The psychosocial experiences of activists living with HIV receiving ARV treatment in Limpopo province, South Africa.

by

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in the Department of Psychology

Faculty of Humanities

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DECLARATION

I, **Emmanuel Ntimani** hereby declare that this dissertation is my own work and that, where applicable, every effort has been made to correctly reference the work of other authors.

Furthermore, I declare that this dissertation is to be submitted to the University of Pretoria and has not previously been submitted to this university or any other tertiary institution.

Signed this 17 March 2023

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Abstract

The HI- virus continues to spread globally and remains an outcry in the international community and a burden disease in South Africa. The influence and presence of HIV activists in the community positively contributes to the fight against HIV/AIDS.

The HIV activist give face to the disease. The question now becomes how do these people navigate their HIV activism role in the community that they live in, especially in a rural province like Limpopo? what challenges do they face when performing such roles? There is a need to understand the psychosocial experiences of HIV activists on ARV medication. This study aims at exploring the experiences of HIV activists who continuously exert influence in the fight against HIV and the stigma that follows it. Their social, emotional, and psychological experiences are explored regarding the ARV medication. It is argued that although ARVs enhance wellbeing, they change the nature and experience of the illness.

The biological experiences of ARVs have been widely studied in research, it is for this reason that the researcher decided to focus on the psychological, emotional, and social experiences of ARVs on HIV activists in Limpopo province. Theoretically, the social constructionism approach was used to provide a theoretical framework as it attempts to understand the human experience, including perception from a historical, cultural, and linguistic way. understanding the experience between individuals, groups, and behaviour, invariably understanding the relationship between HIV related stigma experienced and the support available to the activists.

A qualitative approach was used in the study where in depth semi structured interviews were used to collect data. The snowball sampling method was used to select participants for the study. Data was collected and data analysed using interpretative phenomenological analysis method. It was evident from the research results that upon diagnosis, most HIV activists had a hard time accepting their diagnosis experiencing negative emotions and thoughts including shock, fear of death, sadness, anger, self-blame, and denial. All the participants had experience with the social effects of taking the medication. The study was concluded with relevant recommendations.

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Key words:

- HIV
- ARV
- Psychosocial
- Limpopo province
- HIV activists
- PLWH
- Qualitative research

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Dedication page

I dedicate this thesis to my father. I am very grateful for his support throughout my journey and all the sacrifices he had to make for me to come this far.

I dedicate this piece of work to my mother, thank you mother for holding me down all the time. Your prayers and undying support did not go in vain.

I also dedicate this mini dissertation to my siblings, thank you for all your support.

I also dedicate this thesis to my late grandmother whom I lost last year and had a major toll on my mental health and that of my family. Kokwani this Is for you.

Thank you!

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Acronyms

- HIV- Human Immunodeficiency Virus
- AIDS- acquired immunodeficiency syndrome.
- ARV- Antiretroviral drugs
- ART- antiretroviral therapy
- PLWHI- People living with HIV.
- WHO - World Health Organization

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Chapter 1: Introduction

1.1 Introduction and rationale

The Human Immunodeficiency Virus (HIV) is one of the biggest public health challenges facing the world. According to the World Health Organization WHO (2019) HIV can be defined “as an infection that affects the body’s immune system”. This infection destroys the white blood cells in the immune system which causes the immunity to be weak, leading to many opportunistic infections such as heart diseases, Tuberculosis, and cancer. WHO (2019) recommends that a person diagnosed with HIV should be placed on an antiretroviral treatment regime (ARVs) immediately. ARV treatment does not kill or cure the virus, however when taken appropriately they can prevent the spread of the virus by containing the viral load and suppressing the replication of new HIV cells. Sithole (2013) states that the inconsistent use of ARV contributes to a multifarious problem such as drug resistance which increases the likelihood of drug confrontation that contribute to a direct treatment failure that leads to the growth of the virus.

Recent statistics shows that about 37.9 million people globally are living with HIV, with 62% of that population having access to ARV treatment (WHO, 2019). The inception of ARV treatment during the 1990s gave hope to those living with HIV and AIDS (Park, May 2017). People taking ARV treatment have a heightened rate of survival and reduced occurrence of opportunistic infections (UNAIDS 2019).One of the most common rationale for addressing psychosocial experiences in the setting of HIV is because, people living with HIV (PLWHIV) when diagnosed with depression and other mental health disorders are less likely to adhere to ARV regimens when compared with people living with HIV who are not diagnosed with mental illnesses (Meffert, Neylan, McCulloch, Maganga, Adamu, Kiweewa & Valcour, 2019). Depression may be a consequence of unmanaged psychosocial distress among PLWHIV (Cianelli, Villegas, De Oliveira, Sailsman, Montano, Martinez, Toledo, Sandalaula and Sanchez 2020).

Psychosocial distress is defined as unpleasant feelings of psychological which can include behavioural, emotional, and cognitive factors and social factors which can include spiritual factors that may interfere with the ability to cope with the ARV treatment (Luenen, Garnefski, Spinhoven, Spaan, Dusseldorp & Kraaij 2018). People

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living with HIV are overly affected by higher rates of depression, which is the most important contributor to disability among noncommunicable diseases (Cianelli et al., 2020). It is important to qualitatively explore the psychosocial experiences of people living with HIV on ARV medication because Qualitative research shows that psychosocial distress contributes to the wellbeing and adherence of the ARV medication in people living with HIV (Cianelli et al., 2020).

A study conducted by Duko et al., (2018) shows that people living with HIV experienced depressive symptoms with a percentage of 48.8 in the study population. Further, Duko et al., (2018) went on to say that HIV related stigma, poor social support and lower CD4 count are closely associated with depressive symptoms. It is for this reason, the researcher wants to qualitatively explore the psychosocial experiences of HIV activist living with HIV on ARV medication, Duko et al., (2018) also states that depression is high in people living with HIV and it remains undiagnosed and undertreated.

1.3 Research problem statement.

The primary objective of ARV is to reduce the risk of morbidity and mortality. According to Scheacher (2013) the secondary goal of treatment for HIV is viral suppression. Numerous effective therapeutic agents for viral suppression in HIV have been developed. Their efficacy, however, requires that patients with HIV be adherent to their prescribed regimens. Effective use of antiretroviral agents requires not only good adherence to therapy on the part of patients but sustained adherence over time if viral suppression is to be successful (Scheacher, 2013). The Antiretroviral medication is prescribed with 3 principal indications in mind: for postexposure prophylaxis, for pre-exposure prophylaxis in patients at high risk, and for treatment of the HIV-infected patient, whether acutely or chronically infected (Stanley et al., 2017). Effective antiretroviral therapy is the most important intervention in terms of improving longevity and preventing opportunistic infections in patients with human immunodeficiency virus infection (Scheacher, 2013).

A lot of research has been done on the biological as well as the physiological effects of ARVs on people living with HIV. Minimal research has been done on the psychosocial experiences of taking ARVs consistently for life. There is a huge gap in research in terms of the geographic location of the study being conducted on the

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experiences of receiving ARV. For this reason, it becomes of great importance to conduct the study on the psychosocial experiences of HIV activists living with HIV and taking in ARVs because many of the published articles, books and research mainly focus on the biological effects of ARVs rather than the psychological and social effects of taking in the medication consistently for life.

Limpopo province is one of the rural provinces in South Africa. The literature review conducted shows how minimal qualitative research methodology is used to express the key concerns in HIV related literature. This research project will provide a qualitative research approach to the experiences of living with HIV. Little research is conducted in Limpopo about HIV/AIDS, more specifically the experience that HIV activists go through when taking ARV treatment.

1.4 Aim and objectives

Brief description and statement of the research question:

This research aims to explore the psychological as well as the social experiences of HIV activists who are taking Antiretroviral treatment. To accomplish this, aim the following objectives were developed:

- To gain a better understanding of the social and psychological experiences of HIV activists taking ARV treatment.
- To gain a better understanding of how activists living with HIV cope with the experiences of taking the ARV medication.
- To explore the significance and purpose of ARV adherence.

1.5. Research questions

The above research aims will be explored through the following research questions:

- What are the social and psychological experiences of HIV activists taking ARV medication?
- What are the coping mechanisms of HIV activists on ARV medication?
- What is the importance or taking ARV medication and what does it mean to the activists living with the virus?

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1.6 Structure of the dissertation.

- Chapter Two reviews the background as well as the current literature on the psychological as well as the social experiences of HIV activists who are taking Antiretroviral treatment.
- Chapter Three outline the theoretical paradigm that was used to guide the study.
- Chapter Four outlines the methodology utilised throughout the study, focusing on the sampling method, the data collection method that were used as well as the method of analysis that was used.
- In Chapter Five, a detailed representation of the findings is outlined. Chapter Five focuses on discussing the main findings of the study by situating them within themes.
- Chapter 6 will be the discussion chapter, where the findings of the study are linked with literature. Additionally, the limitations of the study and the recommendations for future research are indicated in Chapter Five.

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Chapter 2: Literature review chapter

Introduction

HIV and AIDS prevalence persists despite developments in antiretroviral treatment. This chapter will discuss the available research on HIV locally and globally. The ARV treatment, HIV activism, psychological and social experiences that HIV activists experience when taking the medication.

2.1 An Overview of Human immunodeficiency virus globally.

The HI- virus continues to spread globally and remains an outcry in the international community. WHO (2016) over the years countries have come together to advance strategies to at least reduce the widespread of the HIV, because it is affecting the human race negatively due to increased mortality rates and increased poverty which affects mostly the young and the most vulnerable individuals in society. WHO (2016) further states that the pandemic keeps on increasing despite the measures taken to ensure that individuals are not infected by the HIV virus. Globally, at the end of 2014 the number of people living with HIV and AIDS was sitting at 36.9 million (Monoto, Lugongolo, Govender, Mthunzi-Kufa, 2018).

2.2 The Overview of Human Immunodeficiency Virus in Sub-Saharan Africa.

HIV and AIDS is a highly noticeable and increasing pandemic in Africa. WHO (2016) reported that Sub-Saharan Africa maintains the status of being severely affected by the virus, almost 1 in every 20 adults (4.8%) live with HIV and AIDS summing nearly to 70% of the global population living with the HIV virus. In their research Monoto et al., (2018) further supports the statement by WHO (2016) mentioning that Sub-Saharan Africa has the highest prevalence of HIV with 70% of the population living with HIV. Amuche, Emmanuel and innocent (2017) found that in Sub-Saharan Africa about twenty-five million people are living with HIV, accounting for approximately 66% of the recent complete world HIV infections and more than seventy percent of all AIDS-related deaths. Wretchedly, more than half of the HIV-infected populace in sub-Saharan Africa are women and children (Amuche et al., 2017).

It is still unclear why the HIV infection and AIDS are particularly critical in sub-Saharan Africa. Several characteristic reasons have been voiced out to explain the high occurrence and uneven flow of the virus in this region (Amuche et al., 2017). Reasons

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include the presence of different strains of HIV, sexually transmitted diseases, poverty, economic marginalization, sex work, absence of male circumcision, jail overcrowding and increased public movement (Amuche et al., 2017).

2.3 Overview of Human Immunodeficiency Virus in South Africa.

South Africa is one of the countries in the world with highest number of people living with HIV. According to Silimela, Venter, Pillay and Barron (2015) of all the people living with HIV in the world, one fifth lives in South Africa. AIDS foundation of South Africa (2014) mentioned that South Africa is facing a swift increase in the occurrence of HIV and AIDS as compared to other countries in the world, with a number of five million six hundred thousand people living with HIV and in 2011 more than Two Hundred and Seventy thousand HIV related deaths were recorded. South Africa has one of the highest HIV prevalence rates in the world. "South Africa has the fastest growing (HIV/AIDS) epidemic of any country in the world. Within five years, one South African will die of an AIDS-related illness every minute unless action is taken now" (Lowell, 2000) (p1). This quote was published in one of the articles in the South African media which incarcerates the importance of the epidemic, it is possible influence on society, and the crucial need for actual interventions (Gilbert & Walker, 2002).

Previous studies indicate that the features of HIV/AIDS are noticeable in the media and the exposure did not stop the growth of the virus (Gilbert & Walter, 2002). Recent research indicates that the presence of the media on HIV related issues, shows that mass media in South Africa continuously play an important role in increasing knowledge and promoting practice in a full continuum of prevention, treatment, care and support (Do, Figueroa & Kincaid, 2016). Silimela, Venter, Pillay and Barron (2015) also mention the efforts by the South African government have yielded positive change over the past 5 years. To date South Africa is one of the largest suppliers of ART in the world with over 3 million people living with HIV benefiting from this programme (Silimela, Venter, Pillay & Barron, 2015). HIV/AIDS is not only a medical issue, but also a social one, as shown by its spread as well as by the inadequacy and deficiency of the medical establishment to control and limit its growth (Gilbert & Walker, 2002). In Limpopo Province, South Africa very little research has been done on HIV treatment attitudes. the literature review that the student conducted on google scholar, the

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University the University library, there were fewer articles on HIV treatment in Limpopo province.

2.4 HIV activism.

HIV continues to be stigmatized, or socially devalued and discredited in the USA and worldwide (Earnshaw, Rosenthal and Lang, 2016). Despite the numerous improvements and development from around the world pertaining to the treatment, management of the virus, it still remains a persistent pandemic (Reed, 2018). The virus is not only defined in biological, biomedical or in pharmaceutical terms it is often loaded with cultural and social meaning (Reeds, 2018). HIV Activism does not only focus on the stigma, discriminations, exclusions, maltreatment and oppression of people living with HIV, it also addresses the inequality in basic and clinical science of HIV, Pharmaceuticals, policy making and creation of a better HIV environment for those living with the HI Virus (Colvin, 2014).

HIV activism began in the early 1900s, with many groups forming from around the world for the advocacy of those living with HIV, as mentioned by WHO (2016) the spread of HIV remains of the most challenging public health pandemic, with countries around the globe working tirelessly to promote positive awareness around the virus, ways to manage it, and the treatment available to those living with the virus in order to curb the fatality rates.

The influence and presence of HIV activists in the community positively contributes to the fight against HIV/AIDS. According to Reeds (2018) HIV activists play an important role in conveying the message to the public and people living with HIV and the people affected by HIV on the importance of taking the pill, managing stress that may be caused due to living with the virus or having a family member who is living with the virus, dealing and managing with the stigma that comes with living with the Virus.

Steven Epstein in his book called the Impure science, refers to the HIV activist as lay experts in the field of HIV (Robins, 2008). The role of these experts included but not limited to translating their knowledge and experiences as activists to people living with HIV and families of people living with HIV into forms of expertise and scientific capital (Robins, 2008). In South Africa, the openness of people freely speaking about the virus has increased over the years. In article called Choma Queens- HIV activist, a lot local south African activists voiced out their opinion and stance with regards to HIV

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activism in modern day South Africa. One of the ladies include Saidy Brown who was born with the virus and only found out when she was 14 years old. She uses her story to inspire others who are in a position similar to her in trying to mitigate the effects of the HIV stigma. She mentions that “I like sparking conversations about HIV. I don't believe in treating it like it's an unspoken subject. I want us to talk about it, because once we talk about it more, then we can de-stigmatize it.” It is prevalent that HIV activism exerts a positive spin into the life of those living with the virus, but an important avenue to explore is how these activists navigate with living with the virus, which is the key focus of this research.

2.5 Antiretroviral Treatment.

The inception of ARVs during the 1990s gave hope to those living with HIV and AIDS and recently there is an accentuated treatment availability which has a heightened rate of survival and reduced the occurrence of opportunistic infections in people infected with HIV and AIDS (UNAIDS, 2005). Van Dyk, Tlou and Van Dyk (2017) alludes that the first antiretroviral drug, AZT (Zidovudine) was permitted for use in 1987, and in 2002 ARVs were used to prevent mother-child transmission in South Africa, but in the world was implemented in 1994. ARVs suppress the replication of new HIV cells. The suppression of HIV replication, immune restitution, a stop in disease progression, increased survival, reduced morbidity, and a better quality of life have been defined as the biological and clinical goals of treatment (Mathiva, 2012). Despite the success in improvements in ARVs, many challenges exist. According to Loue (2013) ART does not fully restore health; HIV positive people still have shorter life expectancy than their non-positive peers. Loue (2013) further states that ARV treatment causes different side effects in the human body. According to Van Dyk et al., (2017) there are four primary goals of ARVs, this includes the following:

- Virology goal; to reduce HIV viral load as much as possible.
- Immunology goal: to restore immunology function and to prevent opportunistic infections.
- Therapeutic goal; to improve the quality of life of people living with HIV/AIDS.
- Epidemiological goal: to reduce illnesses that are HIV related and mortality.

To date, there are twenty antiretroviral drugs that have been permitted for use in the treatment of HIV-Virus. The six classes of Antiretroviral treatment that are available to

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interfere the viral replication include a) Protease inhibitors , b) transcriptase inhibitors, c) Nucleoside/nucleotide reverse transcriptase inhibitors, d) Integrase inhibitors, e) CCR5 antagonists, and f) Fusion inhibitors (Pau & Gourge, 2014). Each of these classes of medications affects the HIV infection at an alternative stage in its life cycle. Recent treatment comprises Highly Active Antiretroviral therapy (HAART), that is, no less than three medications having a place with two classes of antiretroviral agents (Pau & Gourge, 2014).

2.6 Recommended initial Antiretroviral regimes.

The choice of when to start ART ought to be made on an individual premise. For those people whose CD4 count and clinical wellbeing assessment don't demonstrate a high danger of infection movement, starting treatment may cause more damage than anything else in view of the clinically noteworthy rate of toxicities and side effects (Pau & Gourge, 2014). However, Saag et al., (2018) believes that ART should be initiated as soon as possible after diagnosis, including immediately after diagnosis, unless the patient is not ready to commit to starting therapy. Regimens that do not require boosting with ritonavir or cobicistat are favored. Choosing a combination with a high barrier to resistance is important, particularly for individuals with inconsistent adherence (Saag et al., 2018). Raltegravir is well tolerated and has fewer drug interactions than other integrase inhibitor (InSTIs) but has a lower barrier to resistance and a higher pill burden. Elvitegravir regimens also have a lower barrier to resistance and include a pharmacologic booster (cobicistat) that results in more drug interactions (Saag et al., 2018). In combination with 2 nucleoside reverse transcriptase inhibitors (NRTIs), the NNRTIs efavirenz and rilpivirine each demonstrate high rates of virologic suppression as initial therapy. Efavirenz based treatment was standard initial therapy for many years, but studies have demonstrated higher rates of adverse effects such as rash and central nervous system adverse effects than InSTI-based therapy (Saag et al., 2018). Rilpivirine has a lower rate of central nervous system adverse effects and rash than efavirenz and is co-formulated with TAF/ emtricitabine into the smallest single tablet for initial therapy. However, rilpivirine must be taken with food, it requires stomach acidity (Saag et al., 2018).

2.7 Classes of Antiretroviral treatment.

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Antiretroviral treatment manages HIV by surpassing replication activity in the body. According to Mathiva (2012) the clinical goals of antiretroviral treatment is Suppression of HIV replication, immune reconstitution, a halt in disease progression, increased survival, reduced morbidity and a better quality of life have been defined as the biological and clinical goals of treatment. Below the classes of antiretroviral treatment are discussed.

2.7.1 Entry inhibitors.

According to Gullick (2018) entry inhibitors are a class of ARV treatment used in combination therapy for treatment of HIV. The entry inhibitors prevent fusion between the virus and the cell from occurring. A new class of HIV entry inhibitors, CD4 attachment inhibitors, targets the first step of entry. Fostemsavir is a small molecule inhibitor that binds HIV envelope glycoprotein and prevents virus from binding to the CD4 receptor (Gullick,2018). Fostemsavir is an oral pro-drug of temsavir, the active compound, with strong activity in vitro against HIV (Gullick, 2018). Some of the drugs in the entry inhibitors include:

- Crc-5 inhibitors– Maraviroc
- Fusion inhibitor- Enfuvirtide

2.7.2 Nucleoside Reverse transcriptase inhibitors.

The nucleoside reverse transcriptase inhibitors (NRTIs) help fight the HIV virus by blocking the enzymes, HIV needs to copy itself and multiply. According to Cihlar and Ray (2010) the development of NRTIs was seen after 25 years when zidothymidine (AZT) was shown to block the HIV infection. After scientists discovered that AZT could block the HIV virus from multiplying, NRTIs evolved. The NRTIs evolved to be the main component of the Antiretroviral drug combination used to treat HIV (Cihlar & Ray, 2010). According to Cihlar and Ray (2010) a total number of 13 NRTI drugs have been approved and are now available for clinical application. It is important to note, however that these drugs can be available as individual drugs and can also be available in various combinations. The NRTI drugs include zidovudine (Retrovir), lamivudine (Epivir), abacavir sulfate (Ziagen), didanosine (Videx), delayed release didanosine (Videx EC), stavudine (Zerit), emtricitabine (Emtriva), tenofovir disoproxil fumarate (Viread), lamivudine and zidovudine (Combivir), abacavir and lamivudine (Epzicom),

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abacavir, zidovudine, and lamivudine (Trizivir), tenofovir disoproxil fumarate and emtricitabine (commonly known as Truvada), tenofovir alafenamide and emtricitabine (Descovy)

2.7.3 Non-nucleoside- reverse transcriptase.

According to the WHO (2016) the non-nucleoside reverse transcriptase works in an equivalent manner with the nucleoside reverse transcriptase, the only difference is that the NNRTIs interferes with the reverse transcriptase enzyme by directly binding to it. Some of the drugs that fall within the NNRTI Include Doravirine, Efavirenz, Etravirine, Nevirapine and Relpivirine.

2.7.4 Integrase inhibitors.

According to Peñafiel et al., (2017) the integrase inhibitors have become the most preferred anchor drugs for treatment and management of HIV. Some of the drugs that fall under the integrase inhibitors include Bictegravir, Dolutegravir, Elvitegravir and Raltegravir.

2.7.5 Protease inhibitors.

According to WHO (2016) the protease inhibitors, blocks the activity of the protease enzyme. Some of the drugs that fall under the protease inhibitors includes Etavanavir, Duranivir and Lopanivir.

2.8 Provision of Antiretroviral treatment in South Africa.

South Africa is home to the largest concentration of people living with HIV. According to a study by Simelela and Venter (2014) Almost 20% of all people living with HIV globally live within the borders of South Africa, and preliminary data reveals that 6.4 million people in South Africa, 19.6% of all adults or 12.3% of the total population live with the virus (Silimela & Venter, 2014).

Despite intense efforts to reduce HIV occurrence, its estimated prevalence remains high in South Africa. According to a study by Quaife et al., (2016) The fourth national population-based survey conducted by the Human Sciences Research Council, estimated prevalence to be 12.6% in 2012, an increase on the previous survey estimate of 10.9% in 2008.This increase may be explained partly by expanded access to antiretroviral (ARV) treatments and associated reductions in mortality, however, there is also evidence of continued sexual transmission of HIV in those aged 15 years

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or older (Quaife et al., 2016). Marinda, Simbayi,, Zuma, Zungu, Moyo, Kondlo. And Briggs-Hagen, M. (2020). further builds on the above statement by stating that The HIV epidemic in South Africa is estimated at 7.1 million PLHIV, accounted for approximately 20% of the 36.9 million PLHIV in the world in 2017.

According to Bekker, Venter, Cohen, Goemare, Cutsem, Boulle and Wood (2014), in South Africa the provision of ARVs was a very slow process despite the virus being rife and the world AIDS conference delivering important public information on disparities of treatment access globally. This was motivated by political evasion in the middle of AIDS denials. There has been a dramatic escalation in HIV therapy programmes from 2008. This led to South Africa having the biggest number of recipients of ARVs in the entire world, and South Africans living longer than a decade compared to other states (Gilbert & Walker, 2002). However, this resulted in variant challenges posed to the country due to the extension of treatment. These challenges include increased realization within communities, liaison and retention in care, fiscal, operational and logistic and consistent drug supply (Becker et al, 2014). According to UNIADS (2019) South Africa manages the world's largest antiretroviral therapy programme, aiming to provide treatment, suppress viral loads and secure the health of 19% of the world's people living with HIV.

The introduction of the Corona virus (Covid-19) in 2019 introduced a threat to the fight against HIV and treatment adherence. According to Jiang, Zhou and Tang (2020) the introduction of lockdown, self-quarantine and isolation prevented a lot of people from going for their normal HIV tests. Doward, Khubone, Gate, Ngobese, Sookrajh, Mkhize and Garrett (2021) further supported the statement by Jiang et al., (2020) stating that the introduction of COVID-19 had lessen HIV testing in South Africa with a 47.6% decrease in April 2020. People living with HIV who should have started antiretroviral therapy (ART) in hospital might be prevented or delayed because hospitals are focusing on treating patients with COVID-19. Furthermore, because many public health authorities globally are focused on COVID-19 control, allocation of resources for HIV care could be reduced, and situations surrounding the HIV could worsen (Jiang et al., 2020).

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2.9 Experiences of people living with HIV on ARV.

Living with HIV and being on ART has different meanings for different individuals. Bravo et al., (2010) asserted that people living with HIV (PLHIV) experiences diverse and complex psychosocial problems which have not been studied extensively. Gilbert and Walker (2009) termed the diverse experiences that PLHIV on ART undergo as 'social complexities' which include how PLHIV conceptualize their illness and experience the full trajectory of living with HIV. Because early initiation of ART is a relatively new concept which emphasizes ART as prevention, it may change how people perceive HIV testing, prevention and transmission as well as their behaviours towards uptake of HIV testing and ART (Orne-Gliemann *et al.*, 2015). Orne-Gliemann et al., (2015) further went on to say, the acceptability of ART among monosymptomatic HIV positive individuals, their adherence to ART, disclosure of HIV status, stigma and marginalization, quality of life, sexual behaviors and other factors affecting PLHIV may change.

2.10 Perceptions and experiences with treatment

Pierret (2007) asserted that, although ARVs enhance wellbeing, they change the nature and experience of the illness. A study conducted in South Africa showed that PLHIV see ARVs as their lifeline and a means by which they survive yet they also represent dependence and fear, for without them illness would prevail (Gilbert and Walker, 2009). Despite showing gratitude towards ARVs, PLHIV experienced challenges with the quantity and side effects of the drugs and the fact that they are a lifetime commitment without curing the virus (Gilbert & Walker, 2009). Other studies conducted in Zambia found that although ART positively impacted on the health of PLHIV, it was still perceived as harmful, worsening one's condition and causing bodily harm that could lead to death in unexplained circumstances (Gilbert & Walker, 2009).

Taking drugs everyday ignited a depressing thought that reminded PLHIV of their illness, (Simuyaba 2018). Some PLHIV express reluctance to commit to a lifetime treatment that requires them to change their social lifestyles such as alcohol consumption (Pierret, 2007). The nature of the prescription of ART which must be taken at a specific time and often not in the presence of people who are not aware of a PLHIV's condition, disrupts social routines (Veinot *et al.*, 2006). James, Joseph, Peter, Walter, Ann and Atanas (2018) further build on Vientot et al., (2006) mentioning

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that the Antiretroviral regimes are complex, noxious and many side effects. It further disrupts the patients' daily routines because one has to do check-up visit to the clinic which can become a challenge in adhering over time (James et al., 2018).

2.11 The psychosocial experiences of people living HIV on ARV treatment.

2.11.1 Psychological experiences.

Individuals living with HIV are twice as more inclined to experience the ill effects of depression than the overall public (Sordahl et al., 2010). Additionally, psychiatric illnesses such as depression have been constantly connected with lowered chances of receiving HAART, lesser medication devotion and if untreated, greater mortality (Pau & Gourge, 2014). Additionally, psychopathology in HIV-positive populaces have been related with diminished personal satisfaction and may expand high-chance practices, for example, expanded suicide rate, suicide ideation, liquor misuse and hallucinations (Sordahl et al., ,2010). ARV treatment can cause distress to your mental and emotional health. Most notably, the non-nucleoside reverse transcriptase inhibitor (NNRTI) has been linked with depression and restlessness, as well as clear nightmares (Sordahl et al., 2010).

A study conducted by Goodness, Palfai, Cheng, Coleman, Bridden, Blokhina and Samet (2014) shows that depression is the most diagnosed illness in people living with HIV/AIDS, with a prevalence rate two times higher than the general public. People who suffer from depression have a diminished interest in most of their daily activities. Adherence to ARVs becomes a challenge to most people diagnosed with Depression to adhere to their daily treatment regime (Goodness et al., 2014). In as much as Goodness et al., (2014) believe that people that suffer with depression have a difficulty in adhering to their treatment, Loue (2013) postulates that the treatment of depression reduces non-adherence to ARVs. Arguably so, in South Africa, Limpopo province to be precise a lot of people are not at liberty to see a psychologist or a psychiatrist for mental assessments which means that a lot of people that are living with HIV/AIDS are at a greater risk of not adhering to their treatment. Suicide, suicide ideation is also at a peak with people diagnosed with HIV/AIDS. According to Loue (2013) many reasons contribute to suicide ideation and completion of suicide, this includes isolation, stigma from society, chronic pain and side effects caused by the intake of ARVs. The

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intake of non-nucleoside reverse transcriptase inhibitor, Efavirenz, directly causes neuropsychiatric side effects such as depression and worsening suicide ideation (Loue, 2013).

The introduction of COVID-19 also poses new threats to the psychological management of living with HIV. According to Winwood, Fitzgerald, Gardiner, Hannan, Howard and Mutch (2021) The psychosocial impacts of accumulated stress over one's life is likely to increase the chances of poor mental health and premature death in PLWH. In the beginning of COVID-19 a lot of PLHIV were experiencing anxiety and stress linked to both concerns associated with contracting COVID-19 and its impact on their HIV treatment (Winwood et al., 2021). Based on the previously mentioned PLWH at risk of acquiring severe mental health conditions. Winwood et al., (2021) further reiterates that the regulations that were introduced to curb the effects of COVID-19 such as quarantine, social isolation, absence of social contacts with friends and family can further contribute to the loneliness and poor mental health outcomes for PLHIV. According to Bret, Kaygee and Sedat (2014) there is a relationship between the psychological wellbeing of people living with HIV and the social support. According to the results in their study, 643 women viewed themselves as guilty, dirty and shameful because they have the HIV virus which impacted the way they perceive themselves and the support that they need from their loved one which results in stigmatizing behaviour (Bret et al., 2014).

2.11.2 Social experiences**.**

HIV/AIDS is a risk to social and economic advancement. According to Taraphdor et al., (2010) treatment of HIV/AIDS patients must be used with other social measures to improve their physical, mental, and social wellbeing. HIV/AIDS can prompt destitution, affecting especially women and children. Paul and Premraj (N: D) stated that people living with the Hi-Virus experience a lot of societal backlashes, one of them being stigma and discrimination. Winwood, Fitzgerald, Gardiner, Hannan, Howard and Mutch, (2021) further went on to say majority of PLHIV already face social exclusion due to enacted or perceived HIV-stigma, or become socially disconnected as a coping mechanism, which may again influence access to HIV care. Many of the people living with HIV are abandoned by their families which force them to live in improvised conditions, which mean that they have inadequate family and community support,

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which may lead to poor drug adherence (Paul & Premraj, N:D). Loue (2013) states that the sudden consequences of performed HIV related stigma is the loss of individual status. Mills et al., (2010) defines stigma as an undesirable or discrediting attribute that an individual possesses, thus reducing that individual status in the eyes of society. It is a labelling of an individual or group as different or deviant. Parker and Aggleton (2002) added that, HIV related stigma is reinforced by the association of HIV and AIDS with already marginalized behaviors, such as promiscuity, sex work, drugs use and homosexual practices. Earnshaw, Rosenthal, and Lang (2016) further went on to mention that societal stigma weakens the wellbeing of PLWH, these effects ranges from psychological, physical, social health. Earnshaw et al., (2016) further goes on to mention that the response to the stigma from PLWH determines whether they will be negatively affected or not. Activism can help mitigate the negative effects of HIV stigma. Earnshaw et al., (2016) further went on to say that activism allows PLWH to contest and avoid societal stigma and to empower themselves and others.

Consequently, individuals living with HIV are often believed to deserve their HIV positive status because of having done something wrong. People who lose individual status often experience a lot of poor mental health outcomes, such as (depression, anxiety, and negative self-worth), delayed access to using ARVs and poor ARVs adherence (Loue, 2013). Stigma and discrimination to the individuals who are on ART influence adherence to medications, that is, taking medications may indicate that someone is HIV-positive. Moreover, studies on medication adherence have documented that some people do not adhere to medication for fear of side effect because not only can the side effects of ARVs be bothersome, but they can also cause visible side effects, or stigma symbols, which add to existing stigma that one may perceive as a person living with HIV infection (Paul & Premaj, N:D)

Mills et al., (2010) found that, the fear of stigma experienced by people on ART results in postponing or rejecting care, seeking care far from home to protect confidentiality, and nonadherence to medication. The above studies have documented that men who have sex with men and injecting drug users, often avoid or delay accessing HIV-related services, including treatment for other sexually transmitted diseases, for fear of public exposure and discrimination by health workers. According to UNIADS (2019) Ignorance and fear of HIV has nurtured stigma and discrimination against people living

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with HIV since the earliest days of the epidemic. Gender inequality, violence against women and girls, and marginalization of the key populations at highest risk of HIV infection, including sex workers, people who inject drugs, prisoners, transgender people, and gay men and other men who have sex with men pre-date the epidemic by decades, if not centuries (UNIAIDS, 2019). Pushed away by families, friends and entire communities, countless people living with HIV or at high risk of infection have been left stranded and alone, unable to access the services they need.

Culture and beliefs play a huge role in ART adherence. According to a study done by Ondwela et al., (2019) Traditional healers exert a great influence in adherence of ARVs. Ondwela et al., (2019) stated that many traditional healers don't believe in HIV/AIDS as a virus, when patients come to consults, they tell them to discontinue the use of ARVs because they will not help them rather, they take organic herbs that will be of assistance to them. With this statement being said, it becomes clear that people's beliefs can have an adverse effect on their health and wellbeing.

Debilitated family and societal emotionally supportive networks, diminished investment in formal education of young people because of AIDS in the family, alongside exhausted family income because of loss of work, and poor sickness management present extra vulnerabilities (Taraphdor et al, 2010). People living with HIV normally stress about several things, which includes their health, income and their family. According to Taraphdor et al., (2010) many people diagnosed with HIV stress about taking in medication for the rest of their lives, they stress about their CD4 count and frequent visit to the clinics to get medication, since HIV is still one of the most Stigmatized diseases in the world. Religious beliefs, poverty, lack of familial support and unemployment are social factors that were mentioned by Taraphdor et al., (2010) to increase default of antiretroviral treatment which in turn increases mortality rates.

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Chapter 3: Theory chapter

3.1 Introduction

A research paradigm guides the research project. It informs the research perception and understanding of reality. In this chapter the researcher will be discussing social constructionism paradigm. The researcher will further explore the history of social constructionism, the principles of social constructionism and how it will be applied throughout the study.

3.2 What is a research paradigm?

A research paradigm can be defined as a lens through which individuals see the world, and a system by which social phenomenon can be examined and explained (Khaldi, 2017). Paradigms inform researcher's perception and understanding about the nature of knowledge, as well as how can be accessed. Research paradigms are usually guided by three main tenets, namely: ontology, epistemology, and methodology (Denzin & Lincoln, 2011). "Ontology relates to one's perspective of reality, epistemology to one's relationship about what is known, and methodology to how specific knowledge is obtained" (Ellis, 2016, p. 14).

3.3 What is social constructionism?

The study will be guided by the social constructionism paradigm. According to Willig (2013) this paradigm states that human experience, including perception, can be viewed in a multidimensional way, from a historical, cultural, and linguistic way. It suggests that there are knowledges rather than knowledge (Willig, 2013).

3.4 History of Social constructionism

The History of the social constructionist perspective which emerged in the late 1970's, stood in contrast to other theoretical approaches that studied social problems at the time (Schenk, 2019). Schenk (2019) further goes on to mention how the functionalist approaches to the study of social problems dominated the field prior to the 1960's and how these theorists understood social problems as conditions that hindered or obstructed the smooth running of society. In his study of Constructing an "HIV-killer": HIV non-disclosure and the techniques of vilification Speakman (2017) notates that social constructionism originated as an attempt to come to terms with the nature of

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reality. It emerged some thirty years ago and has its origins in sociology and has been associated with the post-modern era in qualitative research (Speakman, 2017). Schenk (2019) further builds on the observations by Speakman (2017) by mentioning that people's reflections, opinions, and feelings are an accurate image of the world that is being reflected.

The terms constructivism and social constructionism tend to be used interchangeably and incorporated under the generic term 'constructivism. According to Srivastava (2020) Constructivism proposes that each individual mentally constructs the world of experience through cognitive processes while social constructionism has a social rather than an individual focus. Social constructionism is essentially concerned with explaining the process by which people come to describe and explain the world in which they live (Barbehön, 2020). Social constructionism is centred on the view that in the process of perceiving and describing an experience, we construct not only our personal knowledge base about reality but also our own reality (Srivastava, 2020). Galbin (2014) also mentions that social Constructionism or the social construction of reality as a theory of knowledge in the field of sociology and how other people communicate and interact with one another examines the development of jointly made understanding of the world. Galbin (2014) further goes on to mention that social constructionism may be described as a perspective which believes that an immerse aspect of human life exists as it does due to social and interpersonal influences.

The social constructionist perspective, which emerged in the late 1970's, stood in contrast to other theoretical approaches that studied social problems at the time (Grandy, 2018). Functionalist approaches to the study of social problems dominated the field prior to the 1960's and these theorists understood social dilemmas as conditions that prevented the smooth running of society (Grandy, 2018).

3.4 Application of Social constructionism in the research study.

From a social constructionist's perspective, individuals will attach different meanings to similar experiences. With this statement being said, many HIV activists have differently constructed meaning in similar experiences that many are exposed to or come across in their lives living with the HI Virus and taking ARVs. Their varied constructed meaning in those experiences is what contributes to multiple realities which is mentioned by McNamee, Gergen, Camargo-Borges and Rasera (2020).

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McNamee et al., (2020) further elaborate that it is in these differences in meanings that constitute different realities. Individuals may attach more than one meaning to an experience, which contributes to the notion of multiple realities (McNamee et al., 2020). The social constructionism epistemology assumes that an individual's reality arises from meanings that develop within a historical, social, and community context (Grandy, 2018). Although the focus of the proposed study will be on the individuals living with HIV, it is important to remember that the individual is part of a specific context, in which they interact with other family members, the community and culture.

The researcher will view participants within their network of relations in an attempt to understand their experiences of living with HIV. In this way the researcher as a social constructionist believes life experiences cannot be studied out of context. One of the aims of the proposed study is to understand the psychosocial experiences of HIV activists taking ARV medication and the specific meanings attached to HIV activism by society and culture within which people living with HIV are located. For the purpose of this study, the focus is on how meanings develop within a social, historical and community context affect meanings attached to being an activist and living with HIV virus.

Freedman and Combs (2020) explains the narrative social constructionist approach, They highlights that there are no fundamental truth and that reality is structured socially, represented through language, coordinated and maintained through stories (Freedman & Combs, 2020). Grandy (2018) also mentioned that social constructionism focuses on an individual's learning that takes place because of their interactions in a group. It is for this reason why the following social paradigm was chosen by the researcher to explore the social as well as the psychological experiences of HIV activists living with the Virus. It is a suitable paradigm of departure to use because many activists have a varied view of the experiences that get created based on their own individual interactions in their respective community. Using this paradigm will enable the researcher to uniquely view each activist's varied experience and how they construct their reality in the world they live in.

3.5 Epistemology of Social constructionism.

They are four basic ideas of social constructionism namely cause, text, meaning, and context (Hui, 2020). There are no essential truths, one of the main aims in social

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constructionism is to interpret experience. There are many possibilities for how any given experience may be interpreted (Freedman & Combs, 2020). Social constructionist thinking is fundamentally postmodern in that the individual's meanings and realities are perceived as created and not as definite truths (Freedman & Combs, 2020). The individual is seen as the expert in his or her life and social constructionist thinking focuses on stories based on a person's lived experience, rather than on expert knowledge (Willig, 2013).

There are no key truths; realities are created through language. One of the main objectives in social constructionism is to interpret experience. There are many possibilities for how any given experience may be interpreted (Haymarket Books, 2022). Freedman and Combs (2020) state that language is the most important system through which humans form their reality. According to them, language tells us how we view our world as well as what we see within it. The social construction of reality is a continuing, active process that is recreated by people based on their interpretations and their knowledge of it, realities are socially constructed (Money, 2020).

3.6 Principles of social constructionism.

There are quite a few basic principles emphasized in social constructionism. These include realities that are socially made; realities are established through language; knowledge is maintained by social processes; and reflexivity in human beings is emphasized Galbin (2014). Society is seen as existing both as a subjective and objective reality. Social constructionism focuses on meaning and power. According to Galbin (2014) meaning is not a property of the objects and events themselves, but a construction. Meaning is the product of the prevailing cultural frame of social, linguistic, discursive, and symbolic practices Galbin (2014). Hui (2020) further went on to elaborate more on the statements of Galbin (2014) by stating that from a social constructionist perspective, language is more than just a way of connecting people, people exist in language. Consequently, the focus is not on the individual person but on the social interaction, in which language is generated, sustained, and abandoned (Hui, 2020). A social constructionist perspective, as opposed to a constructivist perspective, "locates meaning in an understanding of how ideas and attitudes are developed over time within a social, community context" (Srivastava, 2020)

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The social construction of reality describes how ideas, practices and beliefs come to have a reality status in each social group (Nickerson, 2021). Our realities, consciousness, and ways of interacting with one another are socially constructed through our shared language, attitudes, and ideas (Nickerson, 2021). Realities are organised and maintained through stories (Nickerson, 2021). Knowledge can be seen as that which is represented in linguistic propositions, rather than something that people possess in their heads (Nickerson, 2021).

The social constructionist framework proposes that people live their lives according to narratives that are embedded within the available cultural discourse (Patra, 2018). The social constructionism epistemology is thus essentially about relationships. It focuses on the collective and communal aspect, but also on the individual's experiences within a context. It sees events as relational rather than internal and involves the creation of meaning in community with others (Patra, 2018). The context of people living with HIV is pivotal, and their perceptions of their reality cannot be viewed in isolation from their context. According to the researcher, social constructionism is appropriate in providing an understanding of the personal psychosocial experiences of people living with HIV's experience in their communities.

This is done through the medium of language. Dombrowski (2020) comments that within social constructionism language is not an unproblematic means of transmitting thoughts and feelings, but in fact makes thought possible by constructing concepts. In other words, it is language that makes thoughts and concepts possible and not the other way around. Language preludes concepts and provides a means of structuring the way the world is experienced. Freedman and Combs (2020) maintain that conversation is the most important means of maintaining, modifying and reconstructing subjective reality. Subjective reality consists of concepts that can be shared unproblematically with others (Freedman & Combs, 2020). In other words, there is shared meaning and understanding, so much so that concepts do not need to be redefined each time they are used in everyday conversation and come to assume a reality which is taken for granted. This is the paradigm that will guide the researcher in facilitating and conducting the research on the psychosocial experiences of HIV activists on ARV medication in Limpopo province, South Africa.

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3.7 Conclusion

Social constructionism theory was discussed above, the history of the theory, application of the theory in the study, principles of the theory and epistemology.

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Chapter 4: Research methodology

4.1 Introduction

In this chapter, the primary investigator will provide the description of the methodology used. The chapter begins by presenting the aims and the objectives of the study. Thereafter, a description of the research design, participants information; the recruitment procedure, description of the participants that took part in the study. To provide a clear idea of how the research results were obtained and analysed, sampling, the data collection procedure as well as data analysis will be discussed. In addition, the ethical procedure will be discussed.

4.2 Research aims and objectives.

Brief description and statement of the research question:

This research aims to explore the psychological as well as the social experiences of HIV activists who are taking Antiretroviral treatment. To accomplish this, aim the following objectives were developed:

- To gain a better understanding of the social and psychological experiences of HIV activists taking ARV treatment.
- To gain a better understanding of how activists living with HIV cope with the experiences of taking the ARV medication.
- To explore the significance and purpose of ARV adherence.

4.3 Research Methodology/ design.

The research methodology that was employed in the study is a qualitative research approach in exploring and describing the psychosocial effects of ARV intake in HIV activists living with HIV. The qualitative research approach is more appropriate for the study as the aim is to explore experiences of HIV activists living with HIV receiving ARV treatment. A description of the research methods used will be provided here.

4.3.1 Qualitative research

The term qualitative research is defined in multi varied ways by different theorists, researcher scholars and students. The terminology used for the qualitative research approach also differs from person to person. According to Aspers and Corte (2019)

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the term qualitative research is also referred to as ethnographic, interpretative, subjective, and narrative research. With all these terms being mentioned, one would be confused as to what is qualitative research and what does a qualitative research entail? Willig (2013) defines qualitative research as a research approach that is concerned with meaning. The approach is more focused on how people put meaning to various events that are happening in their lives, how they make sense of the events that are happening in their lives and how they experience these events (Willig, 2013). Aspers and Corte (2019) further build on the definition by Willig (2013) by stating that qualitative research focuses on multiple components that involves interpretations, using naturalistic approaches to the research being done. By this definition, they are stating that in qualitative research, phenomenon are studied in their natural habitat, they try to make sense of or interpret an event in terms of the meaning the people attach to it.

Willig (2013) also mentioned in her book that Qualitative primary researchers observe/study people in their own area within naturally occurring settings, be it their workplace, their school, their streets and/or their place of hanging out. Nassaji (2020) also agree that qualitative research should happen in naturalistic place, she adds that qualitative research deals with non-numeral data, which is different from Quantitative that deals with numerical data (Nassaji, 2020). Nassaji (2020) further elaborates that in qualitative research the aim is not to quantify or manipulate variables, but it is to understand and explore the phenomenon being studied.

In this study, a semi-structured interview was used where participants were asked questions about their psychosocial experiences of living with HIV on ARV medication. Nissaji (2020) A good qualitative research is robust, well informed, and thoroughly documented, it is also systematic, involving a careful process of identifying the problem, collecting, analysing, explaining, evaluating, and interpreting the data.

4.3.2 Research design

The research design that will be used in the study is a phenomenological study. According to Leedy and Ormrod (2015) a phenomenological study aims to understand people's perceptions and perspectives relative to a certain situation. A

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phenomenological study aims to probe more on the experiences of what it is like to experience a certain situation (Leedy & Ormrod, 2015). Phenomenological study is ideal for this study because it enables the primary investigator to work together with the research participants in finding meaning into a specific phenomenon, in this case to unravel the experiences of the participants on a daily basis when taking the ARV treatment. A phenomenological study allows the principal investigator to probe on the questions such as what it like is to experience a phenomenon which allows the principal investigator to gain better understanding of the phenomenon being studied (Leedy & Ormrod, 2015).

4.4 Study population/ participants

The population for the study includes people living with HIV on ARV treatment who are vocal about their status. The sample comprises of 6 HIV activists, who are vocal about HIV status.

Six participants were interviewed in this study. There are no set rules for determining sample size in a qualitative study (Smith & Osborn, 2008). Sample size depends on what you are researching, the goals of the study, the richness of the individual interviews, how the findings will be used and what can be done with available time and resources. They further went on to indicate that the trend is to use a “very small number of participants” (p. 56) in an interpretive analysis, especially for novice researchers who may be overwhelmed by the extensive data generated in a qualitative study (Smith and Osborn, 2008)

The following exclusion criteria were employed:

- Participants younger than 18 years
- Participants that have less than 2 years taking ARV medications
- Participants that are not open about their status.

The following inclusion criteria were employed:

- HIV activists who are 18 years and older.
- Participants that have more than 2 years taking ARV medications
- Participants that are open about their status.

4.4.1 Description of the participants.

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The sample comprised of 6 HIV activist between the aged of 18 years and above. The activists have at least two years taking ARVs and should do some activist work in their communities and be very vocal about their HIV status.

4.5 Data collection procedure

The participants were recruited through snowball sampling. The primary investigator identified two activists openly living with HIV. The two activists were asked to name other possible participants who will be interested in participating in the study.

The principal investigator who is also from Limpopo approached the clinic management to get approval to use the clinic as a research site. Interested individuals were given participant information letters about the study as well as consent forms to sign before the interviews. Data was collected using semi-structured telephonic interviews which were recorded and transcribed in English. The use of semi-structured interviews enables the principal investigator to get clear and detailed information from the participants about their experiences. Audio-recordings will be transcribed by the primary investigator.

4.5.1 Semi-structured interviews.

Interviews are conversations which will take place between the primary investigator and interviewee, with the primary investigator being the one who asks the questions for the interviewee to answer (Willig, 2013). In psychological research semi-structured interviewing is the most employed method of data collection. According to Magaldi and Berler (2020) semi-structured interview is an exploratory interview used most often in the social sciences for qualitative research purposes. Willig (2013) mentions that the semi structure interview method is widely used because it is compatible with a lot of methods used for data collection. The method of administration for this method is relatively easier as compared to the other qualitative data collection methods (Willig, 2013). Willig (2013) further mentions that with her stating that this method is easier to administer, does not mean that it is not rigorous but just stating that there are fewer logistical glitches when arranging the interviews as compared to other methods such as longitudinal studies that may involve gaining access to observe participants, gaining participants permission to keeping diaries over time or negotiating with organisations for permission to use their place.

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Willig (2013) further discusses the general characteristics of semi-structured interviews.

- The semi-structured interview provides an opportunity for the researcher to hear the participant talk about a particular aspect of their life or experience.
- Researchers advised to consider the possible effects of their own social identities (i.e. Gender, social class, ethnicity, nationality, age, etc.) on the interviewee.
- The researcher needs to know what the interview means to the interviewee to fully understand the interviewee's contribution.
- In semi-structured interviewing, the emphasis is on meaning rather than lexical comparability.

This style of interview will allow room to cover issues in depth if needed and will give the primary investigator an opportunity to probe into certain issues that would require more information. Probing is a tool used for ensuring reliability of the data, as it enables the interviewer to clarify with the respondent any words or phrases that they may not fully understand (Willig, 2013). Semi-structured interviews allow the primary investigator the chance to be flexible in what they want to ask their participant by not having to follow any specific order.

4.6 Data analysis.

After data collection, the process that comes after is the analysis of the data obtained (Willig, 2013).

4.6.1 Interpretative phenomenological data analysis.

Interpretative phenomenological analysis will be conducted to analyse the obtained data. Interpretative phenomenological analysis is a qualitative approach which aim to provide detailed assessments of personal experiences (Smith & Osborn, 2015). The use of an interpretative phenomenological study will help in analysing the data that the principal investigator will obtain from the interview with the participants. According to Smith and Osborn (2015) the use of IPA reveals a description of lived experiences in its own terms rather than a single pre-existing theoretical bias and it acknowledges that it is an interpretive journey as human beings are sense making organisms (Smith

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& Osborn, 2015). Alase, (2017) further went on to explain that interpretative phenomenological analysis awards primary investigator the opportunity to dig deeper and understand the intimate discussion of the lived experiences of research participants. As an participant's orientated approach, IPA allows the research participants to fully and freely express themselves and their lived experiences the way they see fit without any fear or persecution thus using this approach in qualitative research echoes the fact that its main objective is to understand people's lived experiences and stories (Alase, 2017).

Alase (2017) listed the following as advantages of interpretative phenomenological analysis:

- It allows novice primary investigator the opportunity to explore in great detail the lived experiences of their participants.
- IPA is participant orientated, as Alase (2017) mentions, it is an approach that shows respect and sensitivity to the lived experiences of research participants.

The focus of this study is on the psychosocial experiences of activists living with HIV taking ARV, many people still perceive HIV as a taboo, shameful and secretive disease that should be hidden from the people at all costs (Taraphdor et al., 2010) making it a very sensitive study to conduct. Smith and Osborn (2013) states that IPA is a suitable methodology for examining complex, ambiguous and emotionally laden topics.

The goal of interpretative phenomenological analysis is to explore in detail the lived experience of participants and how they are making sense of their personal and social world (Smith & Osborn, 2007). Interpretative phenomenological study as an approach of analysis encompasses of detailed analysis of the participants lifeworld, it tries to explore the personal experiences and mainly focuses on the perception of participants personal experiences of a particular object or event (Smith & Osborn, 2007). Smith, Flowers and Larkin (2009) state that the use of IPA started in psychology, health psychology to be precise and was later adopted in other streams of psychology such as counselling, clinical and social psychology. Some theorists also describe to interpretative phenomenological analysis as psychology in the real world. This method of analysis is suitable for the study because the participants have varied experiences of taking the ARV medication, using this method will allow both the principal

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investigator and participants to explore the experiences of the participants as opposed to producing an objective statement of their experiences (Smith and Osborn, 2007).

4.7 ATLAS.ti

According to Ronzani, da Costa, da Silva, Pigola and de Paiva (2020) Atlas. ti provides useful analytical resources in academic research, particularly for social science disciplines. To further ensure trustworthiness the ATLAS.ti qualitative data analysis software will be employed. According to Ang, Embi and Yunus (2016) the use of ATLAS.ti help to substantiate the analysis and interpretation of the data. Friese (2019) states that ATLAS.ti is a widely used software in qualitative research that aims to help primary investigator s uncover and systematically analyse complex phenomena hidden in unstructured data (text and multimedia). The program provides tools that let the user locate, code, and annotate findings in primary data material, to weigh and evaluate their importance, and to visualize the often-complex relations between them (Lewins & Silver, 2007). To further assess the rigor of research interpretations, the use of member checking will be employed by the principal investigator to ensure that the interpretations resemble the raw data that was given in the interviews.

4.8 Ensuring quality when using IPA.

Reliability and trustworthiness of the research study in qualitative research is very important in assessing the worth of the research findings. According to Nizza, Farr and Smith (2021) there are four quality indicators in IPA research, namely constructing a compelling, unfolding narrative, Developing a vigorous experiential and/or existential account, Close analytic reading of participants' words and attending to convergence and divergence. In the analysis the researcher made use of the above list to make sure that the analysis are coherent with the quality standard set by Nizza et al., (2021) when analysing research finding being guided by IPA. To further make sure that the analysed results are accurate the researcher was guided by the principles of Nicol and Guba which were explained in an article by Schwandt, Lincoln and Guba (2007) where they stated four basic principles of ensuring that qualitative research findings, namely transferability, dependability, credibility and conformability. This method was employed through the rigorous reading of transcripts, member checking, where the researcher called some of the participants to check if the interpreted data is what they meant

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during the interviews where most of the participants agreed that the interpreted data was accurate, which makes it credible.

4.9 Ethical Considerations

Willig (2013) states that ethics in research are concerned with the standards of behaviours and practical procedures that a principal investigator is expected to follow. Ethical guidelines in research are mainly designed to help protect the interest of participants. Informed consent, confidentiality and right to fair treatment will be applied throughout the study.

- Informed consent

  In order to obtain consent from participants an informed consent form together with an information letter will be given to the participants to read with understanding and where they don't understand the principal investigator will clarify to the participants. The information letter will inform the participants about the aim, objectives, procedures, risks and the involvement of the principal investigator in the study.

- Confidentiality

  The use of anonymity codes is an effective technique for protecting the identity of research participants. According to Burns as cited in Maree (2014) both the primary investigator and participants must have a clear understanding regarding the confidentiality of the results of the study. All participants' information and responses shared during the study will be kept private and the results will be presented in an anonymous manner in order to protect the identities of the participants.

The principal investigator will not violate the participants' privacy and confidentiality, the participants will be assured of confidentiality, therefore their information will not be revealed to other people without their consent. During the study names will be asked but the participants will be required to use Pseudo names and as a result the principle of anonymity will prevail.

- Nonmaleficence

  Careful considerations will be taken to make sure that risk is minimized. Data transcriptions and recordings will be stored on UP Psychology Department Google

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drive for a minimum of 10 years. According to the University of Pretoria Research Data Management Policy (2018) research data sets must be stored for a minimum of ten (10) years after the completion of the original project.

- Avoidance of harm

  In order to reduce the risks, the principal investigator will reassure the participants that the content discussed in the interviews will be kept confidential and the privacy will be of the utmost importance. If needed participants will be referred to the nearest psychological centre for psychological help. Multiple mental health helpline will be provided in the event of the participants feeling distressed because of participating in the study (see appendix A). Furthermore DR Anathi' Ntozini who is a counselling psychologist will be available to offer counselling to those who will be negatively affected by the interviews.

4.9.1 Ethical Consideration from the university.

Ethical provisional approval for the study was granted in August 2022 by the Faculty of Humanities, Postgraduate Research and Ethics Committee (HUM031/0621) All informed consent guidelines were implemented during the original data collection. Confidentiality of information was assured. Data will be stored in the Department of Psychology (HSB 11-24) for 15 years as per the University of Pretoria policy.

4.10 Conclusion

Chapter four outlined the methodology that was employed in the study. A description of the research design, recruitment process used in the study. Furthermore, the data collection procedure as well as the data analysis method were discussed. Chapter Five will provide a detailed account of the results.

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Chapter 5: Results

5.1 Introduction

This chapter reports on the results of the data analysis in terms of the themes identified in the participants' interviews. The themes refer to psychosocial issues that relate to living with the HIV virus on ARV medication as an HIV activist. Background information on each participant is described by way of introduction. Each theme is briefly defined and introduced and is followed by direct quotations that provide support and clarity of the participant's experiences. Pseudo names were given to the respondent for better identification.

5.1.1 Mbuyelo

Mbuyelo is a 32-year-old single woman. She passed matric in her village high school and went to college for a year where she studied IT and graduated the following year. She is the first-born child from her mother's side and 2nd born from her father's side. Growing up she lived with her grandmother, mother, and her uncles.15 years later her mom had a daughter. Who became her little sister, who she absolutely adores. She had a child when she was 21 years old, a baby boy who is 11 years old now. In search of greener pastures, she moved to Gauteng in 2014 where she found employment and is currently residing with her son. She was first diagnosed with HIV in 2014 after visiting the clinic to collect her contraceptive. She saw an HIV testing sign written on the door and she became eager and went in to test for the fun of it, to her surprise she was told that she is HIV positive. She was in denial from 2014 until 2015 November where she went in for a second opinion and they still confirmed that she is living with the virus. She started taking her medication in 2017 and started her advocacy journey in 2020 after opening her YouTube channel to discuss all things related to HIV.

5.1.2 Tiyani

Tiyani is a 21-year-old man who lives with his sister. He passed his matric and is currently unemployed, looking for a job and planning on going to college to further his studies. His sister is his only living family member. He is unemployed and depends on the help from people on twitter where he does his advocacy work. The people have been helpful in putting food on the table. Tiyani found out that he is living with HIV in 2017. He was born with the virus, but the family kept it a secret until he started getting sick at the beginning of 2012 where doctors told him he had lung problems. It was only

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in 2017 when another doctor broke the news to him that he is HIV positive. He uses Twitter and his community-based NGO to spread the word about HIV and his journey living with the virus.

5.1.3 Naledi

She is a 27-year-old HIV activist. She describes herself as a normal girl that is living a normal life but the only thing that makes her stand out is that she is living positively with the HIV virus. She explains that to live positively with the virus means that she is not afraid to talk about her HIV status and she is unapologetic about that. She was born with the virus, but her family kept it away from her. She went on a school excursion in 2009, when she was 14 years old. She went in to take the test with her friends and got the shock of her life when the nurse told her results. She mentions “I was still young, I was not intimate at the time, this was a huge surprise for me”. She left the consultation room confused and in deep shock, it took her 6 months before she could speak to anyone about the news, she heard in that testing station. She finally confided in her teacher who brought her to explain to her aunt who her guardian as her parents is had passed on. The aunt mentioned that she knew that her parents had HIV, but she was not sure whether they had passed it on to her. From there onward her family knew about her diagnosis, but it was an “open secret” as no one ever spoke about it. Her health started to deteriorate when she was 18 years old, and she had to start taking ARV medication. She mentioned that her unapologetic stance to living with HIV is one of the contributors to her being an HIV activist where she started her advocacy work on Facebook and later grew to bigger platforms.

5.1.4 Rose

This participant is a 40-year-old woman. She is a divorcee with two children. She is a hairdresser by profession and own a hair dressing salon in her village. She is currently living with her daughter as her son moved out of the house in search of greener pastures. She was diagnosed with HIV in 2001 when she was pregnant with her son who passed away after 4 years. She mentions that at the clinic while doing the routine pregnancy tests, they tested her for HIV and found that she is HIV positive but did not tell her. After giving birth to her son via natural birth, a few years later she started getting sick, having rush all over her body and her private part. She went to the doctor where the doctor confirmed that she is HIV positive. At that time ARV medication was

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not readily available, she only started taking ARV medication in 2007. She started her advocacy work on TikTok where she educates people about HIV as a virus and offers supports to those that are living virus but battling to come to terms with their diagnosis.

5.1.5 John

This participant is a 39-year-old father of two. His children are aged 7 (girl) and aged 5(boy). He lost his wife in 2019 and later remarried in 2022. He works for the SAPS as a cleaner and an HIV ambassador. His highest level of education is Abet level 4. He was diagnosed with HIV in July 2011. The reason for going to the clinic was because he had diarrhoea, swollen feet which were painful. He was very hesitant on getting tested for HIV, he mentioned that he had to sit for an hour in the waiting benches before finally deciding to go get tested for the virus. The contributing reason why he went ahead and got tested was the prognosis that he received from the nurse. She said to him that the reason why he is feeling the way might be caused by the recurrent climbing of stairs carrying heavy machinery. This caused a lot of confusion as he mentioned, he has been doing the same thing for years. Why is it different now? Which prompted him to get tested for HIV where the results stated that he is HIV positive. After he was diagnosed, the clinic offered pre and post counselling which according to him was only helpful on that day, but things started spiralling out of control the day after the diagnosis. He started taking ARV medication after 2 years of his diagnosis where his health was deteriorating. He also decided to disclose it to his co-workers and family.

5.1.6 Rendzo

Rendzo is a 24-year-old medical doctor. He describes himself as being a shy person, introverted and loves to keep to himself. He mentioned that in as much as he is an introverted person, he describes himself as being a nice person, who is bubbly and loves educating people, even though even in his wildest dreams he would never ever consider being a teacher. Rendzo was in an abusive relationship with his then boyfriend. They had been using protection for the duration of their relationship. The then boyfriend one day decided that they should not use protection when having sex. He agreed and mentioned that the only time that is going to happen is when we go and test together for HIV and other STDs. The boyfriend agreed and stated that they should do individual tests, which the Dr agreed to. The then boyfriend knew that he is HIV positive, he further went to fake his negative HIV result to deceive Rendzo to have

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raw sex with him. That is how he contracted the HIV virus. He prides himself in producing factual medical facts and knowledge about HIV to his followers.

5.2 Themes identified.

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

5.2.1 HIV activism as a journey.

Majority of the interviewed participants highlighted the fact that they entered the activism space to provide more education on HIV and AIDS. Considering the fact this type of education was not available to them when they were first diagnosed, they thought it wise to be the pioneers in the field of HIV education. Most of the participants mentioned that being HIV activists help them heal their wounds of living with the virus. They also believe that the fact that they are speaking about their lived experiences make it a lot relatable to the people that consume their content.

5.2.1.1 Using HIV activism as an educational platform.

All the participants (6 of them, with an even number of males and females) that were interviewed in the research study reiterated repeatedly that the sole reason why they joined the HIV activism space was solely on the purpose of educating the community, be it physical or online community of HIV. Mbuyelo was compelled to create her YouTube channel because she wanted to create awareness about HIV and to be as open as she can about it so that her younger sister whom she is taking care can be open to her about anything that she might face in life as she had become her the sole guardian after her mother and grandmother passed away.

Mbuyelo stated:

“The reason why I started my YouTube channel and my Facebook page was because my mom passed away in 2008 and later in 2016 my Grandma passed away. I am basically a mother to my younger sister because I am taking care of her. The reason why I started my YouTube channel was to educate the younger ones. I wanted to be

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as open as possible to my younger sister so if that if anything happens to her, she can be as open to come talk to me about anything."

Rose further went on to mention that her reason for joining the social media advocacy was that she wanted to educate the masses on HIV virus and to let them know that it is not as bad as people portray it to be(Historical view) as discussed by Willig (2013) this paradigm states that human experience, including perception, can be viewed in a multidimensional way, from a historical, cultural, and linguistic way by. In this case Rose stated that is he would like to change the old ways in which people perceived HIV and people living with HIV through her education using activism. She stated that as much as right now her fan base is only in the TikTok community she would like to expand her reach when it comes to HIV education.

The following statement illustrate Rose desire to do more:

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"I have started to talk about my HIV status on TikTok, but I haven't gotten the opportunity to talk to the masses or people around my community, but if I can get the opportunity to do so I would. I have been living with HIV for 22 years now and I have been on ARVs for 16 years. I would really love to educate more people about HIV."

Being a professional medical doctor who is also openly living with the HIV virus prompted Rendzo to engage in factual medical activism of the HI virus. He mentioned that he focuses on providing this type of information so he can alleviate the stigma that still comes with living with the HI virus.

The following statements illustrate Rendzo's feelings:

"I do confirm that I am an HIV activist. My Activism is centred around factual medical information in the community about HIV. I do this so I can help in fighting the stigma that HIV still carries in our society. I educate them to ensure that members of the community both HIV positive and negative can have enough information about HIV."

HIV Education was a predominant theme in the interviews. To close of the theme of using advocacy off as an educational journey John mentioned that he does activism

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to educate the community about HIV and this is what John had to say to support the statement above:

"We just visit different schools, radio stations and police stations where we do HIV education."

5.2.1.2 I understand how it feels.

This sub theme refers to the participants' understanding of the people that come to confide in them about their experiences of living with the virus. The people that come to confide in your private messages- be it on Twitter, TikTok or YouTube shows that they relate to the content that the activists are posting and feel a sense of safety when communicating with them.

Mbuyelo mentioned that her advocacy with HIV has enabled her to reach out and support several people who found refuge in her posts and the content that she posts where she speaks about her personal experience living with the virus.

This is the statement from Mbuyelo that supports the above:
"It was to allow anyone to come to me and I am also living with HIV, I understand how it feels to live with HIV because I am living with it., so I wanted to open a free space for everyone, so they can share their experiences in a safe space. You know what, other people are holding everything back because they do not want to disclose or tell their families. I am giving everybody this platform to say, listen. I am also HIV positive and allow them to come talk to me because I know and understand what they are going through because I am also going through the same thing."

Naledi also agrees with the relatability that comes with sharing one's experience of living with the virus, mentioning that in her case, she started gaining traction in the number of people that would flood her social media pages. This is what Naledi had to say to support the statement mentioned above:
"I started HIV activism on social media, and because of that, I didn't know what I was doing was activism, I was just sharing my story and my experiences of living with HIV and because of that I started cultivating this community of people that were living with HIV, and because of the nature of the virus that HIV is, people don't speak about it much often. So, what happened is that people will message me about their struggles

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and that is when I noticed that this is bigger than me and now, I have this platform where I got to speak about people's experiences living with HIV."

"the people that I talk to online and I think a lot of times it comes as a shock when I say this, because I relate to them and so do they."

Rendzo also shared how many people embraced his content and wanted more because it was coming from someone who is knowledgeable about the subject matter and is living the virus. He mentioned that people started demanding his content as he was only active via a friend's live video talking about HIV. As supported Money (2020) The social construction of reality is a continuing, active process that is recreated by people based on their interpretations and their knowledge of it, realities are socially constructed. In this case the repetitive nature of the participants sharing their experience with the world made way for other people to construct the same reality as that of Rendzo even though for them it will be different as they are living in different settings as the participant and the spoken language, social context and their world view are different, McNamee et al., (2020) further elaborate that these differences in meanings constitute different realities. Individuals may attach more than one meaning to an experience, which contributes to the notion of multiple realities.

This is what Rendzo had to say:
"I used to do my advocacy offline before moving to TikTok where I used to join the live of one HIV activist and people started demanding that I post content on my page, which later grew".

It is however noteworthy to note the struggles that come with activism, Rendzo struggled with the online trolls and was on the verge of leaving his social media advocacy but being reminded of the impact it has on many people that are consuming the content held him steadfast in his journey of activism.

This is what participant had to say: to support the above statement:
"Even when I was on the verge of leaving TikTok, there are a lot of people that are looking at you and towards your posts and you making a big impact in their lives".

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5.2.1.3 Activism heals me.

In this subtheme, 3/6 of the participants mentioned that participating in activism activities aided in their healing journey and coming to terms and accepting their HIV status. Here is what they all had to say about using activism as a healing mechanism.

Mbuyelo:

"*I just wanted to talk about it. I started telling my friends about it, the more I spoke about it, the more I healed."*

Rose:

"I told myself that I want to be one of the people who will get cured of HIV. I want to be amongst those people. I will do anything that I can to keep alive".

Rendzo:

"I do activism because it's a way of healing, seeing my story changed me and other people out there is what healed me in the process."

5.2.2 Psychological and emotional reactions

People react in many ways after finding out they have HIV. This reaction is also aided by the fact that HIV is a lifelong illness and the stigma that still exists in society when it comes to living with the virus. In this theme all the emotional and psychological reactions to the diagnosis will be discussed. The emotional reactions ranged from feelings of suicidality, depression, anger, denial, confusion, stress-over thinking, and acceptance. Majority of the participants that were interviewed (5/6) had difficulties coming to terms with their status the day they found out, it was only one outlier who was "okay" after finding out that he was diagnosed with the HIV virus. Most of the participants who had difficulties in coming to terms with their status were in denial for the longest of time about their new reality.

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5.2.1 Depression and suicide

Majority of the participants after finding out that they have been diagnosed with HIV had diminished sense of self-worth, sadness and anger with themselves and the partners/ parents that infected them with the virus.

Tiyani developed signs of depression after finding out that he has HIV. He started being sad, started isolating himself from his friends and the things he used to enjoy doing. These strong emotions led him to attempting to take his own life.

Tiyani states that:

"I was depressed for months, thinking that I am HIV, because most people think of it as a negative thing in the community. I however failed to accept myself and tried to commit suicide because of it.

Rendzo also developed signs and symptoms of depression after finding out that he was HIV positive. The abuse that came with the relationship that Rendzo was in and the way he found out that he has the virus caused him to spiral out of control, he became homeless and alone in short period of time, this led to him attempting to commit suicide more than 8 times.

This is what Rendzo had to say:

"His intention was to leave me with the virus. That is when I started spiralling out of control, because I was homeless, university residence was full. I did not have any family in Joburg. So, I just went into full blown depression. I think I attempted committing suicide 8 times, my mental health was just a mess at that point, and I was also busy with my exams at that time."

5.2.2 Denial

Mbuyelo, Naledi and Rose voiced out that they were in total disbelief when the health care professional broke the news to them about their HIV status, it didn't make sense to them because how does one have HIV when they have not even had any sexual intercourse? How is it possible that one can have HIV when they look as healthy as they did, how is it possible that one can have HIV when they only sleep with one person

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and have been tested regularly? These were some of the sentiments from the participants after finding out that they were HIV positive.

The following represent the participants sentiments:

Mbuyelo:

"I did not believe it from 2014 until November 2015 when I went to a different clinic where I wanted to confirm".

Naledi:

"I found out on a school trip. At 14 I was not dating or sexually active, so I was naïve about HIV, I told myself that I cannot be HIV positive."

"*It took me 6 months before I could talk to anyone about what had happened on that trip."*

Rose:

"When the doctor told me, I believed it was a lie."

"*Whatever they told me in that room I did not hear a thing, I was numb and just sat there but I did not believe it and it hasn't sunk in that this is happening."*

5.2.3 Confusion

The confusion that comes with finding out that you have been diagnosed with an incurable virus can be very severe. Many of the participants upon finding out that they have the HI virus were left with a lot of questions and questions that did not have answers, they were in disbelief, and they just didn't believe that this is their new reality. The participants had the following to say about the emotions they were feeling:

Mbuyelo:

"That day was the most horrible day of my life because I asked myself a lot of questions as to where I got the virus from, and I couldn't find the answers."

Naledi:

"I came back home confused and scared."

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Rose:

"*Whatever they told me in that room I did not hear a thing."*

Rendzo:

"*I sent him my negative HIV test results and he also sent me his negative test results, so a few months later when I was cleaning, I found lancet lab test results that detailed that he was diagnosed with the virus about 2 years prior to us meeting, How?"*

5.2.4 Fear.

Many of the participants showed signs of being fearful after finding out that they have the HI virus. Mostly feared death, being rejected by their loved ones, disclosing their status to their families and how to navigate all of that.

The following represent the participants views:

Tiyani:

"*I was asking myself if the people, friends, and my girlfriend will accept me the way I am, I felt a different way. I felt unloved."*

Naledi:

"I felt so ashamed, I am going to be seen as having these pills, that is when I started having to open up about my HIV status."

Rose:

"I felt like my world was crushing, my life was ending, and the daytime just became night-time."

John:

"I was thinking that I am going to die, how am I going to tell my father since he was the only parent I was living with, I asked myself if I am going to have children, you know how parents are, he kept on demanding children from me so that made me scared."

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5.2.5 Acceptance

All of the participants that were interviewed had a unique journey into finally accepting that they have been diagnosed with HIV and they will live with it for the rest of their lives. Accepting that one is HIV positive means that they agree to start with their ARV medication, to take care of themselves both physically and mentally. Accepting their status means they are on their journey of healing and coming to terms with their diagnosis.

One of the participants mentioned that at the time of her diagnosis, ARV medication was limited, she had to live knowing she has the virus but there is no medication to manage the symptoms and severity of it. She mentioned that the only way that assisted her in keeping a good mental outlook was accepting that this is her situation, and she has to live with it for the rest of her life.

Tiyani had to go to another clinic to confirm her diagnosis, stating that once it is confirmed, which it was, she will accept her diagnosis because there is nothing else she can do about than to accept it.

These are some of the sentiments that support the above from the participants:

Rose:

"I told myself if there is nothing, I can change the situation and I won't beat myself up. I will have to accept the situation."

Mbuyelo:

"Right now, that I have finally accepted that I am living with HIV, I just wanted to tell everyone about it."

Tiyani:

". I however let it go and told myself that I must accept my situation, take my medication. I will be fine."

John:

"To anyone living with the virus out there, I would say that please accept yourself and take your medication, don't think about what people will say about you."

Rendzo:

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"It is a journey, one that actually needs you to go through it to get to a point where you are accepting of the fact that yes, I am living with the virus, yes I am taking the pill and yes I will be okay."

5.3 Treatment at the clinic

The treatment that the participants receive when they go to the hospital/ clinic to collect their medicine, routine check-up and for any other medical related query will be discussed in this theme. Four out of the six participants that were interviewed believed that the treatment that they received at the clinic was satisfactory and the nurses gave them all the information and support that they needed upon finding that they have the HI virus and educated them about the ARV medication. They mention that they did not feel discriminated against at the clinic as they received the service that they were hoping to get. The other 2 participants, however, believed that the health care system still needs a bit of improvement. Naledi believes that the treatment she received from the nurses was rather discriminating and problematic. She further went on to state that the way the chronic patients and the acute patients are separated in the clinic breeds further discriminatory behaviour because everyone just assumes that when one goes to the chronic section of the clinic, they are going to get ARV medication. From a social constructionist's perspective, individuals will attach different meanings to similar experiences. With this statement being said, many HIV activists have differently constructed meaning in similar experiences that many are exposed to or come across in their lives living with the HI Virus and taking ARVs. Their varied constructed meaning in those experiences is what contributes to multiple realities which is mentioned by McNamee, Gergen, Camargo-Borges and Rasera (2020). McNamee et al., (2020)

The following will highlight the statements of the first 4 participants that believe that the service and treatment that they received from the clinic was satisfactory.

Mbuyelo:

"*I looked forward to going to the clinic."*

Tiyani:

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"The treatment is good, I have this nurse at the clinic that I have a good relationship with, I can talk to her about anything, even when I stumble into a problem of not adhering to my medication, I tell her the reasons why that is happening."

". I have good experience and advisors. I don't think that the information that I give out to them would be spread to other people."

Rose:

"I am used to it. I go in every month. I cannot complain, the nurses are fine. I really don't have any complaints or concerns. Sometimes if I don't go the nurses will call and remind me that I need to come and collect. I cannot complain."

John:

"It was fine, I really didn't have any problems with them, they educated us about HIV and ARVs, I have learned a lot from the clinic."

The other two participants that believed that there are still some improvements that are still needed at the clinic had the following to say about the health system and its staff.

Naledi:

"The thing about people that work in the healthcare system is that they are very rude. When I started going there, I thought I was going through a phase where if you fight me, I will fight you back."

"When I started going to the clinic, they would be relentlessly rude in how they treat the people. I can't necessarily say they have treated me badly for long because I was quick to set that boundary that you cannot treat me like this especially because you work with us, I want to be treated like a human being, because I am."

"She called this other nurse, and she came in and said "yea this is what they do, they come in here and test after finding out they leave without treatment" and I was just like, I am here. You can see in a position where I am bruised and broken, and she literally said to me you must be on this pills because one thing about being on HIV it's a death sentence , she later changed and said no no she said it's a life sentence, I

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remember I turned and said to her that both the statements that she is saying are problematic"

The statement stated by Naledi that "*she literally said to me you must be on this pills because one thing about being on HIV it's a death sentence, she later changed and said no no she said it's a life sentence"* language is the most important system through which humans form their reality. According to Freedman and Combs (2020) language tells us how we view our world as well as what we see within it. The social construction of reality is a continuing, active process that is recreated by people based on their interpretations and their knowledge of it, realities are socially constructed. To sum it up Naledi also mentioned that this treatment is problematic because it is a continuous process and many people that get told these things in the clinic keeps continuing and that becomes their reality as Freedman and Combs (2020) stated that realities are socially constructed. The construction that HIV is a death sentence is socially and historically constructed as that is how people have been viewing the HIV virus from the early ages and because as money (2020) stated that the continuing active process of the words/language that people recreated become their socially constructed language.

Rendzo:

"I did not have any form of support structure. I would even go to the clinic where I didn't find any psychosocial structure in place where it is supposed to help a person going through a mental health issue."

John mentioned that in as much as the service and treatment that he got from the clinic was satisfactory, the division of the acute and chronic section was a bit problematic because he feared being seen by other people going in there. This is what John had to say: *"The only thing was that when you go to the clinic you would think that you will meet someone who knows you and might discriminate against you but luckily that did not happen with me."* Naledi also shared the same sentiments. *This shows the statement where from Naledi further build on what was said by John : "I think it was 2016 where they introduced a rule that people that are receiving chronic medication were separated from those receiving other medication, for me it was fine because I am already living publicly with it but what about those people who are going to struggle to come to the clinic because we are being isolated. When we speak of*

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chronic illnesses, we know there are a lot of chronic illnesses but when going that side people just assume that you are there for HIV medication and because we are still living under the stigma that is associated with HIV it just becomes problematic and it is unfair.

5.4 Experience with ARV medication

The participants had mixed emotions when it came to the ARV medication. All of them do believe that ARVs assist in suppressing the virus. They do also share the same sentiments that because it suppresses the virus it does come with a lot of emotional, psychosocial and physiological side effects. Some stated that the health care professional did warn them about the side effects of the ARV medication. In this theme, the experiences with the ARV medication will be explored extensively.

5.4.1 Physiological side effects of ARVs

ARV medication has proven to the participants that it can present several physiological effects to their body when taking it. All the participants have experienced one or two physiological effects of taking the HIV medication.

The following statements validate their experiences:

Mbuyelo:

“I only experienced tongue inflammation. After an hour after taking my medication, my tongue will start to be hot, I will take ice and I made sure I had ice cream all the time.”

Tiyani :

“I started taking medication in 2012, at that time I started to vomit and have a running stomach. The flu and the fever were awfully hard on me.”

Naledi:

“The only side effect that I have experienced is drowsiness.”

Rose:

“I started having side effects from them, which they call lipodystrophy, where one starts accumulating a lot of fats in weird parts of the body.”

Participants 5:

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"The only thing that I have experienced with the ARV was a headache. After 4 weeks I was fine."

Rendzo:

"The first time I was placed on ARVs they placed me on the old regimen which showed me flames, from dizziness, fatigue, sweat and nightmares."

5.4.2 Psychological/ emotional side effects of ARVs

The HIV virus entails that a person should consistently take the medication for the rest of their life. This does come with a lot of emotional and psychological burden. After the diagnosis the participants mentioned that they were told in order to manage the Virus they need to take the ARV medication consistently for the rest of their lives. 3/6 of the participants felt like they did not have a deciding factor, they felt that this was forced upon them, and they felt it was a punishment for living with a virus. To support the above statement this is what they had to say:

Rendzo :

"It also gets emotionally overwhelming because it feels like it's a gun held to your head; you can't skip a day".

Naledi:

"You are meant to take these pills for the rest of your life which will make you feel better, but they also make you sick because they have side effects and then eventually you will die."

The participants also revealed how the ARV medication makes them feel emotionally when taking the pill and after taking the pills. They mentioned that it has an emotional toll on them. They feel like they are being punished for having the virus and it gets emotionally exhausting.

The below statements show the emotions of the participants when taking the ARV medication:

Tiyani :

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"After taking the medication, I feel down and ask myself why me, why I have HIV and why did my parents die, and I will say I hate these pills and I would skip the medication because it was useless. I had so many questions that I needed to ask my parents, but I couldn't because they were no more."

Naledi:

"That really affected my mental health firstly and said to myself there is no way I am taking these pills; I would rather die because I felt like I was being punished for living with HIV."

Rendzo:

"I had what we call pill fatigue."

"You get emotionally exhausted from taking the pill every single day."

"As long as you are taking the pill there will always be that emotional drainage to it."

Tiyani:

"This treatment can make you feel down, after drinking it you become emotional, get tired of taking the pill."

5.4.3 ARV Adherence

All participants that were interviewed understood the importance of adhering to the ARV medication. However, one participant stated that due to factors beyond his control, he defaulted on his intake of the ARV medication. Tiyani stated that due to the economic situation at home, adhering to his ARV medication was not an easy journey for him.

This is what Tiyani had to say to support the above statement:

"because of my home situation, where sometimes I don't have food to eat, and you cannot drink the medication without having eaten something."

Tiyani understood the importance of talking ARV medication, even though he stumbled upon hurdles in adhering he stated that that sometimes even without eating he would still try to take his medication which resulted in severe side effects.

This is what Tiyani had to say on the above:

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"Sometimes I was forced to drink it without eating because I didn't have food. I would experience stomach cramps, high fever and nigh mares."

The other 5 participants mentioned that adhering to the medication was the best thing they could do for their health.

This is what the participants had to say about adhering to their ARV medication.

Mbuyelo:

"I adhere to my medication religiously, even my friends remind me that it's time to take my medication."

Naledi:

"That is when I saw that the treatment works, and I have been on treatment, and it is one decision that I do not regret so far."

Rose:

"I started taking the medication and it made me sick, but I knew that, because they told us at the hospital even if you feel sick don't stop."

5.5 Stigma and discrimination.

HIV is still one of the most stigmatized viruses in the world. Many of the participants have shared their fair share of being stigmatized, rejected, discriminated against, and made to feel that they are different as compared to the HIV negative people. There are some participants who mentioned that the stigma is not as rife as it used to be in the past due to the availability of information about the virus. The participants believe that people are now aware that HIV is manageable and is not a death sentence.

2/6 of the participants mentioned that they were the ones that were self-stigmatizing after finding out that they are living with HIV. They mentioned that they did that to stay away from people, so they don't feel their stigma and discriminatory behaviour. Many of the participants mentioned that after the disclosure of their status, they were frowned upon in the community, no one wanted to be associated with them and they were made the laughingstock of the community and the rejection from intimate partners was sadly felt.

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The discrimination through spoken language and behaviour that the participants experiences is what according to Haymarket Books, (2022) stating that there different possibilities for how any given experience may be interpreted, some of the participants decided to be co-depended on themselves and their families to avoid such stigmatizing behaviour while others continued with their journey of activism through education. Freedman and Combs (2020) also stated that language is the most important system through which humans form their reality as evident in the statement by one of the participant's where he stated that other people speak about it in a bad manner where you also start seeing yourself in a bad manner, in this way forming a social reality based of the language that he continuously hears in the community. As freedman and Combs stated that that language is the most important system through which humans form their reality.

The following statements indicate the severity of the stigma and discrimination that the research participants experienced.

Mbuyelo:

"The only situation where I felt judged was when I was in a relationship. I disclosed my status to my partner within 2 weeks of being together. I wanted to give the guys that I am busy with a choice to decide if they want to be with a person who is living with HIV and a lot of times I would get rejected."

Tiyani:

"Sometimes you must expect some people to talk about it in a bad manner where you end up seeing yourself in a bad manner which resulted in me losing myself and my self confidence in the process."

Naledi:

"I feel like the only stigma that I have had to struggle with was the internalized one."

John:

"I was the only person who self-stigmatised." She further went on to say that *"Some people started sending me private messages on Facebook and I would meet them on the streets. They will just wave and leave because they do not want to be seen with me."*

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Rose:

"You know that brings tears to my eyes, yooo! The stigma was so much, the stigma is still so much, especially for the people that do not want to disclose."

"People who knew me when they saw me approaching, they would change their directions, one of my friends when I visited her and I had forgotten my face cloth, my friend did not mind taking a feather duster to give me to bathe with because she felt she can't share a face cloth with me. I didn't say anything to her, that was the most painful thing."

5.6 Support. Structure

The acceptance and support of the participants in coming to terms with their HIV status, the involvement of their family, friends, and community members in dealing with their diagnosis and living with the virus will be discussed in this theme. This theme will be further subdivided into social support and psychological support.

5.6.1 Social support.

The support that the participants received from their loved ones, made the journey of living with HIV much more bearable. The involvement of friends, children, spouses, and family members in the lives of the participants has eased the burden of living with HIV and taking the ARV medication. 2/6 of the participants stated that they were afraid of disclosing to their family because of fear of judgement and hurting them. They however came to terms with their diagnosis after some time where they disclosed, and their family was still very supportive towards their journey of living with the virus. One participant mentioned that her son is her beacon of hope in her journey of living with HIV as he is always there and provides her with her medication when the time arrives. 2/6 of the participants also mentioned that they rely on support from fellow HIV activists. With 2/6 also stating that they are their own support system.

The below statements support what is said above:

Mbuyelo

"Either than that my friends and family members did not judge me. They just said they are behind me, and they will support me."

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“The person that makes 110% sure is my son, as young as he is, he makes sure that I am okay, that I drink my medication. My biggest supporter is my son.”

Naledi:

“My support system is okay; I have a very strong support from my friends and family so that is sufficient for me.”

“The people that I talk to online, and I think a lot of times it comes as a shock when I say this, because I relate to them and so do, they.”

Rose:

“Now I am my own support structure, but back then it was my son who was 6 years old. When I started treatment, he used to give me the pills and remind me to take them when the time comes.”

Rendzo:

“When my mom found out, she was supportive. She allowed me to do whatever I wanted if it meant that I would get to a point where I am okay or emotionally stable.”

5.6.2 Psychological support

Pre-counselling is offered to people that want to do an HIV test and post counselling is offered to people that have been confirmed to be HIV positive. The support from professional mental health workers can help people better navigate their feelings and emotions. From the participants that were interviewed only one out of the 6 attends professional therapy. The other participants did not find value in attending the therapy session with a mental health practitioner. The other participant mentioned that there is no need for therapy as she has been through a lot, she can cope with anything that comes her way.

The statement supports what has been said in the subtheme above:

Naledi

“My therapist- she is good at what she does.”

Rendzo:

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"I attended two sessions of therapy, when I was stable mentally and I went to a psychologist thinking they can unlock something that might affect me in the future. To be quite honest, I felt even more depressed during those sessions."

Rose:

"I have been through a lot, and I feel like I am okay. You know when you have been in so much pain and you end up getting used to it."

Conclusion

In this chapter, the research participants were first described. The researcher further went on to create themes and sub themes based on their experiences of the key occurring phenomenon in the interviews.

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Chapter 6: Discussion chapter

Introduction

In this chapter, the themes identified in the previous chapter are discussed. The chapter will integrate the paradigm which is social constructionism, literature, and the results of the study.

The theoretical paradigm used in this study is the social constructionism. The experiences of HIV activist on ARVs and their psychosocial experience is created not only by factors related to treatment access and availability, but also by the respective roles played by healthcare professionals, the community, and their family structures. Over time, these social forces evolve and combine to influence local understandings and experiences with HIV and treatment intake. This theory will be explored in relation to the results in this chapter.

The participants were evenly distributed amongst gender (3 males/3 females) from age groups ranging from 21 to late 40s. The discussion that follows will be centred around the ARV medication intake, the psychosocial experiences and the support that they get as HIV activists in Limpopo province. Recommendations, limitations of the study will follow discussing the key findings of the experience of those living with HIV on ARV medication.

6.1 Discussion

The purpose of this study was to understand the psychosocial experiences of HIV activists on ARV medication in Limpopo province, South Africa. The Data was collected using semi structured interviews, as explained by to Magaldi and Berler (2020) semi-structured interview is an exploratory interview used most often in the social sciences for qualitative research purposes. The primary researcher further went on to record the audio tape which were used in the analysis of the data discussed in chapter 5. The data was analysed using interpretative phenomenological analysis. As stated by Smith and Osborn (2007) the goal of interpretative phenomenological analysis is to explore in detail the lived experience of participants and how they are making sense of their personal and social world. The primary researcher read the interview transcripts over and over and got immersed in the data where themes and

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subthemes were generated as explained in chapter 5. The following themes will be discussed in this chapter. The theme will be grouped to 4 main themes:

- HIV Activism as a journey
- ARV medication
- Psychosocial experiences
- Support structures

6.2 HIV activism as a journey.

As expressed by Reeds (2018) HIV activists exert great influence in sending the message to the public and those living with the virus on the importance of adherence and dealing with other psychosocial that may arise due to living with the virus. Majority of the participants that were interviewed stated that the main reason why they started activism was to provide more information about the HIV virus and the experiences that come with living with HIV virus. This journey however does come with emotional exhaustion and negative feedback as mentioned by (Earnshaw, Rosenthal and Lang, 2016). 2 out of the 6 participants shared the same sentiments stated by Earnshaw and colleagues about how activisms come along with physical and mental exhaustion. Rendzo mentioned how he was on the verge of leaving the activism route due to the negative criticisms and emotional exhaustion. In as much as literature suggest that activism poses positive influence on those living with HIV (Reeds, 2018) for some participants HIV activisms had negative impacts on their social and personal life especially with the negativity that is poured on them by those who disapprove their message as stated by (Srivastava, 2020).

Social constructionism theory is centred on the view that in the process of perceiving and describing an experience, we construct not only our personal knowledge base about reality but also our own reality. In this case the social and historical context of how HIV and people living with HIV construct their reality in terms of the social and historical discourses. How they behave in public eye got challenged by many people. Challenging the negativity was mentioned by one participant stating that the good always outweighs the bad, they are still devoted to journey of HIV activism, also referring to the statement by Willig (2013) where he stated that an individual is seen as the expert in his or her life and social constructionist thinking focuses on stories

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based on a person's lived experience, rather than on expert knowledge. The participants focused on their lived reality hence the continuing with the activism journey.

6.3 Experience with the ARV medication.

The ARV medication has become a redeeming quality to the people living with HIV. Many research and literature support that ARV gave hope to the people living with HIV (UNIAIDS,2005). However, as Bravo et al., (2010) alluded that the ARV has different meaning to different individuals. Some individuals perceive it to be a good thing while other believe that they feel forced to take the medication and others have mixed emotions about it. All the participants that took part in the study agreed that the ARV medication is beneficial because it enhances their quality of life, health, and longevity. On the hand the very same participants also agreed that same medication that does all that can present with adverse psychosocial problems where Gilbert and Walker (2009) coined it 'social complexities' referring to the varied way people living with HIV conceptualize their diagnosis and how to they experience the full course of living with the virus.

According to Loue (2013) ARV causes different side effects in the body. This side effects ranges from physiological, psychological, and social effects. The participants in the study stated their experiences with ARV medication. They indicated that the severe side effects of the treatment have impacted their lives in differing ways. Rendzo stated that the intake of ARV medication is always mean with emotional exhaustion, pill fatigue and a constant reminder that one is living with the HI Virus. Rendzo further went on to refer to HIV and the intake of ARV as a "life sentence". He also stated that the anxiety and stress that comes with one missing to take the medicine is rife, causing fear and anxiety. Gillbert and Walker (2009) supported this statement in their literature stating that people who are living with HIV on ARVs perceive the medication as their lifeline and a means by which they survive yet they also represent dependence and fear, for without them illness would prevail.

Gillbert and Walker (2009) further went on to state that people living with HIV show appreciation for ARV it does however poses challenges to the quality of life and the Side effects. Participants 2 mentioned that the intake of ARV presented him with

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nausea, vomiting, running stomach and fever. He further went on to mention that the intake of the ARV medication caused of a lot of depression and suicidal ideation which also resulted in him defaulting on the medicine intake. Naledi ,4 and 5 stated that their journey with ARV has been positive impact in their life and health. They stated that after their diagnosis, the rushes that they had started to disappear, and they became less sickly as they were before starting treatment.

6.4 Psychosocial experiences

The health care workers stated that significant amount of time passes from when the patient is diagnosed with HIV and the time, they come back to the hospital to start with their ARV intake. There are many reasons to this phenomenon occurring, firstly being that many of the people that got recently diagnosed are in denial, they fear the stigma and discrimination that will come with their new diagnosis and the mental/psychological feelings accompanied by the diagnosis. According to Sordahl et al., (2010) people living with HIV are twice as luckily to experience the ill effects of depression than the overall public. Tiyani and Rendzo developed signs of depression after learning of the status and when taking the ARV medication. Rendzo mentioned that he experienced pill fatigue, suicide ideation, emotional exhaustion, nightmares, and hallucinations when taking the ARV medication. According to Loe (2013) the are many reasons that contribute to people living with HIV to have suicide ideation, suicide attempts and completion of suicide. For Tiyani the reason why, he attempted taking his live was failure to accept his diagnosis, the perceived stigma that will come with the diagnosis, emotional drainage that come with taking the ARV medication and the financial situation at home. Sordahl et ai., (2010) stated in his article that the feelings expressed by Tiyani and Rendzo stating that psychopathology in HIV-positive populaces have been related with diminished personal satisfaction and may expand high-chance practices, for example, expanded suicide rate, suicide ideation, liquor misuse and hallucinations.

Stigma, social exclusion, and discrimination from the community were mentioned by 3 participants. They mentioned how they were treated differently because of their HIV status, how they were made to feel less of humans and how people didn’t want to be seen around them because of their HIV status. One of the participants mentioned how

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the community members started laughing at her on the streets, calling her name and mocking her weight loss. As stated by Grandy (2018) the social constructionism epistemology assumes that an individual's reality arises from meanings that develop within a historical, social, and community context. In this case the participants were made to feel different and were treated differently in their community because of their HIV status (social context- social exclusion). Naledi also mentioned how the community members discriminated against her for living with the virus as she was the only one who was vocal at the time in her community, about her HIV status. The reality constructed by the community was that she was dirty, tainted and promiscuous and cannot be associated with them (community context).

As stated by Paul and Premraj (N: D) people living with the Hi-Virus experience a lot of societal backlashes, one of them being stigma and discrimination. Naledi also mentioned that people did not want to be associated with her, because of the fear that comes with the association, what are people going to say? Why are you talking to her? Do you also have what she has? These were some of the questions that further fueled the discrimination and stigma experience by Naledi (social context). Further Freedman and Combs (2020) build on the experience of Naledi by stating that language is the most important system through which humans form their reality. According to them, language tells us how we view our world as well as what we see within it. The language that Naledi heard from the conversation between her community member led her to construct her own reality which meant that she should be co-depended on herself and her family to avoid such treatment from the community members. Windwood et al., (2021) further explained why Naledi felt the way she felt by stating that a people living with HIV face social exclusion due to the stigma and they become socially disconnected as coping mechanism.

6.5 Support system

Social support from family members, friends, co-workers, and the community made a difference in how the activists navigated their activisms roles, living with HIV and taking ARV medication. According to Armoon, Fleury, Bayat., Fakhri, Higgs, Moghaddam and Gonabadi-Nezhad (2022) social support is associated with powerful health advantages for people living with HIV.

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The support that the participants received from their loved ones, made the journey of living with HIV much more bearable. The involvement of friends, children, spouses, and family members in the lives of the participants eased the burden of living with HIV and taking the ARV medication. Social support is strongly correlated to ARV adherence.

The support from health care practitioners also aided in adherence and dealing with the stigma of the HIV activist. John stated how the support from the health care workers at the hospital helped in her adhering to her medicine, stating that when she misses her appointment at the hospital, they would call to check up on her and remind her of her missed appointment. Armoon et al., (2022) further mentioned that the health benefits that come with social supports includes less depression, adherence, and improved quality of life.

This was evident from the participants that participated in the study where most of them mentioned that after disclosing to their family, the support that they received improved the quality of their lives and adherence to the medication. As literature suggest that people living with HIV have diminished support system from family, the results from this study proved otherwise as many of the research participants that disclosed to their families had all the support and love that they need from their loved ones. As it can be explained by McNamee et al., (2020) that the differences in meanings that constitute different realities Individuals may attach more than one meaning to an experience, which contributes to the notion of multiple realities (McNamee et al., 2020) One participant mentioned that this is because a lot of people are now aware of HIV and the old myths and stigmatising behaviour is being clouded by educational facts and theories.

Many of the participants in the study feared disclosing to their family members and friends because of the fear of rejection. Participants 6, 5 and 2 took time before they disclosed to their family members because they were afraid of being rejected, judged and discriminated. Most of the participants in the study conducted by Taraphdor et al., (2010) indicated that people living with HIV stress about a lot of things, including their income, family, and their health. Ncitakalo, Mabaso, Joska, and Simbayi, (2021) further build on what was mentioned by Taraphdor et al., (2010) by stating that experiences of social rejection, dissatisfaction, and discrimination related to HIV may

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increase a person's sense of shame concerning their illness and serve to reduce their motivation to maintain ideal health.

6.6 Limitations

There are numerous limitations to this study as acknowledged by the researcher. This section serves to outline the limitations for this study.

The current study made use of qualitative method using snowball sampling, which can be limiting the finding of the research, in Snowball sampling participants refers the researcher to other people that they know who fit the criteria to participate in the research study. The researcher acknowledges that the finding might be biased based of that fact. The study sample included 6 participants who are HIV activists. The researcher struggled to find more research participants that match the criteria for the research. It is also important to mention that two of the research participants stated that they are not from Limpopo province but however met the other criteria needed for the research study. For future research a bigger sample with varied participants from all over south Africa should be considered. The current research had a small and relatively homogeneous sample and should therefore be considered preliminary.

PLWH accessing ARV that participated in the study may be particularly marginalized in terms of socioeconomics, education, and other resources. Results may differ among participants recruited from other settings (those with advanced education, socioeconomic status and bigger influence and reach).

Future research should examine these associations among larger and more.

Diverse groups. Some research participants moved to Gauteng and took their activism online, future research should look at participants that still reside in LP full time.

Results may differ among participants recruited from other settings. (More educated PLWH may engage in more activism). Future research should examine these associations among larger and more diverse samples.

6.7 Recommendations

The researcher recommends that a large-scale study be carried out in a different setting(s) in South Africa to get the perspectives of HIV activists on the influence of

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antiretroviral medications on their daily lives. Such a study can provide insight into the Activist situation from a broader geographic/cultural setting.

More education on the stigma and discrimination issues and acceptance is necessary and especially in the communities, hospitals, and south Africa at large. More education is necessary to enable total acceptance by those on medication and those around them such as parents, family members, fellow students, and colleagues, so that they can take their medication without any fear or pressure. In addition, the health care providers must be flexible and ensure that they tailor-make the schedule to properly accommodate the people living with HIV, so that they do not feel like having to hide when going to take medication at the clinic.

More education on the critical role and indispensable support that the family should provide to own members should be given. It is through this type of education that communities will realize that HIV/AIDS is primarily a family affair before it becomes a government issue.

Researchers can consider extending the subjects of their study to include care givers and health care providers and possibly even contrasting their viewpoints to get information from different perspectives.

6.8 Conclusion

The purpose of this study was to shed light on the psychosocial experience of HIV activists on ARV treatment in Limpopo. A qualitative research approach was employed as it allows for in-depth understanding of phenomena and not just a description thereof. The research question that guided the study was: What are the social and psychological experiences of HIV activists taking ARV medication?

One-on-one interviews were conducted with six HIV activists on their experiences of psychosocial experiences of ARV. IPA was used to analyze the interview material. The results revealed that the experiences of HIV activists vary from person to person. The results highlighted how the HIV is still viewed as death sentence in the community and how the stigma and discrimination is still an issue. Most importantly, the results suggest that living with HIV and on ARV medication can be challenging but the support from family, friends and community helps in adhering to the medication, Lessening the

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symptoms of psychopathology. For future research focusing more on education is of paramount importance In the HIV space.

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