

A narrative study of patients' illness experiences on antiretroviral treatment

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ABSTRACT

Eight female respondents, who have publicly disclosed their HIV-positive status on social media, were involved in a semi-structured in-depth interview process. Using the theoretical frameworks of symbolic interactionism and social constructionism, the study explores the effects of antiretroviral treatment on patients' illness experiences, looking at the personal and social symbolisms and meanings attached to taking antiretrovirals. The study revealed a positive and inspirational aspect of living with HIV/AIDS and especially consuming antiretroviral therapy. It became evident that the knowledge participants had of antiretrovirals before consuming them was misguided and based more on false 'general knowledge' among laypersons than actual medical fact. Moreover, the study revealed that there is a social reconstruction of narratives that has taken place in each participant's life due to consuming antiretrovirals. Publicly disclosing their statuses has also proved to have both negative and positive consequences for the individuals and for society at large. While there is a consensus that participants' illness experiences are directly affected by antiretroviral treatment, each participant's narrative is different, yet positive.

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LIST OF ABBREVIATIONS AND ACRONYMS

AIDS	Acquired Immune Deficiency Syndrome
ANC	African National Congress
ART	Antiretroviral Therapy
ARVs	Antiretrovirals
DoH	Department of Health
DHSS	Department of Health and Social Services
HAART	Highly Active Antiretroviral Treatment
HHDC	Humanities Higher Degree Committee
HIV	Human Immunodeficiency Virus
NHI	National Health Insurance
NNRTIs	Non-Nucleoside Reverse Transcriptase Inhibitors
NRTIs	Nucleoside Reverse Transcriptase Inhibitors
OIs	Opportunistic infections
PIs	Protease Inhibitors
PLWHA	People Living With HIV/AIDS
RNA	Ribonucleic Acid
RUESCH	Rhodes University Ethical Standards Committee Handbook
TAC	Treatment Action Campaign
TB	Tuberculosis
TBVC	Transkei, Bophuthatswana, Venda and Ciskei
UNAIDS	United Nations Programme on HIV/AIDS
UTT	Universal Test and Treat
WHO	World Health Organisation

Chapter 1: Introduction

1.1 Brief introduction to the study

The intention of this study is to focus on the personal level, providing individuals living with HIV/AIDS a platform to share their experiences. This responds to the continually changing nature of and access to antiretroviral therapy (ART) (Karim & Karim, 2010). The research paper considers personal and social symbolisms and meanings attached to taking antiretrovirals. Moreover, it also focuses on how these meanings have influenced individuals' illness experiences. The study follows Toombs' (1992: 104) assertion that the "assignment of meaning and explanation is as much part of the illness as its physical expression" thus the patient's story is vital in the understanding of the patient's illness.

South Africa has the largest HIV/AIDS epidemic in the world (Karim & Cheryl, 2010: 37; Sabi & Reiker, 2017). Therefore, an understanding of patients' experiences, particularly with antiretroviral treatment, provides a perspective that offers insights into their personal lived experiences. This study seeks to advance current knowledge, which mostly looks at the epidemic from a medical perspective (Barnett & Blaikie, 1992), focusing on the evolution of the epidemic (Barnett & Blaikie, 1992; Karim & Karim, 2010), statistics behind it (Steinberg, 2007; Uebel, Timmerman, Ingle, & Van Rensburg, 2010), and how it affects large groups of people (Barnett & Blaikie, 1992; Karim & Karim, 2010). The study is in line with (among others) a report by Simbayi, Kalichman, Strebel, Cloete, and Henda, (2008) on ART as a possible prevention strategy – whereby the focus is on a micro-level – also see (Simbayi, *et al.*, 2007; Chisaka, 2006; Msengana, 2013; Skhosana, Struthers, Gray, & McIntyre, 2006). The study also explores how ART led patients to reconstruct their individual narratives.

In *Towards Universal ARV Access: Achievements and Challenges in Free Province, South Africa*, researchers report that in 2010 South Africa was estimated to have 5.7 million people living with HIV/AIDS (PLWHA). To combat South Africa's burden of the HIV disease, calls were made by HIV/AIDS activists, PLWHA AIDS as well as other groups and organisations such as the Treatment Action Campaign (TAC) in 2003 to provide antiretrovirals to people who needed them (Uebel, *et al.*, 2010: 598). Due to this, the South African government officially approved a national programme that made ART available in the public sector as of 2004 (Van Dyk, 2011b: 235). Consequently, by the end of 2008, it was estimated that over 4 million people had accessed antiretrovirals in developing countries, 700 500 of the people

being in South Africa. In 2009, an estimated 2.9 million South Africans had died of AIDS, with an annual AIDS mortality of 374 000 (Uebel, *et al.*, 2010: 598).

It is clear from the above information that ARVs are available in South Africa and that PLWHA, to a certain level, access the medication. However, public health facilities have experienced stock-outs as well a lack of adherence from the patients among other issues, which affect the whole treatment programme and patients' illness experiences.

Odendal (2013: 1) explains that drug supply issues, among others, threaten South Africa's ART programme the most. The drug supply problems are mainly caused by the "lack of an early warning system for facilities to be able to report potential shortages, drug suppliers failing to meet tender quotes; government failing to pay suppliers and poor ordering practices at health facilities and medicine depots" (Odendal, 2013: 1). Looking at facilities for young people specifically, Mokomane, Mokhele, Mathews, and Makoqe (2017: 125) uncover that, while the government is working towards improving antiretroviral treatment programmes, factors such as "high cost of services, poor skills among service providers on how to deal with young people; stigma associated with using sexual and reproductive health services by young people as well as lack of privacy and confidentiality in service provision" create barriers of accessibility of services. Moreover, there are inequity issues that also strengthen the barriers between people and antiretroviral treatment (Fairall & Wilson, 2010: 507). Mokomane *et al.* (2017: 126) identify the following characteristics as enhancing the issues related to provider, facility and programme design: lack of training of service providers, lack of resources, long waiting times, and poor quality of care – all of which affect patients' adherence to treatment.

In addition, Simoni, Aunon, Kemp, Kutner, Ramaiya, Velloza and Yung (2017: 564) assert that the main obstacle to achieving the best outcomes for patients receiving treatment is adherence. The researchers claim that while there are improvements in availability and affordability of antiretroviral treatment, the UNAIDS' goal of 90 per cent viral suppression is derailed by poor adherence by patients even when there has been funding allocated to interventions to promote adherence in both high-income and low-income resource settings (Simoni, *et al.*, 2017: 564).

As shown above, many factors contribute to the way in which patients respond to and experience the chronic disease.

According to Nettleton (2006: 81), when someone gets sick one's views of illness change and the relationship between the body and the person is disrupted, resulting in a different outlook

on life and illness in general. The way in which people make sense of their illnesses is “within the context of their personal biographies, and in turn, must invariably be influenced by, and meshed with, cultural values of the society in which they live” (Nettleton, 2006: 81).

Therefore, the disruption caused by an illness, such as HIV/AIDS, influences an individual’s narrative to be “reconstructed both in order to understand the illness in terms of past social experience and to reaffirm the impression that life has a course and the self has a purpose” (Williams, 1984: 179). This process helps the individual to deal with the disruption and create a new ‘identity’ in relation to her/his illness. Furthermore, one’s narrative about one’s illness should revolve around the medical world within which the illness is defined (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009: 828).

The emergence of a chronic illness can result in a lot of suffering for the individual. Charmaz (1983: 168) identified the following four key areas that individuals suffer from: leading restricted lives, experiencing social isolation, being discredited, and burdening others. This process takes a different form for different individuals; hence, the period of such experiences will also differ. This study explores how individuals have experienced their illness in terms of the adjustments they have made socially and personally due to consuming ARVs.

1.2 Goals of research

The main aim of the research is to explore the effects of antiretroviral treatment on patients’ illness experiences, looking at the personal and social symbolism and meaning attached to taking antiretrovirals. The study delves deeper into the above by investigating: how individuals have reacted to ARVs over time, the role of stigma in individual’s lives, how factors such as cost, stock-out, accessibility, and availability have affected adherence and lastly, how all these factors combined affect the way in which individuals reconstructed their narratives.

1.3 Theoretical underpinnings

To gain a deeper understanding of the participants’ experiences and narratives, the study followed two closely related interpretive theories: symbolic interactionism and social constructionism. The theories are best suited because of the common goal between them of understanding how individuals create meaning for themselves and others. Even though they have different intellectual backgrounds and emphasis in practice the strength of both theories is their value in a study of meaning creation (Leeds-Hurwitz, 2006: 229). Social constructionism broadly focuses on “making sense of the nature and structure of the social

world” while symbolic interactionism emphasizes “making of self and social roles” (Leeds-Hurwitz, 2006: 238). Mutually, the theories are imperative to the study because the nature of the study is to delve into how individuals create or recreate a sense of self personally and in their social worlds since consuming ARVs.

1.4. Research design

In order to gather an in-depth understanding of the respondents’ experiences due to ARVs, the research was conducted using the qualitative research design with the aims of providing comprehensive, subjective interpretations, personal narratives and experiences. The research method employed included semi-structured, in-depth interviews that were conducted with eight female participants living with HIV/AIDS. Of the eight, one was diagnosed with AIDS in 1993, prior to the introduction of free ARV access in the public sector, whereas the rest of the participants were diagnosed post the new policy. The inclusion of both accounts (pre-and post-free ART) provided a different perspective to the whole discussion on illness narratives.

The choice of methodology allowed for an extensive, open-ended and discursive environment where perceptions could be shared. The methodology also worked well with the social constructionist perspective as the perspective is grounded on showing how understandings and experiences come about. According to Leavy (2014: 85), the idea of social constructionism is that we create our own reality through social interactions, relationships and experiences, therefore providing a space for such realities to be reflected upon aids the research goals.

The interviews took place in different places of preference to the participants. The researcher met with the participants in two group settings hosted by the *Good Stories Organization*¹ (one before the interviews and one after all interviews), however, not in respect to the research – merely just for their monthly session where members of the organization come together to engage on issues pertaining to living with HIV/AIDS in their personal capacity as well as in their communities at large. It is important to note that the organization does not offer support groups, this is merely a platform for all to engage with each other, and there are no restrictions, therefore, both people infected with HIV/AIDS and those who are not, but whose lives are affected by it are welcomed to the sessions. These sessions were valuable in assisting the researcher form rapport with the participants.

¹ An organisation set to fight and change the stigma of HIV/AIDS and TB, through collecting and telling Good Stories, HIV/AIDS and TB Good Stories. The organisation uses social media platforms such as Facebook and Twitter to share the Good Stories.

1.5 Conclusion

Finally, this chapter sought to briefly contextualise the research topic bringing into account the aims of the research as well as the theoretical frameworks employed. Thereafter, the chapter outlined what research methods were used in the research process, and the kind of respondents that were chosen to participate. This brief introduction leads to a broader analysis of HIV/AIDS, ARVs as well as illness experience in the next chapter.

Chapter 2: Introducing antiretroviral therapy (ART) and illness experience

2.1 Introduction

Living with a chronic illness or a new illness is not easy and presents new ways of being and relating to oneself and the world around one. When one is faced with illness or chronic illness one enters a world where “structures of everyday life and the forms of knowledge which underpin them are disrupted” (Bury, 1982: 169). This disruption causes one to form new narratives about oneself and everything around one. Personal narratives about illness are embedded in more than just one’s illness but also one’s social context- the local world in which one lives (Toombs, Barnad, & Carson, 1995). For this reason, it is important to consider the role played by health policies, adherence, stigma, disclosure as well as general healthcare in understanding how individuals form narratives about their illness experiences because “just as the illness experience influences an individual’s capacity to engage in the social world, so the social world (societal attitudes, social practices, public policy), influences the subjective experience of illness and its meanings” (Toombs *et al.*, 1995: x).

Bartlett and Finkbeiner (2006: 67) assert that the history of the treatment of HIV/AIDS is possibly one of the most remarkable success stories in the history of medicine. Additionally, the treatment is certainly the most important development in a widespread, serious disease in the last 30 years. As the primary aim of this research was to explore the effects of antiretroviral treatment on patients’ illness experiences it is crucial to first contextualise ARVs and ART in order to link this to personal illness experiences and narratives. This will be achieved by focusing on the historical background of HIV/AIDS in Africa the treatment of HIV/AIDS and the factors affecting this. Thereafter, this chapter will explore the notion of illness looking specifically at narrative reconstruction due to the experience of living with a chronic disease.

This chapter will be divided up into nine sections. In the initial part of this review the main concepts are defined then followed by a broad historical account of HIV/AIDS in Africa with a specific focus on South Africa. Thereafter, the chapter will discuss in detail what ARVs are as well as how the ART programme in South Africa works. Additionally, the chapter looks at factors that affect the ART programme namely: adherence, stigma, and disclosure. To show how these aspects influence illness experiences and narrative construction the chapter also brings in a brief analysis of health policy and healthcare in South Africa.

2.2 Defining the main concepts

The following section seeks to define human immunodeficiency virus (HIV), acquired immune deficiency syndrome (AIDS), antiretrovirals (ARVs), disclosure, adherence, stigma, chronic disease, and illness experience, with the assertion that there is a causal relationship between these phenomena.

2.2.1 Human Immunodeficiency Virus (HIV)

HIV is a virus that can lead to infection and to a chronic condition called AIDS. According to (Hoffman, 1996: 31) the name describes the virus such that it “infects humans only and it attacks the immune system, rendering it deficient and unable to work as effectively as it should”. HIV differs from other viruses because the immune system is unable to attack and clear the HIV from the body - this will be further illustrated in later sections.

Without treatment, HIV advances in stages, overwhelming the immune system and getting worse over time. There are three stages of HIV infection namely: acute HIV infection, clinical latency, and AIDS (Hoffman, 1996: 32).

2.2.2 Acquired Immune Deficiency Syndrome (AIDS)

As mentioned above, AIDS is the last stage of the HIV progression. It is a condition or a syndrome that develops from HIV. AIDS develops when HIV has caused serious damage to the immune system. The condition is complex, with symptoms that vary from person to person. The hiv.gov (2017) explains that symptoms of AIDS are related to the infections a person develops as a result of having a damaged immune system that can't fight infections as well. These infections are commonly known as opportunistic infections and may include tuberculosis, pneumonia, certain types of cancer, and other infections (Low, *et al.*, 2016: 1596).

2.2.3 Antiretrovirals (ARVs)

ARVs are primarily drugs or medications for treatment of HIV/AIDS. The drugs work such that they delay or prevent the progression from HIV to AIDS and the death of HIV-infected patients (Wood, 2010: 529; Bartlett & Finkbeiner, 2006: 67).

2.2.4 Disclosure

“This is a process in which personal (often private and confidential) information is verbally communicated from one person (i.e. the discloser) to another person (i.e. the target)” (Li, Qiao, & De Wit, 2015: 1).

2.2.5. Adherence

According to Skhosana *et al.* (2006: 17), adherence is the level to which an individual's behaviours of "taking medication – following a diet, executing lifestyle changes – follows medical advice". In this instance, adherence refers to the way in which an individual takes the prescribed regimen of medication, in the right doses, at the same time, every day for the rest of their lives (Skhosana *et al.*, 2006: 17).

2.2.6 Stigma

Smith *et al.* (2008: 1267) assert that stigma is a simplified and standardised image held by a community towards a certain people; this image is frequently of disgrace. Essentially, it is a social construction shared by a group. Thus, stigma is an attribute applied to those who do not meet the definition of "normal" in a given social context

2.2.7 Chronic disease

Defining chronicity is complex (Wyszewianski, 1993: 23; Larsen & Lubkin, 2009: 5). There is no universally accepted definition for chronic disease, however, for the purpose of this paper Wyszewianski's definition suffices. Wyszewianski (1993: 29) defines chronic diseases or conditions as those conditions lasting more than 90 days, additionally:

"chronic conditions often develop gradually with no precisely definable point of onset. Usually they are not self-limiting, and because a complete cure is seldom expected, the goal of treatment is to palliate and prevent further deterioration. Furthermore, in most cases treatment is not aimed at the underlying disease but focuses on the relief of symptoms."

2.2.8 Illness experience

Disease is a biophysical event which is the primary concern of medical practitioners. Whereas illness is the way in which the sick person and his/her significant others and community perceive, live with, and respond to symptoms and sometimes disability (Nettleton, 2013: 73). Illness experience then, is the way in which the illness is reflected in an individual's life.

2.3 Contextualising HIV/AIDS in Africa

AIDS became a globally recognised health problem as far back as 1986 (Quinn, Mann, Curran, & Piot, 1986: 955). In 2001, seventy percent of people infected with (HIV/AIDS) were reported to live in Sub-Saharan African countries.

The magnitude of the AIDS epidemic in Africa became visible in the mid-1980s when the number of cases reported to the World Health Organisation (WHO) increased from 31 in May 1986 to 2,627 by February 1987 (Barnett & Blaikie, 1992: 1). This increase and the rapidity of it can be explained by the lack of health resources, poor general health, as well as the general social and economic disruption and unrest in the continent (Quinn, Mann, Curran, & Piot, 1986: 95 and Barnett & Blaikie, 1992: 1). The nature of the disease is such that, as with any other disease, it does not only affect the physical body but also affects the social body – the relationships between people. Therefore, AIDS was categorised as a ‘social disease’. Like any other epidemic disease, AIDS has deep social effects that vary with each society (Barnett & Blaikie, 1992: 1).

AIDS is largely a sexually transmitted disease transmitted through body fluids that are found in the HIV. The virus is slow-acting, and it reproduces itself via genetic material from the common cold. The virus easily mutates therefore making it difficult to develop a vaccine or treatment that can eradicate it at once (Barnett & Blaikie, 1992: 2). Barnett and Blaike (1992: 1) explain that, due to its nature, identifying the agent of the disease and its mode of transmission became a challenge for medical sciences in the 1980s which resulted in competition between research institutes. Furthermore, the focus on Africa was of particular importance because of the rapidity of the spread of the disease in “impoverished communities which depend on human labour for survival and where levels of national poverty are already so great that the resources for dealing with the care of the sick and dying and the orphans are already extremely scarce” (Barnett & Blaikie, 1992: 1).

The different clinical features of AIDS and the risk factors such as homosexuality and intravenous drug use found in the United States raised questions regarding the nature of the disease and the factors responsible for HIV/AIDS in Africa because African patients rarely reported a history of homosexual activity or intravenous drug use (Quinn *et al.*, 1986: 458). This could be attributed to the cultural differences between the two contexts. In Africa, the spread of the HIV infection and AIDS was comparatively more aligned with “heterosexual activity, blood transfusions, vertical transmissions from mother to infant and most likely the frequent exposure to unsterilized needles” (Quinn *et al.*, 1986: 458).

In 2012 an estimated 35.3 million were PLWHA. Sub-Saharan Africa, especially southern Africa has the highest global burden of HIV/AIDS. It is worth noting that the global epidemiology of HIV/AIDS infection has changed noticeably as a result of the expanding

access to antiretroviral therapy; by 2012, 9.7 million people in low-income and middle-income countries had started ART (Maartens, Celum, & Lewin, 2014: 258).

2.4 HIV/AIDS in South Africa

In South Africa, the epidemic came to light in 1982 through a few hundred cases among men who have sex with other men and persons receiving unsafe transfusions. This changed by the early 1990s when heterosexual transmissions became a dominant mode of spread of the infection as well as the “concomitant HIV epidemic in new-borns and young children through perinatal transmission” (Karim & Baxter, 2010: 37 and Williams & Gouws, 2001: 1077). South Africa has since been estimated to have the largest number of PLWHA. AIDS in South Africa was first reported in 1983, like in many African countries, the early stages of the epidemic were characterised by controversies and theories about the spread and transmission. Karim and Baxter (2010: 39) explain that in South Africa, too, AIDS first became apparent as an urban phenomenon but then rapidly spread to the rural areas.

When the first cases of AIDS were described and detected in the early 1980s, the apartheid government did not adequately address the epidemic as it was presented as a “gay epidemic confined to select high-risk sub-groups within the larger urban centres of the country” (Karim & Baxter, 2010: 40). Later in that period the state Department of National Health and Population Development established various AIDS Training and Information Centres which focused on disseminating information, counselling and HIV testing.

The epidemic continued to gain momentum which led to the XIII International AIDS Conference which was held in Durban. Building up to this, AIDS activists and organisations such as the Treatment Action Campaign (TAC) were putting pressure on and challenging the government, health providers and pharmaceutical companies to be more active in finding solutions and bringing AIDS treatment to poor people through petitions, marches and community mobilisation (Karim & Baxter, 2010: 42). This approach was further extended to legally challenging the government for its failure to recognise and uphold the health rights stipulated in the South African constitution. Following this, in 2002, the Constitutional Court ruled against the government and instructed it to provide antiretroviral treatment, specifically nevirapine, to all HIV positive pregnant women in the country (Karim & Baxter, 2010: 42 and Van Dyk, 2011b: 2). It was the government’s responsibility therefore to actively work towards progressive realisation of the right to health care. The pressure and challenge from the community and organisations continued and infiltrated Tshabalala-Msimang’s Ministry of

Health – which had controversial beliefs and understanding of HIV/AIDS and the treatment thereof – to work towards providing nevirapine and AIDS treatment. The success of the mobilisations, up to 2003, was the turnaround by the Mbeki government’s provision of free treatment in public health services across the country in 2004 (Karim & Baxter, 2010: 42-43).

Uebel *et al.* report that in 2010 South Africa was estimated to have 5.7 million PLWHA. As mentioned above, to combat South Africa’s burden of the HIV disease, calls were made by HIV/AIDS activists, PLWHA as well as other groups and organisations such as the TAC in 2003 to provide antiretrovirals to people who needed them (Uebel, *et al.*, 2010: 598). Due to this, the South African government officially approved a national programme that made antiretroviral treatment available as of 2004 (Van Dyk, 2011a: 235). Consequently, by the end of 2008, it was estimated that 700 500 of the people in South Africa had accessed antiretrovirals (of a total of over 4 million people in all developing countries),. In 2009, an estimated 2.9 million South Africans had died of AIDS, with an annual AIDS mortality of 374 000 (Uebel, *et al.*, 2010: 598).

It is clear from the above information that antiretroviral treatment is available in South Africa and that PLWHA have, to a certain level, access to medication. In fact, South Africa has one of the largest ARV treatment programmes in the world today (Van Dyk, 2011a: 1). Nevertheless, the treatment programme has not gone without challenges - public health facilities have experienced stock-outs as well a lack of adherence from the patients among other issues, which affect the whole treatment programme and patients’ illness experiences.

2.5 Antiretroviral therapy (ART)

As mentioned above, the human immunodeficiency virus is slow acting, and it can self-reproduce using genetic material from the common cold. The virus can lie dormant for many years, “enabling infectious but asymptomatic people to appear healthy” (Barnett & Blaikie, 1992: 2). The HIV destroys the body’s defence mechanism which creates easy access for other infections, therefore, the virus itself does not kill people directly, rather most people die from opportunistic infections which thrive in the environment and to which their comprised immune system allows them to fall prey (Barnett & Blaikie, 1992: 2; Maartens, 2010). Moreover, the virus cannot live for very long outside the human body and is transferred from one person to another through body fluids such as blood, semen, and vaginal secretions. In this way the virus is not exclusively sexually transmitted but may usually be. Barnett and Blaikie (1992: 4)

explain that consequently, in addition to being a deadly disease, it is also associated with so much stigma and moral resonance linked to sexually transmitted diseases.

The primary aim of ART is to delay or prevent the progression from HIV to AIDS and the death of HIV-infected patients (Wood, 2010: 529; Bartlett & Finkbeiner, 2006: 67). The therapy assists in boosting the immune system, thus preventing the reproduction of the virus, leading to viral suppression. Additionally, adherence to ART is required for a lifetime as it cannot eradicate latent HIV. Wood (2010: 529) enlightens that the common drug antiretroviral (ARV) categories include nucleoside reverse transcriptase inhibitors (NRTIs), non-nucleoside reverse transcriptase inhibitors (NNRTIs) and protease inhibitors (PIs).

The antiretroviral treatment era began in 1987 when the zidovudine drug was approved. This is a thymidine nucleoside analogue that targets the reverse transcriptase enzyme which is necessary for the replication of the human immunodeficiency virus (Wood, 2010: 529). The drug proved to be effective, though for a short term, in patients with advanced disease. Other NRTIs were developed following this but these, according to Wood (2010: 560), did not show substantial survival benefits when initiated at earlier stages of the HIV infection.

Through trial and error, more and more ARV drugs of different categories became available until the triple combination was discovered – this proved to have more durable benefits than either mono or dual therapy although the benefits of therapy seemed to be easily demonstrated in patients in the late stages of infection. Wood (2010: 530) further explains that when mortality and the rate of new AIDS defining events were high, the low rate of clinical events in early HIV infection impelled studies on the disease to be both large and prolonged so that there could be adequate statistical power to show how the different combinations of therapy worked. As more research on the disease was presented, and alternative markers of HIV disease progression were realised, it became easier to monitor the benefits of ART both during both the late and the earlier asymptomatic phases of the HIV infection (Wood, 2010: 531). The first reliable marker of HIV disease progression was the CD4+ T-cell counts.

In 1996 the highly active antiretroviral therapy (HAART) era began, which introduced the availability of PIs – a new category of ARVs and a commercial polymerase-chain-reaction-based assay – which made it easier to monitor viral response to potent therapy (Wood, 2010: 530). Wood (2010: 530) explains that the improvements in the new molecular quantitative viral assays “allowed circulating plasma HIV to be measured to a lower threshold of 50 copies of

HIV RNA per ml”, CD4+ T-cells increase and percentage of patients who achieved viral suppression below 50 copies per ml became the standard endpoints of trials of ART.

Following PIs, the third category of ARVs was developed – the NNRTIs. Thereafter, combinations of drugs from the three categories (PIs, NRTIs, NNRTIs) constituted the ‘standard of care’ for ART because even though dual NRTIs were the initial backbone of ART, it was no longer recommended because viral suppression was sub-optimal and resulted in increased development of virus or drug resistance (Bartlett & Finkbeiner, 2006: 69).

2.6 Aims of ART

Primarily, ART aims to stop or delay the adamant progression from HIV to AIDS and to stop the subsequent deaths of HIV-infected patients. When therapy is initiated in advanced HIV disease at CD4+ T-cells counts less than 50 cells/mls, new AIDS diagnosis can still occur in 10-15 percent of individuals, despite virological suppression (Wood, 2010: 531). While benefits of therapy are hard to demonstrate in early HIV disease, Wood (2010: 531) acclaims that favourable responses to therapy usually involve a decline in plasma HIV-1 RNA and can increase in CD4+ T-cell counts.

The most measurable goal and clinical benefit of therapy has been the suppression of viral load and reductions in plasma viremia. However, individuals’ responses to ART vary and the “correlation between CD4+ T-Cell counts can also increase with incomplete viral suppression” (Wood, 2010: 531). Although ART is effective in controlling viral replication, it is unable to eradicate latent HIV-1, which ‘persists in the host integrated within the genome of metabolically inactive, but long-lived memory CD4+ T-cells’ (Wood, 2010: 532). The pool of latently infected cells allows the revival of viremia when therapy is discontinued, hence adherence to ART is a life-long commitment.

Taking ART increases CD4+ T-cells and partially restores the immunity to some opportunistic infections yet there is a failure to restore HIV-1 specific immune responses. Wood (2010: 538) clarifies that when therapy is initiated at a later stage in the clinical course of the disease, the ability to restore immune responses is reduced. Furthermore, the adult thymus’s ability to repopulate the immune repertoire also declines with age.

Since HAART began in 1996, the United States Department of Health and Social Services (DHSS) guidelines have undergone a process of evolution, first towards more aggressive therapy and subsequently towards a more conservative approach (Wood, 2010: 539), therefore,

the question of when to start ART has changed over the years (Bartlett & Finkbeiner, 2006: 68). In 1996, it was recommended that only patients with less than 500 CD4+ T-cells per ml and those with a viral load of above 30 000 copies per ml were to be treated. In 1997 the ‘hit-early-hit-hard’ strategy expanded treatment to include every patient with viral loads above 10 000 copies per ml regardless of what the CD4+ count was. By 2000, treatment was restricted to patients with a CD4+ count of less than 500 or a viral load larger than 30 000 copies per ml. This further changed, in 2002, to those patients with a CD4+ count less than 500 cells per ml or with a viral load bigger than 55 000 copies per ml. Another change saw the expansion of treatment to patients with CD4+ counts less than 350 cells per ml and ‘allowing clinical judgement to be exercised at earlier stages of the disease’ (Wood, 2010: 539).

The most important factor about ART, according to Bartlett and Finkbeiner (2006: 67), is that the individual should take it when they are ready because ‘partial treatment is worse than no treatment’.

2.7 Factors that affect the ART programme

In South Africa, the national rollout of ART has offered an extraordinary opportunity for PLWHA to prolong their lives (Simbayi, Kalichman, Strebel, Cloete, & Henda, 2008: 1). While the aims of ART are clear, reaching these does not go without its challenges. Many factors contribute to the way in which patients respond to and experience their illness. The universal availability of treatment does not guarantee a positive experience with antiretroviral treatment and it does not equate to immediate access for patients.

According to Odendal (2013: 1), drug supply issues, among others, particularly threaten South Africa’s antiretroviral programme. The drug supply problems are mainly caused by the “lack of an early warning system for facilities to be able to report potential shortages, drug suppliers failing to meet tender quotes; government failing to pay suppliers and poor ordering practices at health facilities and medicine depots” (Odendal, 2013: 1). Looking at facilities for young people specifically, Mokomane, Mokhele, Mathews, and Makoqe (2017: 125) reveal that, while the government is working towards improving ART programmes, factors such as “high cost of services, poor skills among service providers on how to deal with young people; stigma associated with using sexual and reproductive health services by young people as well as lack of privacy and confidentiality in service provision” create barriers of accessibility of services. Moreover, there are inequity issues that also strengthen the barriers between people and antiretroviral treatment (Fairall & Wilson, 2010: 507). Mokomane *et al.* (2017: 126) identify

the following characteristics as enhancing the issues related to provider, facility and programme design: lack of training of service providers, lack of resources, long waiting times, and poor quality of care – all of which affect patients' adherence to treatment.

Additionally, Simoni *et al.* (2017: 564) assert that the main obstacle to achieving the best outcomes for patients receiving treatment is adherence. The researchers claim that while there are improvements in availability and affordability of antiretroviral treatment, the UNAIDS' goal of 90 per cent viral suppression is derailed by poor adherence by patients even when there has been funding allocated to interventions to promote adherence in both high-income and low-income resource settings (Simoni, *et al.*, 2017: 564).

With this in mind, the next section will explore factors that affect the ART programme.

2.7.1 Adherence

For ART to be effective, it requires meticulous adherence. It is important to note that adherence is interlinked with many sub-factors, however, for this section adherence will be looked at holistically and then stigma and disclosure will be looked into at a later stage. Maartens (2010: 503) describes poverty, alternative disease constructs, stigma, gender and unpredictable drug supply as important factors influencing adherence.

As previously mentioned, one of the goals of ARVs is to achieve viral suppression - according to Wood (2010: 529) poor adherence is the major cause of failure to achieving this goal. Moreover, poor adherence is a persisting challenge in the developing world even though adherence is possible where patients are supported. Van Dyk (2011a: 1) concludes that, in South Africa, the rates at which people adhere to ART are like those of treatment for other chronic diseases. It has been scientifically proven that an adherence level of at least 90% is needed to suppress the virus sufficiently, increase CD4+ T-cell counts, to “avoid the risk of mutation and to prevent the development of drug resistance strains and drug failure” (Van Dyk, 2011: 3).

The introduction of ARV medication to the body results in dramatic changes to the ecology of the virus. The immediate reaction is the repression of the virus. As the patient adheres to the medication optimally, the reproduction of the virus is obstructed severely. Optimum adherence to ARVs then leads to the viral load being undetectable, thus the person is not infectious and then their “immune system gets the opportunity to replenish itself” (Van Dyk, 2011a: 5). This is what ART hopes to achieve in every patient initiating treatment.

When treatment is not optimally adhered to or if a patient gets an insufficient medication regimen, the ARV will still be active in killing the virus, but viral suppression will be insufficient. Consequently, mutations will gain relative fitness which may give the virus an increased capacity to replicate and in turn reverse the whole process and defeat the purpose of ARVs in the first place. Van Dyk (2011b: 5) explains that while this can be fixed it can have consequences. If a patient changes treatment to a more potent regimen, the mutants will decrease again but there will be some that are archived in memory cells and can re-emerge if ARVs an individual's body has resisted are used in future.

Lack of adherence can lead to the development of drug resistance which does not only affect the individual but the whole treatment programme in general because there are currently only two drug regimens and resistance to one drug may result in "cross-resistance to all other drugs in that same class" (Van Dyk, 2011b: 5; Bennett, Bertagnolio, Sutherland, & Gilks, 2012: 2). When it comes to adherence, a patient's goal should be achieving optimum adherence to maintain viral suppression on the first line regimen for as long as possible (Bennett *et al.*, 2012: 1).

It is without doubt that the healthcare sector has a responsibility to educate people about the importance of adherence and the consequences for both individuals and the ART programme in general.

Van Dyk (2011a: 8) recognizes six factors that affect the ART programme:

1. Practical, environmental and service-related problems

Treatment regimen prescriptions affect adherence, most especially for those who have a larger prescription i.e. people who must take many pills at different times of the day. Moreover, the larger doses involve more side effects which in turn affect adherence (Van Dyk, 2011a: 8). While accessing treatment is free, there are hidden costs involved in being on ARVs; such as money for food and transportation to collect ARVs. The service related problems identified are unfortunately beyond the control of patients. For example, healthcare workers going on strike or holiday without backup plans in place for patients and stock-outs affect adherence (Mokomane *et al.*, 2017: 127). The lack of infrastructural, institutional, and human resource capacity in most developing countries influences the way in which HIV/AIDS is responded to (Auerbach & Mulhern-Pearson, 2008: 176).

2. Lack of support by healthcare workers

Healthcare worker support is a variable that significantly affects adherence (Van Dyk, 2011a: 10; Mwai *et al.*, 2013: 11-12). Healthcare worker shortages as well as inadequate support and education by the available healthcare workers is a barrier to adherence and overall effective response to HIV/AIDS (Auerbach & Mulhern-Pearson, 2008: 175).

3. Personal and psycho-social factors

According to Van Dyk (2011a: 11) alcohol abuse and depression are the greatest barriers to adherence. “Of those ARV users who defaulted on their treatment, 21% -24% said that they had often forgotten to take ARVs when they used alcohol or when they felt depressed respectively” (Van Dyk, 2011a: 11). In addition, forgetfulness, lack of planning, communication problems and treatment fatigue contribute to issues with adherence (Van Dyk, 2011a: 11; Igumbor, *et al.*, 2014: 2).

4. Lack of ARV-adherence knowledge

According to Vijaykumar (2007: 1249), “educating people with HIV/AIDS, their families and healthcare givers about ART is an urgent necessity since unlike other medication, this treatment involves a number of psychosocial factors”. Further, lack of ARV literacy and knowledge disadvantages the users of ARVs as they do not understand the direct relationship between adherence, drug-resistance and drug failure (Van Dyk, 2011b: 236). In addition, some PLWHA have a belief that they have no control over their health and how it progresses and that no effort on their part will change their HIV-positive status thus they choose to not adhere to treatment and surrender to deadly narrative of the disease (Van Dyk, 2011a: 13).

5. Stigma and discrimination

Lastly, a prevalent barrier to adherence is fear of stigma, discrimination and lack of support from significant others and communities. As a result, PLWHA do not disclose their HIV-positive status.

It is clear from the above that adherence is an important aspect of consuming ARVs but this is confronted with many challenges, some that can be controlled by individuals while others are completely in the control of healthcare workers. The next section will look into another factor that affects the ART programme. It is important to realise that these factors are causal and interlinked.

2.7.2 Stigma and disclosure

Even though the face of HIV/AIDS was altered in the late 1990s with the development of ARVs, transforming it from a fatal disease into a chronic illness (Makoae, *et al.*, 2009: 1357), stigma around the illness and ARVs is still prevalent in South Africa. Stigma, discrimination and the lack of social support are closely tied to why PLWHA do not disclose their status and ARV consumption to those close to them which subsequently affects their illness experiences. Additionally, stigma plays a role in the adherence of treatment (Smith, Rossetto, & Peterson, 2008: 1266).

HIV/AIDS has stimulated many types of reactions and responses, from “compassion for and solidarity with as well as anxiety about, and prejudice against, those living with HIV” (Smith *et al.*, 2008: 1266). The disease has also inspired many responses from PLWHA too. Disclosure of one’s status and ARV consumption has both positive and negative consequences. Mostly, disclosure is associated with receiving social support, but it also allows for the possibility of stigma and shame. Gillet and Parr (2011: 337) explain that fear of blame, violence, and abandonment by a partner also contribute to why PLWHA do not disclose. Consequently, stigma and discrimination has developed into a barrier to HIV/AIDS prevention and care (Makoae, *et al.*, 2009: 1357).

Smith *et al.* (2008: 1266) define stigma as a “simplified, standardised image of the disgrace of certain people that is held in common by the community at large”, additionally, AIDS stigma is defined as “prejudice, discounting, discrediting, and discrimination directed at people perceived to have AIDS or HIV, their loved ones and associates and the groups or communities with which they are affiliated” (Smith *et al.*, 2008: 1268). Stigma is perpetuated through communication whereby members teach one another to reorganize the ‘disgraced’ and to react to them accordingly thus stigma is a social construct (Smith *et al.*, 2008: 1266). In this way, a stigmatised person is reduced from a whole and normal person to a contaminated, discounted human by those who perpetuate stigma. As a way of protecting themselves from others’ rejection, PLWHA may be reluctant to disclose their status and the fact that they take ARVs (Geary, *et al.*, 2014: 419). There are various reasons for the stigmatisation of those living with HIV/AIDS. According to Williams *et al.* (2017: 1) attitudes towards people with HIV/AIDS appear to be commonly shaped by religious beliefs where the belief is that “God punishes people with HIV” due to the sexual transmission of the disease. Taylor (2001: 792) on the other hand, furthers this notion by explaining that the stigma stems from the assumed way in which one contracted the virus:

“on a macro level, some population groups are more likely to be regarded by society as ‘innocent victims of HIV’, for example haemophiliacs and babies who have acquired HIV through infected blood or maternal transmission. These groups might be considered ‘innocent’ in the sense that they are perceived as ‘blameless’, responsibility for illness being a dimension of stigma. In contrast, those who may have acquired HIV through drug use or sex between men may carry an additional stigma because of their ‘deviant’ behaviour.”

Lastly, those living with HIV/AIDS are stigmatised because of the lack of information among lay persons whereby PLWHA are perceived to all be infectious and contagious this is a result of faulty sociocultural beliefs and moralistic views toward sex (Jain *et al.*, 2017: 6). Jian *et al.* (2017: 6) further explain that poor education and awareness play a major role with regard to the existence of stigma and discrimination associated with AIDS.

Makoe *et al.*, (2009: 1360) assert that treatment side effects and stigma have a negative impact on an individual’s ability to adhere to medication. For some, the side effects of ARVs are not only short term and minimally bothersome but they also cause visible markers or ‘stigma symbols’. Taking ARV treatment requires regular visits to health care providers and daily intake of several pills – both of which can be difficult to hide. According to Makoe *et al.* (2009: 1361), another setback to treatment and factor likely to increase stigma is the misconception in communities that ARVs are only initiated once one is already very sick – “taking medications is seen as an indication of severity of illness that might, in itself, increase stigma, since it increases fear” (Makoe, *et al.*, 2009: 1361). Instead of being seen as appropriate health monitoring and seeking, treatment is shamed, which goes against the goals of ART programmes, thus health education is necessary both for people infected and those affected by HIV/AIDS.

2.8 Healthcare and social justice

The term ‘social justice’ has been used in different ways and encompasses different things for different people. Rhodes, Batting and Silvers (2012: 2) recognise that the term can incorporate various forms of justice and highlight distributive justice as being important for the health sector. The different forms of justice that can be incorporated include distributive justice, procedural justice, retributive justice and compensatory justice. Distributive justice refers to the way in which goods are distributed among people who deserve them (Rhodes *et al.*, 2012: 3). Procedural justice involves the process of maintaining fairness when dealing with

differences in opinion (Rhodes et al., 2012: 3). Retributive justice involves the process involved in dealing with offensive parties and finally, compensatory justice concerns how to 'repair harms done to parties undeserving of such treatment' (Rhodes *et al.*, 2012: 1). Distributive justice is identified as the most important in discussions of healthcare justice because health systems commonly operate under conditions of scarcity.

Rhodes *et al.* (2012: 1) centre the discussion of social justice on Aristotle's definition of justice which is: "treating like cases alike and different cases differently". While Aristotle's definition seems promising and inclusive of all people, it presents complexities because it is difficult to group 'alike' cases and 'different' cases. In addition, the distribution of goods would be difficult in terms of availability for all the groups recognised and another issue would be making sure that everyone fits into a group. Rhodes *et al.* (2012: 2) warn that, in medicine or health care, it is difficult to determine what justice is, particularly in relation to Aristotle's definition because "are like cases alike when two people have the same illness? Or have the same prognosis? Or when they are the same age, or in the same social situation or have suffered the same past deprivation or have made the same social contributions, or are the same in other respects?" (Rhodes *et al.*, 2012: 2). The idea of groups raises questions in terms of availability of resources for all groups and individuals in the groups.

Daniels (2002: 2) adds that there is a need for a fair process to establish legitimacy when faced with decisions about the distribution of goods, especially when there is no agreement on the distribution principle. He also asserts that what makes healthcare special is the impact it has on opportunity and equality (Daniels, 2002: 1). Therefore, the distribution of goods has to be in line with these principles hence "healthcare aimed at protecting fair equality or opportunity should not be distributed according to ability to pay and the burden of payments should not fall disproportionately on the ill" (Daniels, 2002: 4). In line with this, Rhodes *et al.* (2012: 4) discuss the notion of free market systems where healthcare is treated like any other consumer good which is accessible according to who can afford it. In this regard then, those who can pay have access to excellent health care while those who cannot, are forced, by circumstances, to rely on minimally funded public or charity care. This is why the authors advocate that the goal for a just health care system "ought to be the greatest good for the greatest number" (Rhodes *et al.*, 2012: 4). The above goal is parallel to Daniel's (2012: 2) notion of opportunity in that it gives as many people the opportunity for good healthcare regardless of their circumstances.

While the goal for healthcare is made clear, Rhodes *et al.* (2012: 2) also add that designing a healthcare system needs more than just health as a goal. The right to healthcare is another factor that needs to be unpacked because there is no consensus regarding “whom or what such a claim to be provided with health (as distinct from receiving services to maintain or restore health) reasonably could be lodged” (Rhodes *et al.*, 2012: 2). Baumrin (2002: 79) claims that the right to health care does not exist because there is no reciprocal ‘duty’. By this, Baumrin asserts that it could be argued that there is a right to limitless healthcare, however, it has no theoretical standing and because of that cannot be supported and should be replaced with a better implementation (Baumrin, 2002: 79). To add to this, Daniels (2002: 4) identifies that the right to healthcare exists and it is of moral importance because “it helps to preserve our status as fully functioning citizens” (Daniels, 2002: 4). Daniels continues to say that while the right to healthcare is important, it cannot be looked at in isolation as it forms part of human basic needs such as food, shelter, etc. which all collectively aim to “preserve normal functioning” (Daniels, 2002: 4).

Perhaps the problem is at the definitional level of what exactly the right to healthcare is and what the duties of this right are. As Baumrin points out, “it is not enough to have some airy notion of what physicians or nations are obliged to do” (Baumrin, 2002: 81). By understanding this, it will be easier to know what role the state plays as the guarantor of the right, and in addition, what role the people play in ensuring that their rights are met accordingly. Importantly, this is a two-way process between the state and the people. Daniels extends the notion of a two-way process by asserting that people’s social positions and the underlying inequality of society also affects healthcare, not just the doctor to patient relationship (Daniels, 2002: 6).

Daniels challenges us to look at healthcare according to a top down approach from the point of medical delivery, and question how fair the distribution of goods is because “social policies- not laws of human nature or economic development- are responsible for the social and economic inequalities that produce these health effects” (Daniels, 2002: 2). Clearly, it is more than just poverty and deprivation that diminishes some people’s health. Other inequalities such as race, class and gender, among many, play a role. Therefore, Rhodes *et al.* (2012: 5) are clearly correct when they conclude that “justice is good for health and health is good for justice”.

2.9 Health policy and health care in South Africa

Twenty-three years into its democracy, South Africa has evolved and progressed into an improved country, becoming a better home for more and more South Africans. While there is still much work to be done, efforts have been made to mend the ills of the apartheid system. One area where there has been evident progress is the health and healthcare sector. To understand the progress, one has to first have an understanding of the context during the apartheid era. Most prominent in the history of South Africa is discrimination based on race and gender (Coovadia, Jewkes, Barron, Sanders, & McIntyre, 2009: 817). This form of discrimination informed many of the ills that took place during the apartheid era, in turn affecting the current state of South Africa. Much of the country's history has affected present day health policy and services for the people of South Africa which has sequentially affected the narratives that people construct about their illnesses both during and after apartheid.

According to Tsampiras (2012: 25) prior to 1994 South African policies divided society according to age-based hierarchies, gender, class, mobility and race “which greatly influenced the organisation of social life, access to basic resources of health and health services” (Coovadia *et al.*, 2009: 817). Health services prior to South Africa's democracy were also highly uneven both within the public health sector and between the public and private sectors, this was inspired by the Public Health Amendment Act of 1897 (Coovadia *et al.*, 2009: 825). Tsampiras (2012: 26) shows how apartheid policies resulted in dramatic distortion of health provision in South Africa and the ‘homelands’. She describes how these policies perpetuated disparities in health and mortality and morbidity (Tsampiras, 2012: 26):

“Government spending on the health care of people defined as ‘whites’ was significantly more than any other race group. In 1987, for every R1 spend on ‘white’ people, 60c was spent on ‘asian’ people, 57c on ‘coloured’ people and 23c on ‘black’ people.”

During the 1980s to the early 1990s health services in South Africa were managed by a number of statutory bodies which were organised along racial lines and led to immense disparities in funding such that by 1991 the country had “14 different departments of health, one national Department of Health (DoH), three ‘own affairs’ departments – six in the ‘homelands’ and four in the TBVC ‘states’” (Tsampiras, 2012: 28-29).

When the African National Congress (ANC) won the first democratic election in 1994 the party carried with it many burdens from the apartheid government. It therefore had a lot to repair and

transform. Indeed, Baker (2010: 79) notes that the party “inherited a health service that was indelibly marked with the inequities of the apartheid era, highly privatised and distorted toward the hospital needs of the urban whites” (Baker, 2010: 79; Wilson & Fairall, 2010: 504). Consequently, it was central for the ANC to dismantle the apartheid system and its policies and address issues that had weakened the health system. In the manifesto the ANC promised, among many other things, health equity improvements (Baker, 2010: 79). Some of the improvements that were born out of the manifesto include an increase in primary healthcare funding, an integrated staff that represented the population, and children and mothers received free treatment (Coovadia *et al.*, 2009: 828).

Moreover, the party implemented successful measures such as the transformation of the public health system into a national service aimed at providing health care for the disadvantaged. The 14 health administrations of the Bantustans and South Africa (that were put in place during the apartheid era) were combined to form one national department divided into the nine provinces (Coovadia *et al.*, 2009: 828). Moreover, more clinics were built and others upgraded which means that more people had access to public health care. Primary healthcare became free for all users and “essential drug lists and standard treatment guidelines were developed and issued for both primary healthcare and hospital levels” (Coovadia *et al.*, 2009: 828). The party passed legislation to allow safe, legal termination of pregnancy and also introduced the *HIV & AIDS and STI Strategic Plan for South Africa*.

Coovadia *et al.* (2009: 828) acknowledge that there has also been progress in the redistribution of resources between geographic areas and levels of care which is an attempt at making services equal for all. Even twenty-three years later, the government still continues efforts to make the health system better. Rispel and Setswe (2007: 6) note that the national health system is continuously working towards amending disparities of the apartheid system; as its goals include improving and promoting people’s health, ensuring quality of health care services, protecting citizens against financial costs etc. (Rispel & Setswe, 2007: 6). This has been evident through measures such as the National Health Insurance (NHI). The progress in South African healthcare policy is in line with Daniel and Rhodes *et al.*’s (2012: 4) goals for healthcare and justice – “to be the greatest good for the greatest number” and the notion of equal opportunity for good healthcare regardless of the circumstances (Daniels, 2002: 2).

It is without doubt that the current policy has its faults and this is not only due to implementation of policy or the government itself but also the fact that South Africa is still

newly democratic, therefore, still unlearning and dismantling the ways of the apartheid system. Rispel (2016: 17) asserts that even though the government has implemented a number of policies that have focused explicitly and at times successfully on equity and redressing those affected by the apartheid system, there are three specifically highlighted fault lines in process. The author identifies that these fault lines affect patients, health care professionals as well as policy implementation (Rispel, 2016: 17).

The first fault line identified is the “tolerance of ineptitude as well as leadership management and government failures” (Rispel, 2016: 18). This doesn’t disregard the many committed and competent hardworking professionals, however it highlights that lack of accountability in the system results in this group of people derailing the successes of the country. The second fault is that twenty-three years into democracy South Africa still does not have a fully functional District Health System which is the main means for delivery of primary health care (Rispel, 2016: 19). Thirdly, the government’s failure to deal with the health workforce crisis has resulted in the failure of the policy to be as successful as it can be. The country has more professionals than most of other similar countries, however, there is a crisis of “unprofessional behaviour, poor staff motivation, suboptimal performance and unacceptable attitudes of health workers towards patients” (Rispel, 2016: 21). To add to that there is the problem of underfunding.

These fault line provide a broader view of the disadvantages of the policy implementation and, as Rispel (2016: 21) claims, “explain the large gap between policies and their implementation” which gets in the way of a progressive democracy. It is worth mentioning that the health sector cannot be looked at in isolation from all the other departments in the government as these are interlinked and intertwined.

2.10 Illness experience and illness narratives

Morrall (2001: 49) defines health as an ideal state and the absence of disease; therefore, illness is the subjective experience of not feeling well. Moreover, illness encompasses the “experiences of diseases, including the feelings relating to changes in bodily states and the consequences of having to bear that ailment.” Illness then, relays a ‘way of being’ for the individual (Morrall, 2001: 49).

According to Bury (1982: 169), illness doesn’t only affect the individual, it also involves families and wider social networks and it disrupts the ways in which these networks relate to the individual as well as to the illness itself. When someone gets sick their views of illness

change and the relationship between the body and the person is disrupted, resulting in a different outlook on life and illness in general (Nettleton, 2006: 81). When an individual is faced with an illness a difference between illness and disease is made clearer. Nettleton (2006: 81) distinguishes that disease is a biophysical event and the most important aspect to medical professionals, while illness is the way in which the sick person and her/his social network perceives and lives with the new experience (Nettleton, 2006: 81).

The way in which people make sense of their illnesses is “within the context of their personal biographies, and in turn must invariably be influenced by, and meshed with, cultural values of society in which they live” (Nettleton, 2006: 81). Morrall (2011: 50) adds that the meanings attached to the illness, the reactions that are a result of the illness as well as the way in which medical professionals and society frame and respond to the individual are all dependant on social context, thus are socially constructed.

The experience of a black female South African living with HIV/AIDS will be different from that of a white female South African living with HIV/AIDS because of the different cultures that each comes from. Moreover, given South Africa’s historical background, the illness experiences of HIV positive individuals will differ before and after democracy. The introduction of the *HIV & AIDS and STI Strategic Plan for South Africa (2007-2011)* created a new outlook on the infection, both for medical professionals and society as a whole. This consequently influenced people’s construction of their illness experience. Coovadia *et al.* (2009: 828) acknowledge that there has also been progress in the redistribution of resources between geographic areas and levels of care which is an attempt at making services equal for all.

Once an individual’s life has been disrupted by the illness that s/he is experiencing, such as by HIV/AIDS, the individual goes through a process where his/her “narrative has to be reconstructed both in order to understand the illness in terms of past social experience and to reaffirm the impression that life has a course and the self has a purpose” (Williams, 1984: 179). In agreement, Lorig *et al.* (2013) assert that any illness requires that the individual does new things and incorporates more frequent interactions with the doctor and healthcare system. In addition to that, the individual also learns new skills to deal with the illness and continue with life. This process helps the individual deal with the disruption and create a new ‘identity’ in relation to her/his illness as some illnesses do change almost everything in the individual’s life. During this process, the individual interacts with his/her environment and significant others.

Williams (1984: 181) further explains that one's narrative about one's illness has to revolve around the medical world within which the illness is defined. One's demographics do not only determine how one will experience the illness but also go further to affect whether or not one gets a medical diagnosis. Therefore, the role of the doctor varies in different situations, confirming Williams' claim that "both illness, and the response of professionals to it, suggests a world of power inequality" (Williams, 1984: 185). This links to medicine and social justice in South Africa where the health of the nation is dependent upon more than just wealth and having the right to healthcare (Daniels, 2002: 7). This in turn affects the way one places a sense of identity with the new illness.

The emergence of a chronic illness or illness in general results in a lot of suffering for the individual, Charmaz (1983: 168) identified the following four key areas from which individuals suffer: leading restricted lives; experiencing social isolation; being discredited and burdening others. For some, there is also an element of denial at the initial stages of diagnosis; the denial can act as a form of a defence mechanism (Royer, 1998: 22). Furthermore, Charmaz explains that serious chronic illness also results in "spiralling consequences such as loss of productive function, financial crises, family strain, stigma and a restricted existence" (Charmaz, 1983: 169). This process takes a different form for different individuals therefore the period of such experiences will also differ. The above areas are more internal and personal than those that Williams (1984) and Bury (1982) identified. Charmaz explores the ways in which the individuals lose themselves due to illness, "as they suffer losses of self from the consequences of chronic illness and experience diminished control over their lives and their failures, affected individuals commonly not only lose self-esteem, but even self-identity...diminished self" (Charmaz, 1983: 169). Even though there are individuals who do not recognise themselves as active authors of their narratives and therefore having nothing to reconstruct (Williams, 1984: 179) they still undergo suffering.

As mentioned in section 2.2.8, illness experience is the way in which the illness is reflected in an individual's life. Illness narratives then, are defined as the "story-telling and accounting practices that occur in the face of illness" (Gabe, Bury, & Elston, 2004: 82). Nettleton (Nettleton, 2013: 74) advances that illness narratives are stories told by the patient and significant others to give "coherence to the distinctive events and long-term course of suffering" (Nettleton, 2013: 74).

Further than reflecting illness experience, illness narratives also contribute to the experience of symptoms and suffering. As emphasized previously, all narratives are context dependant such that the narrative a patient shares with the doctors, nurses, family and friends will vary – sometimes complementary and other times contradictory (Nettleton, 2013: 74). According to Kleinman (1988), illness narratives serve two main purposes: to provide patients living with chronic conditions a ‘witness to suffering’ and to address their existential fears. Illness narratives are also important outside the clinical situation. Nettleton (2013: 74) supports:

“Illness narratives not only provide insights into the experiences and views of the narrator, such as the practical consequences of living with symptoms and how illness influences social relationships but more than this, they also afford insights into the cultural and social factors that shape, or give rise to people’s experiences.”

As mentioned before, illness disrupts an individual’s life; illness narratives are central to experience because they help individuals deal with the altered situation and disruption caused by an illness. Gabe *et al.* (2004: 83) add that illness narratives play a role in the integration and reintegration of individuals into their social worlds.

2.11 Conclusion

To conclude, this chapter aimed to introduce ARVs. This was achieved by bringing into account a historical overview of HIV/AIDS in Africa and then specifically looking into South Africa. Thereafter, an in-depth analysis of ART followed looking especially at the aims, and factors affecting ART programmes in South Africa. To put everything in context, the chapter provided a discussion of the health care policy and its implications on ARVs and PLWHA. Finally, the chapter tied the whole discussion together by focusing on illness and illness narratives.

Having explored how individuals reconstruct their narratives after a biographical disruption it is worth agreeing with Chisaka and Coetzee’s (2009: 10) claim that “biographical disruption does not necessarily result from chronic or serious illness,” there are in fact other factors that lead to it and these are influenced by one’s demographics too. When looking at illness experiences, it is easy to generalise and use blanket statements. However, exploring each case individually reveals more than the presented literature provides. The literature has also demonstrated that there is a link between social justice, health policy and illness experience as these are interlinked. The way in which social justice and health policy are addressed will have consequences on one’s illness experience. This proves that personal narratives about illness are

embedded in more than just one's illness but also one's social context- the local world in which one lives in (Toombs *et al.*, 1995).

Chapter 3: Theoretical Chapter

3.1 Introduction

This chapter seeks to create a connection between symbols, labelling and how these are socially constructed, in line with the narratives of people living with HIV/AIDS. Furthermore, the chapter will illustrate the impact of the above on illness experiences. As mentioned in Chapter 2, new narratives arise from a new illness or a chronic illness and these narratives are embedded in factors beyond the illness itself – the social context plays a crucial role in the way in which individuals construct or reconstruct their narratives (Toombs *et al.*, 1995). The chapter will predominantly rely on symbolic interactionism and social constructionism as these theoretical frameworks have some commonalities and add value to the study, as has been highlighted in previous chapters.

This chapter demonstrates that of primary importance to symbolic interactionism is the notion that social life is a process of interaction between the social and the natural environment on the one hand and between human beings who occupy these spaces on the other hand. Additionally, human beings behave in ways that adapt to these environments so that individuals mutually influence one another (Reynolds & Herman-Kinney, 2003: 40; Reynolds & Herman, 1994: 1).

According to Ritzer (2004: 427), labelling theory, which is also referred to as societal reaction theory, primarily investigates how social groups create and apply definitions and labels for behaviour. Aligned with symbolic interactionism and social constructionism, the theory holds that labelling is not an intrinsic behavioural trait, rather that it is acquired through the process of socialization. Herewith, labels attached to PLWHA are not labels with which individuals were born, instead, these are formed and perpetuated through and within the interaction of social groups.

For social constructionists, illness is not just a physical state, it is a social phenomenon. Hence Collins (2006: 110) argues that HIV/AIDS is not just a sexually transmitted disease but a socially transmitted disease as well as it does not only affect the physical body but also affects the social body – the relationships between people. Hence, AIDS was categorised as a ‘social disease’.

Health, illness, and medical care are social facts set to define and give meaning to certain classes of events (Mishier *et al.*, 1981: 141). Further, illnesses are culturally defined through

interaction specifically, “social structure and social stereotypes are part of the social construction of HIV/AIDS” (Collins, 2006: 110).

3.2 Symbolic Interactionism

The actor, the object, the meaning, the act and joint or social action are central concepts to symbolic interactionism. Each of these concepts is highlighted in the premises within which symbolic interactionism rests: first, that humans act toward things (including each other) based on their meanings; second, that meaning emanates from social interaction and lastly, that meanings are contained and changed through an interpretive process (Blumer, 1969: 2). The central concepts will be discussed below, incorporating a demonstration of how the theoretical framework can be used to understand an individual’s illness experiences – the personal and social symbolism and meanings – due to taking antiretrovirals.

3.2.1 The Actor

According to Blumer (1969: 12), the human being is an acting organism, meaning that the individual is not only a recipient of others on a non-symbolic level, instead, the individual also acts, makes indications to others, and interprets their indications. Put simply, the individual also actively participates in the process of meaning-making as an object of his/her own action. Here then, the individual is aware of her/himself, for example, one knows that one is a woman, a mother, a person living with HIV/AIDS etc. This awareness of being an object to her/himself determines the way that individuals act toward themselves and how they present themselves in actions to others. Blumer (1969: 12) asserts that this self-objectification, ‘self-object’, emerges from the process of social interaction where outsiders define the person to themselves. Therefore, for an individual to see her/himself as an object, the individual must see her/himself from the outside through role-playing – “we see ourselves through the way in which others see or define us” (Blumer, 1969: 13; Charmaz, 1990: 1161). Crooks (2010: 15) furthers this by stating that role-playing, social interaction, reflection and self-objectifying also helps individuals get to know themselves better.

Individuals do not only interact with others as a ‘self’, they also interact with themselves as a ‘self’. This interaction, Blumer explains, is social – like any other interaction with others would occur. It is a process of making indications. It is a daily process of constantly communicating with oneself as though one is communicating with another person. For example, noting that one is angry with oneself, or reminding oneself to do daily tasks, or talking oneself through a plan of action (Blumer, 1969: 13). Symbolic interactionists assert that this process is continuous

throughout one's life, showing that human activity is both individual and collective (Crooks, 2010: 14). The process is important because the consciousness of the individual is “equivalent to his indicating the thing to himself – he is identifying it as a given kind of object and considering its relevance or importance to his line of action” (Blumer, 1969: 13). Interaction within the self and with others allows people to understand a situation better, and then make choices. Persons living with HIV/AIDS then, in this context, are not only organisms that responds to a diagnosis, but they are organisms that must deal with the diagnosis and act accordingly thereafter thus giving meaning to what they perceive their disease to be and then using the meaning given as a basis for directing their actions as active beings.

3.2.2 Objects

“Human beings live in a world or environment of objects, and their activities are formed around objects” (Blumer, 1969: 68). These objects, according to symbolic interactionists, are not self-existing with intrinsic natures, rather, they are constructed by humans through social processes and interaction. The nature of objects is determined by orientation and the way people act toward them (Charon, 2001: 29). George Mead defines an object as “anything that can be designated or referred to” (Blumer, 1969: 68). Blumer (1969: 68-69) identifies the following five features of objects:

1. The nature of an object is established by the meaning it has to the individuals who see it as such.
2. The meaning of an object is not intrinsic, it arises from how an individual is prepared to act toward it.
3. All objects are socially constructed
4. People act toward objects based on the meanings they give them.
5. There is no one way of responding to objects, the response is relative.

This perspective views human beings as living in a world of meaningful objects. Moreover, the world is socially produced, and meanings emanate from social interactions. As interactions change, so too do meanings attached to objects change. In this research, both the ARVs and the individual consuming them are the objects. ARVs can be viewed in varying perspectives depending on who is viewing them. Antiretrovirals have different meanings to different people in different worlds. For those living with HIV/AIDS and consuming them, they mean a completely different thing than to those who are living with HIV/AIDS and not consuming them. Furthermore, to medical practitioners and laypersons, the meanings of ARVs will be different.

3.2.3 Meaning

While meaning is central to symbolic interactionism (as outlined in the three premises of symbolic interactionism listed above), the social sciences and psychology have generally downplayed the role of meaning by solely attributing human behaviour to the external factors and the factors producing them. Blumer (1969: 3) explains that factors such as "social position, status demands, social roles, cultural prescriptions, norms and values, social pressures and group affiliation" are given more attention than the "meanings of things for the human beings who are acting". Symbolic interactionism, however, values the meanings that things have for human beings to such an extent that undervaluing them is considered a falsification of the behaviour (Charon, 2001: 1). Meaning is an essential part of the formation of behaviour. Symbolic interactionism views meaning as deriving from two sources: first, the object itself – here the belief is that every object has a meaning whether individuals perceive it or not. Second, the “psychical accretion brought to the thing by the person for whom the thing has meaning” (Blumer, 1969: 4). The above two origins of meaning do not focus on a one-sided view of the creation of meaning. Instead, they appreciate that meanings are social products, created in and through people's defining actions as they interact with one another and themselves (Charon, 2001: 1).

3.2.3 The Act

“Action is seen as conduct which is constructed by the actor instead of a response elicited from some kind of performed organization in him” (Blumer, 1969: 64). As emphasized above, symbolic interactionists see humans as active organisms whose actions are inspired by the way they face, deal with and act toward objects. Individuals are constantly in a process of learning, unlearning and relearning meanings through interaction, which then determines how they view objects, acts, and themselves as actors. Blumer explains that it is this consciousness by individuals that allows them to act as they see fit. In this regard, the narratives of people living with HIV/AIDS incorporate a whole process of understanding the diagnosis and the medical meaning of it and then coming to terms with the treatment of the disease. Furthermore, individuals have to then define for themselves, after the whole process, what antiretrovirals mean, and how they will act toward them.

3.2.4 Joint action/social action

Joint action, or social action, highlights the interlinks in social interaction. Individuals find themselves belonging to more than one group or society, for example, one can be a part of an

organisation, the mothers in a society, the working, those living with HIV/AIDS etc. In each of these groups there are different individuals with different positions and acting differently based on their perspectives, therefore, their ability to fit all these acts together is what makes the joint action, not their commonalities. Blumer (1969: 70) illustrates this joint action as follows:

“Their alignment does not occur through sheer mechanical juggling, as in the shaking of walnuts in a jar or through unwitting adaptation, as in an ecological arrangement in a plant community. Instead, the participants fit their acts together, first by identifying the social act in which they are about to engage and, second, by interpreting and defining each other’s acts as informing the joint act”

It is clear that while each participant in the group has different roles, the entirety of the group shares a goal and as society evolves so do the goals and the actions of members in these societies (Charon, 2001: 30). The course of action in these groups is guided by the way the members construct meanings and use symbols (Crooks, 2010: 11). For Charon (2001: 3), as the action unfolds, individuals get a sense of their environment and then define situations. So, the group acts according to their definitions of situations.

3.3 Symbolic Interactionism and HIV/AIDS

As the above concepts have illustrated, symbolic interactionism probes deeper than the surface level understanding of objects or symbols and what Staggs calls ‘sufferer images’ (Staggs, 2007: 3). It is clear that the person living with HIV/AIDS, the disease and the treatment of the disease are important symbols or objects which in turn act as signifiers of HIV/AIDS. Chapter 2 illustrates that once individuals are diagnosed with HIV/AIDS their narrative changes – their lives, sense of being and the world around them is recast in a different light where they have a ‘before’ and ‘after’ in the way they view themselves (Staggs, 2007: 4). This ‘before’ and ‘after’ consists of new meanings, objects, actors and acts so that the individual has to begin to interact with the lingo of HIV/AIDS. The transformation into this new narrative also means new social actions because the individual now belongs to an additional group in society – that of PLWHA which is also referred to as the risk group.

PLWHA are continuously defining and redefining themselves because of the developing nature of the disease, treatment of the disease and emerging research about the disease. Staggs (2007: 10) explains that some narratives of people living with HIV/AIDS are oriented toward the future and others are present-oriented – this orientation determines the meanings individuals

give to their lives. Their views of the possibility or impossibility of hope transform their narratives, their identities, and their social action. The organizations that some individuals join affect their identity, “based on the type of orientation, a patient can come to see himself as empowered or as simply a ‘manager of illness’” (Staggs, 2007: 10).

3.4 Labelling HIV/AIDS

The labelling theory examines how deviants transpire, how some groups have the power to impose labels on others and the consequences of being labelled (Ritzer, 2004: 427). According to Moncrieffe and Eyben (2007: 19), acts of classification and taxonomy are fundamental to human interaction and behaviour, therefore, labelling is an important social process. This process of classification is guided by values, interests, preferences, and learning from repeated interactions thus people define and construct their identities from meanings acquired in society – “social groups project rules and definitions onto otherwise neutral behaviours” and create labels (Ritzer, 2004: 427). The role of the theory, in turn, is to investigate the way in which this process of labelling takes form.

Moncrieffe and Eyben (2012: 19) assert that labels are made through symbolic processes of interaction. Therefore, they are influenced by rules, stereotypes, and beliefs, hence being labelled may be more about the demographics of individuals than their behaviour. Being labelled has consequences; the label can either be positive or negative; sometimes the label cannot be undone, it can increase the probability of future behaviour and it can also impel society to treat the labelled individual differently – mostly in a negative light (Larsen & Lubkin, 2009: 44). Shepard (2009: 184) explains that negative labels give more room for stigmatization which increases the chances of more ‘deviant’ behaviour from individuals for example, individuals may embrace being labeled outsiders and actively resist the stigmas attached to the labels or they can simply embrace it and completely commit to their ‘deviant’ behaviour (Ritzer, 2004: 428; Larsen & Lubkin, 2009: 39).

"Labelling is a pervasive process, occurring at different levels and within different arenas of interactions" (Moncrieffe & Eyben, 2007: 20). At one level labelling emphasizes a relationship of power whereby some actors have more power to impose labels than others. This dynamic is seen through the construction of social othering and identity creation. Furthermore, labels also affect individuals' self-concepts as they are enforced through interaction which is also how individuals develop definitions of what is taking place in their situations and deciding how to act to the situations as they have defined them (Charon, 2001: 28). Ritzer (2004: 428) argues

that some labels are dispensed in the guise of medical diagnoses and official statistics. For a person living with HIV/AIDS, the diagnosis and the health problems accompanied by it are not the only issues the individuals must deal with, additionally, they have to deal with the side effects of treatment, possibility of their lives being cut short, and then also combating the shame and stigma that is associated with the disease (Staggs, 2007: 2) – which in turn affects how the individual comes to view themselves and their narratives.

Moncrieffe and Eyben (2007: 23) claim that "we are all labellers and therefore, we are all labelled", highlighting that not all labelling is negative (Beron, 2013: xi), hence "the issue is not whether we label, but which labels are created and whose labels prevail to define a whole situation or policy area, under which conditions and with which effects?" (Moncrieffe & Eyben, 2007: 23)

Staggs (2007: 12) states that labels are not only external - individuals can internalize labels and then enact those labels. Once the label is embedded in an individual's self-concept the individual may self-stigmatize (refer to Chapter 2), or assume behaviour in line with the label which is directly linked to the concept of role-playing that Blumer (1969: 13), Charmaz (1990: 1161) and Crooks (2010: 15) demonstrate. Furthermore, labelling is included in discussions about stigma because whether or not PLWHA are "bug chasers, gift givers, or some other exception, they are still seen as deviant because they have been stricken with a stigmatizing illness" (Staggs, 2007: 13). According to Stolley and Glass (2009: 64), AIDS is a socially constructed illness which has been socially constructed in stigmatising ways resulting in negative perceptions of the virus and those who have it as well as resulting in behaviours that reflect that stigmatisation and labelling is one such behaviour.

3.5 Social Constructionism and HIV/AIDS

According to Leavy (2014: 85), the idea of social constructionism is that we create our own reality through social interactions, relationships, and experiences. Social constructionists then are concerned mainly with the meaning-making process and how individuals' understandings and experiences come about, and how they then feed into the larger discourse (Blanche *et al.*, 1999: 278). Leavy (2014: 85) explains that from an ontological perspective, the reality is contextual and socially relative, consequently allowing for many interpretations of reality to exist at the same time. Considering that reality is constructed, knowledge and meanings are rooted in social interactions. To further this notion, Leavy asserts, "the epistemological notion of reality and meanings are not individual in nature but instead are constantly 'negotiating

meaning” (Leavy, 2014: 85). Social constructionism values the complexities of human experiences and the idea that “any one facet of someone’s life intertwines with (contributes to) some other facet” (Roller & Lavrakas, 2015).

Charmaz (1990: 1161) asserts that chronically ill people, like other people, experience their constructions as reality, “their constructions are neither convenient fabrications, nor idiosyncratic inventions” rather, their constructions reflect their understandings of their experiences as well as the diverse situations these experiences take place. Social constructionists appreciate that outcomes are a result of social interactions, negotiations, and power. For constructionists, illness is not just a physical state, it is a social phenomenon (Lober & More, 2002: 1).

According to Lober and More (2002: 1), every society, through cultural and moral values, shapes what being ‘sick’ means – through interaction with members of the individual’s immediate social circle and relationship with healthcare professionals – and is influenced by the shared beliefs about health and illness. Therefore, meanings attached to a behaviour or experience viewed as a sign or symbol of illness are aligned with social norms, cultural values and culturally shared rules of interpretation. Mishier *et al.* (2002: 142) note that constructionists do not regard diagnosis as “the measurement and assessment of specific deviations from biological norms” rather, as a process whereby signs are “evaluated as having cultural significance and in particular, as having the meaning of disease”.

Social constructionists go as far as claiming that a diagnosis is used to construct an illness and in turn cast certain individuals into the role and label of patients. In this light then, one can argue that being diagnosed with HIV/AIDS has implications of labelling which in turn has consequences that exclude the individual from ‘normal’ social groups – for example, individuals will immediately be labelled as patients which removes them from the “healthy” group in society, further, more and more labels will pull them farther away from their immediate circles into new ones. By asserting that a diagnosis is a social process, and illness a social category, Mishier *et al.* (2002: 148), emphasize that there will be variation across cultures and times.

Collins (2006: 110) maintains that HIV/AIDS’ complexity is found in the notion that while the disease is fundamentally mostly sexually transmitted, it delves into individuals’ behaviours that are irrational and ignore warning signs, cautions, and dangers of general sexual behaviour. The disease also encapsulates “myths, stereotypes, lies, and taboos related to our sexual life, our

sexuality, and our social psychological beliefs..." (Collins, 2006: 110) – all of which are influenced by social interactions, structures, and dynamics. Stolley and Glass (2009: 64) claim that the way in which people view and respond to those living with HIV/AIDS has been shaped by a social construction that actually built a triple stigma: firstly, HIV/AIDS, from its early days, was connected with socially stigmatised groups; secondly, HIV is a sexually transmitted disease and lastly, until recently in its history, AIDS was a terminal wasting disease.

AIDS was constructed in a way that the disease and those infected with it became associated with marginalised behaviours i.e. homosexuality and drug use. Moreover, the name of the disease, characteristics and the transmission of it, merges ideas about the illness and those who are likely to suffer from it. Stolley and Glass (2009: 65) explain this as follows:

"A name of diagnosis is crucial. It provides a label, an identity, an organising principle for further discussion. Usually, a disease concept is born with its first name, although the associated illness may have been recognized long before. Having been named, a disease takes on a distinct life of its own, separate from other diseases"

Herewith, the name then influences the way individuals perceive the disease and those infected with it.

3.6 Conclusion

The chapter has demonstrated the link between symbolic interactionism, labelling theory, and social constructionism with an emphasis on the way in which an individual's illness experiences are directly affected by social interaction, meaning making and labelling. It is clear from the above that personal narratives have social origins, consequently, these are not given or established by nature – all three perspectives show the relativity of HIV/AIDS narratives.

Crooks (2010: 13) maintains that illness experience "represents the personal and socially constructed meanings surrounding a disease, even or sequence of events", emphasizing that illness goes beyond the disease, instead it "represents the personal, cultural and interpersonal interpretations of the disease including reactions to disease, changes in state of being and impact on social functioning". This explanation, in line with the study, incorporates the treatment of the disease because the treatment is as important as the disease, especially because ARVs are a lifetime commitment.

Chapter 4: Research Designs

4.1 Introduction

Given that symbolic interactionism and social constructionism were the fundamental theoretical frameworks of the study, the study drew primarily on qualitative research methods, as the research aimed to uncover not just the procedures, strategies and measures adopted by social actors, but also the understanding and perception (in general the experience) of those involved in the research process to “penetrate the frames of meaning with which they operate” (Bryman, 1988: 61). This approach allowed the researcher to obtain subjective interpretations of the world and personal narratives (Johnson & Onwuegbuzie, 2004: 18). In line with Skhosana *et al*, (2006: 18) the study emphasizes that every day lived experiences of participants are informed by the recognition that being HIV-positive is not just “a single crisis moment but a complex ongoing process” therefore, people’s ways of dealing with their chronic disease(s) involves manoeuvres, negotiations, adaptation and growth.

The research is predominantly reliant on the participants’ perceptions and voices and has therefore used in-depth interviews. Banister, Burman and Parker (2011: 9) maintain that even though a degree of systematisation may be necessary at times, the participant's perspective should unfold as the participant views it. Hence, the interviews were semi-standardized –which made room for open-ended and follow-up questions when necessary.

The study used purposive sampling aimed directly at PLWHA who have publicly, through Facebook via the Good Stories page, shared their HIV-positive status and have offered insight into their lived experiences. Incorporating all variables was beyond the scope of the study. It is not the purpose of the study to generalise findings as purposive sampling does not produce a “sample that represents a broader population” (Engel & Schutt, 2009: 96); thus, it sufficed to look at a sample of eight black female participants ranging from 21- 65 years of age.

4.2 Qualitative research

Qualitative researchers study phenomena in their natural or social settings, attempting to make sense of or to interpret them in terms of the meanings people bring to them (Marshall & Rossman, 1999: 106). Qualitative research is a multimethod and multifaceted field of inquiry that incorporates different orientations and methodologies, which enable the researcher to conduct in-depth studies about broad arrays of topics and consequentially obtain an understanding of underlying reasons, opinions, and motivations (Yin, 2011: 1). Researchers

following this strategy study things in their social settings to gain an understanding of the meanings attached to them as well as to make sense of personal narratives. Yin (2011: 7) identifies five crucial features of qualitative research. The first is that the researcher is studying the meaning of people's lives under real-world conditions. Secondly, the researcher's role includes representing the views and perspectives of participants in a study. Thirdly, qualitative research covers the contextual conditions of people's lives. Fourthly, the researcher contributes to the "existing or emerging concepts that may help to explain human social behaviour" (Thomas, 2011: 7). Lastly, qualitative research does not rely on one source as evidence, hence the use of multiple sources.

As a strategy, qualitative research is largely inductivist, constructionist and interpretivist even though researchers do not always subscribe to all three features (Bryman, 2012: 380). Moreover, according to Thomas (2003: 6), the interpretivist paradigm is the most subscribed to because it portrays a world in which reality is socially constructed, complex and ever changing. The strategy is well known for its emphasis on words rather than quantification in the collection and analysis of data. Thomas (2003: 2) adds that the qualitative researcher describes kinds of characteristics of people and events without having to compare them in terms of measurements or amounts.

4.3 Qualitative research and Symbolic Interactionism

Symbolic interactionism has been traditionally viewed as one of the perspectives underpinning qualitative research (Benzies & Allen, 2000: 541). While the framework is well-known for qualitative inquiry, the assumptions guiding it are compatible with quantitative methods. Drawing from evolutionism, symbolic interactionists maintain that social life is a process of interaction between the social and the natural environment on the one hand and on the other hand, it is a process of interaction between human beings who occupy these spaces (Reynolds & Herman-Kinney, 2003: 40). Moreover, human beings behave in ways that adapt to these environments and the individuals mutually influence one another. (Reynolds & Herman-Kinney, 2003: 40; Reynolds & Herman, 1994: 1). Through social interaction, human beings are constantly changing and so is the society within which they find themselves.

Symbolic interactionism proved to be a suitable approach for the study because of the basic assumptions which guide it (Denzin, 1992: 203; Reynolds & Herman, 1994: 1). Firstly, humans live in a symbolic world of learned meanings. Secondly, through social processes and social interaction, symbols develop and are shared. Thirdly, the symbols that arise have motivational

significance whereby ‘meanings and symbols allow individuals to carry out distinctively human action and interaction’ (Reynolds & Herman, 1994: 1). The fourth assumption is that the mind is a “functional, volitional, teleological entity” which operates in the interest of the individual, therefore, unlike other species, human beings have the ability to think and the capacity of this is moulded by social interaction. The fifth assumption follows that the self is a social construct; social interaction aids in creating the self. Lastly, Reynolds and Herman (1994: 1) add that social processes and social interaction create a symbolic society within which individuals interact.

According to Benzies and Allen (2000: 544), symbolic interactionism provides a theoretical perspective for how individuals interpret people and the objects they encounter. The framework also provides an understanding of how this process of interpretation affects behaviour, therefore, researchers using this framework have an increased chance of understanding human behaviour (Blumer, 1986: 4). Reynolds and Herman (1994: 2) assert that understanding human behaviour requires the researcher to learn the participants’ meanings, as the framework emphasises that humans act towards things on the basis of their symbolic meanings. Moreover, ‘sympathetic interaction’ or ‘verstehen’ is required to get a deeper understanding of the participants’ lived experiences and symbolic worlds. ‘Sympathetic interaction/introspection’ or ‘verstehen’ promotes the notion of thoroughly investigating meanings and definitions held by people and not just relying on observations of external behaviour (Benzies & Allen, 2000: 543). Following this viewpoint allows the researcher to use various qualitative research methods to produce theories that are grounded in empirical data, methods include life histories, autobiographies, interviews, focus groups etc.

Within this framework, the main focus of the research entails seeking an understanding of the meanings of a situation from the perspective of the individual and societal groups. Consequently, it is imperative to gain an understanding of what individuals know about their world and what they deem important (Benzies & Allen, 2000: 545). Qualitative methodology, in its broadest sense, refers to research that produces descriptive data – “people's own spoken word and observable behaviour” (Taylor, Bodgan, & DeVault, 2016: 7). Qualitative research, particularly interviews, draws to symbolic interactionism on the grounds that both the methodology and the theoretical framework emphasize the point of view of the interviewee (Bryman, 2012: 470). Both the interactionist and the qualitative researcher are concerned with the meanings which people attach to things in their lives. Lune and Berg (2017: 12) explain that qualitative methods are most useful when the researcher is seeking to gain a deeper

understanding of the “exceptions and special cases” or when the researcher wants to understand the meanings and preferences underlying larger patterns.

Shaw (2003: 59) points out that understanding human behaviour within the qualitative paradigm is not just about identifying cause and effect rather it extends to exploring experiences in chronologies. This approach captures fully, the aim of this study – exploring the effects of antiretroviral treatment on patients’ illness experiences, looking at the personal and social.

4.5 Qualitative research and Social Constructionism

According to Blanche, Durrheim and Painter (1999: 278), social constructionists, like their interpretive counterparts, focus on the qualitative as well as interpretive aspect of research. These researchers are concerned mainly with meaning making process and how individuals’ understandings and experiences come about, and how they then feed into larger discourse (Blanche *et al*, 1999: 278). Social constructionists are led by the idea that humans create their own reality through social interactions, relationships as well as experiences (Leavy, 2014: 85), hence the use of qualitative methods to study things (humans) in their social settings to gain an understanding of the meanings attached to them as well as make sense of personal narratives (Thomas, 2003: 6).

Leavy (2014: 85) explains that from an ontological perspective, reality is contextual and socially relative consequently allowing many interpretations of realities to exist concurrently. Considering that reality is constructed, knowledge and meanings are rooted in social interactions. To further this notion, Leavy asserts, “the epistemological notion of reality and meanings are not individual in nature but instead are constantly ‘negotiating meaning’” (Leavy, 2014: 85). Because of the above mentioned, the researcher’s role was to analyse these interactions in a social context more than the individual context as the main thing highlighted in social constructionism is the social creation of identity (Leavy, 2014: 85).

Roller and Lavrakas (2015) do not view social constructionism as one theory or approach, rather they view it as a creative resource that allows for a new and expanded way of thinking and talking about concepts. The authors claim that qualitative research from a constructionist perspective possibly creates new methods of inquiry that emphasises the relationship between the participant and researcher in narrative research (Roller & Lavrakas, 2015). Both qualitative research and social constructionism value the complexities of human experiences and the idea

that “any one facet of someone’s life (and the researcher’s role in exploring this life) intertwines with (contributes to) some other facet” (Roller & Lavrakas, 2015).

From an epistemological perspective, constructionism assumes that the only way to understand the social world is through accounting for meaning and this can be achieved through the use of qualitative methodology. A qualitative, interpretive researcher then makes use of interviews, although in a more open-ended and in-depth manner with the intention of understanding people’s experiences and the meaning attached to these experiences (Thomas, 2003: 84).

4.6 Data Collection

4.6.1. Choice of participants

As mentioned above, the study used purposive sampling aimed directly at PLWHA who have publicly, through the *Good Stories* Facebook page, shared their HIV-positive status and have offered insight into their lived experiences. The researcher was granted access to *the Good Stories* Organisation, which founded the Facebook page. The researcher worked hand in hand with the Organisation, as gatekeepers, to gain access to members of the Organisation/Facebook page who have a strong online presence about their HIV-positive status.

The researcher communicated with the Organisation to obtain a cross-section of participants. The Organisation was given a criterion to guide the selection of participants. The criteria were as follows:

- participants have to be living with HIV/AIDS;
- participants have to be between 21-40 years of age;
- participants should have shared their stories on the Good Stories Facebook page;
- participants should be South African citizens;
- participants should reside in or around Johannesburg.

While the researcher initially hoped to interview both male and female participants, all the respondents who were interested in taking part in the research were female and ranged from 21-65 years of age. This new dynamic to the participants involved particularly added to the study because one participant (who was 65 years old at the time of the interview) was diagnosed in 1993 when ARVs were not accessible to all PLWHA. Therefore, her narrative adds value to the study because it offers a perspective into the before and after accessibility of ART in SA and how that affected her illness experiences.

4.6.2 The interview method

The study employed qualitative interviewing. Taylor *et al.* (2016: 102) describe qualitative interviewing as “nondirective, unstructured, nonstandardized and open-ended”. This form of interviewing is commonly known as in-depth interviewing. Here, the researcher and participant encounter one another on a face-to-face level. For the purpose of this study, semi-structured/semi standardised interviews were employed. This method involved the employment of some predetermined questions and special topics (Lune & Berg, 2017: 59). The following are the features of a semi-standardized interview (Lune & Berg, 2017: 68; Bryman, 2012: 470): questions asked are more or less structured and may be reordered during the interview; wording of questions is flexible; level of language may be adjusted, and interviewer may answer questions and make clarifications.

The researcher conducted a pilot study with three respondents living with HIV/AIDS to test whether the questions are in line with the specific research aims and to also see if they are not triggering. The results of the pilot interviews were positive and feedback from them was incorporated into the final research questions.

4.6.3 Interview setting

The in-depth interviews each took place at a location chosen by the participant – a safe space for participants therefore suitable for the nature of the research. Before each individual interview the researcher had an opportunity to attend a *Good Stories* session whereby all participants and other members of the Organisation were present. Attending this session gave the researcher an opportunity to create rapport with the gatekeepers as well as research participants. Moreover, the familiarity made setting up of interview times much easier for both the researcher and participants.

4.6.4. Interview questions

As per semi standardized study, the questions were predetermined, yet, flexible and open-ended, see Appendix B. The gatekeepers were given the questions prior to the interviews to guide them in sampling the participants and partially preparing them for the encounter. The researcher also explained the research procedure to both the gatekeepers and individual participants to avoid discrepancies and emphasize the reciprocal nature of the interview process.

4.6.5 Role of researcher

While the researcher is expected to build rapport, Taylor *et al.* (2016: 8) stress that the researcher must distance her/himself from the participants such that her/his own perspective and their taken-for-granted views of the world do not hinder the process. The researcher had a moral obligation and ethical responsibility to be sensitive to participants' lived experiences and circumstances, this will be elaborated in the ethics section below. The interview structure allowed for the process to follow an everyday conversation style, therefore, the researcher took the role of leading this conversation.

4.7 Ethics

Flick (2014: 23) proposes a very good way of looking at ethics for researchers: "consider how it would be for you to do what you expect participants to do in your research". Researchers are expected to respect participants (as they would themselves) throughout the research project and one way of doing so is through using agreed standards of which participants are aware and to which they agree (Alderson & Morrow, 2011: 3). The research was, first and foremost, reviewed and approved by the Sociology Department Research Ethics Committee in terms of the requirements of the Humanities Higher Degree Committee (HHDC) and the protocols in the Rhodes University Ethical Standards Committee Handbook (RUESCH). In conducting this research, the participants and gatekeepers were presented with a consent form which stipulates the terms and conditions of taking part in the research project (see Appendix A).

The researcher acknowledged the ethical obligation to research participants: to protect their identities (maintaining anonymity and confidentiality) and ensuring that there is informed consent from each individual. The informed consent from participants did not put pressure on the individual(s). The participant is important to the research and for that reason, the individual's autonomy was respected, and all steps were taken to avoid causing harm. The research was conducted in such a way as to make the participants feel comfortable and create rapport that enabled the researcher, if necessary, to work with the participants in future (Creswell, Hanson, Clark Plano, & Alejandro, 2007). Additionally, to bridge the gap of the objectification of women respondents in health research; the researcher ensured that participants were given an opportunity to, should they wish, receive reports on the findings of the research to which they were contributing and moreover, participants were invited to comment on the study. This notion was inspired by Roberts' (2008: 101) concern about the absence of women respondents from many finished research projects which alludes to the

subjectification of women. Consequently, both the participants and gatekeepers were interested in being more involved in the research process, beyond the interview process.

Alderson and Morrow (2011: 3) explain that there are two types of researchers - the 'insider' and the 'outsider' – and each of these have their advantages and disadvantages concerning the ethical aspects of the research. For this research project, the researcher was an 'insider' at the social media level because of membership in the *Good Stories* Facebook page. One of the main advantages of the 'insider' researcher is that s/he is familiar with the setting and the “general background of the specific topic” (Alderson & Morrow, 2011: 3) and therefore has ample prior insider knowledge that can assist the research. Access to participants is generally easier for an 'insider' than it is for an 'outsider', however, this project reached participants through gatekeepers who are an additional benefit to the study because there is already trust, rapport and good working relations with participants as the gatekeepers are the founders of the Facebook page and the Organisation.

While the researcher was familiar with the *Good Stories* Facebook context and its participants (at a broad level) the researcher was still largely liable for ensuring that the identity and records of individuals are maintained as confidential. Bryman (2012: 136) furthers this by adding that the researcher still needs to be careful in the publishing of the research - that individuals' identities are not identified or identifiable. The research had minimal risk of triggering as the participants were not required to retell their stories of diagnosis, rather the research was focused on the treatment aspect. Moreover, this is a topic which the participants have openly and strongly disclosed on social media and other platforms. Regarding privacy, the researcher was aware that while participants might sign the consent form they may “refuse to answer certain questions on whatever grounds they feel are justified” (Bryman, 2012: 142).

Essentially, the research is mindful of moral behaviour in the research context and respects every individual's perceptions and opinions without viewing some as more valued than others.

4.8 Conclusion

In conclusion, the above chapter outlined the goals of the research and showed why and how a qualitative research design was best suited to meet this study's objectives, bringing into account what research paradigm has been used and how it interlinks with the symbolic interactionism and social constructionism theoretical framework. Thereafter, the researcher focused on the data collection process highlighting the choice of participants, what research methods were employed, namely: in-depth, semi-structured interviews, the interview setting, interview

questions and the role of the researcher. Finally, the chapter paid particular attention to the ethical guidelines that needed to be adhered to when the interview process was conducted.

Chapter 5: Data Processing and Analysis

5.1 Introduction

After conducting the interviews with the eight participants, it became evident that the knowledge participants had of ARVs before consuming them was misguided and based more on false 'general knowledge' among laypersons than actual medical fact. Moreover, the interviews revealed that there is a social reconstruction of narratives that has taken place in each participant's life due to consuming ARVs. Publicly disclosing their statuses has also proved to have both negative and positive consequences for the individuals and for society at large. While there is a consensus that participants' illness experiences are directly affected by antiretroviral treatment, each participant's narrative is different.

As a means of analyzing these narratives, in line with the theoretical framework of symbolic interactionism including aspects of social constructionism, this section will be divided into two main sections. The first section will focus on the early stages of diagnosis highlighting 1) Views on ARVs before diagnosis 2) The immediate journey after diagnosis and 3) Disclosure. The second section will look into the management of the illness and how individuals have adjusted to living with HIV/AIDS. The section will focus on 1) Management of therapy 2) Adherence to therapy 3) Stigma and 4) Reconstruction of personal narratives.

5.2 Early stages of diagnosis

This section is set out to discuss the journey participants embarked on soon after diagnosis; incorporating the participant's views on ARVs before diagnosis so as to prove that following the diagnosis, participants' perceptions changed. Moreover, the participants were given a platform to discuss the journey after diagnosis in terms of the logistics of accessing treatment, consuming treatment, side effects etc. Lastly, this section considers the process of disclosure.

5.2.1 Views on ARVs before diagnosis

The data ascertained that, prior to getting tested and finding out that they were to consume antiretrovirals for the rest of their lives, most respondents were aware of the therapy and that it is consumed by PLWHA. However, the respondents were either misinformed or had very limited, if any, knowledge about the underlying factors of antiretroviral therapy. One respondent (Martha²) clearly admitted:

“Before [diagnosis] 2005, I didn’t even have time to concentrate on such. It didn’t even cross my mind. Yes, I knew there was HIV, there was AIDS, but I didn’t know anything about ARVs.”

Inga acknowledges knowing about ARVs but identifies the gaps in what she knew at the time:

“I was aware of them [ARVs] but wasn’t as educated about them as I am now. The information I had about them was from pamphlets at clinics, newspaper articles, or school – nothing much. For me, they were treatment taken by HIV positive people on a daily basis and that’s about it.”

Similarly, Precious noted:

“I was aware of ARVs and look, I suppose to an extent it was just really the basic knowledge that ARVs are there for PLWHA and they’re just there to make sure that PLWHA are living a healthy and long life and that’s just about it. I didn’t do any research in terms of ARVs but I knew about ARVs just not as much as I know now because I am affected and infected.”

For some participants, ARVs were familiar because of people around them who had been consuming the medication. Aviwe shared:

“I was aware of them because I have a friend who had been taking them for years, and we lived together...”

Lynette was educated about ARVs through personal experiences and the media:

“I’ve come across too many people living with the virus. These days, even on TV you see people sharing their statuses and you see that people live with treatment.”

² All respondents’ identities are disguised using pseudonyms.

While most participants had a positive outlook on ARVs, some had counter views. Sharon shared her fears:

“So before getting diagnosed I used to think that ARVs were just those pills that are supposed to make PLWHA feel better but at the same time they make them sick, you know, and then you die. So I used to be so scared of them in a way.”

The fear among the participants was mostly drawn from the information that they had been exposed to. This will be explored in depth in section 5.2.1 where participants' experiences after diagnosis are discussed in more detail. Nettleton (2013, p. 65) explains how in Western industrialised societies chronic conditions have increasingly become common such that most people will know at least one person who suffers from some kind of chronic illness and will be “aware that the implications of such conditions extend well beyond biophysical changes” (Nettleton, 2013b, p. 65). The interviews revealed that all respondents, prior to their own diagnosis were aware of ARVs and had known at least one person who consumed them.

The lack of understanding about HIV transmission, the course of illness and potential for treatment among participants' families and communities, is a contributing factor to the stigma experienced by PLWHA. Interventions such as campaigns, movements and media need to be more active in educating people not only about HIV/AIDS but also about ART programs and their successes and failures. Additionally, more positive stories of PLWHA need to be shared so that laypersons see that with ARVs, HIV/AIDS can be a manageable chronic condition.

5.2.2 The immediate journey after diagnosis

As has been repeatedly emphasized in the previous chapters, a new diagnosis presents new challenges for the individual. Petrie *et al.* (2007, p. 46) explain that when individuals are at the stage of diagnosis they are faced with the reality that their state of health and function of their body has changed and are likely to remain impaired. Moreover, the diagnosis of a chronic illness brings with it complex issues such as emotional difficulties and changes in lifestyle. One of the consistent issues highlighted in every interview is the way in which individuals were told about their diagnosis and the treatment for it - healthcare workers and people who have been living with HIV/AIDS for much longer created fear around the side effects associated with consuming ARVs. Respondents showed concern about starting treatment.

Aviwe simply confessed:

"At the clinic, they scare you. They tell you all sorts of things. The one nurse told me that I would have crazy-like symptoms and feel crazy, imagine... The nurses scared me on that day they gave me treatment telling me I'll see things, go crazy, so I wasn't sure what the use of taking these pills is if they are going to make me crazy when I've been all right all along. But I kept thinking about my CD4 count, meaning if I didn't take them I would die which was even more scary."

For Precious, the fear was not instigated by healthcare workers, but by those who had been on treatment for longer:

"I was worried. I was anxious. I got depressed. My main concern was the fact that I would have to marry the pill, you know, my whole life! Plus, the side effects, because I wasn't sure like I told you – I did know about ARVs, but I didn't really read about them in depth so that's when I actually started reading about them. I spoke to people and these are people who were diagnosed a long time ago when side effects were really bad they were getting swollen feet and swollen glands etc. ... so I was really, really anxious and chose not to take treatment immediately."

Likewise, Martha did not want to start taking treatment immediately because of the narratives and views around ARVs, she shared:

"I had information about ARVs, but I didn't want to take them. I think it's because of the things that I had heard, people saying that your body will change, you will look this kind of way, you'll have certain kinds of things growing on you, you know. So, I was like, God, please help me to be strong, I don't want to get to the point where I have to take ARVs."

Sharon also had similar feelings:

"I didn't think that they [ARVs] healed people because I felt like if they are supposed to make people feel better you know, then why are there like side effects, why are there things like you going to get sick. Like, why must they make you sick first for you to get better? I used to feel like they were just there to make people who are living with HIV just feel so ashamed of living with the virus."

The complexity of a chronic disease like HIV/AIDS is that the patient is prone to opportunistic infections as well. In Chapter 2, I explored how the HIV destroys the body's defence

mechanism which creates easy access for other infections which thrive in the environment and to which their comprised immune system allows them to fall prey (Barnett & Blaikie, 1992: 2; Maartens, 2010). Lynette was the only participant at diagnosis stage who was concerned about this:

“After testing I was a bit stressed but not only about the HIV. I was more concerned about HIV related infections, my kidneys, TB, STIs and so forth... I was thinking what if on top of being HIV positive I find out that I have another thing to worry about for example TB or liver issues...”

The fear compelled Inga to want to start the treatment:

“...the main thing I wanted was to start taking treatment as soon as possible. I wanted to get on with it so that I could get used to the change and also to kill the virus as soon as possible. I somehow had thoughts that I would die if I didn't get it as soon as possible. Luckily for the test and treat method, I got on treatment about a week after testing.”

According to Martz and Livneh (2007, p. xvii), persons living with a chronic disease develop coping mechanisms from as early as diagnosis stage. Coping can take many forms – for some, it is growth-oriented where the focus is on problem-solving and thinking positively about the possibilities available in the future. For others, the coping mechanisms are negatively weighted whereby individuals avoid certain situations and catastrophize (Martz & Livneh, 2007, p. xvii). There is no one way of coping or a linear process that individuals go through – each individual responds to their diagnosis and the repercussion of it based on many factors. One of the important factors is the knowledge the individuals have about their diagnosis, which has been explored above. Another factor related to knowledge, which will be discussed shortly, is where the information is coming from. I have demonstrated how fear was created among participants by healthcare workers and other PLWHA about the diagnosis and its treatment.

In the next section, I will consider the different sources of information that participants consulted. When asked who gave them professional medical information about ARVs there was a range of responses. Sharon consulted the internet for answers before consulting with a professional, she admits:

“Well, I consulted at Dr Google, you know [laughs]. Google [clears throat] gave me information: told me that my hair was going to fall off, I was going to get a hunchback, I was going to lose my teeth, lose my mind. And I'm like, but I'm 18 [at the time of

diagnosis] guys, at least wait for me to [get these side effects] when I'm at least 20, 22 or 30. But now I find out that I'm going to lose my teeth, and I'm going to do this and that. It just felt like now these pills were just going to come in and take everything because you're going to lose your money, lose your hair, you going to lose. I was just going to lose. So, I saw them as more of a lose than a win."

When she finally managed to act on her diagnosis Sharon consulted a clinic and she recalls:

"It is protocol that before you take pills you go for counselling right – for pre-med counselling, right. So, I got in there and was so 'informed'. I told her [the counsellor] everything, I was like Google said this, Google said that and then she [the counsellor] was like, listen you're not going to get sick. But because I'm also a very stubborn person and I got there with this information and I'm like no you're lying to me. I can actually read you know, I have a smartphone and I'm in school you know. Eventually, what she said to me was that because it seems like you've already made up your mind, I'm just asking you to just give them [the ARVs] a chance, that's what she said. And that is pretty much what I did, I was like okay I'm giving them a month, if something weird happens in this one month [makes a face] I'm never going back."

Precious also consulted the internet first:

I Googled. Actually, I remember a friend calling me as well because I was so nervous about starting treatment and he told me about the fatigue... The doctor just told me that I need this [ARVs]. I also got information from some of my friends who'd had the virus for a while. Other than that I Googled."

For Martha, who had decided that she was not going to take treatment until she really needed to, the information was obtained from a different source:

"I always went to the clinic to ask questions and then in 2009 [five years after diagnosis], I did a course at the University of Pretoria – Multisexual HIV/AIDS – and with all the information there I just studied and wanted to know what is it that I'm dealing with exactly and how is it going to affect my life you know. So, from there, after doing that course I was very much clued up about ARVs. But I still didn't want to take treatment you know, yeah I still didn't want to. I somehow felt like I could live more than 20 years without taking treatment, that's how I felt. Until 2015 [ten years after diagnosis] ...

So, I just went for my regular check-up, I did the CD4 count and when the results came back my CD4 count was 370 and you know that we start [therapy] at 500 or less and because they had just changed that you need to start at 500 or less so according to them it was low, and I had to start the treatment. I felt like okay if it's something that's going to help boost my CD4 count then I'm going to do it and I was also planning to have a baby so uhm I felt like okay, I don't want to start at a point where I'm planning to have a baby like next year, so let me rather start early you know..."

Inga had a different experience from the participants above but similar to most participants who accessed treatment from a public facility. She stated:

"Well, I didn't get much professional medical information except that HIV was like any other chronic illness and that it was not deadly anymore. The nurse told me that I should see my status as any other chronic illness that requires daily treatment. She then told me to take the pill in the evening after a meal, at the same time every day, because it would make me dizzy. She advised me to set an alarm to remind me. She also warned that I would have weird dreams and would get fatigue in the first few weeks, but this would pass. That's about it. Everything else that I know about the medication I found out on my own through research and asking people who I know live with HIV."

It is clear from the above that the participants actively engaged with their diagnosis – all the participants indicated that they returned to the testing centre for a second appointment where they obtained information, some went to these appointments already informed by friends, relatives and the internet. Due to the different times at which the participants were diagnosed, some (Martha, Precious, Liz and Sharon) did not have to start treatment immediately, others (Lynnette, Imba and Aviwe) had to start immediately due to the Universal Test and Treat (UTT) policy which stipulates that all HIV positive children, adolescents and adults regardless of CD4 count must be offered ART treatment, prioritizing those with $CD4 \leq 350$ (Department of Health, 2016). However, for Charity, who started therapy in 2009, the treatment was not accessible to the public, yet, in 1993 when she was diagnosed therefore she relied on immune boosters until 2009:

"At the time [1993] we didn't get ARVs, only immune boosters so they didn't tell me anything about ARVs. I only started ARVS in 2009, even then, the nurse just gave me instructions about when to take the pills. I used to take 4 pills at night, 4 in the morning

– so I started with 8 tablets. Then it went down to 3 tablets in the same year... I also had to go for counselling. In 2009 I started one pill, the ARV at night.”

Bartlett and Finkbeiner (2006: 67) assert that HIV/AIDS treatment is certainly the most important development in a widespread, serious disease in the last 30 years. The first ARV drug was approved in the USA in 1983 and South Africa only began the programme to give out free HIV/AIDS drugs in 2004 (SA History, 2011).

Knowledge about ART has proved to be an important aspect of the illness experiences of PLWHA and consuming ARVs. After diagnosis, participants needed information about their disease to get a better understanding of what they were facing and for meaning-making purposes. This relates to the symbolic interactionist view that meaning is an essential part of the formation of behaviour (Blumer, 1969, p. 4). Treatment education is critical because unlike other medication, ART involves a number of psychosocial factors. Vijaykumar (2007, p. 1249) explains that treatment education is important in preparing individuals for treatment and the education must incorporate communities, and PLWHA so that they can understand the full range of issues linked with treatment. Moreover, Vijaykumar highlights that there is a direct relationship between treatment education and adherence because individuals have to understand that 95% adherence is required for the treatment to be fully effective. It was clear that participants needed treatment education based on the views they had about ARVs prior to diagnosis and after diagnosis, the education (whether by health workers or by themselves) helped the participants unlearn their previously misguided notions.

During the interviews it was highlighted that those who tested and had a follow-up appointment in a public facility were provided with less adequate information than those who had been to private facilities, especially when it comes to the treatment that they would start. When asked if they went through special tests to find out what medication or regimen would be most suitable, six of the eight participants said they were not sure if the blood tests they did would determine the treatment they took. Therefore, it is clear that they were not given the information necessary. Imba explained:

“The next day after testing I did blood tests to test for STDs/STIs, pap smear, TB, or any other illnesses I may have, luckily those tests were clean, and I didn’t have anything else. They also made me fill out a form that basically asked about my symptoms to find out what stage I was at. I don’t know if that’s all that’s needed to decide what regimen to put me on but that’s all I did. Oh, they also did weight, height, and all that because

apparently, the medication would affect my weight. But I didn't know the difference between the different regimens at the time.”

Contrary to the above consensus among those who accessed public facilities, those who accessed information and treatment from the private sector went through an extensive process of being educated about their treatment following blood tests which were explained to them, stipulating which regimen would be most suitable for them. Precious remembered:

“My doctor did run tests and then I think he recommended Atripla but now my medical aid wouldn't pay for that and only allowed me to go for something generic, so I took Trivenz and I haven't changed since.”

Lynette went through a similar experience:

“The private doctor did tests for my viral load, CD4 count, liver, TB, STIs, and also checked which treatment worked for me because there are different variations of the ARVs.”

The minimal information provided by the health workers in the public facilities emphasize Vijaykumar's claim that it is not only PLWHA who must be educated about treatment, rather there must be a holistic approach to education. "It is equally critical for physicians and staff at government facilities that act as a point of contact between PLWHA and the health system to be educated on all aspects of administering treatment" (Vijaykumar, 2007, p. 1250). Furthermore, the wider community also must be educated about treatment to create an inclusive space. The reasons for the lack of information are not the focus of this study so will not be looked into further here.

5.2.3 Disclosure

Even though the study used purposive sampling aimed directly at PLWHA who have publicly, through Facebook, disclosed their HIV-positive status and have offered insight into their lived experiences, the participants went through a process before reaching a stage where they were comfortable to disclose on a public forum. Gillett and Parr (2011, p. 337) note that disclosure by PLWHA is critical for prevention and care, however, many choose not to disclose for different reasons including "fear of negative outcomes, such as blame and rejection". Nevertheless, PLWHA do have the motivation to disclose and the reasons for this include feeling a sense of duty to others, responsibility to the wider community as well as to encourage

and support treatment adherence (Gillett and Parr 2011: 339). The respondents expressed that disclosing was a process and that they did not publicly disclose until they were ready to do so.

Charity recalled how it wasn't her own fear that made it difficult to disclose but that of those close to her:

“I took a while [to disclose] ... they [family] only found out I was HIV positive when one day I got really sick and on that day I was trying to sleep but my son and my younger brother were outside making a lot of noise so I yelled ‘you’re disturbing me I’m trying to sleep’ and my brother said something back and I said ‘because I have AIDS’. I realized I shocked them, so I said I’m joking. The reason I said that is because I saw the fear in their eyes. A few weeks later I called my son and asked him what if someone in the family is HIV positive, what are you going to do? He told me he would not live with them or even stand next to them. When I asked why he told me he doesn’t want to get infected. So, he believed that it was contagious... They wouldn’t use the same spoon, cups as me. They thought I would infect them. As time went on they got used to it because there was nothing they could do. They started supporting me and they still do...”

Inga, like Charity, was also worried about the reactions from those close to her. She used a social media platform to disclose from the beginning:

“I literally took a picture [of the ARVs] and sent it on WhatsApp to my friends and told them I’d started treatment and asked them to please remind me if I forget but I’d set an alarm. With my family, I just told my mom and she told everyone else. It wasn’t easy, but it was necessary. From then on, it became easier. I feel bad for people hearing the news more than I feel for myself coz you can see how helpless they feel, and they worry.”

Martha had a similar encounter:

“I came back [from the clinic] and just told them [family] that I'm going to start taking treatment and I think they were more scared than me you know because they thought I'm going to be more sick because of all the things that people say.”

Sharon recalled how the process of disclosure unfolded:

“So what happened is that because I had struggled during the first six months [of diagnosis] once I got to open up, I told my teacher – she’s the first person I told and then I told my aunt and then it gradually went on to my sister, big brother, you know, but then it was just family at the time and for the next 4 years because I was not on treatment from 14 until 18 we never spoke about it and I usually feel like maybe they just, they were just scared of being insensitive if they brought up the topic so it was like we knew that yah, it’s happening but no one spoke about it. I knew that eventually now I’m going to need to start disclosing to like my friends because now they’re going to be seeing me popping these pills every day for the rest of my life so I had no other choice but to start disclosing. Then I started telling my friends, but because I was afraid of questions like why didn’t you say anything earlier on, I just lied and said I found out at 18. I did that, I was like, no I recently just found out and it was so easy for them to like to believe me because I was literally going through the most, so it was easy to believe at the time. From there, it was easy to tell anybody and everybody.”

For Precious, the side effects were a hindering factor to starting her treatment but those close to her were positive about her journey:

“By the time I started treatment [10 months after diagnosis], I had already disclosed that I had HIV so starting treatment was like yay, I’m going on treatment and everyone was like yay! Seriously, I disclosed my status within 3 months, in fact, the first person I called was my friend. By the time I started treatment the whole world knew it was just a matter of yay, best decision. Everyone but me was happy because I was really concerned about the side effects.”

Even though the respondents had concerns about disclosing that they were taking ARVs there were also positive responses to their disclosure. These responses will be discussed in more detail later in section 5.3.3 when I discuss disclosing on social media.

5.3 Management of the disease

Hegemonic narratives of HIV/AIDS were altered in the late 1990s with the development of ARVs, transforming it from a fatal disease into a chronic illness (Makoae, *et al.*, 2009: 1357), thus it is manageable and many PLWHA do live many years with their condition. Living with a chronic illness includes dealing with its ongoing demands, such as treatment, medical checkups, solid nutrition, living a balanced healthy life etc. Petrie & Reynolds (2007: 46)

describe that patients living with chronic diseases need to cope with the requirements of the medical treatment and the symptoms of their condition which mean "learning new techniques for managing symptoms or administering therapy and coping with daily life disruption from both symptoms and treatment" (Petrie & Reynolds, 2007: 46)

5.3.1 Management of therapy

While the management of therapy is a personal journey, it should also be noted that there are factors beyond one's control that affect the way in which one manages one's therapy. For example, healthcare infrastructure, hospitals and service centres equipment, along with delivery systems, are huge factors affecting HIV prevention, treatment, care and support (Auerbach & Mulhern-Pearson, 2008: 176).

This section will discuss how respondents have managed their therapy with a focus on the affordability, regularity and availability of ARVs. As mentioned above, the respondents access their treatment through either public or private facilities. Some started with the one and changed to the other while others have been consistent in the facilities of their choice. Charity and Lynette were tested and accessed their treatment at private facilities and then later shifted to public facilities. Lynette explained

"I moved from private to public due to cost, firstly as the pills were very expensive but also because I realised that I am not hiding or ashamed. I feel like going to the clinic shows others that they are not the only ones who are sick, in fact, we are not sick, we are living with a virus and by taking treatment we are preventing the stage of getting sick... it has been really efficient, after 6 months of moving I did the bi-annual tests again and found that I am undetectable."

For Liz, it was a matter of convenience and accessibility:

"I'm using a public facility, it's the closest facility. I also don't know any other place and because this is the first place I used I just stuck to it."

Martha had been using a private facility prior to her diagnosis but changed to a public facility due to a misdiagnosis. She disclosed:

"From day one when I found out about my status I've always used the clinic coz when I got sick – I had TB right – and I went to the private doctors and they couldn't even

see that I had TB only when I went to a public facility that's where they found out that I had TB and it had already been after a month or two. I had been changing private doctors and only when I got to the clinic they found out and told me that I have TB and once I was being treated for TB they advised me to test for HIV and that's how I found out about my HIV-status. So ever since then, I never went to a private doctor I just continued doing everything at the public facility until now. And it's the same one since."

Imba and Precious both use private facilities and share sentiment on this. Imba stated:

"I'm using a private facility. I felt like it was the safer option given my age and how young people are discriminated against for just about anything, even contraceptive pills, now imagine HIV. So I didn't want the stress of having to deal with bitter nurses, long queues, or coming across anyone I know. But that was when I first found out, now I'm just using it because I'm comfortable there. I've gotten used to it I can say. But its expensive and soon I'll be moving to a public facility because I am not on medical aid and I'm unemployed."

Precious related:

"I use a private doctor and I get my pills at Dischem. I prefer that. I know that my medical aid can deliver to my house but I like the guys at the store. Well.. you know what, I am not a patient person and we've got a long way to go in the clinics. If it wasn't that hard I would go get it for free, but now sitting in a queue for the whole day at the clinic just to get my next dose of ARVs when I can get it in two seconds at the mall. That's exactly why I'm taking it via my medical aid."

Respondents using public facilities raised concerns about stigma, discrimination at the early stages of accessing treatment and the long hours spent at the clinics or hospitals. These concerns constitute the reasons some opted for private facilities. Aviwe shares her experience at a public clinic:

"At first, I was shy because I thought I would bump into people I know, and they would know why I am there, especially because there is a special room for ARV collection but that stopped after I had told myself that my life comes first. On one occasion I came across someone I know, and she told me that she was there to collect for someone else. It's then that I spoke up for the first time and said I am collecting pills for myself. That's

how I started being open about taking my ARVs. The irritating thing about the clinic is the long hours we spend there. The nurses also don't have a sense of urgency and some of us have work to go to."

Based on the participants' responses, it is clear that there are enough facilities in their respective communities that provide ART, even though the services offered differ. When asked if they had ever used another person's dose of medication, half of the respondents said yes and the other half said no. The popular justification for using another person's dose was linked to the importance of adherence which shows that the individuals are aware that if they fail to maintain a 90% level of adherence it will be detrimental to their health and increase the risk of mutation and to cause the development of drug resistant strains and drug failure (Van Dyk, 2011: 3). Additionally, respondents shared how difficult it is to take treatment daily, at the same time.

Sharon confessed:

"... expecting people to take treatment every single day of their lives at the same time is very unrealistic for anyone. So usually I'll be at a friend's place and now its 20h30 and I'm not at home and like because I have an alarm, the alarm will be going off and I'm not at home then I'm like khawundiboleke [please lend me] to a friend...so sometimes I do that, or... I also have a relative that in the house living with HIV so sometimes, because I travel a lot, usually what happens is that I either forget them [ARVs]. Like I'm here, and then I have to go back home, then I forget them here, so sometimes that's what happens I borrow from her..."

Lynette admitted:

"I have used my closest friend's medication, who has been on treatment for much longer than I have. We both take the same regimen. The reason I took her dose is because I ran out of money before explaining my financial situation to the doctor so she looked at my pills and we saw that they were exactly the same and loaned me 2 pills, after the second day I managed to start at the public clinic and then replaced her two pills."

Likewise, Aviwe shared:

"I have been in sticky situations where I've had to ask a friend a couple of times. Sometimes you forget the pill you know... obviously the first time I had to check if the pill was identical to the one I take."

For Martha, it has not been her who uses other people's doses, rather, other people use her dose:

“I have a friend who is always sleeping over neh [right] and like, always, she forgets her medication and she knows she'll get from me. So the other day I asked her like, and she said she also always gets extra as well and I was like no you have extra because you drink mine.”

It is clear from research, as presented in Chapter 2 that antiretroviral treatment is available in South Africa and that PLWHA have, to a certain level, access to medication. However, public health facilities have experienced stock-outs. In 2013 more than 100,000 people, on ARVs or TB treatment, were dependent on 300 facilities served by the Mthatha depot. According to Odendal (2013: 1), patients at the affected facilities were sent home without treatment and these stock-outs were

“reported to last, on average, 45 days at a time and have been ongoing since October 2012...The organisations estimated that at least 5494 adults were not able to take some of their ARVs and 561 children were sent home without treatment since September 2012 when the drug supply issues began” (Odendal, 2013, p. 1).

In 2015 the South African Department of Health launched the world's first early drug stock-out warning system due to previous stock-outs and the distress this had caused to patients. The system was put in place to combat medicine shortages (Gonzalez, 2015, p. 1). While none of the respondents was directly affected by the stock-outs, all the participants shared a fear of such happening again.

Aviwe:

“To be quite honest it's scary so much that I've lied to the nurses time and time again when they ask how many pills I have left at home and even though I know I have a full bottle of pills left I will say I have six pills so that they can give me more. In that way, I avoid rainy days where the clinic runs out of pills and we have to go days without. That's why at the end of each cycle I have about six pills extra which means I'm covered should anything happen. I also get lucky sometimes my bottle comes with 4 extra pills so then they add up to my emergency pack. A week ago I got enough for the next four months, that's a good month for the clinic meaning that I don't have to go every month to collect. On bad months we get one bottle and have to repeatedly go back.”

Lynette:

"I haven't experienced a stock-out no, not completely. But instead of getting more than a month's dose (28 pills) like other clinics I have only gotten a month at a time because apparently there are many of us accessing treatment at the one clinic... its scary but I would have to make a plan, perhaps ask for a referral to go to another facility because this is my life. The moment I miss one pill I compromise so much. I have gotten used to having them daily, it's like my daily sweet or coffee, such that I don't want to go without it. There are people I know who have defaulted on treatment and that isn't ideal."

Precious:

"...you panic because I mean you'll become resistant if you don't take your pills. I think my biggest fear was that I wasn't going to get to a stage where I can stop taking pills but imagine being forced to stopped by circumstances, that doesn't make sense – you'll be resistant and I know people who stopped taking treatment and are gone [dead] which could have been avoided somehow."

Inga:

"It's really scary. I can't be told that I have to take these pills every day of my life and then it's not available you know? I know I sound entitled, and privileged but if the government is going to start this process it must ensure that we get it you know. I wish it never happens to anyone. That would be so heartbreaking and would defeat the purpose of taking pills every day. Imagine people who have been taking pills for longer than me, who have taken the pill every day now all of a sudden it's not there and then you default."

Martha:

"It freaks me out. Especially because I know that if I don't take my medication just for one day it's affecting my system. I can't be working hard for like ten months and then at the eleventh month I just drop like that you know so it's very useless for me to be working hard and it worries me that I can get to that point. That I've worked so hard to stay healthy and make sure that nothing jeopardizes my health and then just in a blink

of an eye because of a stock-out then its all compromised. So yeah, that really freaks me out.”

Sharon:

“To be honest with you, I used to think about that a lot when I started treatment but now because it's been four years and I've never really experienced something like that so I never really think of it that way. I hardly ever think about it that way. I used to stress about it, in the beginning, now I just hope it doesn't happen.”

Charity:

“They [stock-outs] affect me because I know of people in the rural areas who have no access to constant medication and then you find people in this area who take the pills from the clinic and waste them. So then it hurts me to know that. There are people suffering and in need of these pills yet they waste them. People could be saved.”

Lastly, Liz:

“I just need to take care of myself in a way that it'll still help me be healthy if I can put it like that. I can't control a stock-out and I refuse to let myself even think about going a day without medication because of a stock-out, it's a terrifying thought.

Lorig *et al.* (2013) emphasise the importance of understanding the chronic condition in the process of managing it. Therefore, the individual becomes a self-manager, whereby s/he keep track of the logistics related to her/his illness. Thus for individuals, knowing whether ARVs are accessible in their communities, understanding stock-outs, keeping track of their pills, knowing costs just in case they need to access their medication from a private sector all play a role in managing the therapy. Moreover, Lorig *et al.* (2013) explain how self-managing requires learning new skills that are in line with the condition which will, in turn, benefit the management of therapy. The management of therapy also requires that PLWHA learn to cope. According to Nettleton (2013: 77), the coping takes place at all stages of the illness and coping is a multifaceted process.

5.3.2 Adherence

The primary purpose of ART, as described in Chapter 2, is to stop or delay the progression of HIV to AIDS through controlling viral replication, reversing the loss of CD4 cells and essentially decreasing the amount of HIV (Wood, 2010, p. 531; Bartlett & Finkbeiner, 2006,

p. 68). This goal, however, can only be reached if ARVs are optimally adhered to. As Barlett and Finkbeiner (2006: 68) note: "partial treatment is worse than no treatment". This is important because partial treatment is more detrimental to one's health than no treatment at all. The respondents showed that they have an understanding of the importance of adherence to their treatment.

All the respondents claimed that they had never stopped taking treatment but had skipped treatment for various reasons. The reasons for skipping, fortunately, were not as potent as the barriers identified by Van Dyk in Chapter 2 (Van Dyk, 2011a, p. 8). The reasons were minor and not consistent. Moreover, the respondents are all aware of the advantages and disadvantages of optimum adherence.

Inga has never skipped and her reasons are as follows:

"No, I have never skipped. I hope I don't get to that point. I told myself that I have to do my part for this medication to work. Skipping or stopping is not an option, especially if I can help it. I've had to exclude myself from some social gatherings because I was scared it would interfere with my treatment but now I'm getting used to it. It has slowly become a part of my life."

Liz, who claims to have only skipped her treatment once, said it was due to unforeseen circumstances. She recalled:

"No, I haven't stopped. I have skipped though. I didn't have my pills with me. We had a group assignment and it took longer than expected. I'd left my pills at home. Came back the following day so I couldn't take it [ARV] into the next day but I had asked, like way before, like when I started taking treatment if there was a point where I can miss and she was like yes, but I wouldn't advise you to do it. She said its better to maybe, if you skip, at least let it be maybe once a month, or once in three months you know, but let it be a rare thing, don't make a habit out of it. And I was like, okay, because that one time it happened, now when I go for meetings or if I have an assignment I take it with me so that in case we go over the time. When my alarm goes off, I can still just take it then and there."

Charity shared a similar encounter:

“I have skipped once. We were visiting a family friend and I misplaced my pills. I felt extremely bad about that. I was disappointed in myself. Another time, I thought I lost them but I managed to find them but 4 hours after my normal pill time, so I quickly took it – I defaulted on the time. I told myself that I would never let that happen.”

Unlike others, Sharon (who earlier on admitted to having difficulty packing her pills when travelling) missed three consecutive days :

“I didn't stop, but as I did mention earlier on, I'm a human being and sometimes I'm at the wrong place at the wrong time and I need to get my pills but I can't so I just have to skip. So there was this other time I went home on a Friday. I think I had forgotten my pills again. I realised when I got home that I didn't have pills. My relative, at the time, was in hospital so I obviously didn't have like her to take from so on the Saturday morning I wake up, on a Saturday morning and I walk and I walk, and our clinic is very far. I get there and I'm like okay can I please have [pills] that woman is like why are you coming on a Saturday? So I explained to her, because I'm very honest and I'm not gonna lie about this, I forgot them. And she's like yeah you're being so careless and I'm like but I honestly forgot them and I'm here, I took effort and she's like no actually we don't give out treatment on weekends so you gonna have to come on Monday. So that really ticked me off. I was so angry.”

Martha recalls previously skipping her pills less than three times and as a result, has found herself consuming more than what is prescribed. She shared:

“I remember the one day I took two pills. So that day, when the alarm rang I took the medication but when I was asleep I thought ‘no man I didn't take the medication’ and then I woke up and took it again. Plus, I usually have extra so I couldn't count... I think it's better to take two than nothing. Not taking it at all comes with like the guilt of just thinking I didn't take my medication today. It's stressful. I was so stressed when I skipped.”

It was clear from the interviews that respondents assumed the role of an actor, as identified by symbolic interactionists where the individual only interact with others as a ‘self’ they also interact with themselves as a ‘self’ (Blumer, 1969, p. 13). Respondents go through a time in their day where they question whether they have consumed their ARVs or constantly checking the time to see if they had missed the alarm or not. This process of making indications is a daily

process of constantly communicating with oneself as though one is communicating with another person hence they are all able to tell themselves never to let the skipping of medication happen again. Even during the interview, as they recalled their experiences, this process of the social-self speaking to the private-self played out.

One of the factors that encouraged optimum adherence is the motivation behind consuming treatment in the first place. The respondents' answers showed that they are conscious of the meanings they have attached to ARVs and that they identified ARVs as given kind of object where they considering its relevance or importance to their line of action (Blumer, 1969, p. 13). Consistent with all the responses is that the participants are motivated to continue taking treatment to live longer.

Aviwe simply stated: "I need to live."

Lynette's motivation was drawn from her support system and wanting to be normal again:

"What keeps me going are my children who are very supportive. It also makes me proud of myself that I have been following my treatment religiously without fault. I know a lot of people who don't even get to the undetectable stage because of inconsistency. I remember my nurse telling me how proud she is of my progress. That motivates me to keep going. Also, I am healthier. I always tell myself that I want to live a normal life like everyone else."

Meanwhile, Precious (who at diagnosis stage did not want to start treatment immediately) explained:

"I don't want to die! It's because I know that there is a danger of defaulting like you become resistant as well. I mean then you have to go on another pill, I think its alluvia which eliminates resistance and I don't wanna go through that hence I'm happy just sticking to my routine, thanks."

Inga also refers to the information she has about ARVs and showed an understanding of the aim of treatment and she had the same goals as the ART program:

"I want to live the life I was created to live before this diagnosis. I still want to live my best life and reach my full potential and that's what they [medical professionals] said would happen if I take my treatment and live a healthy life. I also I want to reach an undetectable stage where the virus is suppressed then I can live in peace without fear

of infecting anyone even by mistake you know. Nothing is as scary as knowing that you're infectious and potentially dangerous to the next person. I don't want the next person to go through this."

Charity acknowledged the benefits of the ARVs:

"I have seen this pill work. It has healed me. It gives me energy. I was extremely sick when I started but look at me now. I also always think about how other people have it harder – some other diseases require many pills. For me, it's just one pill and it changes so much in my body. It's like my immune booster. I also know that if I stop then I will be making an opening for other illnesses that I shouldn't even have. It's like I would be giving them a chance to kill me."

Sharon shared similar sentiments about the ARVs but in addition, is motivated by her activism:

"I've seen how it's changed my life, how it's changed me physically. I've seen them work in me. I also feel the pressure to always take my pills and lead this healthy lifestyle because I know that there are a lot of people who are actually looking up to me so imagine just having to get sick out of my own irresponsibility you know. So, I literally know that I have a lot of people who are literally just looking at me hence I'm saying that sometimes I get hard on myself, but I think it does help me keep in track."

Martha described how the pills will benefit her in the future:

"Knowing that, because I don't have a kid yet and I want to have kids and my partner is HIV negative, knowing that the risk of me infecting him are very slim if my viral load is suppressed like it's undetectable. Now, I'm undetectable so I know that it's not easy for me to infect him. Also knowing that I want to have a child and my child wouldn't be infected so that just keeps me going and I don't want to compromise that you know."

Liz's motivation to continue taking treatment was partly motivated by fear:

"[laughs] to live! Besides that, I've heard that there are people who've lived without treatment, but I just don't want that option because what if I think I'm one of those people who think they'll live without it for ten years then I live without it for a week and then I'm gone, you know what I mean... I don't want to take chances [laughs]. Rather take it, even if maybe let's say ten years from now they say it didn't do anything

to your system I think it's better to have it than to not have then ten years down the line they say it actually could have been beneficial to you... you know. My main thing right now has been to like get to the point of being undetectable and by drinking it and having it on a daily that's what helps you..."

Nettleton (2013, p. 65) argues that people's interaction with the social world becomes perilous when they cannot rely on their bodies to function 'normally' and this affects individuals' senses of self hence they will do everything possible to maintain 'normality'. Living a 'normal' life again, not dying, and reaching a stage where the viral load is fully suppressed hence undetectable were recurring themes in the responses regarding motivation. Reaching an undetectable viral load seemed to give participants sense of hope and relief from the burden of the illness.

Sharon expressed:

"It's freedom. I mean reaching that stage means that you can never infect another person and I personally have this huge fear of infecting other people. I literally take all the necessary steps just to avoid me passing on my HIV to other people. It's freedom because I don't have stress about infecting other people. I obviously also want to live a longer life, want to get married, want to have children, and because I'm a product of mother to child transmission obviously that's like a nightmare in my head. I don't ever want to have a kid go through what I went through, not only my kids..."

Inga:

"I know it sounds ridiculous but to me, it almost sounds like I'm cured! Not that it means I will be promiscuous or will stop taking treatment but not having the virus in my body will mean living freely. When I reach that point I will reconsider dating, starting a family in future and just maintaining my healthy virus-free life... perhaps people will start treating us differently if they knew that we too, like cancer survivors have somehow conquered the virus you know. I feel like reaching undetectable stage will be an achievement for me, even though society doesn't see it as such. For me, it will be a big deal. It will mean the medication is working and that I am also doing something right. It's a second chance. It will be my second chance at life without a virus... Reaching that stage will prove that HIV is a manageable chronic illness. I live for that stage of my disease."

Lynette remembered what it felt like when she found out that she had reached a stage where the virus had been suppressed:

“It’s an achievement. It made me so happy. It’s like being born again. As if I was never sick, well I was never sick, but I don’t feel that burden anymore... it’s like being HIV negative again but still identifying as positive you know... but I still continue religiously taking my treatment because I don’t want to reverse so much hard work and I want to continue preventing opportunistic infections.”

Aviwe had also recently found out that the virus is suppressed, four years after beginning her medication:

“The nurse just told me the virus is suppressed... sort of like you can’t find it. It feels great because I can see that it’s [the ARVs] paying off. I have been taking care of myself. Also shows that the pill is working even though I can’t now stop taking it, but it feels good to know that I am normal again. I wish it was possible that being undetectable meant that you’re no longer supposed to take your medication or that you’re cured. I somehow feel like it could mean that and maybe they are not telling us the truth because maybe we won’t be responsible. It gives you freedom, your partner can go without using a condom but it’s your responsibility as the person taking the pill to continue regardless of the choices your partner makes. So, while its freedom, it doesn’t mean irresponsible sex coz that has repercussions for your own viral load – the aim is to keep it at its lowest not sleep around without a condom and risk it shooting up again.”

An undetectable viral load seems to reduce HIV-related stress and fears and proves the efficiency of treatment and how manageable the disease can be. I also observed a level of pride in respondents for adequately adhering to their treatment and defying what was seen as a death sentence. Lorig *et al.* (2013) state that a healthy way of living with a chronic disease is to work at overcoming the physical, mental and emotional problems caused by the condition. While respondents are aware that an undetectable viral load does not cure the virus, it does give them a sense of control over the disease and also eliminates some of the concerns related to living with HIV/AIDS. Part of the victory in reaching an undetectable level was the idea of being ‘normal’ again and asserting their ‘normal’ identity again.

The DoH has partnered with private pharmacies to dispense chronic medication at no cost to patients. This partnership allows PLWHA who are accessing ARVs from public facilities to access them at their nearest pharmacy like Clicks and Medirite (Health, 2016, p. 24). This system is spreading and allows more people living with chronic conditions to have greater access to their chronic medication. There were mixed feelings regarding these new methods, which highlighted stigma, concern for adherence as well as freedom.

Charity was ecstatic and saw this as a way of asserting her role in society:

“I’m so happy! It gives us power and control. Instead of waiting in long queues we will fetch the pills on our terms. Gives you a sense of dignity as well. You can be like any other person now.”

Even though Sharon was happy about the new method as it meant less time with nurses, she expressed concern for the vulnerable:

“For me personally because I am forever fighting with the nurses if I had a chance to like see less of them I’d take it [laughs]... but I feel like it’s so convenient ... for some people. Because there are some people who, for instance, virally suppressed people, who don’t need to be going to the clinic every month for checkups, coz what are you checking up. So, yah they are convenient for some people but there are people with fragile immune systems who forever need to be at the clinic.”

Martha also saw this as a distancing tool between herself and the healthcare workers and their services:

“Nice! I hate long queues, number one. I hate long queues and I know that I always fight with the nurses because I don’t want to sit there the whole day so I don’t even have to see them. Like, you know sometimes, like, I feel that the government hires people who don’t have the passion for what they do you know. So sometimes you meet people who are doing things that they don’t have the passion for and they tend to be short tempered and don’t have the patience to be helpful and to be understanding and to be patient with so I’m glad I don’t have to deal with all that anymore. I’ll only have to deal with that like twice in a year which is every six months when I go and do my blood. So I’m very happy with that.”

Liz was more worried about the practicality of the system:

“I think it could possibly be a good system... I think it might need a bit tweaking coz it can't just be your card coz of corruption. You might just go with my card and they think it's the right person. If there's a pin then maybe you know...it would actually make everything easy and convenient to get the medication when I have the time not by schedule and it would be nice to go just once to the clinic for your CD4 counts and whatever. It would so much better coz it's actually on the go.”

Inga shared her views regarding stigma:

“I don't know about these, it sounds good to me but I fear that it may increase stigma towards PLWHA, especially those who haven't yet publicly disclosed.”

For Precious the stigma was more prevalent in the clinics, therefore, this method was more convenient, she shared:

“I feel that people default because of the stigma of going to the clinic and everyone can see you in that ARV queue and now people know their status. I've heard of bad treatment from professionals there. That is not nice because at the end of the day you are not your status and it's a health facility and they should know better.”

Contrary to all the other respondents, Aviwe was against the new methods:

“I don't like them at all. It's too much exposure, particularly for people who have not disclosed their status publicly. Even though the clinic isn't the safest space for us its better than being in Shoprite for example where you know almost every cashier by name with their red lipstick and then they talk you know...”

5.3.3 Stigma

Stigma around HIV/AIDS and ARVs is still prevalent in South Africa (Makoae, *et al.*, 2009: 1357). Stigma, discrimination and the lack of social support are closely tied to why PLWHA do not disclose their status and ARV consumption, do not optimally adhere to treatment and consequently experience a disruption in their life trajectory which in turn affects the whole illness experience. According to Nettleton (2013: 85), stigma occurs when there is a discrepancy between virtual and actual self-identity. Virtual social identity is defined as the “stereotyped imputations we make in everyday life” and then actual self-identity refers to the attributes an individual actually possesses.

Earlier in the section (5.2.1), I discussed respondents' views on ARVs before diagnosis, in this next section I will be looking into the respondents' perceptions of the views of outsiders i.e. people who are not living with HIV/AIDS. Looking at respondents' perceptions of what ARVs means to outsiders I found an interesting link to the views they themselves held before diagnosis.

Inga shared her frustration with outsiders as follows:

“... [laughs] people have so much to say about ARVs and our statuses, yet they don't know their own statuses. It is frustrating. People think ARVs are from the devil to mini devils. We are ostracized for trying to make things right with our health. We are treated like we are deadly for taking this medication. Nobody sees it as a healing process, especially young people and media... people speak of ARVs as if they speak of something that's supposed to finish us off and take away more than it restores.”

Similarly, Charity expressed:

“people have that thing that we are a lost cause if we take them. People think there's something completely wrong with you. People are ignorant.”

Aviwe went as far as comparing HIV/AIDS to other chronic diseases, she stated:

“As soon as you take ARVs people think you have reached the end of the road, that you're on your death bed and that's not true. In fact, we get stronger and healthier because of these pills. We're even better off than people living with diabetes and cancer actually, but nobody sees it like that, they don't realize that it is a manageable chronic disease.”

Precious is the only respondent who made the link between what she thought prior to her diagnosis to how outsiders view ARVs:

"Well, I'll tell you what I thought when I was an outsider. I was shocked that people take a pill every day. It's like jeez so much work..."

Because Martha only started taking ARVs years after her diagnosis, she has both before and after treatment insights into the views people have:

“People think that when you're taking ARVs it means that you're really sick. I think when they know that she's HIV positive but not taking the treatment they think she's

still fine. But once you take medication you're really, really now sick. People generally don't have the right information you know, people just assume that okay just because you are on medication it means that anytime from now you can die. They don't understand that this medication is making it much easier to for you to live even longer you know..."

Sharon's frustrations were directed towards outsiders and health care providers and services. She highlights how stigma is perpetuated:

"People from the outside are so annoying. They are so fucking annoying. Number 1, I hate the fact that in clinics there's like a separate queue [for PLWHA]. I hate that so much. For me, I don't really mind that so much because I don't really care but can you imagine because now they've implemented this whole 'test and treat' thing. Can you imagine finding out your status today and then you have to immediately go on that queue? I hate that. I do. And I have a feeling that whoever came up with that beautiful idea to do that is an outsider. It's not someone living with HIV because someone living with HIV would never do that. That is the stigma. Imagine getting stigma in a clinic. Outsiders are annoying. Taking ARVs for them means you don't need to have a life, you don't need to date, you don't need to date HIV negative people because you're busy spreading just by sitting next to you. To them, you must go and get a new start wherever alone. The minute you lose weight, its AIDS, you gain weight its ARVs. They always have something shitty to say about people who are living with HIV and I hate that so much. And, not just because of me, like I did mention before, I'm now very, I'm at a stage where whatever you say is just ah okay [shrugs]. But there's a lot of people who actually take those things to heart."

In explaining what it means to them that they are consuming ARVs respondents linked this to their motivation to taking treatment and showed growth in their knowledge from their earlier views prior to diagnosis.

As someone who was reluctant to start treatment and only started four years after diagnosis, Sharon had a positive outlook on the meaning of ARVs:

"It means that I'm HIV positive [laughs]. It means a lot. It means that I can have freedom. It means that I literally have control over my health, that's power, we all love power. I literally have power over how my health pans out. It means that I am

guaranteed a healthy life. Yes, there is the reality that we all like running from, but it is a reality that sometimes HIV decides to become AIDS and you die but taking pills kind of gives you hope that I'm not headed in that direction."

Likewise, Martha expressed:

"It means a happy life, a longer life. A positive life because I know now I don't have to worry about being sick and taking care, the pills are boosting my immune system, and I'm getting stronger every day."

Inga's response revealed her mixed emotions regarding her diagnosis and consuming ARVs:

"Well, it's a daily reminder of the mistake I made in my life but it is also a reminder that I can change my future and that I can somehow fix this mistake I made. It means I am constantly fighting to restore my dignity, health and to get to viral suppression or undetectable stage. I remember someone said I'm sick because I am on treatment, I snapped. I am not sick. Yes, I have a virus in my blood, but I am not sick. As you can see, I am very strong, beautiful, able and active. Sick people are in hospital sick beds. Yes, according to my CD4 count I am not as healthy as the next person who is HIV negative, but nobody gets to tell me that I am sick. I am living with the virus. I am working towards suppressing this virus. That is what taking treatment means to me. Taking ARVs is like taking any other medication, and I will not be made to feel any less of a human being by media and people for taking care of myself."

The rest of the respondents also alluded to seeing ARVs as any other pill now that they have been consuming them for a long time. Moreover, that ARVs are a part of who they are and their way of keeping healthy. One can see ARVs as a coping tool that PLWHA adopt to maintain their maximum relative health status and normality. The respondents' perceptions regarding stigmas attached to ARVs and people taking the treatment revealed a discrepancy between virtual and actual self-identity.

Liz's explanation showed the way in which outsiders viewed different illnesses and the treatment thereof:

"Taking ARV is not seen like taking other treatment. Like I said, people think people on ARVs will drop dead anytime or just infect them just by sitting next to them. I even see bad jokes about ARVs. I hate comparing illnesses but once its chemo people are

nice and sympathetic, but God forbid HIV is something you did to yourself. People are cruel to us. I saw a Facebook status saying I'd rather die than date someone taking pills every day how stupid is that? So much work needs to be done in fighting the stigma hey. We are fighting internal battles, and still, have to fight people treating us like shit on a daily basis.”

Sharon also used other chronic diseases and sex to illustrate the root of stigma:

“I feel like people shun upon ARVs so much. I hate it so much because I usually say HIV is a chronic illness, like diabetes, like hypertension, like whatever that is chronic. It's just a chronic disease... I personally feel like people are shunning upon HIV so much because it's an STI and I really don't understand why we would shun upon sex when we all know we're having it anyway. Like, why is it that when I say I'm HIV positive the first thing you are gonna say is 'ahh so you were having sex at 14?' What if I was you know? Why is such a big deal that I have sex? Why is the HOW so important you know?”

Precious clarified that much of the stigmatization was directed at the illness itself not necessarily the treatment:

“I don't think the stigma is attached to the ARV, it's attached to HIV. I think mainly because you get it via sex, okay you do get it in other ways – blood transfusions, etc. unfortunately, and people have a stigma against sex, but sex is nice, and people enjoy sex. People still also have this idea that you get it when you are promiscuous, I was not promiscuous I got it from one guy. Literally one guy. I think it's the ignorance. All of a sudden, my lifestyle is judged as if I have sex with every man I've come across. The stigma is more attached to how you get it but it's not fair because sex is nice and healthy.”

Williams *et al* (2017: 1) maintain that stigma and discrimination are not only limited to social spaces; health settings also perpetuate stigma – sometimes it is health providers who fail to maintain confidentiality and also treat patients inappropriately. The respondents all at some point in their interviews referred to the way in which clinics and hospitals perpetuate stigma through having boldly labelled rooms and sections for PLWHA and ARVs which obviously has negative impacts for those who have not disclosed their statuses. Williams *et al.* (2017: 1) also attributed stigma to a lack of information about HIV among the general public and call for

interventions to address the shaping of perceptions of HIV and education campaigns to reduce HIV-related stigma.

All the participants shared that they had no direct encounter with stigma due to consuming ARVs but their HIV-positive status elicited stigma from people, especially in intimate relationships. Furthermore, they acknowledged that their experiences of stigma lessened with time, particularly because they had publicly disclosed their statuses. The impact of publicly disclosing on social media will be explored further in the next section.

5.3.4 Reconstruction of personal narratives

The global pandemic of HIV/AIDS has disrupted the lives of many people. As a chronic condition HIV/AIDS disrupts the structures of everyday life and forms of knowledge which underpin them. Lorig *et al.* (2013) assert that a new illness requires that the individual adopt new skills and do new things. These may include taking medicine, using an inhaler, or using oxygens etc. The application of new behaviours, according to the authors, is necessary for individuals to continue living their normal lives. Being diagnosed with a chronic illness changes one's future and the changes require one to adjust one's plans which consequently affects one's emotions. Indeed, Nettleton (2013: 74) adds that the way in which people make sense of their illness is "within the context of their personal biographies and in turn must invariably be influenced, and meshed with, the cultural values of the society in which they live." Thus, individuals' narratives contribute to an understanding of the experience of illness. The recurring themes in this section include dating, isolation and adaptation.

Consuming ARVs resulted in changes in respondents' lives. Liz's shows the difficulty of living with a chronic illness, how one has to make adjustments to one's social life in order to incorporate the new dimension of one's life:

"It has been difficult to be quite honest. I am generally an outgoing person and social person but in my first month I lost so much weight I felt like people could tell what was going on or they would ask questions, so I just cut down on social events and public appearances and I generally avoid anything in the evening because I don't wanna miss my pill time. I am also scared of dating, so I told myself that I will wait till I reach undetectable stage before I can consider dating or getting intimate with anyone... My life has changed but I think it's for the better. I am living a healthier life. Remember I made it my mission to help these pills help me."

Aviwe shared a similar process as Inga:

“My life didn't change per se, I made a choice to change my lifestyle to accommodate my diagnosis and to get better. I didn't want to date because I was afraid I would infect someone you know. It was hard enough that I didn't know who I got it from so I didn't want anyone going through that. I also had to tell myself that HIV is a virus in my blood nothing more, I had to pick myself up and know that life goes on.”

Participation in the *Good Stories* Facebook page and Organization contributed to respondents experiences. The responses were all positive, highlighting the supportive nature of these platforms as well as the responsibility that comes with disclosing on social media and being part of an organization that aims to change mindsets and fight the stigma of HIV/AIDS & TB and to prove that HIV/AIDS & TB are not the end of one's life. Hardon *et al.* (2013: S2) maintain that practices of disclosure are heterogeneous and largely dependent on the social profile and social context of the concerned individual.

Inga expressed her love for the *Good Stories* Organization:

“Wow, I love being with those people. They showed me that I can do it. They are my constant motivation to keep going. All these good stories give me hope. I have recently had my story shared on the page and many people have been really kind to me, some have even messaged me to say thank you for sharing you have given me hope so I think I made a difference to someone which is great.”

Precious simply expressed:

“It's really, really made my life better. It has given me a sense of purpose. It's something that I really enjoy so it's been a great experience.”

For Martha, being a part of this organization and using the social media platform has been more meaningful to others than herself:

“[sigh] for me I feel that me publicly disclosing my status has helped a lot of people. It has helped a lot of people be comfortable with their situation you know, even though some of them are not ready to come out. When I look back there are so many people saying if it wasn't for you I wouldn't have come out or I wouldn't have accepted my status...”

Nostlinger *et al.* (2015: 36) assert that disclosing comes with a lot of decision making, particularly because there are both positive and negative consequences of disclosing. Further, disclosing may make it easier to access social support which is a "prerequisite for constructive coping, enhanced self-esteem, adherence, and other health-promoting behaviours" (Nostlinger *et al.*, 2015: 36). Keeping this in mind respondents shared the advantages and disadvantages of disclosing publicly as follows:

Liz:

"The main advantage is that I can talk about it [HIV status] whenever like now I can be sick and I can freely say I'm actually sick because another thing that we usually overlook in terms of PLWHA is how it destroys their mental health. You can have something as easy as flu, and then you're like shit what if its TB or what if its whatever, so at least now that I'm talking about it more... It also kind of made me learn more about the virus because now everyone feels like they wanna ask me questions. At least now I've opened a space where I can talk to people about it [HIV], which is something that I used to need so I'm glad I'm at a point where I can at least be that somebody that I needed. But the disadvantages of it, it's just the outsiders..."

Martha:

"The advantages are that you don't have to worry about somebody saying that you infected them you know... I remember the one thing that made me be open about my status is that I met someone I think probably after a year... because after I was diagnosed in 2005 I only started dating 3 years after in 2008. So for 3 years, I didn't want anything to do with men coz I felt like whoever that I'm going to sleep with I'm going to infect them you know... so, I was still finding myself and what I was dealing with in terms of my situation you know. So I met this guy and he didn't say anything about his status and I didn't say anything about my status. We dated for like a month and we were together and slept together and we used protection. The next day I wake up, you know how we are as girls, I wake up and he went to the gym right. I somehow found a card, he was already taking treatment and remember now I know these things from the clinic. So I saw his name and ID number and everything, hawu this person and then he didn't tell me, so I keep quiet. I just realised that this person has the same status as me okay then I don't have to be worried. The next day I ask him, I'm home now and he's at his place, I ask him how would you feel if I were to tell you that I am HIV

positive and he says to me, I would be very mad. So I'm like huh? Why? And he says because what if you had infected me if we hadn't used protection? So I'm like what are you saying? So it means I must also be mad at you because you didn't tell me about your status. Then he got angry and said you can say that coz it's not my card and I told him I saw his name and surname and ID number, then he said he'll sue me and I said go ahead. So after that I realized that I don't want to be in that situation ever again so it's better to tell a person and the person knows what they are getting themselves into, because there are people who will get into a relationship knowing their status and want somebody to blame for it. So I just feel if you're living openly you're saving yourself from all that but the disadvantage again, is how you always have to explain argh. I hate explaining myself.”

Precious:

“It took so much weight off my shoulders and it's much more manageable... it's really the best thing that I have ever done and also that thing of saving someone's life without even knowing or planning it... There aren't any disadvantages of disclosing publicly hey because I laugh at all those people who try to bring us down and not because I'm really being funny or anything but it's like yah that's me. How does my status change your life?”

Lynette:

“Publicly disclosing isn't easy... some people listen for the sake of listening but then go off and speak badly of you. But it helps other people know they are not alone and that its okay to speak up. I don't believe that people should be forced to disclose, but I do think it's much better when people know it's a relief.”

Aviwe:

“It's a relief hey! Removes the burden off your shoulders and I have become a source of knowledge for some people. I can now advise people when they want someone to talk to or are not sure about symptoms and all... makes you live carefully. You learn to take care of yourself and others.”

Charity:

“It’s better when they know... you can motivate them and inspire people to go test. I am very open about my status and I want to educate people that it’s not a death sentence. You can live a normal life.”

Sharon:

“Publicly disclosing has been kind of been mind-blowing actually. There are two sides to it. There's the positive side which I didn't really expect especially from twitter because I've always felt that tweeps [Twitter participants] are just nasty people. So, I never expected the amount of love that I have received that side... So, it has changed my life, publicly disclosing. It’s even changed how I used to view my HIV because when I first started disclosing it was just – because I refused to go for counselling – I literally needed to talk but I didn't wanna talk. So, by me disclosing was just me trying to cry for help – back at 18. And I’ve been doing that since then so obviously it has also made me so comfortable in my space. I’m more content and a bit happier than I used to be.”

And lastly, Inga shared:

“Well, living with HIV is mentally strenuous, well for me it has been. You’re constantly trying to think ahead, like, will things really be okay, or you stress that nobody will ever accept you for who you really are. So publicly disclosing triggers such thoughts. An advantage is that you have sort of released what’s been bothering you, but the disadvantage is that you don’t know for sure how people will receive it. The responses no matter how much you try to close them off, come back to you when it’s just you and your HIV in bed before you sleep. You get paranoid as well, when my friends check up on me I’d snap and say I’m HIV positive not dying. Like, you feel like everyone is treating you like some fragile item. An advantage is that you inspire someone, and you contribute to cutting the stigma, but people are cruel too. Some think you’re seeking attention or they want to know more than they need to, like where you got it from and stuff.”

It is clear that the *Good Stories* Organization and Facebook page have created an online community for PLWHA and broader society to engage with issues pertaining to HIV/AIDS. Hardon *et al.* (2013: S3) look into how disclosure increases both practical and emotional support and enables self-acceptance for those disclosing and those who are privately dealing

with their diagnoses. All the respondents agreed that since they started consuming ARVs they have had to live healthier lives, incorporating taking the pill daily, gaining a bigger purpose and also showed a greater appreciation of their health and lives.

Martha captures most of the respondents' feelings regarding adjustments due to ARVs:

“Firstly, keeping the same time for medication. Making sure that 8 o'clock I don't compromise. I didn't care what time I was assigned but I made sure that I need to work with this ARV. I can't be stressing and taking ARVs. I have to help them help me. I also had to choose what to stress about because there are certain things I don't need to stress about, and I need to put my health first because I always say it's useless for you to take ARVs and not help them. You need to help them. So, eat right you know... I used to drink a lot, I had to cut down on drinking. I have faith in these pills because my viral load is now suppressed and I'm undetectable, so I believe that they are working... I believe that God puts us in some situations for a reason and I think God wanted me to be where I am. Maybe if I had not been HIV positive I wouldn't have touched people's lives the way that I do you know...”

5.4 Conclusion

This chapter has showed that once an individual's life has been disrupted by a chronic illness the individual goes through a process of narrative reconstruction both in order to understand the illness in terms of past social experiences and to reaffirm the impression that life has a course and the self has a purpose (Williams, 1984: 179). It is also evident that the process has helped the respondents deal with the disruption and create new identities in relation to their illness.

I have demonstrated the way in which respondents' views on ARVs significantly change from the way they viewed them prior to diagnosis to when they consumed them and especially when they reached a stage where the virus is fully suppressed and undetectable. The respondents showed that the journey after diagnosis was filled with much learning, unlearning and relearning about the chronic disease and its treatment as well as about themselves and the societies they occupy. The journey after diagnosis was also filled with many decisions about beginning with ART, adhering to ARVs, and disclosing among others.

Even though the participants had a positive outlook on their HIV-positive status, it has not been without challenges, particularly regarding the management of therapy, disclosing and dealing

with stigma. Disclosing through a public forum has contributed to participants' illness experiences. Nettleton (2013: 86-87) explains that the use of social media also helps create more positive images of illness and creates a space where people living with chronic conditions can be proud, create positive self-identities and have power over their narratives.

Lastly, in reconstructing their narratives, PLWHA have had to adopt new skills and coping mechanisms as the chronic disease comes with many burdens emotionally, financially, socially and personally.

Chapter 6: Conclusion

The overall aim of this research paper was to explore and discuss the effects of antiretroviral treatment on patients' illness experiences. This research was contextualized within the theoretical framework of social constructionism and symbolic interactionism. The research strategy took the form of a qualitative research design, whereby eight female respondents were involved in individual face-to-face interviews that took place at each respondents' preferred location.

Having explored each case individually, it was revealed that respondents' views of illness changed and the relationship between the body and the person was disrupted, resulting in a different outlook on life and illness in general, due to sickness or illness (Nettleton, 2006: 81). The research revealed that being diagnosed with HIV/AIDS was initially frightening due to lack of understanding about HIV transmission, the course of illness and potential for treatment among participants, their families and communities. However, once individuals engaged with the disease more and more, it was discovered that ARVs are there to help PLWHA live longer instead of making "people who are living with HIV just feel so ashamed of living with the virus" as Martha shared.

The research also revealed that interventions such as campaigns, movements and media need to be more active in educating people not only about HIV/AIDS but also about ART programs and their successes and failures to eradicate the stigma attached to HIV/AIDS. Additionally, more positive stories of PLWHA need to be shared so that laypersons see that with ARVs, HIV/AIDS can be a manageable chronic condition.

Positive and inspirational aspects of living with HIV/AIDS and especially consuming antiretroviral therapy were shared. It became evident that the knowledge participants had of antiretrovirals before consuming them was misguided and based more on false 'general knowledge' among laypersons than actual medical fact. Publicly disclosing their statuses has also proved to have both negative and positive consequences for the individuals and for society at large. While there is a consensus that participants' illness experiences are directly affected by antiretroviral treatment each participants' narrative is different, yet positive.

Newman and Benz (1998: 2) explain that all qualitative researchers reflect some sort of individual phenomenological perspective, irrespective of their theoretical differences; therefore, there is an emphasis on a common reality that people can agree on. From a phenomenological perspective, the belief is that there are multiple perspectives on reality and

multiple interpretations from different individuals and all these are equally important (Newman & Benz, 1998: 2). The researcher has made it a priority to ensure that respondents are aware that their opinions and experiences are equally valid. In line with Thomas's (2003:2) view on qualitative research, this study attempted to make sense of or interpret, phenomena in terms of the meanings respondents attach to them. The in-depth interviews created a space where respondents were encouraged to openly talk about their experience. According to Liamputtong (2011: 3), a successful discussion is reliant on the advancement of a "permissive, non-threatening environment" where participants can feel comfortable to discuss their opinions and experiences without fear of judgement. This was successfully achieved, hence the depth of the interviews.

It is worth noting that the researcher's participation in the *Good Stories* sessions helped the participants get to know the researcher better prior to engaging in interviews, moreover, the rapport was easily formed from these sessions which enabled a smooth running of interviews.

6.1. Limitations and Improvements

While all the aims of the study were achieved, and I was able to provide individuals living with HIV/AIDS a platform to share their experiences and highlight that the "assignment of meaning and explanation is as much part of the illness as its physical expression" (Toombs' 1992: 104), the study could have been broadened. If I were to continue with research in this area I would include three more categories of respondents: PLWHA who had not publicly disclosed their HIV-positive status, PLWHA who had not disclosed their HIV-positive status at all, as well as people who are not living with HIV/AIDS. This would have given me the opportunity to analyse the role of publicly disclosing – and disclosing in general – in illness experiences and further provide perspectives of those to whom people disclose their HIV-positive status. The inclusion of laypersons would work well to support or undermine the accounts of stigma from the outsider shared by those living with HIV/AIDS. It may have also been useful to have male participants involved in the study.

Overall, however, this research has been significant in that it provided valuable insight into narratives of PLWHA due to consuming ARVs.

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APPENDICES

Appendix A: Consent Form Example

<p>Rhodes University Department of Sociology AGREEMENT BETWEEN STUDENT RESEARCHER AND RESEARCH PARTICIPANT.</p>

I (participant's name)_____agree to participate in the research project of Lindiwe Tsope on exploring the effects of antiretroviral treatment on patients' illness experiences.

I understand that:

1. The researcher is a student conducting the research as part of the requirements for a Master's degree at Rhodes University. The researcher may be contacted on 0833310389 (cell phone) or g13t0913@campus.ru.ac.za (email). The research project has been approved by the relevant ethics committee(s), and is under the supervision of Professor Michael Drewett in the Sociology Department at Rhodes University, who may be contacted on m.drewett@ru.ac.za
2. The researcher is interested in capturing my experiences with antiretrovirals as a person living with HIV/AIDS and understanding how the treatment has affected my illness experience.
3. My participation will involve being a part of a face to face in-depth interview with the researcher. If necessary, there will be a follow-up interview, depending on whether or not the researcher has obtained sufficient information.
4. I may be asked to answer questions of a sensitive nature, and I can choose not to answer any questions about aspects of my life which I am not willing to disclose.
5. I am invited to voice to the researcher any concerns I have about my participation in the study, or consequences I may experience as a result of my participation, and to have these addressed to my satisfaction.

6. I am free to withdraw from the study at any time – however, I commit myself to full participation unless some unusual circumstances occur, or I have concerns about my participation which I did not originally anticipate.

7. The report on the project may contain information about my personal experiences, attitudes and behaviours, but that the report will be designed in such a way that it will not be possible to be identified by the general reader.

8. The information will be recorded and may be used for future references.

9. There is no remuneration for my participation in this research.

10. Should I wish to; the researcher agrees to send me reports on the findings of the research which I am contributing to and I am invited to comment.

11. The researcher has fully explained the research aims and given a breakdown of my role in it.

Signed on (Date):

Participant: _____ Researcher: _____

Appendix B: Interview Guide Example

Interview Questions

After diagnosis

1. Prior to getting tested and finding out that you are HIV positive, were you aware of ARVs and what did they mean to you?
2. After diagnosis, were you concerned about taking medication? If so, what were your concerns?
3. Who gave you professional medical information about ARVs and what did they say?
4. Did you go through special tests to find out what medication would be most suitable for you?
5. Tell me about the first time you accessed treatment?
6. How did you first disclose that you are on treatment for HIV/AIDS to those close to you? Has it become easier to disclose?

Affordability. Regularity. Availability

7. Are you accessing treatment from a private or public facility? Why?
8. How does it feel to use this facility?
9. How accessible are facilities for people living with HIV/AIDS in your community?
10. Have you ever had to pay for your treatment?
11. Have you ever used another person's dose?
12. Have you ever experienced a stock-out? What did you do in this case?
 - a. How does it feel to know that you need the medication but it's not always available?
13. Have you had to change your treatment regimen since the first time you started? How did you respond to this change?

Adherence

14. Have you ever stopped or skipped taking treatment, why?
15. What motivates you to continue taking treatment?
16. How do you feel about reaching undetectable stage?
17. What role does the cost of treatment play in your life?
18. How do you feel about the new methods of accessing ARVs such as the collection of ARVs at MediRit?

Stigma

19. What do you think taking ARVs means to outsiders (community members, colleagues, etc.)?
20. What does it mean to you that you are taking ARVs?
21. How have those close to you responded to you taking treatment over time?
22. Do you think there are the stigmas attached to ARVs and people taking treatment?
23. Have you personally experienced stigma because you take ARVs?

Reconstruction

24. How has your life changed from the time you started taking treatment to now?
25. How has your participation in the Good Stories Facebook page and Organisation contributed to your experiences?
26. In your experience, what are the advantages and disadvantages of publicly disclosing your HIV-positive status?
27. Do you see ARVs in the same way you did before you started treatment?
28. What is the biggest adjustment you have had to make?

Appendix C: Email correspondence between researcher and gatekeeper

From: Lindiwe Tsope

6/15/17

To: Thula Mkhize

Good morning,

My name is Lindiwe Tsope. I am a Master's student at Rhodes University interested in the Sociology of Health, as a result, I'm writing a thesis on the development of ARVs and how this has affected patients' illness experiences.

I have been fortunate enough to follow the Good Stories Facebook and Twitter pages, where I have drawn a lot of inspiration and a growing interest. I was wondering if it would be okay for me to visit the organisation, with hopes of forming relationships and further meeting potential participants for my study. Of course, this will be with the consent of all who are involved.

Furthermore, I'd like to know how one can be involved in the organisation.

Regards,

Lindiwe Tsope

From: Thula Mkhize

6/20/17

To: :Lindiwe Tsope

Good morning Lindiwe

That would be great – I'm sure all parties would learn from this experience.

Good regards

Thula Mkhize

CEO and Chairperson

Mobile : 072 812 3534 | Fax2mail : 086 535 9605 | E-mail : thula@goodstories.co.za |

Website : www.goodstories.co.za | Twitter and Instagram : @GoodStoriesSA | Facebook : www.facebook.com/GoodStoriesSA |

LinkedIn : <http://www.linkedin.com/company/good-stories-ziza-izwe-npo-?trk=biz-companies-cym>

From: Lindiwe Tsope

Sent: 7/31/17

To: Thula Mkhize

Good day Thula,

Hope this email finds you well.

My research topic has been approved and I have gotten the green light to proceed with data collection. I was wondering if it would be possible for the organisation to assist with linking me to members of the Good Stories Organisation who would be interested to participate? I am also going to be in Joburg for the whole of September, and would like to please attend the Good Stories Session on the 16th?

Thank you

From Thula Mkhize

Sent: 7/31/17

To: Lindiwe

Fantastic Lindiwe

This is great news - well done.

Please send me the kind of questions you'd want to ask and I'll forward it to the ambassadors to attend to.

And yes, we'd love to have you at the session.

Thula Mkhize

Sent from my iPhone

From: Lindiwe Tsope

Attachments

Sent: 8/21/17

To: Thula Mkhize

Good afternoon,

Please find attached, a copy of the questions and the consent form. I have conducted a pilot study just to test whether the questions are in line with the my specific research and to also see if they are not triggering - while the results of the pilot interviews where positive, I would appreciate any feedback you have regarding the questions before actually interviewing the participants.

If possible, please select participants within this criterion: participants have to be living with HIV/AIDS; participants have to be between 21-40 years of age; participants should have shared their story on the Good Stories Facebook page; participants should be a South African citizen; and lastly, participants should reside in or around Johannesburg.

The interviews will be roughly one hour long.

Thank you so much for your continued assistance, looking forward to the next session.

Regards,

Lindiwe Tsope

Thula Mkhize <thula@goodstories.co.za>

Sent: 8/21/17

To: Lindiwe

Evening Lindiwe

Hope you're keeping warm.

Ideally how many people are you looking for?

Good regards

Thula Mkhize

CEO and Chairperson

Mobile : 072 812 3534 | Fax2mail : 086 535 9605 | E-mail : thula@goodstories.co.za |

Website : www.goodstories.co.za | Twitter and Instagram : @GoodStoriesSA | Facebook : www.facebook.com/GoodStoriesSA

LinkedIn : <http://www.linkedin.com/company/good-stories-ziza-izwe-npo-?trk=biz-companies-cym>

From: Lindiwe Tsope

Date: Monday, 22 August 2017 at 2:11 PM

To: Thula Mkhize

Subject: Re: Working with Good Stories

Good morning,

It would be nice to have 7-10 people, but I can work with whatever we've got.

Keeping warm is not an option on this side of the country lol. Hope you're warm too.

Regards,

Lindiwe