the information, they understand the benefits of being more on the ART and what it means not only for them but for other people as well. Their partners as well.*

Support systems

Study participants fell into two groups: Those who had no support system and decided to travel the journey on their own for the moment and others who had support systems around them.

Healthcare provider support

Mr C1.3 related supportive experiences that promoted ART adherence from PWID programme staff:

> *I will say it's the way they treated me; always like be supportive to me, like 'yebo, man, did you take your ARVs, when did you take them', things like that is the questions they follow up asking me always. How do you feel; things like that.*

Mr C2 concurred saying that the nurse: "… she's the one also who encouraged me to adhere to my medication and stuff like that, and then since then, I was like okay".

Peer support

Mr C6, on the other hand, reported not having peer support, as he feared disclosing his HIV status:

> *…I'm not able to discuss even with my friends like "okay, this is what I'm feeling and it's simply because of one, two, three". So, sometimes I'll just be in the crowd, but I'm not there. And I cry a lot also. I cry, hey? I'm…, in that state where I can't hold it in…* (Mr C6)

Mr C1.2 emphasised the importance of peer support: "Luckily, I've got a couple of good friends that can help with stress and support me. They come, when I'm stressed out, or depressed, they try and pick me up wherever I am".

The PWID programme manager described how loss of peer social support could lead to interruption of ART adherence: PWID management described a process among PWID people whereby they have lost social skills to cope with loss of support or trauma and as a result, stop adhering:

> *… he and his brother were always together and his brother sort of started moving. ..he's moving to go move with a girl, right. ..they had been together for like 15 years hustling together and he was, now he's on his own and he internalized all of that quite badly. And, he decided to stop taking his meds.*

Self-efficacy, determination to succeed for longer life and faith in higher being

Participants used a variety of HIV care and ART adherence coping mechanisms. These included self-efficacy, determination to survive and avoid illness and religious beliefs. Mr C2 articulated a sense of what I term self-efficacy as follows:

> *When I was growing up, I normally hear people talking this okay, once you start this treatment, right, HIV treatment, you should always adhere to it and once you stop taking it, you might fall ill, very sick and stuff like that. So, I was like, okay, let me just get it done and hold on to it, yeah … Well, ever since I started, I never stopped. Never stopped. I never, so.*

Participants expressed the importance of adhering to ART for longer life. Mr C3 said: “So, I think of myself as still a very young person and I would like to live a prolonged life. So, I just had to come and get the help that I needed”.

Mr C1.2 agreed saying: “I want to live longer and if you’re going to default, you’re going to get resistance strains”. Mr C1.1 talked about reclaiming his life back from injectable drugs, by starting the methadone programme as a first step: “How I ended up coming here? It is because of the methadone program. And I was also looking for a job that what’s motivated me of course”. Mr C1.1 got a job in a unit of the programme: “there is a network actually as well that’s called DUG. It represents the drug user rights. That’s the one that I am working for

Mr. C5 cited what I term, “personal self-efficacy” and trust in the medical doctor who initiated him on ART as promoting ART adherence:

> *… if you don’t need medication for that why would there be medication?... I always trust people…in that position. You’re the doctor. You know better than anyone. I was working as a banker for so much years* [and] *I have doctors who have to trust me.*

Mr C1.3 and C5 both credited prayer as motivation for ART adherence. Mr C1.3 observed: “I just pray to God that everything one day will come alright”. Mr C5 concurred saying: “Connect with that religion wise. That helps me...”.

Sexual orientation acceptance

Participants reported acceptance of sexual orientation by peers who were PWID. Mr C1.1 provided this input: “But they just want to know but they won’t ask about me maybe seeing another person that comes here for access… That and that then they accept. They are just curious like everybody else… They are cool". Mr C1.2 reflected: "They don't care because mostly guys are straight here. When the guys are gay, nobody's got a problem. Nobody".

The PWID programme manager agreed with this:

> *Everyone knew him. They were very, very nice guy. And … if* [a] *queen ever faced any stigma or discrimination from other people, the using* [PWID] *community would actually take it on. So, they would actually look after him and protect him, in a way they used to call him 'our gay'. But in a way, no one would stand for someone picking him out on his sexuality, which is very interesting.*

4.3.5 Theme 5: Differentiated service modelling and delivery

HIV and ART retention services have over the years had several service models, to improve either, HIV counselling and testing (HCT); ART initiation and ART adherence and retention in service or combination of all three. Some of the subthemes that emerged can be categorised as: Flexibility within service delivery; Limited drug side effects; Pre-exposure prophylaxis for discordant couples and bio markers as motivation for adherence and harm reduction/understanding drug use culture.

Flexibility within service delivery

Flexibility of provision of ARV medication provision, within service delivery models offered by the clinic was cited specifically by the PWID clients as a strong motivation for retention in service and adherence. Mr C1.1 expressed this as follows:

> *then they started actually making preparation that if ever something like that happens [cannot attend the clinic] at least I would be prepared… they would give me three months [supply] then I do not have to be worried.to organise money, transport to come to town.*

The PWID programme manager shared this reflection on community sensitive delivery of service: "They don't like it [fancy branded buses], but put everything in a backpack go under a bridge and sit on a bucket and talk to people, have conversations and sit there and give out meds [ART] and test and do that".

Mr C1.2 too talked about how his medication was arranged for him, when he was away in Durban:

> *I was once in Durban and I couldn't access* [ART] *in Durban.… if you access in Durban you have to wait in Addington Hospital. A long wait. So, then Nelson, his boss.., came down to Durban. He brought me back up again* [for medication].

The PWID programme manager had these similar views on flexible service modelling:

> *I said in the beginning is what I've experienced is that, once they see you showing value and effort. They really do meet you halfway they know that they supposed to come to the clinic they know that. No, they really do, and they know they supposed to sit in a three-hour queue, they know that you by getting in your car driving to them monthly and giving them their tablets [ARV medication] at the corner. You have saved them three hours*.

> *So, I think the trick we've learnt being around through the years is that when someone says they're ready, and they want to take their treatment, we've got to make sure they get the treated immediately. And then we have to look at the individual's lifestyle and we need to make it as accessible as possible for the individual.*

This shows that this PWID programme, seems to have studied the nuances of the behaviour of PWID persons and modelled an ART adherence programme that considers these by introducing flexibility in service delivery.

Limited ART drug side effects

Seven out of 9 clients interviewed reported that they had initial ART drug side effects like nausea and hallucination, but this resolved itself within the first week of treatment. Mr C4 reported that on ART initiation: "I couldn't concentrate in class because I felt dizzy the whole day, at night I would have nightmares…But …it resolved after a few days".

One of the clients reported having kidney failure with when initially taking the fixed dose combination (FDC):

> *I started with that at the local clinic. Then when I was admitted to hospital, they introduced me to FDC, which is [atriplar?], you name it. So, that's the one that cost me my kidney, whatever, failure, stuff like that. Yeah, it was strong for me; I couldn't take it for long. Then I have to change again, from FDC to that three-pill regimen multiple times per day (Mr C1).*

All but of one of those who had previously had medication side effects had them resolved and said that side effects were not strong enough to prevent them from adhering to ART. The participant who reported kidney failure from FDC, stated he had had no further problems since he had had an ART drug switch. The only client who continued experiencing side effects a year after initiation felt that the side effects were a hindrance to his adherence. He complained that he struggled to eat properly and reported:

> *It’s difficult to take the medication. Every day medication is difficult, but I try my best to. I will not leave it to pass days, but sometimes I just don’t want to feel dizzy from the medication…. Maybe sometimes I have had a little bit too much to drink and I feel like I don’t want to have the medication and then have complications in my sleep. I’m afraid to die in my sleep if I take the meds.* (Mr C6)

For the most part, clients felt that the drugs did not cause significant difficult side effects as to prevent them from adhering to ART.

Use of preventive options in discordant couple relationships and bio markers motivating adherence

A sub-theme that emerged was use of preventive options open to clients like pre-exposure prophylaxis (PREP). PREP and information on PREP for use in discordant intimate relationships. The resident nurse reported:

> *A person will actually kind of give them this information on their profile on dating apps like “grindr”, to say that, this is who I am, I'm HIV positive or I'm HIV negative. If I'm negative, I'm on PREP and so forth. So, people actually want to be on PREP to be able to also… how to put it... to communicate with other people on PREP or to be able to have more chances and options of dating partners.*

This is full disclosure prior to meeting partners and might be seen to foster positive support systems. Some see having information on PREP as a making it their responsibility to protect their partners and a starting point for educating partners on discordance and being a PLHIV. Mr C1.1 reported: “I actually made him go on “PREP”, but I didn’t tell him… I felt that I wanted to teach the partner before, so that he could understand more. Because other people are wrongly educated about it”.

Biomarkers like viral load and CD4 were a sign of good health and fulfilment of the initial motivation to adhere. This included, survival and not wanting to be sick. Mr C1 reflected: “So, but, since from let’s say, 2013, 2014, that’s when I was consistently taking my medication until now. Even my viral load; it’s lower than detectable. I’m good, I can say that”. Mr C4’s view was that: “I don’t have my file with me right now. But the last time I took blood tests, it [viral load] was undetectable”.

Part of being on ART medication is having to have difficult conversations with partners on how they can protect themselves, if it is a discordant relationship. This issue emerged as part of the lived experience of participants in this study.

Drug use culture/routinization

PWID are used to the regularity of taking drugs and so can also routinise taking of ART medication. The gay men and MSM who were also PWID interviewed in this study were all poly drug users. So, they used multiple drugs, classified broadly as “uppers” and “downers”. They snorted, sniffed or injected the “uppers”, which always included methamphetamine, but they used “downers”, mostly heroine, which they all injected. The “uppers” were most frequently taken during the day, and the “downers” as the day wound down. In my study, the routine of “uppers” and “downers” and modelling of ART usage around the mechanism and effects of “uppers” and “downers” led to fashioning ART routine around these practices.

Hence PWID tied their ART adherence to something very important in their day and therefore something very routine. This tied in with different phases of drug use during the day the period of “uppers” and “downers”. Mr C1.2 stated: “I normally take mine at the evenings, at 20:00, and when my PWID friend’ …, and if I don’t take it, ja, that will get onto my head. Because he [PWID friend], makes sure I take it”. Mr C1.3 made this remark: “Ja. I take my uppers first and downers after, my ART, I take in the evening”.

Mr C1.1 had this understanding about ART use and the culture of “uppers” and “downers”, which is important to note:

> *I did ask them, I did actually get to ask a PWID staff and his other colleagues because he* [PWID staff], *is working more, even on the HIV side. So, then he explained it to me very well that shouldn’t disturb me I should continue.*

4.4 CONCLUSION OF FINDINGS

The findings from this study presents multiple factors that potentially could pose as barriers or support for ART adherence. The specific target group of the study were sub-sets in society that continuously deal with multiple levels of intersectional oppressions in their daily life. Further, the study brings to the fore nuanced commonalities and differences in factors that affect adherence amongst for example gay men and other MSM on one hand and a subset within this group who have another marginal identity, which is drug use (PWID). The next chapter will interpret these findings and give a comparative analysis with existing literature and seek to highlight new knowledge emanating from the study not found in current literature.

CHAPTER 5: DISCUSSION

5.1 INTRODUCTION

This Chapter discusses the major research findings relating to adherence to anti-retroviral treatment (ART) by gay men and other men who have sex with men (MSM) and a sub-set within the group who are people who inject drugs (PWID). It further aims to ground the discussion in relation to its study objectives and the relevant comparative literature. To my knowledge this is the first study that explores the intersectionality and interrelatedness of gay men and MSM who also have other marginal identities (in particular, MSM and gay men who also are injecting drug users) and their experiences of ART adherence. This study yielded 5 themes: (1) service integrity; (2) service standards; (3) the process of dehumanisation; (4) imagining re-humanisation; and (5) differentiated service modelling and delivery.

5.2 SUMMARY OF RESULTS

This study was carried out to understand a research problem: what are the lived personal experiences of gay man and other MSM who are on anti-retroviral treatment (ART)? Further, it was intended to help shed light on the four objectives of this study: (1) to understand the lived personal experiences of gay men and MSM living with HIV on ART; (2) to fully grasp the challenges gay men and other MSM living with HIV face on ART The study objectives; (3) to understand the lived personal experience of adherence amongst gay men and MSM and gay men and MSM living with HIV who are also people who inject drugs (PWID); (4) to understand how the interplay of having different marginal identities – being simultaneously gay or MSM, and a PWID – affect adherence to ART. This study yielded 5 themes: (1) service integrity; (2) service standards; (3) the process of de-humanisation; (4) imagining re-humanisation; and (5) differentiated service modelling and delivery. The first theme, ‘service integrity’ relates to ethical expectations of clients in relation to issues like confidentiality and stigma free health care delivery. The second theme, service standards, relates to procedural expectations of clients when they access services. Are the services friendly or competent or both? The third theme, ’the process of de-humanisation’ is a societal ill that puts gay men and other MSM on the margins of society and systematically devalues them. This process is a structural issue and occurs across all societal spaces. This theme cuts across all the 4 objectives and gives depth and richness to the answers to my research question. The fourth theme, ‘re-imagining re-humanization’ speaks to the journey of acceptance of HIV and processes to achieving optimal adherence to ART as a result of this acceptance. The subthemes within this theme speaks to self-determination and efficacy, power of information as tools for motivation to adhere to ART. The fifth theme, ‘differentiated service modelling and delivery’, addresses ART service delivery systems. This is grounded in an understanding of the target population and with copious input from them in the design. My results answer directly my research question by providing rich insights into the behavioural, health systems and structural challenges gay men and other MSM face, in the pursuant of ethical, stigma free health care delivery, friendly and competent hassle-free service delivery. Their constant experiences of rejection and stigma in their pursuit of ART services serve as the narrative within my research of their lived personal experiences. Further my study findings of a process of dehumanization and process of re-humanisation both address structural and personal level issues. For example, the process of de-humanisation is a product of structure and belief systems within a society that excludes, ostracizes and rejects. My study contributes rich insights on the resilience of gay men and other MSM to adhere to ART despite a system that excludes them.

5.3 SERVICE INTEGRITY

Service integrity as a theme within this study relates to the ethical expectation of clients from the facility and staff at the facility. Four sub-themes emerged from the insights provided by participants in this study as critical to adherence and retention to HIV/ART services: (1) friendly spaces with a critical mass of familiar faces; (2) preservation of confidentiality; (3) degrading service; and (4) stigma associated with disclosure of sexual identity. These issues either reflected positive experiences with services that enhanced participants' ability to adhere to ART or were challenges that impeded their adherence.

5.3.1 Friendly spaces with a critical mass of familiar faces

Gay men and other MSM who are also PWID, interviewed for purposes of this study valued the presence of a critical mass of persons from their community in services they attended, thus allowing them to seek and attend HIV/ART retention services in a friendly non-judgemental clinic space. They felt safe in spaces of togetherness with persons who have similar life struggles to their own and saw these spaces as providing a community of support. While some expressed reservations at their first engagement with these spaces, as they knew some of those working there this dissipated with time they became more comfortable and trusting and they felt comfortable after the second or third visit. These lived experiences of health services represented positive elements that can facilitate ART adherence. The contrast in the way in which gay man and other MSM and a subset of this group who are PWID engaged with friendly clinic spaces is interesting. In understanding this phenomenon, one should understand that gay men and other MSM seem to harbour a heightened internal stigma due to being gay, being a person living with HIV (PLHIV), and by further internalising the stigmatised societal perceptions of gay persons. They expressed concern that society wanted to deal only with issues related to their sexual behaviour and not other aspects of their identity. On the other hand, gay men and other MSM who are PWID, by virtue of their PWID identity are most likely homeless and on the margins of society and have gone through a process of devaluation of self. Devaluation and dehumanisation act as hindrances or challenges in their HIV care and ART adherence. As a result of the process of devaluation and dehumanisation, they have lost social skills to engage with society, they feel comfortable only in the company of persons who have the same kind of life struggles, illicit drug use and routine, as they do. Therefore, a critical mass of persons like themselves seems to give them a sense of normalcy, safety and hope. This could potentially be an area of research that needs to be explored.

5.3.2 Preservation of confidentiality

This study confirms the importance of strict confidentiality in delivering HIV/ART services to gay men and other MSM to their adherence to ART (Rispel et al., 2011; Mimiaga et al., 2007; Lane et al., 2008; Magesa et al., 2014). The importance attached to confidentiality can be explained by the stigma still attached to PLHIV in South Africa, the negative history of the disease being associated with promiscuity and death, and the scars left on all South Africans by the government's complicity in the worsening of the pandemic in the country due to damaging policies (Natrass, 2007; Simelela & Venter, 2014)

The creation of an environment of trust between patient and provider that makes disclosure of sexual orientation possible was identified in this study as an important factor in ensuring adherence to ART and retention in ART-related services. Participants who attended services at the facility where this study was conducted related sensitization and competence training of healthcare workers in delivering services to lesbian, gay, bisexual and transgender (LGBT) persons as critical for the healthcare worker being able to relate and understand the nervousness and judgment associated with building sufficient trust for disclosure of sexual orientation. Further, some participants expressed the opinion that because the clinic where the study was conducted caters specifically for LGBT persons and PWID, they felt comfortable to disclose their sexual orientation and drug use. This aligns with several other studies (Cloete et al., 2008; Fay et al., 2011; Graham et al., 2013), which stress the importance of a trusting patient-provider relationship for optimal adherence to ART by gay men and other MSM.

5.3.3 Degrading service

Gay men and other MSM and those within this group who are PWID all gave disturbing accounts of a process of degradation foreshadowed by heightened stigma and discrimination from healthcare providers in their bid to access HIV/ART retention services. The Rispel et al. study (2011), which looked at health service utilization by gay man and other MSM, confirmed that key barriers to adherence included personal perceptions of the competence of healthcare providers in attending to their needs; and compassion and stigma reduction as part of service-delivery. The Mimiaga et al. (2007); Lane et al. (2008); and Magesa et al. (2014) studies all confirm the findings of this study in this respect.

Interesting in this the study is the difference in degradation suffered by gay men and other MSM, on the one hand, and gay men and other MSM *who are also PWID*, on the other. For the first sub-group (gay men and other MSM), degradation was related to hierarchies of masculinity. This hierarchy, in which the dominant male identity is that of the imaginary "Alpha male" is presented as the apex of the hierarchy, and the "effeminate male" is situated at the bottom of the social ladder. Presentation of self as anything below the standards on the hierarchy of what was socially accepted as "masculine", elicited a negative response from healthcare workers. Similarly, healthcare workers displayed negative attitudes based on sexual behaviour. This may be on the premise that gay men and other MSM are "unmanly" in having anal sex. For the second sub-group (gay men and other MSM who are also PWID) the response from healthcare workers was distinctly different. Members of this sub-group seem to have elicited a negative response from healthcare workers as a result of their untidy personal presentation, which render visible their identity as homeless people and users of illicit drugs. It is unclear from this study whether a PWID person who happens to be effeminate in presentation would have experienced triple-layered stigma (based on being effeminate; the perception of sexual behaviour (anal sex); and having a dishevelled physical appearance). Taking all this into account, the study participants were all consistent in their dislike for accessing state hospital and other public sector health services, feeling that this set them back in their adherence journey. It is therefore clearly important to devote attention and resources to stigma reduction as a means to improve adherence to ART services for this grouping.

5.3.4 Stigma associated with disclosure of sexual identity

Participants in this study sharing their personal experiences at state hospitals provide in depth insights as to why disclosure of sexual orientation is still a hurdle to accessing health care for gay men and other MSM as well as those who are PWID. They cited judgemental attitudes, a refusal to acknowledge their sexuality even after disclosing their sexual orientation, rude remarks an attitude that they should 'repent from their sin" as barriers impeding their adherence to ART. Against this background, it is imperative that sensitization, medical ethics and competence training for all hospital personnel – from the reception gate to the hospital to the senior management – be instituted as part of service integrity standards. This supports the findings if Van der Elst et al. (2015) study, that concluded that sensitization training improved attitudes towards gay men and MSM. Narratives from study participants illuminated the specific kind of limitations to HIV service access they experienced and indicate how this may serve as hindrances to ART adherence.

5.4 SERVICE STANDARDS

Service standards relate in the main to procedural issues within relevant healthcare facilities. Participants had clear and specific understandings of what they perceived as the minimum requirements for service reach, accessibility and processes at clinics offering HIV/ ART services. Participants made it clear that good service standards serve as motivation for retention in ART care . In this regard three sub-themes emanated from this study: (1) service reach/accessibility and competent hassle-free service; (2) humane sensitive service delivery; and (3) comfort of space and service provider.

5.4.1 Service reach/accessibility and competent hassle-free service

Study participants highlighted the frequent lack of accessibility to competent hassle-free service, tailored to gay men, other MSM and PWID. Services available that are integrated like OUT 1081 Clinic (facility where study was conducted, which caters to gay men and other MSM AND PWID) and the state hospitals and health services are not suitable to offer the kind of service that is enabling for retention in ART programme for gay men and other MSM. The existing literature supports integrated models of care. These take the form of one-stop-shop ART clinics where all tests, consultations are offered by a multidisciplinary team. This should include peer educators, laboratory scientists, adherence counsellors, nurses and medical doctors (WHO 2006a, Beane et al., 2014; Carhill, Mayer & Boswell, 2015). While there are different definitions for integration, WHO defines it as follows: "The organization and management of health services so that people get the care they need, when they need it, in ways that are user friendly, achieve the desired results and provide value for money" (WHO, 2008). Therefore, the WHO definition qualifies the OUT facility as integrated because of the multidisciplinary approach, user friendliness and ease of access. Therefore, the existing literature supports the preference of participants in my study for a clinic with ease of access, user friendliness and hassle-free delivery of service, as being supportive of adherence to ART.

It appears from my study that services generally are situated in areas far removed from the reach of black gay men and other MSM who hail from either the townships or the suburbs. This can pose a challenge in their ART adherence journey. While some of the study participants talked about distance and transport fares presenting some problems, they seemed to find solace in scheduled monthly appointments that give them adequate time to plan. Hence, the cost of transport did not present itself as a significant hindrance to accessing services and ART adherence. This finding contrasts with some other studies, which identify transport costs and accessibility as important hindrances to adherence (Kagee et al. (in respect of the generalised population), 2011; Magesa et al., 2014 (in respect of MSM in Tanzania)). This difference in findings may be due to the fact that research participants in my study who are PWID benefit from a flexible model of service delivery, tailored to their specific accessibility needs. This may have accounted for why the cost of transport fares did not affect their views on accessibility and as a result their adherence to ART. This aspect will be discussed in more detail later in this chapter under the theme "service modelling".

5.4.2 Humane and sensitive service delivery

A prevailing theme was the importance of the humanity in delivery of service. As one client articulated this, the ideal: service delivery by a health worker is one who is "in touch with the issues", who comprehends the nuances of the difficulty of being gay, black, PLHIV and from the townships and ensures "comfort of space" when clients access services. The intersectional of issues at play here needs to be better understood by healthcare workers. My understanding of this theme that emerged from participants is that they can achieve more optimal adherence if they could have access to a clinic which is reasonably sensitized, whereby there is comfort in "being themselves". Better linkages between sexual minorities and heterosexual persons that personalise experiences may help facilitate a better understanding of the intersectional oppressions that sexual minorities face. This study corroborates another study's findings (Wesier et al., 2003) that allude to more optimal adherence being achieved when clients perceive they are being treated with respect and dignity. This underpins the importance of the sensitization of health workers and their competence in delivering this kind of service. The importance of spaces of acceptance within the healthcare system emerges from the results and the absence of this might pose a challenge to adherence to ART.

5.4.3 'Comfortability' of space and service provider

The study participants, in alluding to "comfortability of space" as a positive platform for adherence and seeking ART retention services, seems to suggest that they prefer stand-alone dedicated clinics where the service is dedicated to gay men, MSM and/or PWID. Part of this assurance or "comfortability" is also knowing that the service providers themselves are gay men, MSM or PWID.

This corroborates studies that underline the importance of “cultural competency” (Arnold, Weeks & Benjamin, 2017), captured in ethnic, cultural and sexual orientation commonalities between service provider and clients. This allows them to have a more nuanced understanding of the issues of these groups. Culturally competent service provision yields more trusting relationships and improved adherence.

5.5 PROCESS OF DE-HUMANISATION

The process of dehumanisation explains the events and lived realities of gay men, MSM and specifically a subset of PWID that put them on the margins of society, depriving them from enjoying dignified lives as citizens of a country. This exposes them to societal ostracisation as a result of their sexual orientation and/or drug-use habit. It is grounded in an understanding of two key concepts: societal stigma; and social production of space.

To understand dehumanisation, one should view the interplay of stigma as a social process, put in place and enacted and continuously re-enacted to enforce power relations and dominance within a space of intersecting inequalities (Parker & Aggleton, 2003). The concept explains the intersectional oppressions that gay men, MSM and a sub-set of PWID must constantly navigate. Navigation involves social spaces, and social spaces are grounds where structural inequalities are at play. Social spaces provide a platform on which structural inequalities shape social life around hierarchical lines of dominance based on the superiority assigned to race, class, gender, masculinity, sexual orientation and social class. These determine confinement, inclusion and exclusion (Garcia et. al, 2014; Low, 2011) in ways that affect health and sexual practices and choices (Hirsch et al., 2009; Keene & Padilla, 2014). Dehumanisation is a process of devaluation of human beings. It is difficult to ensure attendance of HIV care and treatment adherence in a context of loss of identity and self-worth. Four sub-themes emerged from the theme of de-humanisation: (1) loss of control; (2) broken family ties and structures, and homelessness; (3) arbitrary arrest and detention; and (4)_negotiating stigma-laden social spaces. These themes are based on the lived experience of participants of this study, to whom ostracization, rejection and exclusion posed a constant challenge.

5.5.1 Loss of control

Loss of control describes a gradual process that can be likened to a slow leak of water from a hand-operated valve of a faucet, to the point that the valve wears out and the water prattles out like a fountain. Participants in this study described their gradual descent into drug use and the hold it exerted over them, their mental wellbeing, decision making, addiction with finally, injecting drug use becoming the centre point of their lives. For some, it is a story of decline from privilege to being downtrodden, homeless, and deprived of family ties, structure and support systems. What is striking from some of the information gathered in this study is how loss of control seems to happen simultaneously at three levels: the personal/ interpersonal, community and structural. The personal level relates the way in which injecting drug use became a disease and the major basis of decision-making in their lives. At the community level, participants experienced broken family ties, rejection from their communities and eventual homelessness. The structural level reflects the manner in which state actors, in addition, take control away from them through arbitrary arrest, detention and confiscation of their belongings.

This study departs from other studies that have linked sub-optimal adherence specifically to injecting drug use (Marquez et al., 2009; Gordillo et al., 1999; Knobel et al., 1997). In contrast, in my study adherence was optimal among PWID participants. As the gay men and MSM who were PWID interviewed in this study were all poly drug users, using multiple drugs as "uppers" and "downers", the use of a illicit drug routine, seemed to be a key feature to high adherence among gay men and other MSM who are PWID in this study.

Further, findings from my study setting did not concur with previous studies that disruptions to ART adherence were caused by methamphetamine use. Rajasingham et al.'s (2013) systemic review which looked both at qualitative and quantitative studies addressing the behavioural impact of methamphetamine on PLHIV who are MSM, and another study on methamphetamine use (Parsons et al., 2013) concluded that the daily aggregate of methamphetamine use caused disruptions in that day's ART routine. By contrast, my study suggests that loss of control at the personal, community and structural level did not affect adherence to ART. The Rajasingham et al. (2013) and Parsons et al. (2013) studies focused on MSM who used methamphetamine as "sex party" drugs. They did not consider PWID who are poly drug users, or addicts whose whole existence is centred around drug use. Rather, the subjects of their studies seem to be quite functional drug users who used them recreationally. Additionally, the setting of their research could also be a significant reason for the difference in findings. Specifically, in my study the participants on methamphetamine viewed themselves as being "creatures of routine", with lives lived in the same way every day. They found it absurd being continuously thought of as non-adherers when seeking ART services and viewed a person who has drug use at the centre of their life as quite able to accommodate another form of drug use, such as ART, in their routine. My study suggests that understanding the drug use culture of "uppers" and "downers" could potentially help healthcare workers, along with PWID, design an ART adherence model based on building taking ART medication into a personally tailored simple routine for a PWID.

5.5.2 Broken family ties/structures and homelessness

At the community level, broken family ties may lead to homelessness and unstable living conditions. This study confirms other studies that linked homelessness with sex work and transactional sex (Green, Ennett & Ringwalt, 1999; Surratt & Inciardi, 2004) and experiences of substance-use problems (O'Toole et al., 2004). This present study further agrees with a number of other studies (Culhane et al., 2001; Estebanez et al., 2000; Aidala et al., 2007; Kidder et al., 2007) that assert that being a MSM, homeless and PWID may be linked with HIV acquisition, but disagrees, besides the effect of PWID on arrest and detention, with these studies' findings on sub-optimal ART adherence being linked specifically to a combination of with being MSM, homeless and PWID.

In my view, my study confirms the need to 'feed' a habit (poly drug use) at any costs; hence the links of being PWID with sex work and transactional sex. Aside from the benefits afforded by the financial benefits of sex work, having shelter and a bed for night at a client's house, is a temporary reprieve from the reality of their homelessness and offers some comfort Sometimes, they become a regular client of that person and the sex moves on to becoming just transactional. Nonetheless, the motivation for sex work or transactional sex, is the financial reward first and foremost, if an additional reward like shelter comes as a result, then this is accepted PWID becoming HIV positive as a result of this form of sexual relations has to do with the unequal negotiation of power relations (condom use) in this context. The client in this instance has the upper hand in power relations and can decide whether condoms are used, especially if the "end game" of the PWID is to get money for drugs.

The point of departure of my study from available literature as pointed out, remains the issue of sub-optimal ART adherence in homeless PWID with HIV. Existing literature (Tiyou et al., 2012) associates non-adherence with financial constraints. My study did not show any links between financial constraints and ART adherence. In my study, other explanations emerged for high adherence amongst PWID, such as the support, interest and flexible delivery model instituted at the OUT facility, in contrast to the reverse situation. My study was qualitative rather than quantitative and in a different setting. This may contribute to differences in additional to these perhaps being real general differences.

My personal reflection from insights obtained from participants, was that they came to a decision to survive, beat their drug use habit and make something of their lives. This drives their motivation to adhere to ART. Further, PWID participants described how multiple gestures by staff at the PWID programme served as motivation to adhere. Another human being showing interest in their wellbeing, such as the drug counsellors who followed up with them about their wellbeing and adherence, induced retention in the HIV/ART programme.

5.5.3 Arbitrary arrest and detention

At the structural level, the factor of state actors taking further control away from PWID through their arbitrary arrests and detention emerged. Arrest and detention come at a cost to HIV/ART programmes. It slows down gains made by injecting drug users who have initiated life changing opioid substitution therapy (OST), or registered for needle syringe programmes (NSP). Prevailing studies from the United States (Clark, Dolan & Farabee, 2017) and the systemic review looking at the 5 countries with an injection drug use driven epidemic (China, Vietnam, Malaysia, Russia and Ukraine) by Debeck et al. (2017) confirm that punitive measures are barriers to ART adherence and come at a cost to gains made by HIV/ART programmes. The criminal justice system in South Africa in many ways violates the human rights of PWID. Information from my study suggests lengthy periods of detention (of some 4 weeks) before case is brought against PWID. To this should be added the duration of hearing and trial, which may take another 2 weeks. In this time, PWID do not have access to ART which they have initiated and have been adherent to. It calls for reflection and re-examination of state polices which favour punitive measures and punishment over drug dependence treatment.

5.5.4 Negotiating stigma-laden social spaces

Despite constitutional protection, participants related continued deep-seated societal stigma associated with being a sexual minority or PWID in social spaces. Difficulties in navigating social spaces were one of the most problematic barriers to ART adherence. Gay men and MSM and a subset of PWID articulated disturbing encounters of stigma and abuse at public sector health facilities. They also gave vivid descriptions of degrading encounters at the hands of the society at large. Negotiating social spaces for themselves, paints a picture of re-enforcement of rejection by society, ostracization and may result in mental health damage from continuous devaluation at encounters. This is premised on the fact that social inequalities play out in social spaces and are responsible for inclusion and exclusion. The results of my study are in agreement with studies by Weiser et.al. (2003) that optimal adherence is linked to patients being treated with dignity and respect. This holds true when taking into cognisance the issue of marginal communities, who are at the centre of different intersecting inequalities. This includes being gay or MSM, PWID, PLHIV, in some instances black, of lower socio-economic status and possibly homelessness. A gay man presenting as effeminate may find himself at the bottom of the masculinity hegemony and much psychological and mental effort goes into facing the resulting discrimination.

Dignity and respect is the least any client expects when they access services. It is clear from this study that clients understandably tire of being judged in so many social spaces and expect the focus in seeking healthcare to be on why they are seeking help for an ailment, rather than on their sexual orientation or injecting drug use. Other studies (lyon et al., 2016; Treves-Kagan, 2016; Van Loggerenberg et al., 2015) corroborate my study's finding that stigma reduction in health spaces can improve adherence and retention in HIV/ART services.

Gay men and other MSM who are PWID in my study alluded to refusal of service because of their dishevelled presentation and being told blatantly that they "stink". Gay men and other MSM have been verbally abused and told not to speak about their sexuality or sexual behaviour, even when it is relevant to the ailment they are presenting. The logical conclusion is that gay men who are PWID present wearing their marginal identity "on their sleeve" and gay men and other MSM, in particular effeminate ones 'wear' it in their expression or presentation, and as a result they are rejected or excluded within a social or health service space. Having to negotiate a constant barrage of negativity from people and spaces was an important part of the lived experience for participants of this study.

I introduce a further concept relevant in understanding stigma in social spaces- the 'social production of space' and how spaces remain active grounds of reinforcement of intersecting oppressions. This aligns with a large number of studies (Hirsch et al., 2009; Keene & Padilla, 2014; Parker et al., 2017; Micheni et al., 2017; Baral et al., 2009; Risher et al., 2013). These studies explain the ways in which 'social production of space' excludes or includes people and helps shape sexual practices and also shape health seeking behaviour like adherence to ART.

In discussing exclusion and rejection in social spaces, it is important to refer to two concepts, which I have introduced in Chapter 3: "passing" and "congruence". These concepts describe protective mechanisms devised by gay men and other MSM and a subset who are PWID to escape rejection. Being "passable" stems from the process through which sexual and gender minorities negotiate spaces in their daily lives and refers to how efficiently they can do it, without being scarred by stigma, discrimination, violations and violence. Since they may experience multiple intersecting oppressions, they may have to deal with being gay, black, effeminate, living with

HIV, and using injecting drugs. They are required to choose the particular marginal identity they can present, in specific spaces, in order to “pass” in that space and thus escape stigma, discrimination, violence and violations.

As previously explained “congruence” is similar to “passing”, but “congruence” addresses harmonious consistent presentation of self, across all spaces, in order to “pass” (be accepted) in these spaces. So, for example, a PWID who is also gay, may choose to appear in a hospital as clean and “presentable”, and not to appear effeminate, so as not to faced discrimination based on his injectable drug use or sexual orientation.

These strategies are formed or adopted consciously or unconsciously in some instances, as mental coping mechanism and skills, gay men and other MSM and PWID adopt to protect themselves when navigating social spaces against stigma. MC 1.1 for example, expressed this as having to live two type lives to avoid discrimination at home. This provides *a* perfect example of “passing” to escape stigma. Since stigma is a social process deployed to enforce powerful and dominant structures within society these play out in various social spaces. Mental health strategies should form part and parcel of any HIV/ART programme in tackling the hindrances both to ensure mental health and to diminish the potentially negative mental health consequences on ART adherence. The fact that gay men and other MSM and a subset who are PWID have to be something other than ‘themselves’ remains a challenge in respect of access to ART.

5.6 IMAGINING RE-HUMANISATION

Imagining re-humanisation is a term I have introduced to describe the process gay men and MSM and a subset of PWID go through in their journey towards acceptance of their HIV status and self, and processes they put in place to ensure optimal adherence to ART. Before delving into imagining re-humanisation in more detail, two concepts introduced in chapter 1 should be considered.

“Social risk”, as described in Chapter 1, is any threat to culturally valued resources by a decision or behaviour that could have negative stigmatizing consequences in the present or future (Castaneda et al. 2010; Eaves et al. 2014). It is the reason people decline to take health-promoting decisions and instead take decisions that are averse for health-promotion (Hirsch et al., 2009; Parker et al., 2017). Social vulnerabilities impacts on vulnerability to HIV as a result of the way persons occupy different positions within a social structure (Mann & Tarantola 1996; Parker et al., 2017).

The acceptance journey entails developing self-efficacy to take responsibility for their own lives, adhere to their ART regimen and most of all take steps to take charge of their lives despite the stigma laden social spaces they must continuously navigate. It describes a picture of resilience in face of structural inequalities. It is an attempt to make the consequences presented by concepts like social risks and social vulnerabilities, work for them in the process of “re-humanisation”.

The three sub-themes that emerged to describe Imagining re-humanisation were: (1) power of personal and external information as motivation; (2) support systems; and (3) self-efficacy /determination/faith and intersectional spaces of acceptance within the PWID community.

5.6.1 Power of information and information as motivation for ART adherence

Some participants described a journey of acceptance of HIV status and self, that initially may have involved a process of denial and even defaulting on ART and subsequently use of information sourced by themselves and from informed trained counsellors to decide to initiate ART and adhere to it. Most the participants in this study described going through a process of information seeking by self, using internet platforms like Google, online PLHIV support groups and interpersonal fact finding of information from known PLHIV peers. This helped shape the first process of their decision making to seek HIV/ART services. Their follow up access of HIV/ART services, brought them in contact with HIV counsellors, nurses, drug counsellors, doctors and sometimes psychologists. Many participants cited contact with a drug counsellor or nurse or both as the “light bulb” moment that ensured their adherence to ART. Against this background, my study strongly supports the importance of healthcare providers’ positive affirmation and interest in wellbeing of clients as a crucial determinant of self-efficacy to adhere to ART. My study supports Bandura’s study (1997) that social support is about positive affirmation and thus may improve self-efficacy to adhere to ART.

One the one hand, gay men and other MSM had a propensity to seek information personally from the internet and social media platforms, and less so from social networks and peers. On the other hand, PWID sought information mainly from social networks and peers. This opened a door for discussion of modern use of social media as the first contact source of information for gay men and MSM, in their decision-making on accessing HIV/ART services. I did not find literature that analyses or describes the importance of the internet or social media as the first port of call, in the chain of processes from initiation of ART to adherence to ART. This could be a potential area of further exploration.

Gay men and MSM seemed to do this as a way of empowering themselves and weighing their health seeking behaviour options before making a decision. This process describes a form of agency by gay men in taking critical decisions on their health. Further, they seemed to be concerned about potential cosmetic changes to their physical appearance which ART regimens might cause. It is important in this context to note the body image “stigmata” of the first-generation ART regimens of stavudine/ zidovudine, which caused lipodystrophy. McFarland & Kaminski (2009) and Olivardia et al. (2004) studies associated body image dissatisfaction amongst gay men and other MSM, with potential non-adherence. The gay men and MSM in my study grew up in townships at the height of the HIV deaths in South Africa and saw the body fat redistribution that the first-generation medication caused in those on first-generation drugs. My study findings therefore concur with these other study findings. These findings are important especially when initiating gay men and other MSM on ART regimens. These could be a ‘make or break moments’ in their decision-making process of adherence to ART as they might not adhere if their medication alters their desired physical look.

Studies have highlighted the importance of an integrated model of service, a “one-stop-shop” or a multi-disciplinary services provision model of HIV/ART retention as the gold standard for ensuring adherence to ART. This study supports the literature on this topic (WHO 2006a; Beane et al., 2014; Carhill, Mayer & Boswell, 2015). A one-stop-shop service model ensuring the presence of drug counsellors, psychologists, doctors, nurses, outreach staff and other relevant role players, treats the client comprehensively, as a whole human being. It should acknowledge the relevance of mental health as integral to health more generally.

My study supports the model in literature that theorises adherence as a joint pact, agreement or understanding between client and healthcare worker on how to take ART regimens as opposed to compliance, which is just a one-sided set of instructions that clients must obey. In the latter, the power relations are skewed towards the healthcare in contrast to adherence where decision- making lies with the client (Chakrabarti, 2014).

5.6.2 Support systems

Support systems for the purposes of this study were divided into three categories: family support, peer support, and health care provider support. Participants who did not have family or peer support leaned heavily or exclusively on support from health facilities. Some gay men in this study relied almost exclusively on family support or on trusting relationships with healthcare workers or both, They rarely on peer support. In contrast gay men and other MSM who also injected drugs for the most part relied on support from drug-using peers as well as healthcare workers in the facility.

Previous studies in African-American gay men and MSM found that the kind of support deemed ideal was from friends, HIV-specific health care providers and other HIV positive networks (Galvan et al., 2008; Tobin & Latkin, 2008; Wohl et al., 2010; McCoy et al., 2009). My study findings partially agree with these studies. My study acknowledges family support as a particularly significant source of support for gay men and MSM. However, my study further deviates from the literature that identifies friends as important pillars of support. Gay men and MSM whom I interviewed were often sceptical about disclosing to friends and social networks. Wohl et al. (2010) study, found that gay men and MSM who disclosed their HIV status to social networks, did not necessarily receive support from these networks and improved adherence to ART. In keeping with this my study suggests that disclosure to social networks was not necessarily an important support for adherence. In addition, gay men in my study expressed hesitation in initially attending ART clinics where there were many gay PLHIV in attendance. However, they felt comfortable attending these clinics after a few extra visits. I view these extra visits as silent disclosure to those in their networks attending the same clinic. This could result in improved ART adherence as they addressed the potential stigma in their own way.

As the centre of most communities in South Africa remains the family in some form, it is understandable that gay men and MSM acknowledged that discomfort with their sexual orientation started at the family level. This is a factor of key importance in developing internalised stigma. The first hurdle in the life journey of these men was getting affirmation from family to help them have their sense of self-worth. Further hurdles to navigate were then added: being gay, being HIV-positive, and needing to adhere to ART. Many gay participants mentioned that at least one family member had been a source of positive motivation in their adherence journey. Historically heightened stigma about HIV in black communities, although this is perhaps changing, made it nearly impossible for gay men to disclose their HIV status to their social networks for fear of being 'outed' and having to deal with dual intersecting forms of stigma – this included being gay and having become a PLHIV. From participant narratives I gathered, this fear had been a significant hindrance to their ART adherence journeys.

The one participant who was an HIV counsellor and a PLHIV's fear of the stigma of being found out caused him to abandon an ART process in which he had been enrolled. This landed him in the clinic with kidney failure and other complications of full-blown AIDS; Only when he became severely ill did "re-imagine his re-humanisation" and disclosed to some of his social networks This insight finds support in the Wohl et al. study (2010), which suggests that gay men who disclose to close friends and their gay social networks adhere better, not so much because they need support from the social network, but because they do not have to hide or run away for fear of being "found out". Eliminating the fear of being "exposed" helps eliminate the fear of stigma, which is a crucial barrier to adherence. Other gay men and MSM in this study who had not disclosed to their social networks mentioned fear of their social networks knowing that they were PLHIV as an hindrance to seek HIV or ART services and to adherence. They needed additional clinic visits to be assured by the facility and quality of services in order to overcome their initial scepticism.

Amongst gay men who are PWID, existing studies cite emotional support, female support and social support as ideal for their adherence to ART (Knowlton, Hua & Latkin, 2005). This partly corroborates my study, which identified for PWID positive social support and affirmation to adhere from peers and clinic staff as linked to adherence. The Wohl et al. study (2010), however, found no association between social support and adherence amongst gay African American men who are also PWID. On the other hand, my study participants did not mention female support as useful to adherence among gay and MSM who are PWID, however the findings suggested emotional support might help ART adherence. An explanation for this is that PWID persons may have lost social skills to cope with emotional trauma. and Illicit drug use may be used as an escapist path for them not to deal with emotions. The PWID programme manager highlighted difficulties in dealing with emotional trauma and change as constant elements in their daily lives. Loss of a support system from a friend or peer had significant effects on their adherence. The loss of support from peer or friend was likely loss of emotional support. Against this background, it is worth exploring what emotional support means to PWID gay or MSM persons. This can help design interventions that prevents the spiralling out of their commitment to adhere to ART.

Support that involves service models where ART medication is picked up and taken to clients were seen to be supportive to adherence in some studies (Ulett et al., 2009; Vyavaharkar et al., 2007;

Gonzalez et al., 2004; Kelly et al., 2014). This was the case in gay men and MSM who are PWID but not if they weren't PWID. Gay men who are PWID live their lives based on fixed routines. Typically PWIDs' lives, observed in this study, were characterised as follows: they wake up; take an "upper" to get them through the day; go out to look for money to buy drugs; eat; use another "upper"; and, when the sun sets, they start with their "downers" and fall asleep. This is repeated daily. Deviating from this routine is challenging at first, because every time they spend not looking for money for the next drug "fix", is seen as a loss of potential income. A programme that understands the nuances of their lives and models its HIV/ART service delivery with this understanding will likely have better adherence success. As PWID improve in health and sense of self-worth, they are likely to take more responsibility and start accessing services. The key point here is the initial modelling of the service tailored to their lives and expereinces.

Study participants who worked with the PWID programme were said to have no problems with adherence.

A study by Parsons et al. (2013) found that improved ART adherence may be achieved in PWID s by some form of cognitive behavioural therapy, contingency management, motivational and skills development which supports findings from my study highlighting a service delivery model tailored to the sensitives of the community offers motivational talks, constant encouragement and affirmation.

5.6.3 Self-efficacy, determination to succeed for longer life and faith in higher being

A common denominator cited frequently by gay men and other MSM and a subset who are PWID as important in their choice to adherence is the desire to survive, to live longer lives and fulfil initial life aspirations they had before becoming PLHIV. Many participants in this study cited the need to survive, to avoid illness and avoid full-blown AIDS as motivation to adhere.

Pecoraro et al. (2015) study in St. Petersburg, Russia, theorises that personal beliefs about HIV and ART affect adherence to ART. They found that a significant number of study participants believed HIV to be a form of punishment and the use of ART medication to be a further punishment and shameful. While my study participants acknowledged the stigma and negative 'badge' attached to HIV and ART, their personal keenness to survive overrode the stigma attached to the disease and the medication.

A number of other studies (Musheke, Bond & Merten, 2013; Beer et al., 2009) established that people's sense of physical wellbeing had a strong impact on their adherence to ART. So, if PLHIV experienced no HIV-related symptoms, there was higher likelihood that they would not seek services, and if they sought ART services, that they would be less likely to adhere. I did not find anything in my study to corroborate this view. This may be explained by the WHO/UNAIDS previous treatment guidelines that initially benchmarked initiation of ART on a low CD4 count which may have been current at the time my study participants-initiated ART, so they may have already shown illnesses or symptoms of AIDS. The current WHO/UNAIDS treatment guidelines with its clear prescriptions of "test and treat" and "treatment as prevention" (WHO, 2015) regardless of CD4 count or illness may change this scenario for future PLHIV. Nevertheless, the participants in my study voiced defined motivations why they adhere, such as choosing life or survival over death, and having goals they still needed to fulfil.

Another motivation for adherence may be historical experience of HIV. A significant number of black South Africans saw or had a family member die of full-blown AIDS at the height of the AIDS denialism under President Mbeki. At the time, everyone wore the classic signs and presentation of HIV on their person in that they were ill with AIDS. As a result of this history, some participants (gay men) did not want these “classic presentation” symptoms to show on them and hence were motivated to adhere to ART.

Some studies found an abandonment of ART adherence in favour of traditional healing, not because of loss of faith in the efficacy of the ART, but because of loss of faith in the health system, toxicity of the drugs and the thought of being on life-long treatment (Fox et al., 2010; Musheke, Bond & Merten, 2013). I did not find any data in my study to support this finding. While my study participants were not happy with the state of public sector health clinics, they saw themselves as being privileged to have access to a facility that catered to their concerns. Most likely on this basis, they did not experience the same loss of confidence in the health system.

Studies done in white Swedes associated adherence and self-efficacy with clients’ feeling of wellbeing, so, the healthier they were, the more likely they were to adhere and be self-efficacious (Schonnesson et al., 2007). This was corroborated in other studies (Ammassari et al. 2001; Gonzalez et al. 2007; Holzemer et al., 1999). This insight aligns perfectly with the findings from my study. Further, my study brought out the power of good information sharing during the pre- and post-counselling phase, and the value of on-going follow up visits. They seem to have understood that adherence had to be a life-long commitment in order to remain healthy.

One cannot over-emphasize the power of the clarity and correctness of information to catalyse changes in behaviour. My study participants consistently mentioned sourcing information from different mediums as a reason for initiating ART and emphasized the continuity and updates on new information about HIV and ART as a motivation to adhere. The keywords are: “clarity of information” and “correct and consistent” information. It is important to highlight these two phrases, because HIV is surrounded by urban legends and myths that thrive within groups, manifesting as group beliefs. For example, conspiracy theories among black African American historically that HIV was manufactured and that persons on ART are government “guinea pigs” drove non-adherence within this group (Bogart et. al, 2010). Urban legends and myths can only be refuted by clarity of information and provision of factually, correct and consistent information, updated as new information becomes available. My study participants did not share any of these beliefs, although these ideas may have had traction previously among some South Africans. The message is therefore two-fold: (1) Correct and consistent HIV/ART messaging to clients at the initial stage of initiation and through their journey of adherence is crucial. (2) Personal traumatic near-death experiences experienced by clients due to non-adherence, contrasted with being a “picture of health” after proper information sharing, encouraged adherence.

Some clients mentioned the reason for adherence was belief in a higher being who had a plan for them, and they tapped into this spiritual space through prayer when they felt “weak”. More literature will need to be examined to establish the link between faith and adherence to ART amongst marginalised groups who themselves have suffered and continue to suffer from condemnation by religion.

5.6.4 Acceptance of sexual orientation

A narrative that stood out from the interviews among PWID was that their community seemed very open to accept sexual orientation and to embrace and protect sexual minorities. As sexual orientation (being gay, for example) was not an additional stigmatizing identity or oppression they had to navigate with their peers and community, it did not present an additional difficulty on adherence to ART. Conversely, among gay men and MSM it was highly stigmatizing to “descend” into drug use. As a result, gay participants who became PWID were largely rejected by and ostracised from the gay community. I did not find any literature to help illuminate and explain the difference in reactions from the two communities, one being highly judgemental and oppressive, and the other embracing sexuality. My initial reflection is that PWID communities see the commonality among them as drug use and see themselves as a collective of social “rejects”; to them it is important to support each other and stick together in a common front to ensure collective protection for their communities.

Compared with injecting drug users, gay men and other MSM may be more individualistic in their approach to their lives. They may perceive their multiple levels of intersecting oppressions as individual burdens and not as group burdens, even if they organise well within groups and fight fiercely because of their individual agendas. Some evidence from my study supports this, especially because a significant number of participants seem to struggle with disclosure to potential support system and seem to want to face their HIV or adherence journey personally. They may face the world collectively in groups but seem to all have fractured competing needs. My theorising of this phenomenon will need further exploration through further research.

5.7 DIFFERENTIATED SERVICE MODELLING AND DELIVERY

Differentiated service delivery modelling becomes important when dealing with gay men and MSM and a subset who are PWID. This groups have been tagged as “hard to reach” or “difficult to reach” populations in the public health research spheres. This is consequent on the fact that MSM, gay and PWID are social groups who have particular behaviours or habits that present challenges to study by established methods of sociological research (Spreen, 1992). This study highlighted some gaps and some strengths in service delivery and how adjustments and improvements in some areas could improve adherence among members of these populations. Some of the subthemes that emerged can be categorised as: (1) flexibility within service delivery; (2) limited drug side effects; (3) pre-exposure prophylaxis for discordant couples and biomarkers as motivation for adherence: and (4) understanding drug use culture.

5.7.1 Flexibility within service delivery

Flexibility within service delivery system mainly refers to a model of service delivery that tailors HIV/ART programme to the life and routine of newly initiated PWID, developed in conjunction with PWID. Understanding the routines of PWID and their drug-use culture was taken into cognisance when modelling ART dispensing to them. The results of the study show that PWID at the start of ART programmes are still trying to develop trust of a new system, they would have to add on to their routine. In the modelling of services, all persons working in the PWID programme, for example drug counsellors and nurses, were either former PWID or PWID on their way to turning their life around by stopping drug use. The model entails using persons with similar life struggles. The clinic staff also met drug users in their normal environment and personalised ART dispensing by delivering monthly to newly initiated PWID. As trust is developed over time, PWID start wanting to come to the facility themselves and that is when it becomes clear that they have started imagining their lives in a different way. Some of them (in particular Mr C1.1) got on the methadone programme and training programmes to work under the advocacy component of the PWID Programme. This shows that this PWID programme seems to have studied the nuances of the behaviour of PWID persons and modelled an ART adherence programme that considers these by introducing flexibility in service delivery.

There is an absence of studies on individually generated HIV/ART service modelling in literature in the Global South. However, there is an interesting study from Ukraine, Indonesia and Vietnam that corroborates the findings in my study to the extent that it agrees that inputs from the affected target group could help model HIV/ART service. This in turn improve adherence (Lancaster et al., 2019). This study, however, did not explore if a differentiated modelling of ART dispensing to PWID could potentially improve their adherence to ART.

5.7.2 Limited ART drug side effects

With the advent of the newer ART drugs, especially with the fixed dose treatment (FDC) regimens, clients in my study registered less side effects. The side effects were also not significant enough to keep them from adhering to their ART regimens. Only one client on FDC still complained about intolerable symptoms; and he was also the least adherent. Another client could not tolerate the FDC and reverted to the three-pill regimen, which he tolerated much better. The roll-out of FDC means less pills to take and less difficulty in other associated issues such as forgetting to take pills because of the need to take them multiple times in a day. Further, the FDC are more forgiving of missed pills doses when compared to the older regimens, as long as patients remember to take the pills immediately when they remember to do so. There is paucity of research on drug formulations and drug-use side effects, specifically for MSM and other gay men and injecting drug users, and how this affects their adherence to ART. More research needs be done on this area.

5.7.3 Use of preventive options in discordant couple relationships and biomarkers motivating adherence

With the advent of pre-exposure prophylaxis (PREP) as a preventive option, mostly for those at high-risk for HIV, a new fight against HIV infection has emerged. Participants in my study showed a high level of knowledge about PREP with some of them having recommended them to partners and some of them using social media apps like “GRINDR” to advertise their sero-status (positive or negative) and even making declarative statements about their status or what medication they are on as a form of open disclosure. This appears to be a form of coming out to whoever is interested in an intimate relationship with them despite them, being PLHIV. They can then have open conversations about living with HIV and have an undetectable viral load. This provides options that their prospective partners who are sero-discordant can choose. In doing so, they may be hoping to forge a supportive atmosphere for their own personal adherence and making their partner share some of the responsibility for their own health, by keeping being negative with PREP. They may be able to further support each other in adhering to ART and PREP respectively. There is no available literature from the Global South that explores the benefits of information on PREP and the supportive environment for adherence by gay men, MSM and a subset within who are PWID and adherence to ART and PREP. Some participants saw PREP as a preventative method that will give some respite and peace to persons who are in discordant relationships.

Further, participants associated undetectable viral load and, in some instances, higher CD4 counts with success of their treatment and motivation to adhere. As a result, participants cited the importance of regular checks of viral load to further encourage them in their motivation journey. However, viral load measurements and checks remain out of reach for most PLHIV in South Africa. Access to virological measurements remains confined to 16.4% on private medical aid (STATSSA, 2019). This seems like missed opportunity in ensuring adherence and retention in care for PLHIV.

5.7.4 Drug use culture/routinization

My study reveals that gay men and MSM who are also injecting drug users were empowered with information that ranged from how to embed their ART usage within their drug use culture of “uppers and “downers”, when to use the drug, and if there is a possibility of an interaction with their illicit drugs. This empowerment came about through the help and advice from the doctor at the clinic. This builds intervention based on routines that fit in with the culture of the individual PWID. Any serious HIV/ ART retention programme addressing PWID persons must be designed to align with how to insert ART use into their drug-use routine. The prevailing practice in many services shows reluctance to place PWID on treatment as prevention (Cohen et al., 2011 and 2016). This is even though there is information that early initiation reduces the risk of transmission and health outcomes (Lifson et al., 2015; Lundgren et al., 2017). The Lancaster et al. study (2019) covered structural and system barriers hindering access to HIV/ART care and adherence. It further developed manualized sessions to debunk myths around conventional ART initiation requirements. However, they did not seem to explore the cultural way of life of drug users to get a deeper understanding of the importance of routinizing ART drug use along with their illicit drug use routine culture. More attention should be devoted to drug use culture and routinisation of

ART when designing HIV/ART programmes for PWID.

5.8 LIMITATIONS

The study contains several important limitations. Firstly, it deals with gay men and MSM and a subset who are PWID in only one geographic area of the country, namely Tshwane. Linked to this is the fact that the sample size (of nine gay men and other MSM and a subset of them who are PWID) is quite limited. Although this small number allowed for in-depth interviews and saturation of data was reached. These findings cannot be extrapolated to the whole of the targeted category. Additionally, this study was carried out in what can be regarded as a 'best practice' clinic for gay men and other MSM, with services specifically modelled for them and a guaranteed audience of only gay men and other MSM. Against this background, the outcomes and results generated in this study may not be transferable, if the same study was carried out amongst gay men and other MSM receiving ART health services in public sector health clinics. In addition, I am a medical doctor and this may have affected responses from participants. I tried at all times to be conscious of and document my reactions to what participants said and their attitudes towards me. Secondly, the participants in this study were not randomly but purposively selected, as is the custom in qualitative research. Hence results from my study unlike a quantitative study cannot be seen as representative of gay men and MSM and a subset of PWID in Tshwane. Although an effort was made to include a diversity of races, ages and backgrounds, this was not done systematically. Especially among black participants, there were some difficulty in getting specifically gay and MSM PWID person to self-identify their sexual orientation, as it was difficult for them to accept labelling. Thirdly, although I confirmed the history of adherence to ART from nurses, I relied on self-reports of behavioural and drug related variables from information supplied by participants. As gay and PWID identities are highly stigmatized, I cannot be sure of the accuracy of information presented to me – there might be over-reporting or under-reporting or some embellishments on some issues. Notwithstanding, I meticulously applied source triangulation of information from other key informants like the two nurses and PWID programme manager to help corroborate some of the information from the participants to ensure rigour.

5.9 CONCLUSION

My study has explored the impact of having different intersecting marginal identities (gay, MSM and PWID) on adherence to ART. I have used insights from gay, MSM and a subset who are injecting drug users to understand how their intersecting oppressions or their positive identities or activities shape their adherence or non-adherence to ART. The information obtained from the participants shows a complex mix of individual, structural and systemic barriers that to pose barriers in adhering to ART. The continued focus on individual level interventions like condom use, PREP, and ART, with very limited investment and focus on structural and systemic barriers, will keep derailing pathways to ending HIV and AIDS. More investment and academic research should understand the interplay of social vulnerability, social production of space and social risk and how they shape health seeking behaviours among populations facing multiple intersecting oppressions and inequalities. These can be used to address stigma and promote ART adherence The study findings also provide positive measures people within these groups adopt to ensure ART adherence., My study shows the importance, when modelling HIV/ART programmes, of a more nuanced individually sourced and tailored service delivery model for addressing some of the barriers to adherence to ART and possibly improving adherence to ART within this grouping.

CHAPTER 6: CONCLUSIONS AND RECOMMENDATIONS

6.1 INTRODUCTION

This Chapter summarizes the mini-thesis and highlights recommendations to improve sub-optimal adherence to anti-retroviral treatment (ART) among gay men and men who have sex with men and a subset who also inject drugs. I first give my conclusions and then move on to make some recommendations, before offering with some suggestions for future research.

6.2 CONCLUSIONS

This research reinforces findings from other research studies about the barriers in accessing HIV/ART services encountered by gay men and MSM and a subset who are PWID in their quest to live as healthy PLHIV. These difficulties in access lead to further problems in respect of adherence to ART, following initiation of ART. Important findings it reinforces from other research include: (1) understanding societal stigma and the devaluation and de-humanisation it causes and the challenge to adherence to ART by gay men and gay men and other MSM who are PWID; and (2) the damage the insistence on criminalisation of injecting use by the Government of South Africa has caused, and continues to do, that inhibits adherence to ART. This sets back the overall the fight against HIV.

At the same time, the findings from my research also provides new insights on three concepts that can potentially improve adherence to ART: (1) understanding the cultural anthropology of the drug use sub culture of PWID (“uppers and downers”) and how this through proper “routinization” could create improvement in service modelling and delivery to PWID and boost optimal adherence to ART; (2) understanding ideal support system models for gay men and MSM, on the one hand, and gay men or MSM who are PWID, on the other; and (3) understanding how and from what platforms and mediums gay men potentially source life changing information that serves as motivation to seek HIV/ART services that lead to adherence.

Prevailing HIV and AIDS programmes by donors and funders are mostly focused on individual-level factors that could enhance entry into and retention of HIV and ART services. This focus on the individual issues stands in marked contrast to the approach of WHO/UNAIDS, which in their HIV and AIDS guidelines frequently mention the overcoming of “critical barriers” as an essential minimum requirement for effective interventions targeting gay men and MSM, and PWID. In this context, the term ‘’critical barriers’’ highlights the need to address stifling legal and policy environments, stigma and discrimination. My study confirms that gay men and MSM and a subset who are PWID have relatively few problems with respect to individual-level factors and do well with bio-medical interventions. The factors identified as most likely to derail their adherence journey and prevent the 90-90-90 UNAIDS cascade are mainly structural in nature. These are the factors that have largely remained unexplored within the funded response to HIV and AIDS.

Structural factors are of particular relevance to adherence by PWID. Injecting drug use remains criminalized in South Africa. Needle exchange programmes (NSP) and opioid substitution therapy (OST) still face considerable resistance from provincial and national health governments, despite overwhelming results from programmes in the Global North and countries such as Tanzania, showing their public health and social level gains. These results further indicate that instituting these programmes is supportive of ART adherence, as opposed to criminalisation and incarceration for injecting drug use. These compromise adherence. My study confirms a multi-intervention of NSP, and OST could potentially help PWID to “re-imagine” their lives differently and improve their adherence as a result.

Heightened stigma laced with historic inequalities, which have reinforced the spatial distribution of persons with marginal identities (gay, MSM, PWID) that excludes them from social spaces and places them at the margins within social structures is still at play from the findings from my study. Gay men, MSM and PWID persons have to continuously navigate social spaces and “pass” in those spaces for them to be included. These patterns of conduct are frequently enacted and re-enacted at health clinics with hate speech, preaching and refusal of services. The importance of sensitization and competency training cannot be overemphasized to help tackle these ethical breaches at health clinics.

Being a lifelong commitment, adherence to ART is not linear journey for gay men, MSM and PWID. Like the general population, they go through “hills and valleys”, periods of sub-optimal adherence and optimal adherence. These are caused by individual, community and structural factors. Paramount in designing ART adherence interventions is to take into account the multiple intersecting oppressions and inequalities they (gay men, MSM and PWID) negotiate in comparison to most people in the general population.

This study further suggests that PLHIV who have another marginal identity (injecting drug use), in addition to being gay or identifying as “MSM”, did not significantly differ in adherence to ART, provided there is a tailored HIV/ART programme that fully takes into account and understands the r illicit drug-use culture amongst gay men, especially drug use routines.

6.3 RECOMMENDATIONS

This study sought to understand how the interplay of having different marginal identities – being simultaneously gay or MSM, and a PWID – gives rise to multiple intersecting inequalities. It explored how the oppressions that go with these forms of inequality affect PLHIV in these groups’ adherence to ART. It found that a myriad of factors is at play that affects adherence to ART, ranging from the individual to the community and the structural level. The following recommendations are therefore proposed across the 5 thematic findings of the study, which can potentially address sub-optimal adherence among gay men and MSM and a subset within this group who are injecting drug users.

6.3.1 Ensuring service integrity through sensitization and training

Stigma reduction in all clinic spaces is crucial. I propose that thorough continuous sensitisation training for all hospital or clinic staff, from the security guard to the medical director, be instituted. Further, all clinic staff should undergo a modular competence training that will equip them with the skills to understand the practical issues that gay, MSM and PWID face. This will better enable them to deliver services tailored to these issues. These should be “modular” because there should be some modules specific to doctors, others for nurses, for general staff, and so on. In addition, medical ethics including the importance of confidentiality must be reinforced as an important part of the modules within the training manuals and programmes.

6.3.2 Improving access to services

Based on the study findings, it is recommended that government should invest in a "one stop shop" clinic with a multidisciplinary sensitised and competently trained health staff to deliver ethical affirming services to the groups discussed in this study. Most provincial governments in South Africa have the 5 km radius catchment area rule, which imposes a situation in which clients must access services within a 5 km radius of where they reside. The generalised primary health care system is not equipped to provide HIV and ART services to gay men and other MSM and a subset who are also PWID. Against this background, government should scale up stand-alone services such as the OUT facility at which this research was conducted. Alternative these should be integrated into the primary health care system without compromising quality of service delivery. This will require investment in health system strengthening by government and careful study of stand-alone models, which are currently offering excellent services.

6.3.3 Process of de-humanisation

Criminalising identity and conduct associated with identity is at the heart of de-humanisation. The South African Government should decriminalize drug use. Instead of arresting, prosecuting and incarcerating PWID, it should offer drug dependence treatments and institute regulatory measures at least for drug use and possession. Trafficking or sale in large amounts could be prosecuted and lead to prison sentences, but the prison sentence must respect the right to health of the convicted drug user. In respect of the right to health, incarceration that involves drug dependence treatment should keep in mind the need for social integration and for preparing PWID inmates for parole or exit from the prison system. As far as short-term arrest and detention is concerned, the Police must allow unhindered access to ART by anyone who requests access to medication, including without discrimination gay men or MSM who are injecting drug users.

6.3.4 Imagining re-humanisation

HIV and ART services should move away from delivery of healthcare system only in physical spaces. Findings from my study show that gay men in particular do significant research online before seeking ART services. I therefore recommend investment in social media by clinics advertising their services, providing an interactive platform to provide correct and updated information on HIV and ART (chat pages), support centre online, instagram, gay social media apps and telephonically. These should serve gay men and MSM in their decision making of adherence to ART. In addition, every HIV/ART programme should consist of a multidisciplinary team and, most importantly, a mental health unit with a psychologist to support clients who are struggling with mental health issues.

6.3.5 Differentiated service modelling and delivery

HIV/ART services must be modelled in consultation and with the inclusive participation of the target community, with them giving inputs into the process and clear descriptions of their culture, issues and their needs. Further, service delivery including staff delivering the service should be representative of significant members of the target community. Service modelling should take into cognisance flexibility in delivery. This means that multiple interventions should be used to reach the "hard to reach" populations. This involves instituting an outreach component, flexible ART dispensing for adherent gay men and other MSM and PWID. Further, specifically for criminalized communities such as PWID, there should be no "marked" or branded mobile units, which will draw attention to them as a community and put them in danger of reprisal attacks by the larger community. A study of the cultural and social anthropology of drug users, especially an understanding of their routine illicit drug use should be instituted by the state and interested funding bodies with consent from PWID communities. This study should thoroughly explore the understanding of their routine of “uppers and downers” to appropriately model services that will ensure adherence to ART and deliver services that are culturally and culturally sound, affirming and evidence informed.

These steps should be taken if the commitment to addressing key populations more at risk for HIV and ART adherence is to be adequately met.

6.4 FURTHER RESEARCH

Given the small sample size of this study, its results need to be confirmed. Some interesting insights, especially related to the drug use culture and routinisation of ART, in particular should be explored further, with a view to impacting on the design of HIV/ART programmes for PWID.

There is paucity of research on drug formulations and drug-use side effects, specifically for MSM and other gay men who are injecting drug users in this and similar settings, and how this affects their adherence to ART. More research needs be done on this area.

My study confirms that support systems remain the hallmark and standing pillar of most adherence journeys. The study further strongly suggests that gay men prefer to recruit a smaller mass of persons as support systems (either one trusted friend or few family members). Gay men who also injecting drug users seem to prefer a critical mass of persons with similar struggles attending the same HIV/ART service with them. This insight should be confirmed, and its implications for HIV/ART programming should be more fully considered.

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APPENDIX 1: INFORMATION SHEET (CLIENT)

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INFORMATION SHEET (Client)

Project Title: *Adherence to Anti-retroviral treatment among gay men and other men who have sex with men living with HIV in Tshwane, Gauteng*

What is this study about?

This is a research project conducted by myself in partial fulfilment of my Masters in Public Health degree from the University of the Western Cape. I am gathering information on gay men and other MSM attending this clinic, to get a better insight and depth into your experiences and challenges on adherence to ART. Furthermore, if you happen to inject drugs and her also gay or MSM, I would want to understand how this affects your commitment to taking ART. I am inviting you to share your knowledge and understanding with me so that we can contribute to these missing pieces of information and get grounded personal information from real people with real life experiences. We would like to ask your permission to interview you as one of the key informants for this study.

What will I be asked to do if I agree to participate?

If you agree to take part in in this research, I will ask you if you are willing to be asked some questions and discuss your experiences and challenges related to adherence to ART. This will take around an hour. I the researcher will speak to you on my own. The interviews will be tape recorded with your permission, so that I can listen to it after to make sure I have remembered everything you have said.

Would my participation in this study be kept private?

The researchers will give you a number if they interview you and will not give your name or make known your identity in what you have said, to anyone. Only the researcher will have access to your consent form and he will keep this separate to the information you have given him.

To ensure your confidentiality, your data will be locked in filing cabinets and storage areas, using numbers only and will be kept in locked cupboards. If we write a report or article about this research project, we will not mention any names or anything else what may identify you.

What are the risks of this research?

There is a slight risk that you may share some confidential information by chance or that you may feel uncomfortable talking about some of the topics. However, I do not wish this to happen, and you may refuse to answer any question or not take part in a portion of the interview you feel the question(s) are too personal or if talking about them makes you uncomfortable.

What are the benefits of this research?

There will be no immediate and direct benefit to you, but your participation is likely to help us find out more in depth information around factors influencing adherence to ART among gay men and other MSM and to get a more human angle to the problem of experiences around adherence amongst gay men and other MSM. This would in turn help us better understand these complexities and help our intervention approaches to management of HIV and adherence to ART

Do I have to be in this research and may I stop participating at any time?

Your taking part in in this research is completely voluntary. You may choose not to take part at all. If you decide to take part in this research, you can stop taking part at any time. If you decide not to take part in this study or if you stop taking part at any time, this will not in any way affect your care or treatment at this centre.

What if I have questions?

This research is being carried out by Dr. Olusegun Odumosu, an MPH student at School of Public Health at the University of the Western Cape. If you have any questions about the research study itself, please contact:

Dr. Olusegun Odumosu
Cell: +27 833516230
Email: odumosuolusegun@gmail.com

If you have any questions about this study and your rights as a research participant or if you wish to report any problems you have related to the study, please contact:

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APPENDIX 2: INFORMATION SHEET (STAFF)

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INFORMATION SHEET (Staff)

Project Title: *Adherence to Anti-retroviral treatment among HIV positive gay men and other men who have sex with men in Tshwane, Gauteng*

What is this study about?

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Would my participation in this study be kept private?

The researchers will give you a number if they interview you and will not give your name or make known your identity in what you have said, to anyone. Only the researcher will have access to your consent form and he will keep this separate to the information you have given him.

To ensure your confidentiality, your data will be locked in filing cabinets and storage areas, using numbers only and will be kept in locked cupboards. If we write a report or article about this research project, we will not mention any names or anything else what may identify you.

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If you have any questions about this study and your rights as a research participant or if you wish to report any problems you have related to the study, please contact:

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APPENDIX 3: CONSENT FORM (CLIENT)

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Private Bag X 17, Bellville 7535, South Africa
Tel: +27 21-959 382 Fax: 27 21-959 2872
E-mail: odumosuolusegun@gmail.com

CONSENT FORM 1 (client)

Title of Research Project: *Adherence to Anti-retroviral treatment among gay men and other men who have sex with men living with HIV in Tshwane, Gauteng*

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name………………………..

Participant's signature…………………………….

Date………………………

Researcher

I have read this document to the participant, in English or given this to them to read. I have tried to answer his questions to the best of my knowledge.

Date:_____________ Signature of Researcher:______________________

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

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New Arts Building,

C-Block, Top Floor, Room 28

University of the Western Cape

Private Bag X17

Bellville 7535

APPENDIX 4: CONSENT FORM (STAFF)

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Private Bag X 17, Bellville 7535, South Africa
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E-mail: odumosuolusegun@gmail.com

CONSENT FORM (staff)

Title of Research Project: *Adherence to Anti-retroviral treatment among gay men and other men who have sex with men living with HIV in Tshwane, Gauteng*

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdrawn from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

Participant's name……………………….
Participant's signature…………………………….
Date………………………

Researcher
I have read this document to the participant, in English or given this to them to read. I have tried to answer his questions to the best of my knowledge.
Date:____________ Signature of Researcher:______________________

BIOMEDICAL RESEARCH ETHICS ADMINISTRATION

Research Office

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Bellville 7535

APPENDIX 5: IN-DEPTH INTERVIEW GUIDE WITH HEALTH CARE PRACTITIONERS

IN-DEPTH INTERVIEW GUIDE WITH HEALTH CARE PRACTITIONERS

Topic: *Adherence to anti-retroviral treatment among HIV positive gay men and other men who have sex with men in Tshwane, Gauteng*

Form of data recording: *(1) Audio-recording of interview. (2) Notes of key points recorded in a note book during the discussion.*

Venue: Private spaces within the Clinic and /or away from Clinic (in case of some injecting drug users)

Time: Explain that this interview will take no longer than an hour 40 minutes and will be recorded for research purpose only.

Participant details:

Name of Interviewer(s): ____________________________

Date: ______________ Time period/duration of interview: __________________

Location [District, Province]: ___________________________

Place interview conducted: _____________________________

Age [in years]: _____________

Sex [circle one]: FEMALE MALE OTHER

Good day, my names are Olusegun M Odumosu – as I have already mentioned I am conducting research for my Master's degree in Public Health. We have covered some details on you when dealing with the demographic details. I would like to move on to ask you some questions about the health services and therapy you receive and about your insights on some of the things that may affect this.

Key interview areas: Interview will cover health system related factors, therapy related factors, patient related factors, socio-economic factors.

At the beginning of the interview, remind the participant of how valuable sharing his or her experiences are to the study and that some questions may be sensitive and are free to skip any question/s that they are uncomfortable with.

Topic Area 1: Experiences on access to HIV services; health system-related factors

1.1 What is your impression about availability broadly of gay/ MSM friendly HIV health services in Tshwane?

a) Can we speak about your experience of giving services at the state hospitals and also at specialized clinics like this one or any other you worked in previously? If this is your first work experience with gay/MSM clients, what do you think, from your contact with them, is their impression of services rendered here? How does it compare with public sector facilities? (*Probe for example: What do they tell you about the general environment of this clinic? Do you think they are satisfied with your skill level? Have you gotten into a conversation about healthcare worker attitudes in this clinic in comparison to other state hospitals? If yes, what is their general perception about this?)*

1.2 In your experience, what motivates clients to access HIV testing services?

a) What issues do your clients face after a positive HIV test result? Can you share with me how you think the test result impacts them physically, psychologically and emotionally?

b) Can you tell me about the difficulties that your clients face in their acceptance of their HIV status? What in your experience ameliorates the difficulties and improve their journeys of acceptance (*Probe for example: Who do they confide in about their HIV status, if anyone; what were their reactions; did they get support or not, from whom do they get this support and what kind of support? What things helped you in accepting your status; What things hampered them; what made the biggest difference in acceptance?*)

1.2 Can you go through with me, step by step, the process that explains how your clients access ART at the clinic for each visit

1.4 What negative or positive experiences relating to clients accessing ART at this Clinic, have clients shared with you? In your experience, how do they think this clinic measures in service delivery to them compared to previous places they say they have accessed ART services.

Topic Area 2: Patient-related factors

2.1 Among the clients assessing services at this Clinic, have you noticed any kind of trend around demographics in relation to adherence (race, age, socio-economic position)? Please explain. (*Probe for example: what role does financial stability play in your clients' adherence to ART?)*

2.2 In your experience of seeing multiple clients, what do you think persuades clients to start taking ART and adhering to it? Can you describe the common motivating and demotivating factors to begin treatment and to stay on it? What are the common reasons given as inspiration to start treatment? And to remain on it? (*Probe for example: Psychosocial factors/ self-efficacy/ support*)

2.3 Can you tell me what your clients describe as major stressors in their lives and how these affect their adherence? Have you had clients complain about depression or anxiety? What mechanisms have you worked out with them to cope with this? What mechanisms have they shared with you that helped them overcome it? Can you describe how you handle clients with depression or anxiety? Have you had clients share with you dependence on alcohol or other drugs as a result of their depression or anxiety?

2.4 In practice, what are the experiences of your clients concerning their support systems/people/ family in their adherence journey? How much information about their status and orientation do they share with these trusted people? – family and community factors

(*Probe for example: What kind of relationship ties do they have with these people (are they close family members, partners?)   How do you think this has helped them adhere or not?*

2.6 Describe how your clients speak about openness to their partner/s on their HIV status and progress in treatment and how this may have affected how they adhere or not.

2.6 Do your clients cite openness to parents, siblings, other family as helpful to their adherence? If they do, what reasons do they give for how this is a positive influence on their adherence? *(Probes: Do your clients speak about friends as support systems and even some friends who are also living with HIV and how they mutually support themselves? How do they describe this relationships and how this allow them adhere?)*

Topic Area 3: Treatment related factors

3.1 When your clients start ART, what are the experiences they shared with you concerning the side effects of the drugs/ drug formulations/ drug stockouts? (*Probe for example: How do you describe to them their expectations around side effects; Can you tell me how clients describe the impact of the ART on their overall health?*)

3.2 Can you share with me what your clients cite as major reasons for staying on treatment and adhering to ART
B. and also what makes them discontinue?
C.How do they describe their overall journey of consistently adhering or not consistently adhering to ART?

3.3 Can you speak about poly pharmacy (using other unprescribed drugs/concoctions along with their ART drugs) amongst your clients. How do you deal with this and what are their motivations for using other drugs in your experience?

Topic Area 4: Societal and economic factors

4.1 Based on your close contact to your clients,

A. what is your perception about the portrayal of their sexual orientation in society/ public.
B and how this affects their adherence to ART?

4.2 Can you describe how your clients explain the impact of their personal living conditions on their adherence? (*Probe for example: shared living conditions (with parents/ partner/ friends) and how this affects adherence; mobility and fixed status. Are they moving around constantly, how does this affect adherence?)*
b) Tell me about your reaction when clients first disclosed their sexual orientation to you in your present position here as a health care worker. (*Probe for example: Describe the clients' disposition in respect of their comfortability, feeling of safety and trust when they disclosed their sexual orientation. Did you feel that it was a difficult process for the client? If you do, why so? Did you feel that you had enough knowledge, sensitization and competency to deal with the information on your clients' sexual orientation? If yes, why do you come to this conclusion? If no, why do you come to this conclusion? Can*

you describe your reaction after they disclosed, if any? How in your opinion did you think your reaction made them feel?)

d) Do you think that your clients feared that disclosure of their sexual orientation will affect negatively or positively quality of services they will receive in the future? Why do you think they had this fear or not? What do you think – do you feel it has made any difference to you?- move to stigma/ family and community factors

4.3 To what extent do your clients ascribe discontinuing taking their medication to happenings and events in their lives at the time?

Topic 5: PWID-specific section

5.1 Can you give an overview of drug usage amongst your clients in this clinic? (*Probe for example: what stories can you share on how some of them started on drugs? What drugs are commonly used)*

a. What are your views on the relationship between societal perceptions of sexual orientation and injecting drug use? How do you think this affects their adherence to ART?

b. How do your clients speak about the effect of injecting drug use on their relationship with their families? How are they supported in their adherence journey?

c. In your experience, do you feel that injecting drug use has impacted on the ability of some of your clients to adhere to ART?

d. Can you share with me, how your clients separate injecting drug use periods from taking their ART medications? Have any of your clients experienced any unexpected reactions from taking the ART and the injecting drugs around the same time periods. Can you explain what kind of reactions, if any?

Open-ended

Can you speak broadly about your personal challenges and triumphs in helping your clients adhere? Can you share an account of challenges and triumphs of some of your clients in their adherence journey?

Thank you for your time and open discussion on such sensitive issues. I really appreciate it.
Is there any question(s) you will like to ask me or anything you will like to discuss with me?

APPENDIX 6: IN-DEPTH INTERVIEW GUIDE WITH CLIENTS

IN-DEPTH INTERVIEW GUIDE WITH CLIENTS

Topic: *Adherence to anti-retroviral treatment among HIV positive gay men and other men who have sex with men in Tshwane, Gauteng*

Form of data recording: *(1) Audio-recording of interview. (2) Notes of key points recorded in a note book during the discussion.*

Venue: Private spaces within the Clinic and/ or away from Clinic (in case of some injecting drug users)

Time: Explain that this interview will take no longer than an hour 40minutes and will be recorded for research purpose only.

Participant details:
Name of Interviewer(s): ____________________________
Date: ______________ Time period/ duration of interview: __________________
Location [District, Province]: ___________________________
Place interview conducted: _____________________________
Age [in years]: _____________
Sex [circle one]: FEMALE MALE OTHER

Good day, my names are Olusegun M Odumosu – as I have already mentioned I am conducting research for my Master degree in Public Health. We have covered some details on you when dealing with the demographic details. I would like to move on to ask you some questions about the health services and therapy you receive and your insights on some of the things that may affect this.

Key interview areas: Interview will cover hospital services-related factors, therapy-related factors, socio-economic factors and also individual efficacy related factors

At the beginning of the interview, remind the participant of how valuable sharing their experiences are to the study and that some questions may be sensitive and are free to skip any question/s that they are uncomfortable with.

Topic Area 1: Experiences on access to HIV services- Health System-Related Factors

1.1 What is your impression about availability broadly of gay/ MSM friendly HIV health services in Tshwane?

a) Can we speak about your experience of receiving services at the state hospitals and also at specialized clinics like this one or any other you assessed services (*Probe for example: What did you think about the general environment and atmosphere at the facility? How did you feel about the skills of those who attended to you? How did you find the attitudes of the healthcare workers who attend to you, towards you? Do they ask you what you felt were appropriate questions about yourself? Do you have a chance to and want to ask them questions? the amount of time you spent with them; the length of time you waited to see them? Whether they asked you questions and explained things well or not; whether you wanted to ask questions and had time to ask them. In comparison to other centres you have assessed ART services, is the experience different. Can you talk about the differences? And the reason you think they are different.)*

1.2) What motivated you at the time to access HIV care services?

a) Can you share with me how the test result impacted on you at the time

Probe for: How it affected them physically,
psychologically and
emotionally at the time?

b) Can you talk about how you accepted your HIV status or not and share your journey of acceptance of your HIV status? (*Probe for: Who did you confide in about your HIV status, if anyone; what were their reactions; did you get support or not, from who and what kind of support? What things helped you in accepting your status; what things hampered them; what made the biggest difference in acceptance?)*

c)Tell me about your experience on disclosing your sexual orientation at the ART Clinic. (*Probe for:*

Did you feel that the health care worker had enough knowledge, sensitization and competency to deal with the information on your sexual orientation? If yes, why do you come to this conclusion? If no, why do you come to this conclusion? Did he ask appropriate sex positive gender and sexual orientation affirming questions? Can you describe the actual reaction after you disclosed? How did this reaction make you feel?)

d)Do you think this impacted on quality of services that you received? Why do you think it did or did not?

<u>Topic Area 2: Patient-related factors</u>

2.1 Can you share your experience with me about how you decided to start taking ART?

Follow up: What were the motivating or demotivating factors to begin treatment,
your inspiration, what spurred you into action?
Was there anyone who persuaded you it was the right time to begin?
If so, who, what did they say and what made you feel persuaded?

3.1 Can you share with me your journey in being able to consistently or not consistently take your ART medication since you started the medication? (*Probe for: events in their lives that made discontinue or adhere less or adhere more*)

3.2 Can you talk about the major stressors in your life and how they affect adherence?

3.3 At times we all feel low and down for different reasons and in some cases we feel low for long periods of time and it is like a burden and there is no reason for this feeling. Can you describe broadly your experience with this feeling? What mechanisms have you put in place to cope with this?

3.4 What is your experience with support systems/people/ family in this adherence journey? *Probe for: Who are they, can you talk about their relationship with you and how this has helped you or not adhere to ART? Do they play a part in helping or hindering you to adhere? How they got involved?*)

b. What do they know about you? Describe? Probe for sexual orientation and HIV? how they feel about not disclosing their sexual orientation? (*Probe for: Who are they, can you talk about their relationship with you and how this has helped you or not adhere to ART? Do they play a part in helping or hindering you to adhere? How they got involved?*)

3.5 Can you talk about openness to your partner /s about you being a person living with HIV, and how you think this has affected how you adhere?

Topic Area 3: Treatment-related factors

3.1 Can you speak about your experiences with ART medication? Failures/ changes in drugs etc? overall experience with drug taking. (*Probe for: drug formulations/ drug stockouts/ side effects/ comorbidities*)

3.2 What other remedies and treatments are you currently using or have used in the past together with your ART medication? What do you use these other remedies for? What is your motivation for this? (tradition/faith/ poverty?)

Topic Area4: Societal and economic factors

4.1 Based on your experience, do you think that there is any relationship between societal perceptions of your sexual orientation and your adherence to ART? (*Probe for: How have you felt about the ways your sexual orientation been portrayed? Have you been able to be open about your sexual orientation, if so to who and what has been the reaction? What about your HIV? Has the way sexual orientation been viewed or portrayed impacted on your own or others views of your HIV status?)*

4.2 What is the importance or not of financial stability on your adherence to ART?
(*Probe for example: shelter/ gainful employment/ access to food*?)

4.3 Can you share with us your personal living conditions and how it impacts on your adherence? (Probe *for: shared living conditions (with parents/ partner/ friends) and how this affects adherence; Probe for mobility and fixed status. If he is moving around constantly, how does this affect adherence)***.**

Topic 5: PWID specific section

5.1 Are you using non injectable recreational drugs? If yes, describe your non injecting drug use habits? Which ones are you using? If this does not apply to you, can you share with me about someone you knows' story on how they started using drugs?

5.2 Are you on both injecting and non-injecting drugs presently or at any time? If yes can you share with

me how you manage the poly drug use? If this does not apply to you, can you tell me about someone you know? How does this affect your relationship with ART drugs and adherence?

5.3 What are your views on the relationship between societal perceptions of your sexual orientation and injecting drug use? Does this affect your adherence to ART and if so, how? If this does not apply to you, can you speak about how this may affect others you know who are injecting drug users? (*Probe for example: relationship with family, work society, friends)*

5.4 As adherence to ART is a lifelong commitment, please share with me your experience in the journey of being someone living with HIV/ gay and also an injecting drug user. If does not apply to you, can you speak about someone you know in this situation?

Thank you for your time and open discussion on such sensitive issues. I really appreciate it.

Is there any question(s) you

APPENDIX 7: IN-DEPTH INTERVIEW GUIDE WITH PROGRAMME MANAGER OF PEOPLE WHO INJECT DRUGS (PWID) PROGRAMME

IN-DEPTH INTERVIEW GUIDE WITH PROGRAMME MANAGER OF PEOPLE WHO INJECT DRUGS (PWID) PROGRAMME
Topic: *Adherence to anti-retroviral treatment among gay men and other men who have sex with men living with HIV, in Tshwane, Gauteng*
Form of data recording: *(1) Audio-recording of interview. (2) Notes of key points recorded in a note book during the discussion.*
Venue: Private spaces within the Clinic and/ or away from Clinic (in case of some injecting drug users)

Time: Explain that this interview will take no longer than an hour 20 minutes and will be recorded for research purpose only.

Participant details:
Name of Interviewer(s): ______________________________
Date: _______________ Time period/ duration of interview: ___________________
Location [District, Province]: _____________________________
Place interview conducted: _______________________________
Age [in years]: ______________
Sex [circle one]: FEMALE MALE OTHER

Good day, my names are Olusegun M Odumosu – as I have already mentioned I am conducting research for my Master's degree in Public Health. We have covered some details about you when dealing with the demographic details. I would like to move on to ask you some questions about the health services and therapy you receive, and ask you about your insights on some of the things that may affect this.

Key interview areas: Interview will cover hospital services related factors, therapy-related factors, socio-economic factors and also individual efficacy-related factors

At the beginning of the interview, remind participants how valuable sharing their experiences is to the study and that some questions may be sensitive and that they are free to skip any question/s that they are uncomfortable with.

PWID specific questions

1. To what extent have you been exposed, among the PWID you are dealing with, to gay men and other MSM who live with HIV and also are on ART?
2. Drawing from this experience, what in your view is the level of adherence with ART among gay men and other MSM who live with HIV and also inject drugs?
3. What do you view as the main reasons for failures and triumphs among individuals in this group in their adherence journey? Which of these reasons are specific to their situation as PWID?

4. Have you noted any measures taken by gay men and other MSM who live with HIV and also inject drugs, and who are on ART, to improve adherence to their treatment?

5. In your experience working on this programme, do you think that gay men and other MSM who also inject drugs suffer from stigma from other injecting drugs users who are heterosexual? If yes: How do you think this further impact on their adherence?

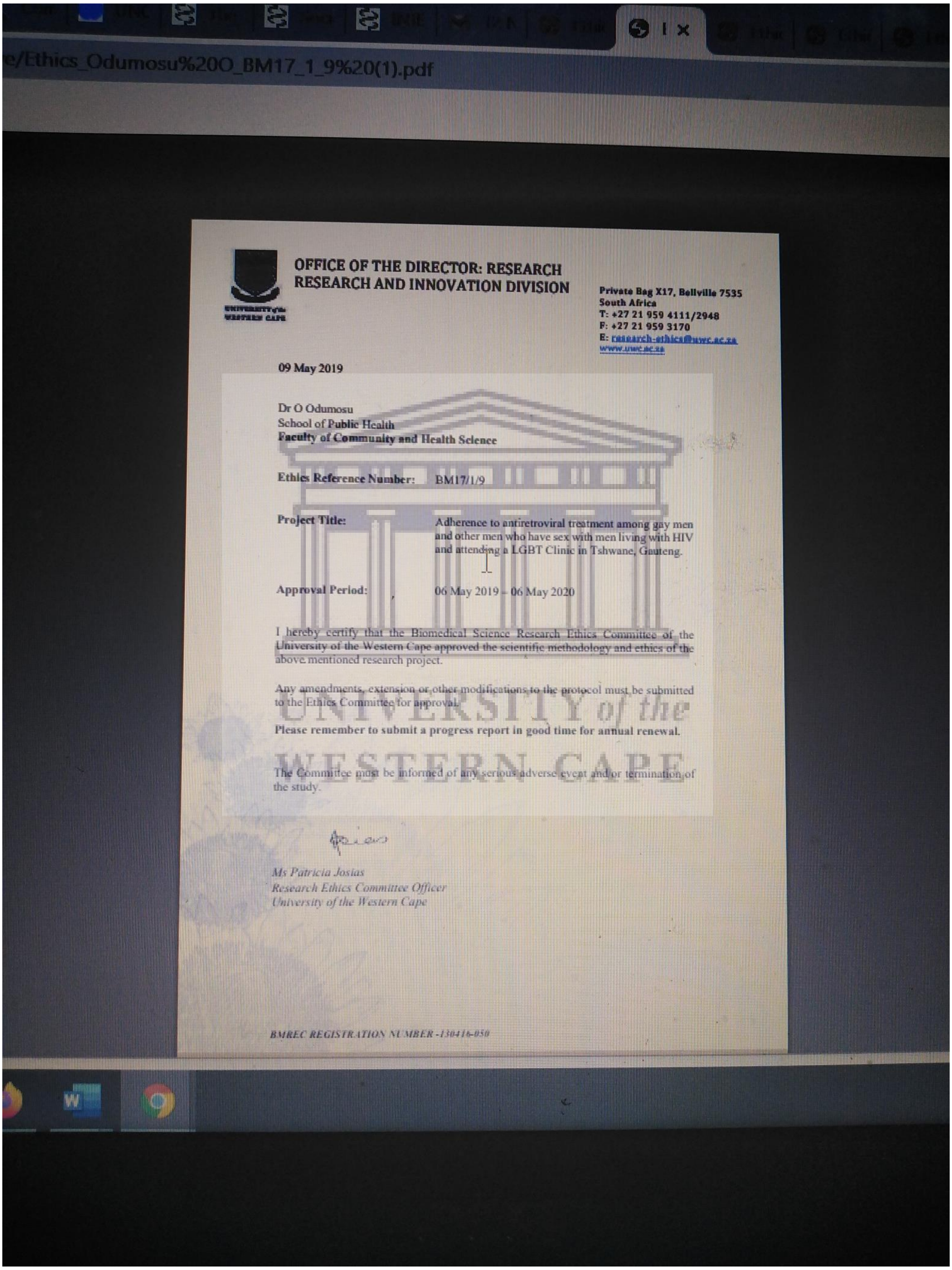
6. How do PWID manage their injecting drug use while they are on ART? (Probes: have they complained about perceived drug interactions that manifested as side effects? What kind of side effects, if any? How have they managed the side effects if they experience such effects?)

7. How do you think the social conditions of PWID (lack of shelter, gainful employment, support systems aside their injecting drug networks etc) impact on their adherence to ART? What is the psychological and mental effect of the lack of support systems, social support and inclusion, on adherence to ART among PWID, generally, and gay men and other MSM who live with HIV and also inject drugs, specifically?

8. What do you think your programme can do to improve adherence to ART amongst PWID, generally, and gay men and other MSM who live with HIV and also inject drugs, specifically?

Thank you for your time and open discussion on such sensitive issues. I really appreciate it.
Is there any question(s) you will like to ask me or anything you will like to discuss with me?

APPENDIX 8: ETHICAL CLEARANCE CERTIFICATE



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09 May 2019

Dr O Odumosu
School of Public Health
Faculty of Community and Health Science

Ethics Reference Number: BM17/1/9

Project Title: Adherence to antiretroviral treatment among gay men and other men who have sex with men living with HIV and attending a LGBT Clinic in Tshwane, Gauteng.

Approval Period: 06 May 2019 – 06 May 2020

I hereby certify that the Biomedical Science Research Ethics Committee of the University of the Western Cape approved the scientific methodology and ethics of the above mentioned research project.

Any amendments, extension or other modifications to the protocol must be submitted to the Ethics Committee for approval.

Please remember to submit a progress report in good time for annual renewal.

The Committee must be informed of any serious adverse event and/or termination of the study.

Ms Patricia Josias
Research Ethics Committee Officer
University of the Western Cape

BMREC REGISTRATION NUMBER -130416-050