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Exploring the embodied experience of HIV positive women on antiretroviral therapy

A research report submitted in fulfilment of the requirements of the degree of **Master of Arts in Community-Based Counselling Psychology**

By

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ABSTRACT

The introduction and usage of highly active antiretroviral therapy (ART) has changed the history of human immunodeficiency virus infection (HIV), which can result in acquired immunodeficiency syndrome (AIDS) when left untreated from a deadly condition to a manageable chronic disease. Despite the great success of antiretroviral therapy in managing HIV, women taking the treatment have reported several side effects which produce a body that appears ill. The ART side effects are fundamental to the experience of living longer with HIV. Research linked to side effects of HIV is primarily conducted in Western countries**,** which leaves a gap in our knowledge of the embodied experience of side effects among women living with HIV/AIDS in Sub-Saharan Africa. This research project explores how women living with HIV experience their bodies and focuses on antiretroviral therapy's embodied side effects. It is crucial to study how HIV-positive women experience their bodies when they are on ART, considering that their bodies are perceived as sex objects, as objects of beauty, and are subject to continuous evaluation and judgment, making it more difficult for them to attain a comfortable embodiment. Eleven HIV-positive women living on antiretroviral drugs for two years or more were interviewed using phenomenological semi-structured interview methods. Their age group was from 26 to 60 years old. The data were analyzed using interpretative phenomenological analysis, and the themes were grouped using the functional, affective, material, and social dimensions of embodiment. The disruptions of the side effects of ART require adjustments as the women in the study need to come to terms with their altered body and deterioration of the body's capabilities, a disruption to their embodied positioning to the world and everyday activities.

KEYWORDS: WOMEN, HIV/AIDS, ANTIRETROVIRAL THERAPY, SIDE EFFECTS, AND EMBODIMENT.

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INTRODUCTION

In 2018, Mosha et. al (2020) reported that 37.9 million individuals lived with HIV worldwide, 1.7 million new cases, and 770,000 AIDS-related deaths. 7.5 million of these individuals were South in 2019 as a result South Africa is recorded to have the greatest number of people living with HIV in the world (Dorward et al., 2021). 60 percent of the 7.5 million HIV-positive people in South Africa (SA) are women (Klazinga et al., 2020). HIV has no known cure. However, there is antiretroviral therapy (ART) to manage the spread of the virus by slowing the development of the virus in the body (Chiu, 2018).

The ARV program in South Africa started in 2004 after a long struggle for access by civil society organizations and the Treatment Action Campaign (TAC) led the struggle against the South African government and multinational pharmaceutical companies ('Big Pharma') (de Weta & Wouters, 2016). The battle centered around issues like the South African government's AIDS denialism, over-priced and patent-related restrictions on producing generic ARVs by 'Big Pharma.' Since then, the South African ARV program in the public healthcare sector has moved ahead quite rapidly. Consequently, there were over four million people living with HIV on ARVs in 2016 (Browne et al., 2019). The availability of ARVs has transformed the course of the epidemic in South Africa, shifting HIV from a potentially deadly illness into a controllable chronic condition: deaths linked to HIV/AIDS have declined by 45% between 2005 and 2015 (Nansseu & Bigna, 2017).

There are side effects associated with ARVs that can undesirably impact the quality of life (Khan et al., 2014; Chen et al., 2013; Gagnon & Holmes, 2016). Women living with HIV (WLWHIV) are significantly more vulnerable, as more women are affected by the side effects of ARVs than men (Quatremère et al., 2017). Gagnon and Holmes (2012) point out that women often liken the experience of side effects to chemotherapy - a treatment that destroys one's body while it heals it. There are even indications in the West that women have a lower adherence rate than men (Quatremère et al., 2017). However, women in South Africa have shown more optimal adherence than men (Moosa et al., 2019).

There are common short-term and long-term side effects of ARVs. The short-term side effects include diarrhoea, dry mouth, nausea, vomiting, and weight loss or gain (Chen et al., 2013), as well as hypersensitivity rash (Khan et al., 2014). Other short-term side effects include vivid hallucinations, off-balance or erratic walking, light-headedness, drowsiness, feeling hungry, feeling like dropping or spinning, and difficulties with concentration, fatigue, and anemia (Hawkin, 2010). They generally disappear on their own after weeks and months of treatment; sometimes, they can also continue over time (Gagnon & Holmes, 2016).

The long-term side effects include a condition such as a lipodystrophy syndrome (Rossouw et al., 2013). Lipodystrophy is a medical problem characterized by fat redistribution in the body (Finkelstein et al., 2015). For example, lipohypertrophy (fat accumulation in the abdomen, breast enlargement, and circumferential neck enlargement, particularly in the dorsocervical area and lipoatrophy (fat loss in the arms, legs, buttocks, and face with loss of subcutaneous tissue) are both present (Gagnon & Holmes, 2012). Fat loss or accumulation could co-occur in different body parts in the same person (Tsuda et al., 2012). Women are susceptible than men to develop lipodystrophy, and the reason for this is unknown (Zinn et al., 2013). Other long-term side effects include cardiovascular, renal, digestive, metabolic, neurological, and musculoskeletal disorders (Hawkins, 2010).

When WLWHIV complain about the side effects of ARVs, their complaints are very frequently trivialized, thereby delegitimizing their experience (de Weta & Wouters, 2016). In the context of limited resources, more attention in the health sectors of sub-Saharan African countries understandably invested in reducing HIV-related deaths and achieving viral suppression rather than treating ARV side effects (Renju et al., 2016). Women suffering from ARV side-effects are referred for HIV counseling services, and there is no investigation and management of their side effects (Quatremère et al., 2017). More research is also needed on the experience of ARV side effects, especially by women (Gagnon & Holmes, 2012).

Rationale

The majority of research on ARV side effects is undertaken in Western countries (Chen et al., 2013). As previously stated by Renju et al. (2017), there is a scarcity of qualitative studies in Sub-Saharan African countries that investigate HIV treatment side effects, particularly their influence on HIV-positive women's daily lives. Because women living with HIV/AIDS have not been given a voice on this problem and are still underrepresented in HIV/AIDS research, the limited study done on this topic is troubling (Gagnon & Holmes, 2012). Furthermore, WLWH are more vulnerable to HIV/AIDS stigma, and are usually described to as "vectors," "diseased," and "prostitutes" (Agu et al., 2012).

Mancini and Secchiaroli (2015) argue that visible body changes experienced by women on ARVs make them identifiable by physical appearance as HIV-positive. When the side effects of ARVs become more visible, they not only resurface HIV but also invite the social gaze of others (Abel & Thompson, 2017). Indeed, ARV-related body changes make HIV status more visible and may even lead to different kinds of feelings associated with either shame, self-doubt, or self-renunciation (Alexias et al., 2016; Yaron et al., 2017). The visible signs of ARV side effects could also challenge the control of disclosure of HIV status in making HIV less concealed or private (Persson, 2005; Gagnon & Holmes, 2011; de Wet & Wouters, 2016).

Women's bodies are frequently viewed as sex objects and beauty objects that are constantly evaluated and judged, making it more difficult for HIV-positive women to achieve a comfortable embodiment (Chrisler et al., 2018). Because of the changes that their bodies may go through when on ARVs, it is critical to understand the lived-body experiences of women living with HIV/AIDS.

Research aims and objective

The goal of the study is to learn more about how HIV-positive women view their bodies, with a focus on how they describe the adverse effects of antiretroviral therapy. The four dimensions of the experience will be explored which include the possibility of action, how they feel and position their bodies, and how others view them. The objective of the study is to paint a picture of how HIV-positive women deal with the side effects of antiretroviral therapy (ARVs).

Overview of the following chapters

The literature is reviewed and critically addressed in Chapter 2. The study's theoretical foundation, phenomenology, is introduced in Chapter 3. The research methodology, research design, data collection technique, and how the findings were analyzed are all covered in Chapter 4, as well as the study's ethical considerations. The study's findings are presented and analyzed in Chapter 5. The research report finishes with a review of the findings, reflections on the research's strengths and shortcomings, and areas for future research in Chapter 6.

LITERATURE REVIEW

The literature on the embodied experience of HIV-positive women will be reviewed in this chapter. I will do this by discussing how others perceive the HIV body, the stigma experienced by WLWHIV, how visible HIV symptoms worsen the stigma experienced by WLWHIV, loss of oneself, how they experience their body as different, unfamiliar, and strange, how living with HIV impacted their sexuality and intimacy and their day-to-day experiences of living with HIV. The existing literature on embodied experiences of WLWHIV will be discussed.

The body with HIV is contagious, contaminated, and promiscuous

The body of women living with HIV has been positioned as a source of infection, dangerous, contagious, and a threat to others (Lawless et al., 1996; Chapman, 2000). The HIV-positive body is regarded as a vehicle or weapon for the virus's spread. It has generated fear, requiring containment, precautions through prevention strategies, and control by medical institutions (Persson, 2013; Kaplan, 2014). A body with HIV is perceived as deadly and creates the fear of the body being invaded, penetrated, and polluted by the virus. People may feel a need to distinguish between "us" and "them" (Rohleder, 2007), the basis of HIV stigma (Brenera et al., 2013). In a study by Davtyan et al. (2016) WLWHIV said that they experience stigma as a separate act of division between "morally impure" and the "morally elite," and a systematic labelling of WLWHIV as "unworthy" and "blemished". To be stigmatized is to be constructed as the ‘other’ and considered "disgracefully different from and threatening to the public" (Liamputtong, 2013, p.3).

The HIV-positive body is perceived as unclean and contaminated. For WLWHIV, it is difficult not to internalize it (Persson, 2013). For example, in a study conducted in Canada, WLWHIV reported feeling "unclean" and "contaminated" (Palmer et al., 2011). The theme of contamination is echoed by one of the participants in a study conducted in the Western Cape in South Africa. In her words, "I think they feel that we are dirty people because if you are clean, like a virgin or only have one partner your whole life, then you would not get it" (Judgeoa & Moalusi, 2015, p.79). The participants in these studies believe the perception of their bodies as unclean and contaminated is widely shared by others.

The perception of contamination is linked to the perception of immorality and promiscuity (Gibson, 2012). The negating moral judgment of promiscuity, irresponsibility, and immorality are more frequently attached to WLWHIV (Nack, 2009). The unfavourable perception of WLWHIV is based on inaccurate and misinformed beliefs, such as the belief that all WLWHIV engaged in unprotected sexual practices with several partners (Davtyan et al., 2016). We know that a person can contract HIV with one unfaithful partner, but these assumptions continue to influence how PLWHIV are judged (Judgeoa & Moalusi, 2015), especially WLWHIV.

The stigma within

The association of HIV/AIDS with promiscuity, the resulting discrimination, and stigma, mainly internalized stigma, have been investigated in several studies (see Liamputtong, 2013; Armstrong, 2014; Paudel & Baral, 2015). Internalized stigma is when negative judgments and misconceptions are directed to oneself (Audet et al., 2013), or the acceptance and application of unfavorable society characterization labels, and perceptions to the self (Turan et al., 2017).Davtyan et al. (2016) have found in their study in the United States (US) that some women living with HIV adopt disparaging appraisals about themselves, such as dirty, different, isolated, promiscuous, and stained. Gibson (2012) also reported similar results, that HIV-positive women used words like leper, contaminated, walking disease, and germ to describe how they perceived themselves.

Internalized stigma can lead to self-isolation and avoidance of social interaction to avoid the shame and humiliation of others, and this could result in mood disorders and reduced social support (Kaplan, 2014; Ho & Goh, 2017). Both HIV-related stigma and social support are independently associated with depression, according to a recent study done among HIV-infected men and women in South Africa (Brittain et al., 2017). Turan et al. (2017) and Rohleder (2007) discovered that WLWH who internalize stigma suffer from guilt, self-blame, embarrassment, and low self-worth, as well as anxiety and a sense of being dirty. When societal meanings attached to HIV are negative, they retain a profound effect on the way women see themselves and how they consider others evaluate them (Alexias et al., 2016). When pessimistic social representatives of HIV are internalized, there may not be a visible change in behaviour from individuals in one's social circle; rather, knowing one is HIV positive is enough to cause a spoiled identity (Chapman, 2000). As Turan et al. (2017) have argued based on the results in their study, women often carry these internalized representations into daily interpersonal interactions.

Visibility of HIV and stigma

When the body of a woman living with HIV has visible symptoms of the disease, these symptoms can be used to discredit and discriminate against her (Varas-Díaz et al., 2005). We know from Stutterheim et al. (2011) that men who have sex with other men living with HIV with visible symptoms experience more stigma than those who conceal their condition. Like men who have sex with other men living with HIV, women too are marginalized in many societies around the world and bear the most brunt for HIV/AIDS (Liamputtong, 2013). Visser (2012) argued that women are typically unjustly labelled as the disease's main carriers, they face greater social disadvantages because of the virus and referred to this as the 'double stigma' of HIV for women.

Changes in a woman's skin body may be interpreted by others as a sign of disease, attracting unwanted attention (Chen et al., 2013). Body changes reveal health status, which can invite the gaze of others and increase stigmatization (Alexias et al., 2016). When a woman shows visible signs of the disease, it is a challenge for her to manage stigma and control the information regarding HIV status when her body appears ill. Let us use the example of lipoatrophy, one of the symptoms of ARVs associated with loss of fat to the face (Gagnon & Holmes, 2012). Lipoatrophy can mean that HIV is written on the face, and thus invites social gaze and makes the possibility of maintaining secrecy problematic (Abel & Thompson, 2017). In general, a few of the body changes associated with ARV side effects challenge women's control over their HIV status in social interactions. Their ability to conceal or keep their status private becomes limited. Their subjective experience turns into the public display (Persson, 2005). Disclosure is also no longer a choice when the symptoms of the illness are visible.

Varas-Diaz et al. (2005) have found that when HIV/AIDS is not concealable, it may cause fear of contagion to those around a HIV-positive person and negatively affect social interactions. Increased access to support networks, improved mental health, earlier initiation, and greater adherence to antiretroviral therapy (ART) are all linked to HIV-positive status disclosure (Karim et al., 2015). However, the importance of having control of disclosure of HIV status is that it helps with limiting negative comebacks, such as cheating accusations, abandonment, rejection, discrimination, disruption of family relationships, emotional and physical abuse, loss of economic support (Visser et al., 2014). Having personal control in the decision to disclose or conceal one's HIV status might help with enduring being "discredited" in the eyes of others (Stutterheim et al., 2011).

Losing oneself

The subjective disruption of an HIV diagnosis has been covered by several South African and international studies. A common finding in the studies is a description of the moment of diagnosis as a type of biographical disruption or a sense of loss of oneself (Mancini & Secchiaroli, 2015; Iwelunmor et al., 2017). The sense of loss of oneself comes from knowing that one has an incurable and stigmatized condition which may change their everyday life (Seeley et al., 2012); and the fear of losing control over one's body and becoming incapable of doing what one used to do (de Weta & Wouters, 2016).

For Iwelunmor et al. (2017), knowledge of HIV is life-defining for WLWHIV, a challenge to their sense of self, and requires the creation of a new identity. Forming a new identity as an HIV-positive person is perceived as a threat to one's existing identity in the sense that past conceptions of the self tend to be questioned and need to be reconciled with the new HIV identity (Kaplan, 2014). This process transition, as defined by Russell and Seeley (2010), relates to a person's adjustment to integrating HIV and its treatment into their lives, identities, and interactions with others. Without this process of transition, coping and acceptance of HIV becomes a challenge. In their study, Ho and Goh (2019) have shown that not every person living with HIV copes by integrating it with their identities. They do not deny the existence of HIV; instead, they prefer to define HIV as a health condition, splitting it from their identities. For them, HIV is less disruptive to their valued identities. If the process of integrating an identity involves incorporating its meanings and role expectations, identities that take in negative meanings could cause psychological distress. Several participants in the Ho and Goh (2019) study believed that by separating themselves from HIV and enjoying their pre-HIV diagnosis identities, they could retain their positive psychological well-being.

A strange, unfamiliar, and uncontrollable HIV body

A study conducted in Singapore among men showed a profound shift in their lives when they tested positive for HIV, who found themselves adjusting from their familiar world to an unfamiliar one of a PLWHIV and feeling out of touch with their bodies (Ho & Goh, 2019)**.** Being diagnosed with HIV might leave you feeling as if you don't understand your body's language, which inevitably leads to a lack of trust because your once-familiar body is now fundamentally unknown (de Wet & Wouters, 2016).In Mulubale's (2020) study in Zambia, for both men and women, awareness of having the virus in the body resulted in feelings of being different from one's former self. The knowledge of the presence of the virus in the body results in the feeling of estrangement from a familiar body as if it is different or a foreign body. The radical changes experienced by WLWHIV in their bodies (Alexias et al., 2015) are linked with perceptions of losing control over the body (Abel & Thompson, 2017).

Gagnon and Holmes (2011) have found with some of their women participants living with HIV that taking control of their body by improving their physical appearance does not help them regain it or as if the antiretroviral treatment permanently damages them. The study by Nyamaruze and Govender (2020) sheds even more light on the experience of ARVs for women. The women they interviewed in KwaZulu Natal (KZN) who were taking ARVs reported discomfort with the presence of sores and patches on their skin. They remind them of prior HIV-related sores that they had before starting ARVs and make them feel self-conscious about revealing their skin. Wearing "length jeans, if not pants, then leggings" helped them cover the areas of their bodies that bore blemishes.

Sexuality and intimacy

WLWHIV experience the diagnosis of HIV as disruptive not only to their sense of self but also their life course, particularly concerning sex, relationships, and family plans (Iwelunmor et al., 2017). Chronic illness can be highly disruptive in relationships resulting in a loss of self (Baumgartner, 2007; Laws, 2016). PLWHIV were advised not to have sex again when HIV/AIDS was associated with illness and death in the early years of its emergence (Carter et al., 2017). Some women decided not to have children, marry, and engage in sexual activities (Dos Santos et al., 2014). Taking antiretroviral medication (ART) as directed and maintaining an undetectable viral load (UDVL) lowers the chance of the virus spreading to others (Carter et al., 2020). Even though ART reduces the risk of HIV transmission, some HIV-positive women prefer to avoid sex altogether or report lost or impaired sexuality (Carter et al., 2017). For these women, engaging in an intimate relationship, getting pregnant, and giving birth continues to be difficult decisions (Mattes, 2014). The moral discourses surrounding HIV continue to desexualize WLWH's bodies and identities, making them feel like their sexual lives are fundamentally changed (Kaplan, 2014). Women with HIV are generally seen and see themselves as a risk to sexual partners, rather than as sexual beings with their own sexual rights (Carter et al., 2017).

WLWH fear passing the virus to others and the potential to be rejected when trying to find a romantic partner (Audet et al., 2013). Their struggle with forming new romantic relationships is due to feelings of loss of sexual interest to avoid passing on infections; the burden of disclosure before engaging in sexual activity; fear of being rejected, and anxiety of infecting others despite the use of safer sex strategies (Herrmann et al., 2013). Women reported that they are constantly pressured to declare their HIV status and to use safer sex (defined strictly as male condoms) with everyone, always (Carter et al., 2017). Those who do reveal frequently face violence, rejection, and abandonment from partners, as well as fear, prejudice, and moral judgment from society (Carter et al., 2017). Some women thus avoid relationships after being diagnosed with HIV, and others negotiate safer sex practices without disclosing their HIV-positive status (Baumgartner & Niemi, 2013).

When someone chooses to reveal their HIV status to a sexual partner, it is out of a wish to keep the other person safe from infection. The fear of losing a relationship drives the decision not to disclose to an intimate partner (Seeley et al., 2012). According to Carlsson-Lalloo et al. (2016), HIV-positive women experience much more sexual issues than uninfected women, as well as significantly lower scores in sexual desire, activity, and satisfaction than women without HIV. Some women will continue to have sex after being diagnosed with HIV, while others will stop having sex entirely (Carter et al., 2017).

Day-to-day living on ARVs

Studies report different physical and mental effects of antiretroviral therapy on everyday performance. Adherence to ART demands taking medication on a regular basis, which is typically accompanied by physical side effects such as drowsiness, impaired focus, weakened mental capacities, headaches, nausea, vomiting, and exhaustion (Bhatti et al., 2016).Other physical associations include neuropsychological impairments such as problems in executive functioning, psychosocial problems such as depression and anxiety, and medical problems such as fatigue and illness-related side-effects of antiretrovirals (McGoldrick, 2012).

Fatigue is a common and unpleasant sign among persons suffering from chronic illness, particularly among people living with HIV/AIDS. It has a detrimental influence on their ability to work, everyday functioning, quality of life, sociability, job desire, productivity, physical activity level, psychological well-being, health-seeking behavior, and adherence to the ART regimen (Baye et al., 2020; Webel et al., 2016). In PLWH, fatigue may endure after rest, signifies illness, and makes HIV visible (Stutterheim et al., 2011; Schuft et al., 2018). Opportunistic infections can also occur shortly after beginning with ART. They can limit the ability to work and maintain employment or re-enter the job market (McGoldrick, 2012). In a South African study, a participant said that opportunistic infections left her depressed about her body's altered state and that she didn't feel healthy or energetic, making her unable to cope with daily activities (de Weta & Wouters, 2016).

These difficulties notwithstanding, ART does appear to offer long-term gains in the ability to perform everyday activities, such as entering or remaining in employment. A study of adult ART patients at three South African treatment centres found that physical and psychological well-being, as well as economic activities, improved significantly within one year of starting therapy (Rosen et al., 2010). The improvement in patients who stayed on medication for the full three years after starting treatment either continued or remained steady (Rosen et al., 2010). Consequently, women living with HIV, who would otherwise have become seriously ill to work without ART, they could enter the workforce and re-enter the job market as long they adhere to treatment (Fair et al., 2018). HIV patients on antiretroviral therapy can remain employed and return to work after they initiate treatment, and when they are out of work, their unemployment could be explained by other factors faced by the general population (Bor et al., 2012) such as high employment rates in South Africa.

More generally, the employment concerns of PLWHIV include fear of discrimination and stigma or regarding medication schedule and how health will affect their work (McGoldrick, 2012). Living with HIV requires frequent medical appointments that result in regular work absenteeism, making it more challenging to maintain consistent performance over time (Fair et al., 2018). Disclosure of one's health status at work may provide PLWHIV with necessary accommodations such as modified work schedules and alteration of physical demands of tasks at work to compensate for fatigue and decreased strength and endurance, but there is also always the fear of being discriminated against and stigmatized (Barkey et al., 2009). The possibility of returning to work could therefore be perceived as threatening if linked to disclosure of HIV status (Mancini & Secchiaroli, 2015).

In the UK, a study found that stigma and fear of discrimination were a significant concern for almost half of those not working, with only 11% of those employed who reported stigma and discrimination at work (Rodger et al., 2010). There could be a gap between the perception and reality of stigma in the workplace. As Rodger et al. (2010) and Fair et al.

(2018) have found in their studies, shame and anxiety regarding disclosure to a future employer and co-workers can be a very significant discouragement in the search for employment for PLWHIV. A gap that remains underexplored is that fear of stigma might be less of discouragement in searching for work in contexts of high unemployment and limited employment opportunities.

Research questions

This report, like earlier research, explore the aspects of HIV diagnosis and antiretroviral therapy that were identified in the literature review. The study examines how HIV-positive women on antiretroviral therapy (ART) experience their bodies, drawing on the theoretical framework of phenomenology, which will be explored in the next section of this chapter. The question is explored through the following four sub-questions:

1. How do they experience their bodies as a disruption or empowerment to engage in day-to-day activities?
2. What are their appraisals and feelings about how they experience their physical body?
3. In what ways do they experience their bodies differently, as strange, or familiar?
4. How are they aware of their bodies in social interactions?

THEORETICAL FRAMEWORK

Health researchers have used phenomenology to describe the experience of being ill (Fernandez, 2020; Carel, 2010). Slatman (2014) points out that the phenomenological framework is widely used within health and medicine because it is helpful in describing the experience of suffering from HIV by focusing on the first-person point of view of what it is like to be ill. This research project also adopted a phenomenological framework for the potential it offers to open first-person as well as in-depth accounts of what it is like to live with HIV and its treatment for the women that were interviewed. Clinicians who take a more inclusive approach to HIV care, paying more attention to the illness as it is experienced by the individual rather than relying solely on predefined medical categories for diagnosis and treatment, could assist women living with HIV (Gergel, 2012).

The Background of the Phenomenological Framework

Around the turn of the nineteenth century, Franz Brentano (1838-1917) and his student Edmund Husserl (1859-1938) established the phenomenological framework (Moran, 2008). Edmund Husserl (1859–1938), on the other hand, is often regarded as the originator of phenomenology (Zahavi, 2019). Martin Heidegger (1889–1976), Jean-Paul Sartre (1905–1980), and Maurice Merleau-Ponty (1908–1980) are three more phenomenologists who came after Husserl (Zahavi, 2019). They differed from Husserl in their interest and conception of phenomenology, but they share an emphasis on experience and its interpretation, the so-called "phenomenological approach" (Toombs, 2001).

Phenomenology, according to Moran (2002), is a radical, anti-traditional kind of philosophizing that emphasizes the desire to get to the truth of things, to describe phenomena as it appears to the person experiencing it. Phenomenology emphasizes a method of comprehending one's experience rather than focusing on the reality of things, the purpose being to describe the experience of the phenomenon as it is perceived and experienced from a subjective standpoint (Carel, 2016). The philosophical, theoretical, and methodological framework of phenomenology is concerned with the world as experienced by a person. The world and reality for phenomenology are not independent of the person experiencing it, and their constitutive phenomena exist only when they are perceived (Kalaldeh et al., 2018).

Embodiment

The notion of embodiment is a crucial area of phenomenological inquiry (Toombs, 2001). The body for Merleau-Ponty is not only an object but the subject of experience (Lape et al., 2019). Husserl saw the body not only as a physical object like other objects in the world, but for him, the body is also the locus of sensations, as well as the source of meaning and knowledge (Grīnfelde, 2019). The distinction between the objective body - *Körper* for Husserl or *le corps objectif* for Merleau-Ponty- and the body as lived - *Leib* for Husserl or *corps proper* for Merleau-Ponty – is the basis for understanding one's experience of being in one's body from a phenomenological perspective (Slatman, 2014). Körper refers to our physical bodies, who we are as physiological, neurological, and skeletal beings. Leib is how we interact with the physical body in our daily lives (Aho & Aho, 2008). The lived body is the one I am, and the physical body is the one I own (Fernandez, 2020).

When the lived body is affected by illness, the illness is not only a "biological dysfunction ."Illness is also the disintegration of the patient's world beyond the breakdown in the mechanical functioning of the biological body (Sholl, 2015). Embodiment is, therefore, the foundation for comprehending oneself, others, and engaging in daily life; the body is a living and not only a material object in the world (Kitzmüller et al., 2013). The relevance of this perspective for the current research is that living with HIV could be experienced as the disruption of the lived body and a malfunction of the biological body (Toombs, 1992). In the phenomenological perspective, the lived experience of the dysfunction is the primary emphasis. The dysfunction could disrupt habits, capacities, and actions (Sholl, 2015). Physical changes associated with illness diminish the control of the body, demand adjustment, and there could be a new experience of the body.

Women with HIV who have to take antiretroviral therapy could undergo changes in their bodies and experience them anew. These changes are, to a large degree, out of their control. During their struggle to adjust to the drastic changes in their bodies, they may feel disembodied or overwhelmed by bodily sensations (Wilde, 2003). In this research, the embodiment of HIV and the effects of ARVs are investigated. There are four dimensions of an embodiment of HIV to consider: "the functional, affective, material and social dimensions of embodiment" (Grīnfelde, 2018, p.109). In the research, these four dimensions are applied to the lived experience of HIV-positive women on ART to understand the relationship women living with HIV have with their bodies from their perspective, as it is not simply a breakdown in mechanical functioning, but a disordered way of being-in-the-world which affects how the relationship one has with their own body and others (MacLachlan, 2004). I want to explain each dimension and how it is utilized in the research:

Functional embodiment

The inability to engage in activities that one would normally engage in before illness is referred to as the functional dimension and this ability to act is compromised by illness (Grnfelde, 2019). The functional dimension is a disruption in the lived body - an incapacity to engage with the world in the same way that one normally does (Toombs, 1992). The experience of disease, according to Carel (2016), is a breakdown of physiological certainty or "the subtle feeling of 'I can' that pervades our activities" (p. 90). The phrase "I no longer can" causes physiological doubt and "disruption of one's most basic sense of being in the world" (Grnfelde, 2019). Body movements and activities that were before performed with no issues become impossible (Bullington, 2009).

Fatigue is a common complaint among HIV-positive women, and it has a detrimental influence on their capacity to work, everyday functions, and quality of life (Webel et al., 2016). According to Gebreyesus et al. (2020), fatigue impacts women living with HIV's ability to complete daily tasks and productivity. Exhaustion is typical after physical action in HIV-negative people, whereas fatigue persists after rest in HIV-positive women. It's a persistent feeling of exhaustion, lack of energy, inertia, or fragility that worsens with activity and limits a person's usual capabilities (Langseth, 2018). Because of an imbalance between available physical and psychological resources and the resources necessary for the resources required for optimal functioning, fatigue produced by HIV and its treatment hinders the ability to complete everyday chores and produces bodily doubt.

Affective embodiment

The living body is experienced as a bearer of experiences and a means of action in the world (Grnfelde, 2018). The affective dimension is concerned with bodily feelings, emotions, and moods as they relate to the physical body. The focus of this study is on the physical sensations and emotions linked with HIV. For example, shame, self-blame, pain, exhaustion, nausea, worry, helplessness, melancholy, and itching which are common experiences of living with HIV. When someone is in pain, it is possible for the suffering to take control of their lives. One's sense of self is reduced to pain - the painful body and the pain-filled world

(Bullington, 2009). This may lead to a sense of helplessness, loss of control, and vulnerability due to lost bodily capacities and the inability to control the illness, increasingly limiting one from performing certain activities (Carel, 2016). In the research, the bodily feelings and emotions linked to both HIV diagnosis and the experience of taking antiretroviral therapy were examined.

Material embodiment

People with illnesses may experience physical symptoms such as pain, discomfort, and identity loss, in which they feel alienated and disconnected from the activities that once gave significance to their lives (Bullington, 2009). Grnfelde (2018) defines the material dimension of embodiment as "the experience of one's body as alienated from oneself as a result of disease." Disembodiment or dissociation with one's body can occur because of illness (Wilde, 2003; Svenaeus, 2014). As Bullington (2009) has observed, "in health, I am my body, but when my body does not work, I experience a split between myself and my body, and my body is no longer me. I take this malfunctioning body to the clinician and ask her to fix it so that I can once again become one with my body” (p.102). The body-self unity exists on a continuum of embodiment, with extremes on each end. The body feels alienated in dysfunction, as though it belonged to someone else (disembodiment) (Lape et al., 2019).

Let's use HIV as an example. Gagnon and Holmes (2012) observed that women living with HIV experienced bodies changed because of HIV and its treatment. The women felt alienated from their bodies because of the body changes. They also said their bodies felt like an external object to them because they couldn't control the changes they were going through. The material dimension of embodiment regarding illness, from a phenomenological standpoint, focuses on our experience of day-to-day control over our bodies.

Social embodiment

The social dimension of embodiment involves adopting the perspective others have on one's body, like their view that one's sick body is unacceptable or unattractive, among others (Grīnfelde, 2018). In most contexts or social environments, any physiological characteristic, especially one that deviates from the norm, is attached to a specific meaning (Fernandez, 2020). Usually, a person's viewpoint on embodied experience is inextricably linked to an outside perspective on their body. In the history of HIV, the perception of PLWHIV is a good example of this link. As several studies (see Palmer et al., 2011; Persson, 2013; Judgeoa & Moalusi, 2015) have demonstrated, when the prevailing perception of PLWHIV is that they are unclean or contaminated, it is difficult for them not to internalize it into self-stigmatization. We must study not just how one's body is lived or experienced "from within," but also how it manifests itself in a shared world; how it appears "from the outside" for others as well as for oneself (Slatman, 2014).

Conclusion

The chapter gave a quick overview to phenomenology, covering the concept of embodiment and its four dimensions of application. According to Klausen (2021), phenomenology is influencing contemporary endeavours to give more weight to patients' lived experiences and transcend the limitations of a one-sided biological explanation of sickness or illness. There are faults in using a phenomenological approach to examine disease experiences, especially when it is utilized to study experiences of illness. They will be explored in the report's concluding chapter. The application of the four dimensions of embodiment proved to be quite beneficial in adding more depth to the analysis.

METHODOLOGY

The study design and procedures used to answer the research questions are referred to as methodology (Kivunja & Kuyini, 2017). The method, on the other hand, refers to the tools that are used to collect and analyze data (Mackenzie & Knipe, 2006). This chapter discussed the data collection method, why it was utilized or chosen, and how it was used. It describes the research strategy and techniques for selecting and recruiting participants, as well as gathering and analysing data. Finally, the project's ethical considerations, limitations, and validity are examined.

Research design

A phenomenological research design seeks to describe the phenomenon being investigated by looking at it through the eyes of people who have been through it (Neubauer et al., 2019). There are several phenomenological approaches. The one used in this research is a Husserlian phenomenological approach. It is also known as descriptive phenomenology. This approach allowed the women interviewed to describe their experiences in their own words with very little influence of the researcher's interpretation of the phenomenon under investigation (Stapleton & Pattison, 2015). In the Husserlian phenomenological approach, experiences are described, and the researcher's perceptions are set aside or 'bracketed' (Rodriguez & Smith, 2018). This enabled the researcher to enter the lifeworld of the research participant without any presuppositions. A phenomenological research design should provide access to direct experiences of the research participants before any causal explanations, thus enabling the researcher to apprehend and understand their meaning for them (Grīnfelde, 2018). From the perspective of the research questions, aims, and objective of this research project, phenomenological research design offered a unique understanding of how the research participants experiences with ARVs disrupted their sense of being in the world (Yaron et al., 2017).

In qualitative research, data is collected using a range of approaches, including observations, textual or visual analysis (e.g., from books or videos), and individual and group interviews (Gill et al., 2008). This study used a semi-structured interview method to collect data, and one-on-one interviews were conducted.

Recruitment strategy

The recruitment strategy used in phenomenological research is purposive, as the study participants consisted of individuals who will know or have a lived experience of the investigated phenomena (Mapp, 2008). Only HIV-positive women on antiretroviral therapy for two years and more were approached and selected to participate in this study. Eleven women were interviewed, and one of them was a pilot to test the interview schedule when the data gathering started. Her transcript was included in the analysis. In a phenomenological study, there is more emphasis on quality than on quantity (Smith et al., 2009; Bolderston, 2012), and the aim is to produce an in-depth examination of the phenomena under investigation, not to produce a theory that is generalizable to the whole population (Pietkiewicz & Smith, 2014).

Recruitment of participants

Recruitment is often a three-step procedure that begins with finding possible participants based on inclusion and exclusion criteria, contacting them about the study, and getting their willingness to participate in the study, including their informed consent (Preston et al., 2016). In this research project, the researcher identified Non-Governmental Organisations (NGOs) to assist with recruiting women who met the criteria for participation in this research. A few organizations were approached until the Treatment Action Campaign (TAC) agreed to assist in putting the researcher in contact with potential participants. TAC is well-known in South Africa and around the world in leading the fight for access to ARVs in public health facilities, encouraging quality public health care, and campaigning for an equitable health system that delivers equal treatment for everyone in South Africa.

Potential participants were identified by the TAC's Chairperson from the organization's support group membership roster. She also facilitated the recruitment drive and even provided support in building trust with the participants. The researcher was able to then contact potential participants to arrange for an information session with them. At this meeting, they were given an information sheet (see Appendix A) consisting of information on what the study is about, what their participation will entail, how much time their participation will take, and the possible risks and benefits associated with their participation. There was only one information session set up. Those who attended were also afforded an opportunity to ask the researcher questions about the study and their participation. After the information session, the researcher followed up by phone with everyone to explore their willingness to participate and to arrange a suitable time to do the interview with each willing participant. Before each interview started, the researcher sought the agreement of each participant for their participation in the research project, including obtaining their informed consent (see Appendix B). The interviews took place in a private office provided by TAC. This location was convenient and comfortable for the participants as it was a familiar environment for them.

Research participants

The participants and their demographic information are in the table below:

HIV-positive women	**Age**	**No of years of diagnosis**	**No of years on ARVs**	**Employment status**	**Race**
Gladness	43	18	15	Unemployed	African
Nomzamo	59	23	15	Unemployed	African
Karabo	58	10	10	Employed	African
Nobuntu	46	8	3	Unemployed	African
Sandile	28	17	12	Unemployed	African
Lerato	36	3	3	Unemployed	African
Ayanda	38	8	8	Unemployed	African
Nandipha	60	15	3	Unemployed	African
Lungile	51	17	15	Employed	African
Lihle	26	2	2	Unemployed	African
Nosipho	55	14	14	Unemployed	African

Table 1: Participants and their information

The youngest and oldest participants were 26 years and 60 years old at the time of the interview, and the highest number of years a participant has been on ARVs was 15 years. Only two participants were employed at the time the interviews were done.

Research instrument

The research used the semi-structured interview method, the most common interviewing technique in qualitative research (Barrett & Twycross, 2018). A semi-structured interview method allows the interviewer to ask about the core elements of the phenomenon studied. As already mentioned previously, one-to-one interviews were conducted. One-to-one interviews are manageable, allowing for a rapport to be established and give participants the space to reflect, share their inner thoughts and feelings, and be heard, and are therefore well-suited for sharing in-depth and personal experiences (Smith et al., 2009). An interview schedule was prepared (see Appendix D) to enable the natural flow of the conversation, to facilitate a comfortable interaction with the participants whereby they are free to provide detailed accounts of their experiences (Smith et al., 2009; Pietkiewicz & Smith, 2014). The interview schedule was comprised of open-ended questions. Open-ended questions do not make assumptions about the participant's experiences or lead them in the direction of answers (Smith et al., 2009). Each interview started with a question that permitted the participant to tell a descriptive experience and encourage the participant to talk at length: "*Can you tell me about when you received an HIV diagnosis and how you felt* ."The open-ended question helped build rapport with the participants by putting them at ease, building up confidence in the interview, and generating rich data that further developed the interview (Gill et al., 2008).

The duration of the interview depends on several factors, including the type of interview method used (Bolderston, 2012). Interviews can also vary depending on the topic the conversational dynamic between the interviewer and interviewee, but on average, interviews can last for 20-60 minutes (Gill et al., 2008). The duration of the interviews in this research ranged between 20-50 minutes, and the pilot interview lasted for 15 minutes. The pilot interview was helpful to establish if the schedule is clear, understandable, or answerable and the changes required to the interview schedule (Gill et al., 2008). There were questions in this study that were confusing or misinterpreted by the participants. These were then altered. The minor alterations helped ensure that the rest of the interviews yielded as much information about the participants' experiences as possible and addressed the aims or objectives of the research.

The location of the interview should be private, quiet, allow for an uninterrupted experience, and be conducted in a location convenient and comfortable for the participant (Bolderston, 2012). As previously noted, the interviews for this study were conducted in one of the TAC offices. The office was comfortable, safe, and free from interruptions. Each participant was able to choose a time that was convenient for them. The interviews were conducted in IsiZulu and were tape-recorded with the permission of the participants (see Appendix C). Note-taking may disrupt the natural flow of the conversation. Hence, when possible, it is preferable to audio record the interviews (Doody & Noonan, 2013). The transcripts were transcribed verbatim, as this protects against bias and provides a permanent record of what was and was not said (Gill et al., 2008), and can be studied in detail and linked with analytic notes (Bailey, 2008).

Interpretative Phenomenological Analysis

Interpretative phenomenological analysis (IPA) was the analysis method employed in this study. It is concerned with evaluating individual lived experiences and how they make meaning of them (Smith et al., 2009). The phenomenon of interest is investigated from the perspective of the participants, with a focus on how they experience it and the meaning that these experiences have for them (Rajasinghe, 2019). IPA entails a lot of reading and taking notes, then transforming those notes into creating ideas and looking for relationships and clustering themes. Through a rigorous analytic and quality assurance procedure, the method assists researchers in producing more interpretative accounts of participants' experiences (Rajasinghe, 2019).

Immersion in the data is the first step in IPA (Smith et al., 2009). Listening to the audio recording, reading the transcript multiple times, and recalling the setting of the interview, particularly the location where it was done, were all part of this study (Pietkiewicz & Smith, 2014). Active involvement with the data is required to comprehend the participant's experiences (Smith et al., 2009). In the second step, the researcher keeps an open mind and takes notes on anything that catches his or her attention in the transcript (Smith et al., 2009). The researcher was able to become more familiar with the transcripts and discover the unique ways each participant talked about their experience. Steps 1 and 2 were combined by reading each transcript and taking notes. With more reading, more exploratory notes and comments were added (Smith et al., 2009).

The following step focused on the notes generated in step 2 rather than the transcript, as well as transforming the notes into themes to provide a summarized report of what was important in the transcript notes (Smith et al., 2009). The transcripts were represented in the detailed and comprehensive notes prepared in step 2 (Pietkiewicz et al., 2014). The themes, on the other hand, reflect not only the participant's original words and thoughts, but also the researcher's interpretation (Smith et al., 2009).

The final stage involves looking for links between emergent themes, grouping them based on conceptual similarities, and assigning a descriptive label to each cluster (Pietkiewicz et al., 2014). After that, a table was created depending on how well the themes worked together. The table aided in the identification of emerging themes and the creation of a structure that allowed participants to highlight the most fascinating and relevant aspects of their experience (Smith et al., 2009). (See the table in analysis and discussion chapter). With each transcript, steps 1-4 were repeated. The final stage was to seek for patterns throughout all 11 cases (Smith et al., 2009).

Ethical considerations

The ethical clearance was obtained from the University of the Witwatersrand, Human Research Ethics Committee (HREC). The ethics clearance, together with a request letter for assistance with the recruitment of participants and the study's information, were circulated to several NGOs.

After TAC offered their assistance, an information session with prospective participants was arranged. The Chairperson of TAC helped with organizing the information session. Those who attended the information session were introduced to the research, its purpose, and procedures. The audio recording of the interviews; the types of questions that were likely to be asked; the risks and benefits of the research; the voluntary nature of participating in this research and the right to withdraw their consent at any time; and the procedures that will be followed to protect their confidentiality in the report and other published work generated from the research were all verbally explained to them. The language of the information sheet was accessible and understandable. There was also time set aside for them to ask questions about the research (Richards & Schwartz, 2002).

According to Pietilä et al. (2020), valid informed consent can only be gained if a potential study participant is accurately informed about the research, has the capacity to understand what they are told, and is willing to participate. In this study, the same approach was used: potential volunteers could choose whether or not to engage in the study. Agreeing to participate involved signing an informed consent form (see Appendix B) to participate in the study which also entailed consenting to the audio recording of the interview (see Appendix

C). Informed consent refers to a participant's explicit permission to participate in a study after obtaining and digesting all the information regarding the study (Townsend et al., 2010). The study's 11 participants all gave full informed consent.

Participants trust that their personal information will be kept secure and that only predefined individuals will have access to it when they share it for research reasons (Pietilä et al., 2020). Confidentiality in research with human subjects refers to data management and storage, who has access to it, and the degree to which it is shared with others outside of the research project (Cacciattolo et al., 2015). The data collected in this research was stored in a password-protected folder to maintain confidentiality and minimize the risk of a participant's identity being exposed. Only the researcher and the researcher's supervisor had access to the data. All the identifying information about the participants was removed, whether it relates to the location or dates of the interviews or names of the participants. The participants' names were replaced with pseudonyms to ensure that no one who participated was linked or traced back to the written work resulting from the research.

The principle of beneficence refers to a researcher's ethical obligation to promote well-being and maximize benefits for study participants and society, while the principle of non-maleficence refers to the researcher's ethical obligation to reduce risk and avoid harm to study participants and society (Pietilä et al., 2020). It is impossible to precisely evaluate risk, especially emotional risk, when getting consent for an interview study. The greatest thing to do is to foresee its potential and take proper precautions to avoid injury (Townsend, 2010). A list of publicly available and nearby support and counselling services (see Appendix A) was provided to the participants in this study in case they required or needed it. No one stated that they require it.

The principle of justice in research involves ensuring that anyone who is eligible to participate is treated fairly and equally (Pietilä et al., 2020). In this research, this principle initially informed the selection of participants. Only the research questions were a guide for the selection of participants to avoid or minimize excluding anyone, select participants because they are vulnerable, or because they are easy to access (Barrow et al., 2020). No one was chosen because they are representative of all population. To guarantee fairness, all potential volunteers were given an equal opportunity to participate in the study and were free to choose whether or not to do so. Participants may perceive a lack of access to research as a lack of voice especially those who already feel unheard or that their experiences in medical consultations are "invalidated" may be particularly sensitive (Townsend, 2010).

Trustworthiness

In qualitative research, trustworthiness refers to the systematic rigor of the research design, the researcher's credibility, the believability of the findings, and the applicability of the research methods (Rose & Johnson, 2020). The credibility, reliability, confirmability, and transferability of the research findings were among the factors employed in this study to determine trustworthiness (Forero et al., 2018).

Credibility is the level of trust that may be placed in the accuracy of a study's findings (Korstjens & Moser, 2018). Participants' credibility was ensured by asking follow-up questions, requesting additional information, and encouraging them to provide instances for clarity (Forero et al., 2018). During the interviews, the method increased their participation and improved the relationship between the researcher and the participants (Rose et al., 2020; Barusch et al., 2011).

Dependability refers to the consistency and reliability of research findings, as well as the extent to which research procedures are documented, allowing someone outside the study to observe, audit, and evaluate it (Moon et al., 2016). The researcher's supervisor reviewed the audio recording and transcripts to validate the themes detected and the study's conclusions, which increased the study's reliability. Another strategy to improve the reliability of the findings is to make the research process more transparent (Moon et al., 2016). In the preceding discussion, the research method is discussed in detail.

Confirmability is concerned with proving that the data and interpretations of the findings are not made up, but rather are clearly drawn from the data (Korstjens et al., 2018). Confirmability was achieved in this study by keeping a reflexive diary throughout the research process for daily notetaking and documentation of reflections that would be useful and relevant during the study and analysis (Cypress, 2017). The practice of translating findings to different contexts or settings with other participants is referred to as transferability (Korstjens et al., 2018). The use of a purposively recruitment technique in this study aided transferability because the participants were well-versed enough in the phenomenon under study to provide detailed descriptions of their experiences with it. The researcher's descriptions of the participants and the research process are also hopefully detailed enough for the reader to evaluate if the findings are transferable.

Conclusion

The method was presented in the previous chapter, and the results discussed in the next chapter are based on its application. The method's overview includes a full description of the recruiting strategy and procedure, as well as a description of the study participants, the research instrument, the method of analysis, the study's ethical considerations, and the criteria for establishing the findings' trustworthiness.

ANALYSIS AND DISCUSSION

In this chapter, the analysis and discussion of the data collected are presented. The presentation draws upon the four dimensions of an embodiment of the phenomenological framework: the functional, affective, material, and social dimensions. These are incorporated within a discussion of the main themes and sub-themes that emerged from the data.

Main Themes			
Functional embodiment	Affective embodiment	Material embodiment	Social embodiment
Subthemes			
Sleep disturbance	Difficult emotions	'This is not my normal body'	HIV-body as frightening, diseased, and underserving
Nutrition and the HIV-body	Difficult bodily sensations	The strange and unfamiliar body	A contagious body
Consciousness of the living body		Conceal the HIV-body	Anticipated and lived stigma
			Body evaluations in social situations
			The promiscuous HIV body
			Sex with a condom as unenjoyable
			An undetectable and not using condoms

Table 2: Themes

The functional dimension of embodiment

The functional dimension of the lived body of women living with HIV is the possibility of action in the world. An example is the ability of the body to freely engage with one's environment and daily activities (Grīnfelde, 2018). The subthemes identified are sleep disturbance, nutrition and HIV-body, and inability to engage in daily activities.

Sleep disturbance

Illness could be a disability when it results in the "inability to" engage with daily tasks in habitual ways (Toombs, 1998). The findings of this study show that some of the participants experienced different complications in their sleeping patterns when they started with antiretroviral therapy. These included nightmares, difficulties with falling asleep, and dizziness:

> Extract 1
>
> Nomzamo: when I started with treatment- the first day I started with the treatment, I had a horrible dream *yoh*, the second day, I had a horrible dream again. But they [healthcare professionals] informed me that the pills would disturb me. I endured, I endured. I got used to them as time went by.
>
> Extract 2
>
> Lerato: When I started [pause] the first day, the first day I drank the pill, I did not sleep that day. I remember - I do not know, but I did not sleep. It was like my head-I did not know how to explain it.
>
> Extract 3
>
> Nosipho: I started with three pills. I would feel dizzy when I was sleeping after taking it, but as time goes my body got used to it.

Sleep disturbance is not uncommon when patients start with antiretroviral therapy but is expected to go away after three months (Taibia, 2013; Hawkin, 2010; Gagnon & Holmes, 2016). A daily routine that Nomzamo, Lerato, and Nosipho had previously performed without any problems was disrupted by antiretroviral therapy. Their sleep disturbance continued beyond the three months. They had to adjust to it.

It is unclear whether sleep disturbance is related to HIV infection itself or to the type of antiretroviral drugs used (Lee et al., 2012). Nandipha has a different experience with ARVs:

> Extract 4

> Nadipha: The thing with ARVs, they are not from the same company; there are white ones. After drinking it, I fall asleep immediately. The brown-ish pill does not have that effect on me. They give you the brown pill or sometimes the white pill.

When Nandipha took the white pills, she would fall asleep immediately. Switching to the brown pills helped her regain her usual sleeping pattern. Karabo was lucky that the ARVs she started with suited her. She never experienced any sleep disturbance:

> Extract 5
>
> Karabo: They say sometimes you get nightmares, but I did not have nightmares. The pills treated me well. I did not experience bad dreams. The pills were right for me.

For Nandipha, the side effects of ARVs depended on the company that manufactured the drugs. The ARVs Karabo started with were, in her words, "right for me". The rest of the participants did not report any sleep disturbance.

Nutrition and the HIV-body

When you are HIV positive, actions that were performed habitually, such as walking, running, lifting, sitting up, eating, talking, and so forth, can become effortful (Toombs, 1988). Some of the women interviewed in this study reported that when they started with ART, eating became impossible. They lost their appetite, with some of them vomiting after eating:

> Extract 6
>
> Nosipho: Yes, I used to eat, but sometimes I would lose my appetite. I would buy *amahewu* and drink them, but sometimes I would vomit. At the Clinic, they [the nurses] told me I should not stop drinking my pills. My body got used to the pills as times go.

> Extract 7
>
> Sandile: Yes, I was taking pills. But they were not for weight gain. They were to increase appetite because I was not eating (.). The vitamin B complex from the Clinic was not helpful. I decided to buy pills to increase my appetite, and they were helpful. If I did not buy them, I do not know what I would be or look like now. I think I need

> to buy them again because my appetite has decreased again. Even today, I did not eat anything since I left the Township, and I am still not hungry. I need to get the pills again.
>
> Extract 8
>
> Lerato: Even when I wanted to eat, I did not have an appetite, and I also started to lose weight a bit- a bit-do, you understand?

Nosipho vomited after eating and lost her appetite, and healthcare professionals advised her to continue drinking her medication. Sandile took vitamins to increase her appetite as she was not eating well. She lost weight from not eating well. Lerato lost her appetite, and she struggled to eat even when she wanted to eat, and like Sandile, she lost weight. Enwereji et al. (2019) have found that a variety of reactions are associated with the side effects of ART, including vomiting, lack of appetite, and weight loss. For Nosipho, Sandile, and Lerato, taking ART was initially foreign to the body. ART produced unpleasant consequences of vomiting, loss of appetite, and weight loss for them. Nosipho and Lerato eventually regained their appetite. Sandile still struggles with maintaining a healthy appetite – she takes vitamins to boost it.

Not everyone interviewed ever had or had a problem with their appetite, nor reacted negatively to food. Nandipha could "eat everything including fat cakes," and Karabo too. Both the participants have never had to either limit or watch their dietary intake. Most of the women interviewed had been advised on what they can and can no longer eat by their healthcare practitioners:

> Extract 9
>
> Lerato: At the Clinic, they tell us we must eat healthy food such as fish, chicken- fruit, or juice, do you understand.
>
> Extract 10
>
> Nobuntu: Now that I have gained weight, the dietitian at the Clinic tells me what to eat and not eat, but how am I going to do that when you are not working? If they [family] are eating pap at home, I will also eat pap. I cannot eat what they [dietitians] tell me to eat because I am not working. How am I going to buy food? I eat what is available, which is what they say I must not eat. I cannot change the food I eat to what

> the dietitian recommends. It is difficult to change my diet, even if I am willing to, because I am not working. I eat everything besides the food I did not eat before receiving an HIV diagnosis.
>
> Extract 11
>
> Lungile: she said I should not eat pizza, decrease the number of slices of bread to two, eat brown rice and reduce fats like I mentioned I do not like losing weight, people complimented me, they said 'I am beautiful,' but one day I was angry, and I decided to cook pap with cooking oil and put the pills in the pap, and I ate. I wanted my weight back; yes, people say I am beautiful, but I did not like my body. Yes, I listened, and I ate everything she recommended. I stopped eating pizza, Rama [butter], and I eat brown rice, it is not nice, but I eat it, I boil vegetables and meat, I do not eat fried food most of the time, but I want my body back.

The main challenge for Nobuntu in extract 10 above is a financial constraint, not so much what to eat or not. She was not working during the time of the interview. A diet heavy in vegetables, fruits, whole grains, and legumes, lean and low-fat protein sources, restricted foods with added sugar, proteins, carbohydrates, and a little beneficial fat in all meals and snacks are all meals and snacks that provide maximum health for HIV-positive people (Enwereji et al., 2019). Nobuntu was not the only participant who could not afford the healthy diet recommended by healthcare professionals. Unemployment and very limited financial means prevented the participants from adopting a healthy diet. For someone taking ART, maintaining a healthy diet is very difficult when you are unemployed and you have no personal income (Moyo et al., 2017).

Lungile in extract 11 faces a different challenge: she hates her body because she has lost weight. Unlike the other participants, she is employed. She makes an effort to eat what healthcare professionals have recommended, but she wants to gain weight. She, therefore, struggles to maintain a healthy diet. A healthy diet for someone taking ARVs is a must to keep a healthy body, improve immunity, limit disease complications and improve quality of life (Enwereji et al., 2019); however, for the women who were interviewed in this study, unemployment and financial constraints make adopting a healthy diet a significant challenge. Dissatisfaction with weight loss is another barrier to maintaining a healthy lifestyle. For Lungile in extract 11, being comfortable in your body is as important as a healthy diet.

Consciousness of the living body

WLWHIV reports they no longer go about everyday life without conscious awareness of what their bodies can and cannot do. They spoke about how their bodies can no longer function the way they used to before and the health complications of trying to do what they used to do previously with their bodies. Sandile, Gladness, and Karabo even stopped working:

> Extract 12
>
> Sandile: (.) I can say it has an influence because I used to work at… [name of the company] before and we used to work in the fridge room. I think that is the reason I had asthma. I saw that I would not be able to stay in that job when they [employers] wanted to take me as a permanent staff member because I thought it would affect my health.

> Extract 13
>
> Gladness: I used to work for [name of the company], but I stopped working because I had painful feet. The working environment was strenuous because I had to stand the whole day.

> Extract 14
>
> Karabo: Here [pointing her hip], my hip is giving me problems. I think it is because I used to drink alcohol too much. When I reduced alcohol use, it was better. I noticed it again at work when I worked with a spade. My work is also detrimental to my health, and our employers do not care about our well-being; they do not provide us with gloves and masks to protect our well-being while working in toilets and streets because dust and smell affect us. At the Clinic, they said my nose was blocked because of the work I do.

Sandile was diagnosed with asthma. She attributed her deteriorating health to her work environment rather than HIV infection. Respiratory diseases are common among patients with HIV (Lorenc et al., 2014). Moreover, Maciel et al. (2018) have found that with increasing age, non-HIV-related comorbidities are likely to be reported. Comorbid illnesses can interfere with the clinical management of HIV. Sandile eventually resigned from her job.

Gladness in extract 13 also quit her job. She thought that her work environment was strenuous, and she suffered from painful feet. Both Sandile and Gladness stopped working because their bodies were unable to cope with their work conditions, and they were concerned that remaining at work might make them more ill or shorten their lifespan. Their bodies became an obstacle, taking all their attention. They were very aware of how their work environment could compromise their physical well-being. Karabo in extract 14 is still employed. She, too, is very conscious of how her work environment is not conducive to her health. Karabo described her work environment as unhygienic and unsafe. She always has a blocked nose because of her work environment. In their study in the US, Baumgartner and Niemi (2013) found that there was a split between their HIV-positive participants pertaining to the decision to stay employed. Some of their participants left stressful or strenuous work situations to pursue less taxing employment. Others showed a strong commitment to their work identity despite physical challenges to their bodies. The three cases, in a way, support the findings by Baumgartner and Niemi (2013). Sandile and Gladness quit their jobs with the hope of finding alternative employment that will accommodate their physical health. Karabo does not want to be constrained by her body and continues to work despite the risks to her health.

Most participants also reported that on some days, they wake up feeling tired to do anything:

> Extract 15
>
> Nosipho: I would sleep and not want to do anything, but I did not give up on the treatment. I told myself that I would drink them until my body got used to them. Even when I started with the new treatment, I experienced similar side effects.
>
> Extract 16
>
> Nobuntu: At home, I do everything I used to do before, but there are days when I wake up tired. Days are not the same; let me put it that way. Some days I wake up feeling not okay, but other days, I am able to do my normal daily activities.
>
> Extract 17
>
> Ayanda: Sometimes, I wake up feeling weak and unable to engage in activities that require physical strength. Sometimes I wake up feeling right. I am not certain if it causes mood swings as well because sometimes you are angry and irritated for no reason. Sometimes you want to be alone, and I do not know if it's stress or not sure.

It seems like what Nosipho, Nobuntu, and Ayanda are describing is fatigue. Fatigue is a common and distressing symptom reported by people living with HIV/AIDS and negatively impacts their ability to work, their daily functioning, and quality of life (de Weta & Wouters, 2016; Webel et al., 2016; Fair et al., 2018; Gebreyesus et al., 2020). The feeling of fatigue is characterized by overtiredness, low energy, physical weakness, and an intense desire to sleep that disrupts normal daily activities. For most people, fatigue is expected after physical activity, but in people living with HIV, fatigue may endure after rest and is described as an overwhelming sense of tiredness, lack of energy, inertia, or fragility that increase with activity and reduce the person's normal capacities (Langseth, 2018). As Perazzo et al. (2017) would explain, the three participants experience an imbalance between their available physical and psychological resources and the resources required for optimal functioning. They do not feel like themselves; their daily routine and ability to perform daily tasks have been interrupted. The certainty about the ability of their bodies to carry out daily activities has given way to bodily uncertainty affecting their sense of bodily trust. There is always the chance that the body just goes its own way.

Some of them even doubt they will be able to engage in activities they used to do before taking HIV treatment:

> Extract 18
> Ayanda: I cannot say that, but when I was in… [name of the country], I used to do arts, I used to do acting, dance and sing. I used to attend gym too, but now that I am taking treatment, I am not certain if I can be that flexible again. I ask myself, 'will my body allow me to go to the gym and do art again worse part is I have an operation as well. I do not know; I am scared, and what I tell myself is my life will never be the same again.
>
> Extract 19
> Gladness: Yes, if I get a job that is not strenuous. So maybe not working the whole day, then I will be fine.

In Extract 18, Ayanda feels like she is not the same person she was before taking HIV treatment, who was flexible and engaged in activities such as acting, dancing, singing, and exercising. In Extract 19, Gladness, too, doubts her body will be able to cope in a strenuous and full-day working environment. Both the women have experienced a breakdown of their bodily certainty, or they are not confident they can engage with activities they used to perform before taking HIV treatment. Their "I can" has shifted to an "I might be able to," to paraphrase Van der Meide et al. (2018), as the possibility of non-ability is now present in their experience.

Lihle, in the next extract, forces herself to do her daily activities. For her, it is important because she wants control over her body and how other people respond to her HIV status:

> Extract 20,
>
> Lihle: I was able to do my daily activities. I would force myself; the rash and vomiting did not mean that I was deadly sick. I am not sick [laughing]. I would wake up early in the morning to prepare my child [for school], clean, take a bath and do whatever that I do every day. But I did not go out, I would nurse my rash [laughing] (.), but when I saw I was better, I will go out to parks with other kids [friends] so that they can see me and get used me that I am like this now. The more- I stayed at home and hid because people would gossip about me or say I am dying now without knowing the rash is the side effect of the treatment.

Fulfilling her social obligations - her occupational, parental, and general social obligations - is very important for Lihle. Yet, meeting these obligations requires effort from her. Lihle posits wilfulness in avoiding the feeling that her body is unable to perform home duties, attend social gatherings or engage in other daily activities.

Karabo, in the extract below, values that her employers have allowed her to carry on with her responsibilities at work. Her diagnosis with HIV has not made them discriminate against her:

> Extract 21
>
> Karabo: I was not working; I was doing domestic piece jobs. They could see my condition, but they did not discriminate nor think I would infect them because I am HIV-positive. I was working for the right people who understood me.

Karabo may have anticipated that her employers would not respond well to her HIV diagnosis. In their study in the UK, Rodger et al. (2010) found that PLWHIV fears that their HIV diagnosis will affect their prospect of either finding or maintaining employment. In the literature, this is referred to as anticipated stigma, the expectation of negative repercussions in the form of discrimination in the future (Turan et al., 2017). Only 11% of those in employment reported stigma and discrimination in the UK study by Rodger et al. (2010), indicating a gap between perception and the reality of stigma in the workplace. The participants were unemployed at the time the interviews were conducted for this study. It is not clear how much of impact anticipation of stigma had on their employment-seeking practices. If Karabo anticipated stigmatization or discrimination from her employers, the study by Rodger and colleagues (2010) in the UK has demonstrated that it is not uncommon with PLWHIV. Karabo's case and the UK study also demonstrate the potential for a gap between expectation and experience.

The affective dimension of embodiment

When we are ill, it is not just a matter of experiencing the disruption of one's engagements with the world. It is also an experience of a variety of sensations and feelings (Grīnfelde, 2019). The affective dimension of embodiment refers to the bodily sensations, feelings, and moods linked to the experience of illness. The affective dimension themes that were identified in this study are difficult emotions, including unpredictable mood swings and difficult bodily sensations.

Difficult emotions

A positive diagnosis of HIV/AIDS is often accompanied by a set of difficult emotional reactions, such as shock, disbelief, fear, shame, anger, despair and desperation, and even suicidal thoughts (Barkish et al., 2019). The participants in this study also reacted with shock, fear, hurt, and shame after receiving a positive diagnosis of HIV/AIDS:

> Extract 1
>
> Nandipha: I was shocked, but I told myself there was nothing I could do. I had to accept that I was HIV positive. I am not dying. I went home to tell my mother; she was so shocked as well. She told me that even my younger sister is HIV positive, and she was afraid that we would both die. I told her I would not die; I would continue to live.
>
> Extract 2
>
> Nobuntu: … But with my family, it was better because I was supported. Although, they were shocked because I test every year. But at least there were there for me when I told them the very same day when I received my results.

Shock is the most frequent reaction to HIV-positive diagnosis (Baumgartner, 2007). The shock is often related to not expecting it, as Nandipha and Nobuntu illustrate with their stories. The diagnosis was equally shocking for their loved ones. Although HIV testing and counseling is recognized as effective intervention for secondary prevention of HIV (Moradmand-Badie et al., 2014), shock is a normal reaction to an HIV-positive diagnosis. Testing annually did not make an HIV-positive diagnosis any less shocking for Nobuntu and her family.

Some participants cried or knew of someone who cried after receiving the diagnosis of HIV:

> Extract 3
>
> Nosipho: Yes, I encourage them. You find people crying about their diagnosis, and I say to them, 'let me tell you about my journey with living on HIV treatment. Take your pills well- I do not have a man right now, but when you have a man speak to your man, encourage him to go to the Clinic, use a condom when you are having sex and take care of your HIV'.
>
> Extract 4
>
> Nobuntu: … But the hardest part was I went with my child to the Clinic because s/he had to see a dentist. We cried all the way from the Clinic until we got home after I told her I was HIV positive.

The diagnosis of HIV can be a very stressful experience (Moradmand-Badie et al., 2014) and can lead to feelings such as powerlessness and helplessness. The crying or weeping is induced by the feeling of helplessness or powerlessness. Nobuntu cried all the way back home from the Clinic after receiving her HIV diagnosis. Ramovha et al. (2011) have found that their participants had sad faces, or they would lower their voice when they spoke about being diagnosed with HIV-positive during interviews for their study with PLWHIV. Likewise, there was still a visible sadness in Nobuntu when she narrated her reaction to a positive test result for HIV.

For Karabo, crying over her HIV diagnosis was brought on by shame. She spoke about the shame she felt over her HIV positive diagnosis, owing to the misconceptions about HIV that prevailed at the time of her diagnosis:

> Extract 5

> Karabo: During the time I was diagnosed, having HIV was a shame, and people thought that when you have HIV, you sleep with everyone. That is how people perceive it; they perceive people living with HIV as *gemors* [rubbish], and as if they sleep with anyone that is why they have HIV. I was also embarrassed and ashamed.

There is a gendered dimension to misconceptions about HIV (Nack, 2009). A positive diagnosis of HIV for women is associated with promiscuity, irresponsibility, and immorality (Davtyan et al., 2016). The sense of shame that someone like Karabo felt about her HIV-positive diagnosis is a result of these misconceptions and functions as a painful but mistaken self-conscious emotion in which one perceives oneself to be defective, often in response to a perceived failure (Bennett et al., 2016).

Crying can also be linked to the fear of dying. Some participants initially perceived their positive diagnosis with HIV as a death sentence. This reaction, a common psychological sequela experienced by people diagnosed with HIV (Millern et al., 2012), is very well demonstrated in the literature. For example, a study that was conducted in Limpopo found that for some of the participants, an HIV-positive diagnosis is associated with imminent death, as if they had been told that they would die the next day or very soon thereafter (Ramovha et al., 2011). The reaction is still understandable even in this age of ARVs because, for a long time, HIV/AIDS was experienced as a death sentence (Nkosi & Rosenblatt, 2019).

As the following extracts from Sandile, Nosipho, and Nandipha illustrate, it could be your own reaction to your diagnosis, or you could experience it from other people:

> Extract 6
>
> Sandile: It was so painful, *yho* it was painful. I thought I would not live for this long. But I kept on praying because I did not want my child to lose both her parents. Her father died in 2002. I did not want my child to lose both of us. She does not know her father. When her father passed away, she was one year old and a couple of months.
>
> Extract 7
>
> Nosipho: People feel like they are alone, or they will die. I tell them they are not alone, and if they take their treatment, they will live.

Extract 8

> Nandipha: I was shocked, but I told myself there was nothing I could do. I had to accept that I am HIV positive; I am not dying. I went home to tell my mother; she was so shocked as well. She told me that even my younger sister is HIV positive, and she was afraid that we would both die. I told her I would not die; I would continue to live.

The fear of dying from HIV for Sandile is because her child has already lost one parent to HIV. It is possible that the other people that Nosipho encountered who feared dying from HIV, or even with Nandipha's mother's fear that she will lose both her daughters to HIV, that the fear arises from witnessing other people around them succumb to the illness. The availability of ARVs has reduced this fear. That is why Nosipho can encourage those people she knows who fear that an HIV-positive diagnosis is synonymous with a death sentence that if they take their ARVs, they will live longer. Her trust in ARVs enables Nandipha to affirm that she is not dying and assure her mother assurance that she will not die.

Reacting to a diagnosis of HIV can occur in several stages, among which are: the stage of diagnosis, where the person is normally in shock, and the stage of acceptance (Arias-Colmenero, 2020). Acceptance of an HIV-positive diagnosis can be immediate, but not without mixed feelings, as Ayanda and Nobuntu illustrate:

Extract 9

> Ayanda: I accepted it because (.) I was thinking of my mother and my child. I had one child during this time. After, they gave me a card for pills- what is the name of the pills [thinking out loud], I forgot the name of the pills. I was still working, and I left work crying.

Extract 10

> Nobuntu: You know, from the beginning, I accepted the situation but what hurt me was finding out he (boyfriend) knew all along. I felt betrayed because he could have given me a choice and told me the truth from the beginning of the relationship allow me to make a choice if I wanted to stay or leave the relationship. He infected me knowingly; he did it purposefully. Before I met him, I tested. I showed him my results, and I told him, 'If my results changed, it would be you who infected me because there is no one else I am sleeping with, and you are the only person I am involved with .'He said, 'he was healthy.'

At first, she cried at the news of her HIV-positive diagnosis, but Ayanda had to accept it because of her mother and child. Nobuntu eventually grew to accept her HIV-positive diagnosis, although it was not easy initially. What hurts her feelings was finding out her boyfriend knew about his status and chose not to disclose his status to her. She feels as if he intentionally infected her. With both Ayanda and Nobuntu, there were underlying feelings of hurt and sadness. Hlongwane and Madiba (2020) have found that it is not uncommon for PLWHIV to report during research interviews that they accepted their diagnosis, but also show an underlying tone of passive acceptance as later they would express difficulties in disclosing and finding closure with their status. Ayanda and Nobuntu demonstrate that acceptance does not always preclude experiencing emotional difficulties with disclosing or finding closure with your HIV-positive diagnosis. A diagnosis of HIV is a journey from a combination of fear, anxiety, shock, terror, distress, numbness, regret, anger, and shame to loss, grief, isolation, and self-acceptance (Albright & Fair, 2018; Walker, 2019).

An HIV-positive diagnosis can lead to mental health problems, and some of these mental health problems are side effects of ARVs (Remien et al., 2019). Two participants below had a suspicion that they might not be well emotionally and mentally, while one participant was placed on antidepressants because of the association between depression and antiretroviral therapy:

> Extract 11
>
> Ayanda: I am not certain if it [treatment] causes mood swings as well because sometimes, I feel angry and irritated for no reason. Sometimes I want to be alone; I do not know if it's stress or not sure.
>
> Extract 12
>
> Lerato: No, the problem I had was that- I started being cheeky, harsh, and had anger towards people even if they did not do anything wrong.
>
> Extract 13
>
> Lungile: When I was growing up, I was suicidal starting from the age of 7, and the Doctor said, 'since I was suicidal, and I am taking HIV treatment, and it has efavirenz it can cause depression. He will write me a letter to the Clinic to take antidepressants for a year. But I have been on antidepressants since 2011 till today.

Both Ayanda and Lerato reported difficulties with their moods, with Lerato recalling that when she started on ARVs, she would be easily irritated and angered sometimes. Lerato was not sure if her mood swings were related to her taking ARVs. Lungile, who was placed on antidepressants, had been informed by her Doctor that HIV treatment might cause depression. Depression is a persistent mood disorder characterized by feelings of sadness, loss, anger, and frustration that interfere with daily living (Tao et al., 2018). The anger and irritability that colored and transformed the three women's being-in-the-world into a mood disorder (Svenaeus, 2013) might be a side effect of ARVs.

Difficult bodily sensations

Bodily sensations refer to feelings and sensory experiences associated with one's body, such as aches, tickles, pain, sadness, love, and fatigue (Martin, 1998). The common bodily sensations reported by the women interviewed in this study included pain, itchiness, and dizziness:

> Extract 14
>
> Ayanda: (.) I cannot say that much, but I had painful feet, but I told them [healthcare professionals] at the Clinic.
>
> Extract 15
>
> Nobuntu: They are painful; can you see [pointing at her feet] even now I bind them.
>
> When I am sleeping, and I must get out of bed, I use things to support me. I cannot walk straight.
>
> Extract 16
>
> Nomzamo: After, I started having painful feet again. I had painful feet. I was losing my body shape as well, specifically my legs [pointing at her legs].

These are sensations the participants grappled with they started on ARVs, although the participants were uncertain if they could be attributed to the effects of ARVs. For instance, when Ayanda was asked if her painful feet were the side effects of the ARVs she is taking, she could not "say that much," but she "told them," referring to her healthcare professionals at the Clinic where she gets her medication.

The painful feet are described by the participants as almost unbearable and debilitating, especially from the perspective of carrying on with day-to-day activities. Nobuntu, for example, finds getting out of bed a difficult undertaking when her feet are painful. In order to bear the pain much better, she often has to bind her feet, but as she described the effort of getting out, "I use things to support me. I cannot walk straight." Another participant who has painful feet is Nomzamo. The pain comes and goes for her. Unlike Ayanda or Nobuntu, she attaches a sense of loss to the pain that comes with the body disfigurement she perceives it is causing: "After I started having painful feet again…I was losing my body shape as well specifically my legs". Pain is one of the most reported symptoms of living with HIV, whether someone is on ARVs or not (Parker et al., 2017). Nobuntu, Ayanda, and Nomzamo also demonstrate that the experience of pain can take over one's life, which Bullington (2009) had observed in a study with HIV-positive patients. Pain can occur across the clinical stages of HIV disease, but it is also believed to increase in severity and intensity as HIV disease progresses (Azagew et al., 2017).

The next bodily sensation reported by some of the women interviewed in this study was dizziness in the early days when they first started on ARVs. They indicated that the dizziness is experienced immediately after they take their medication:

> Extract 17
>
> Lungile: After taking the treatment, you would feel so dizzy; it is safe when you take it
>
> close to your bed because you would just fall on top of the bed. You will feel like
>
> your feet are walking on air.
>
> Extract 18
>
> Lihle: I vomited all the time after taking treatment; I felt dizzy and blank. I was so
>
> weak. I could not walk; I was right before taking the treatment, but now I am sick; this
>
> is not on. My eyes started being closed, and I do not like pills generally.
>
> Extract 19

> Nosipho: They were treating me well, but when I started, I felt dizzy, and I told myself
>
> that my body will get used to them, and as time went by, my body did.

The dizzy sensation is described by Lungile as almost "like your feet are walking on air." Lihle would vomit before she felt dizzy, weak, and unable to walk. The dizziness made Lihle feel as if ARVs make her sicker because why would she ask, "I was right before taking the treatment, but now I am sick…" Getting used to the dizziness involves the body adjusting to it and the kind of self-talk described by Nosipho: "I told myself that my body will get used to them and as time goes my body did." Nosipho illustrates that experience of the body before receiving a diagnosis of HIV and initiating treatment not only changes but there is also a need to become familiar with the "new" body and modify your actions. The body living on ARVs feels different than before the disease, and its possibilities have also been altered (Renju et al., 2017; Van der Meide et al., 2018).

Itchiness is another bodily sensation reported by the participants:

> Extract 20
>
> Karabo: When I started, I was right, but my body would be itchy at night after drinking them; my legs were itchy, it shows that they were working.
>
> Extract 21
>
> Lihle: When I was out, the heat would make the rash itchy, and my skin was sensitive. I stayed at home for itchiness; when it stopped itching, I would ask myself why I was not going out.

Drug rashes usually develop on the tenth day after starting therapy, and in hypersensitivity reactions, the symptoms appear after each tablet is taken (Khan et al., 2014). In extract 18, Karabo reported that her legs started being itchy after initiating ARVs. In Extract 19, Lihle said that after initiating treatment, she had a rash that made her skin itchy and sensitive to heat. Itchiness and a rash can be a symptom of HIV infection as well as a side effect of antiretroviral therapy (Svenaeus, 2011). The sensation of itchiness or rash can make the body feel unhomely, as it seems to have done for Karabo and Lihle.

The material dimension of embodiment

The material dimension of embodiment refers to the experience of one’s body as a material object which is characterized by the experience of alienation between the self and the body (Grīnfelde, 2018). The subthemes identified under this theme include the participants' experience of their body as uncontrollable and not normal, as well as their challenge of relating to a strange or unfamiliar body and the extent some of them are prepared to go to conceal any signs of ARV side effects in their body.

‘This is not my normal body’

Body changes experienced by people living with HIV have been linked with perceptions of loss of control over the body (Abel & Thompson, 2017). The women in the study shared their discomfort with the way their bodies are transforming in uncontrollable ways. Their discomfort relates to how they feel like they are not in control of their bodies, what they can do and what can happen to them. They struggle, furthermore, with the body shape changes linked to taking ARVs. Ayanda and Nobuntu spoke very distressingly about their perception that they no longer feel in control of their bodies:

> Extract 1:
>
> Ayanda: “It is not nice; it is not nice at all. When my body changed like this, I asked myself if 'I am going to die,' what is going to happen next? Will I be disabled, crippled, or what? You never know."

Ayanda is made uneasy by not knowing if the changes her body goes through could eventually lead to either her demise or long-term physical incapacitation. In the next extract, Nobuntu conveys a similar feeling with regard to her own body. She has a constant need to urinate every five to ten minutes. Nobuntu is unable to hold her urine for a long time until she can get to the loo. It is a recent development:

> Extract 2
>
> Nobuntu: ... I was telling my Doctor last week that I am experiencing a constant need to urinate every five to ten minutes. I must go to the loo, and I must go now when I have it. If I do not go now, I lose control of it. When I try to hold it when I get to the toilet, it's already out; it is something that has started recently. He [the Doctor] asked if I tested for diabetes, and I said yes, and I do not have it. He [the Doctor] took my urination to get tested, and I must go back for results on the 3rd of this month.

It seems like the main concern of the two women is that the changes they see already with their bodies are a signal to more changes they can anticipate in the long run. They have to live with the constant fear of losing control of what their bodies can and cannot do. For the women interviewed in this study, the feeling of loss of control of the body makes them feel like their bodies are not normal anymore. It is as if they now live in a different body than they had before.

In the next three extracts, Ayanda, Lungile, and Nobuntu point out the paradox of taking medication that simultaneously sustains your life and diminishes your sense of who you are in terms of your body image:

> Extract 3
>
> Ayanda: I wished they stayed on the pink ones [description of ARVs] because the pills seem to be right and treat everyone well. Several people complain about the white ones [Stavudine]; it makes them lose their body shape. Even with me, I am like this-I complain, but I do not complain much. This is not my normal body, but now (.) the body here [pointing to upper body] my body is big but here [pointing to lower body] is small. But I must accept because I want to stay alive.
>
> Extract 4
>
> Lungile: I did not have big breasts before, but now I have big breasts now [laughing]. I had big legs; I could not wear long boots before because I was unable to zip them. But now I have lost fat in my legs, and I can wear long boots. Yes, I did not have big buttocks before, but now I do not have buttocks at all. I had a nice body shape, I did not have big breasts, and I was full-figured, but I started losing the lower body. Now I have a big tummy, yes, I like being full-figured, but I did not like a big tummy. What disturbed me the most was my cheeks; I started having cheekbones. The doctors would say, 'you have nice cheekbones'; my response would be, 'I do not love myself because now my cheeks are gone. They would say you are beautiful; you have a horse face etc., trying to encourage you and comfort you, but I was not happy with changes in my body. The other side effects did not last long. The changes in my body shape-when they decreased the 40 milligrams to 30 milligrams of Stavudine [one of the pills], and then they changed it totally to another pill. After I noticed that my legs and cheeks were slowly going back to normal, there was a change.

Extract 5

> Nomzamo: My legs were becoming hard and coming out lumps. I went back to the Doctor, and I said to him, 'look how I am, look at me. He looked at me, and he said, 'what are we going to do .'I said, 'make a plan, change the treatment .'He said, 'we do not have other pills and go to… [name of the hospital]'. When I got to… [name of the hospital], they wanted to counsel me, and I said, 'do not counsel me, just change my treatment because I already received counseling twice about drinking pills and I drink my pills every day; hence I am like this [pointing to lumps in her legs] .'The Doctor said, 'okay,' and they changed my pills. I drank them until they told me there was one pill now. I have been taking one pill for three years now. I had lumps here and here [pointing to her back and legs], I told the Doctor, and he changed my treatment; hence I am looking better now. I did not have any issues with side effects because when I changed the treatment, the lumps started fading, although my shape did not get back to normal completely. It is better compared to how I was before I changed treatment.

The medical term of the condition the participants are describing is lipodystrophy syndrome (LDS), an abnormal redistribution of adipose tissue in the body (Gagnon & Holmes, 2011). LDS can manifest in two modalities: first, sunken cheeks, thin arms, and legs, clinically defined by the term lipoatrophy; and second, fat accumulations or lipohypertrophy in the abdomen, in the jaw, breasts, and in the back of the neck (Mancini & Secchiaroli, 2015). Fat loss and accumulation can occur simultaneously in different regions of the body in the same individual (Tsuda et al., 2012). LDS is a complication of antiretroviral therapy, specifically the use of Stavudine (d4T) (Tsuda et al., 2012). Nomzamo also singled out Stavudine. Svenaeus (2010) would say that for Ayanda, Lungile, and Nomzamo, the body has become an alien being (being me, yet not me), and this reorientates their entire being-in-the-world in an unhomelike way from the perspective of their bodies.

When healthcare providers can assist with managing LDS, they are not only dealing with a side effect of a medication. They also bring back to home-likeness, or at least in proximity to it, the body of the patient they are assisting (Svenaeus, 2010). The physical changes of LDS are not completely reversible, although, with the new treatment, they can be managed better. Nomzamo's lumps began to fade away when she was put on a new treatment of ARVs. Lungile also saw an improvement after she changed her treatment. When it comes to feeling like their bodies are not normal, the improvement in their LDS did not alleviate this feeling for Ayanda, Lungile, and Nomzamo, as they still insisted that they do not see their bodies as normal.

The strange and unfamiliar body

According to Persson (2005), body changes tend to compound feelings of "difference," of having a body already "set apart" by medical management. The participants in this study likewise expressed a sense of feeling like their bodies were different, strange, and permanently damaged. It is the ARVs and not HIV that bring on this feeling for the participants. The next three extracts unpack this estrangement from one's body the participants had had to grapple with when they started with ARVs:

> Extract 6
>
> Ayanda: Yes, my body shape has changed, I was right, and I was not fat nor slim. I can see that I am different; I did not look like before I started with HIV treatment. I have lost confidence, but I have accepted the body changes, and there is nothing I can do to change it. I can never change it. I am still taking the pills because I want my life to be right. I can never change the body shape I have. They [health professionals] gave me different pills, and I do not know which drugs they combine.
>
> Extract 7
>
> Nobuntu: When I started, I did not experience any symptoms, but now, there are so many things that are changing, such as I have constant headaches, my feet being painful, I cannot walk properly, so I do not know what is happening. I have back pains as well; there are so many things I have that I did not have when I was not on treatment. They have tested me for diabetes, and I do not have diabetes or high blood pressure. The pills make my weight go up. I am trying to lose by walking, but it does not go down.
>
> Extract 8
>
> Nomzamo: I was considering stopping taking the treatment and dying if I die. I was encouraged by a professional nurse at… [name of the hospital] because I told her 'if there is no treatment that will help me, I cannot live like this. she said, 'No, the new treatment will help you in getting your body shape back.'

The three participants experience a split between themselves and their bodies; they feel different as if their bodies are no longer theirs (Bullington, 2009). Through Ayanda, we also see that the split engenders a feeling of helplessness as she feels like there is nothing she can do to reverse the body changes. She is left with no other option but to accept the body that she now lives in. Her surviving HIV depends on it. Nobuntu suffers from constant headaches, painful feet, back pain, and her weight has picked up. These side effects have not stopped her from taking ARVs. Like Ayanda, Nobuntu pins her prospects of living longer on the pills. As Gagnon and Holmes (2016, pg. 6) put it, bearing with the side effects of ARVs is "a price to pay for being alive." Nomzamo is different from Ayanda and Nobuntu. She considered stopping the ARVs, even at the risk that it could cut short her life. Not all people living with HIV are willing to pay the price. Her healthcare professional intervened by promising that new treatment would reverse the body changes and managed to convince her and keep her going. The intervention of her healthcare professionals helped her to shake off the growing strangeness and unfamiliarity of her body and work towards restoring unity between herself and her body (Bullington, 2009).

The silver lining for Ayanda is that as 'not nice' the changes in her body shape have been or are for her, she still looks better compared to other people she knows with LDS:

> Extract 9
>
> Ayanda: …But as much as my body shape has changed, it is not that bad; with others, it is worse. You can tell from a distance by the look of the body that this person is HIV-positive because the pills [treatment] have changed their body shape, the upper body is big, and the lower body is small. Some have- what do you call it [thinking out loud] big lumps behind the ear and wounds on the face. This makes one want to ask the person which pills she/he is taking, but at the same time, you do not want to provoke a person. It is painful when you see it to other people, but there is nothing we can do; we follow and take the Doctor's order at Clinic.

Ayanda's body is less recognizable for someone with HIV. LDS can make HIV recognizable to others, or as Persson (2005) realized with her participants, invite unwanted attention and questions on oneself and your HIV status. We can assume that Ayanda's relief is that the changes in her body shape are not so bad to make her HIV status visible to everyone else. Ayanda is grateful she looks better than others, but she empathizes with them as well. The reason she can and does empathize with them is that in wishing to ask them what treatment regimen they are taking, they are maybe a reminder of her own situation and the uncertain trajectory of her condition. Persson (2005) has also shown with her research participants that the anxiety implicit in Ayanda's curiosity about people's treatment regimens is not only not uncommon but also understandable. The side effects of ARVs are unpredictable; there is no way to tell which ones anyone living with HIV will experience. It is also impossible to know if, when, and how they will manifest. There is a level of uncertainty and anxiety for people living with HIV with every treatment regimen they are put on (Gagnon & Holmes, 2016).

Concealing the HIV body

Most women in this study used beauty products to remove and conceal the visibility of the side effects of antiretroviral therapy:

> Extract 10
>
> Karabo: I used aqueous cream. I asked the Clinic to give me things to apply, but they were not helping. Sometimes at the Clinic, they do not give you aqueous cream or calamine lotion. When you asked, I had to go to the pharmacy to buy calamine lotion at times.
>
> Extract 11
>
> Lerato: Side effects on my skin- I used to wash my face with face wash, but now I use green bar soap. I used to wash my face with facewash, but my skin started to have pimples. I changed facewash to bar soap, and my skin is better now. It was only my face that was affected. Before using the bar soap, I tried Garnier, ponds, and Avon products to moisturize, but they did not help.

The visibility of side effects of ARVs makes concealing HIV a challenge. It becomes difficult to keep an HIV status private; the body turns personal experience into a public spectacle (Persson, 2005). When they were asked how they deal with visible side effects of ARVs, some of the women interviewed in this study mentioned that they use beauty products, like Karabo using aqueous cream and calamine lotion to cover wounds and dark spots in her body. These products do not always help, as we see with Lerato. She has tried several products - Garnier, Ponds, and Avon - to moisturize her body with not much success. Someone like Lerato may eventually have to concede that this is an effect she will have to live with for as long as she depends on ARVs to prolong her life. This possibility is borne out by Gagnon and Holmes (2011) in their research with women living with HIV on ARVs, who, after numerous attempts at using different beauty products to conceal the side effects, they had to accept and integrate them into their body image.

The women in the study who managed to improve their appearance or decided to stop concealing the side effects reported they gained much better control over what happens to their bodies:

> Extract 12
>
> Title: It was the side effects; I had a rash, but I can control it now. I changed products; I use children's products. I do not use the products I used before because they were too strong for my skin.
>
> Extract 13
>
> Karabo: Yes, I would go out and spend time with my friends. Even when you try to hide the wounds and spots by wearing long sleeves t-shirts they would still show because they were all over my body. I did not want to wear long sleeves; I would wear short sleeves t-shirts, and that made me not be afraid of anything and to be free.

Lihle manages the rash in her face by changing her facial products and by using products designed for children. They are working for her. Karabo has tried to hide her wounds and the spots in her skin by wearing long sleeve shirts. The strategy Karabo has adopted is not uncommon. Nyamaruze and Govender (2020), for example, asked women living with HIV in KZN how they feel about visible spots on their skins and also how they deal with them. Many of them were uncomfortable showing off their skin, and they covered those parts of their body that bore spots by wearing long jeans or leggings. Karabo's strategy has not worked for her. She thinks that being free and letting go of her insecurity has enabled her to gain better control of her body. For the women in this study, there are two approaches to gaining control of the visible side effects of ARVs. When they work, some of the beauty products are effective at removing markers of HIV and ARVs. If they have tried using beauty products like Karabo has done before, and they have not worked for them, they decide to live with the visible side effects and work towards integrating them into their self-concept and body image.

The social dimension of embodiment

The social dimension refers to adopting the perspective that others have on one’s body, how others see and what they think of one’s body (Grīnfelde, 2018). The subthemes that were identified within this dimension include how participants spoke of how others relate to their bodies as frightening, diseased, and underserving, as well as contagious and promiscuous. Furthermore, they accounted for how their bodies are evaluated in different social situations, their experiences with anticipated and lived stigma, and some of the complexities they are confronted with related to using or not using condoms.

The frightening, diseased, and undeserving body

The participants questioned if they are really frightening, diseased, and undeserving because of struggles to form and maintain romantic relationships. The common experience between them is of potential partners who disappear after they disclose their HIV-positive status:

> Extract 1
>
> Nobuntu: You know it is difficult to find someone when you are HIV positive, especially with me because I am living openly with my status. If a man starts proposing, I tell him that, look, this is my situation. It is up to him if he decides to stay or not. People nowadays are not serious and playful. After I share my status, maybe he will stay for 2 to 3 weeks. Suddenly, he changes, and I do not see him anymore. It is difficult to find a stable relationship when you are HIV positive. I do not feel nice because I ask myself that 'because I am HIV positive, I do not deserve to be happy. I do not feel right at all.
>
> Extract 2
>
> Gladness: I always wonder if I disclosed my status, will he run away or support me? Two men out of 3 I met before ran away. They just left, and when I called, they would not pick up my calls. It was painful. I asked myself, will I not have a boyfriend because of this disease? (.)
>
> Extract 3
>
> Lungile: He [husband] passed away in 2001; with the support of the support group and seeing others living a normal life, I got involved in a relationship in 2003. But I had problems in the relationship- I had the first person after HIV diagnosis, and I tried disclosing my status, and he vanished, and it was like I am a monster. I spoke about it in the support group; I was hurting and felt like I was no longer a person; I was a monster. They said, no, you must not disclose, just protect yourself, use a condom.

Nobuntu talked about how hard it is for her to form and maintain romantic relationships when you are living openly with HIV. She often experiences rejection when she discloses her HIV-positive status to potential partners. The rejection makes her question if she is deserving of happiness. Gladness similarly wonders if potential partners will always flee if she is open about her HIV-positive status. It has happened to her with 2 out of 3 men she met after her HIV diagnosis. She thinks having HIV is an obstacle to finding a boyfriend. Lungile described her experience with a potential partner who vanished after she disclosed her status to him. She felt dehumanized by the rejection; it made her feel like a scary monster who frightens potential suitors. Previous research (see Lawless et al., 1996; Sathiparsad & Taylor, 2006) has highlighted how social representations of women living with HIV as the source of infection or as diseased and undeserving may result in the self-doubt expressed by Nobuntu, Gladness, and Lungile in terms of their chances of meeting and forming a relationship with someone. Their bad experiences with relationships have, if anything else, confirmed their self-doubt. Once a negative representation of HIV is internalized, it can lead to a deep-seated sense that to be HIV-positive is to be frightening, diseased, and underserving (Chapman, 2000).

A contagious body

People with HIV are perceived to be responsible for their illness and blamed for spreading it (Yuh et al., 2014). Some women in this study have opted to remain single to avoid infecting others or even re-infecting themselves with HIV. We can see in the next three extracts by Nomzamo, Sandile, and Nosipho that they have chosen the single life because they do not want to be blamed for infecting others:

> Extract 4
>
> Nomzamo: I never got involved with anyone since 2006 until now. When I discovered that I was HIV, I decided to stay single because I did not want to infect others.
>
> Extract 5
>
> Sandile: I wanted to raise my child. I knew if I had a boyfriend, I would be tempted to sleep with him, and he might not know his HIV status. I thought I would die if I slept with someone who is also HIV positive. I prefer to stay with mine [HIV positive status] alone. There was also a stigma, and having a boyfriend meant I had to disclose my status to everyone I met. Women are not like men; when a man hears that you are HIV positive, he thinks it is the end of him.
>
> Extract 6

> Nosipho: I do not want to be involved with anyone. I want to stay with my HIV, and I do not want to abuse myself. Some people do not want it [HIV]; they do not want it. The person I used to live with died, but it was not because of HIV; it was asthma. He did not listen to my laws, and he did not drink his pills. He reminded me to drink my pills; when there is no condom, there is no sex. He died, he used to work with paint, and he had asthma. I met someone else, and he did not want to use a condom. After having sex with him last year, I got sick and sick. I decided to leave him and stay single.

In the early history of the HIV/AIDS epidemic, the HIV-positive body was considered infectious, dangerous, and abominable (Persson, 2013). The three women in the extracts above are clearly conscious of their responsibility to protect others and themselves from infection or re-infection with HIV, but it is also a burden on their shoulders to avoid being blamed for spreading HIV. All three women in the extracts above believe they are infectious. It seems like this thinking, and their avoidance behavior emerges from not only fear of passing the virus to others but also the potential of being rejected when it comes to trying to find a romantic partner (Audet et al., 2013). The three women have themselves internalized the association of the HIV-positive body as a fearsome vehicle or weapon for the transmission of the virus needing containment (Kaplan, 2014). The stigma directed at PLWHIV is a significant influence on their decision to avoid being entangled in any romantic relationship that requires them to disclose their status. Their fear of re-infecting themselves coupled with the risk of infecting others or being forced to disclose to potential partners who may flee anyway, because when men hear HIV-positive, they run, as Sandile puts it, has made them decide that romantic relationships are not for them.

The other women in the study were equally fearful at first of the consequences of disclosing to their potential partners. However, their approach and outlook on relationships are different. They do not compromise on disclosing their status, and they are willing to leave it up to potential partners to choose for themselves if they want to be with them. These women, furthermore, were no less conscious of their responsibility to themselves and others in preventing HIV re-infection or infection. The following extracts are illustrative:

> Extract 7
>
> Gladness: After two years, it was difficult during that time because I did not know if a person was positive or negative, so it was difficult for me because I did not know if I

> should tell my partner that I am HIV positive or not, but I decided to disclose my status at the beginning of the relationship although when you tell people there is a chance that they would run away, now it is okay. In my current relationship, my boyfriend knows my status, and we are okay even though he is HIV negative.

> Extract 8

> Lihle: okay- before my current relationship, I feared being rejected or what men would say when I disclosed my status; maybe they would say, 'you want to infect me with your HIV' I was so afraid. I told myself that whoever wants to be with me must know that I am HIV positive, an activist, and living openly with HIV. If someone has a problem with that, bye-bye but if someone wants to come and support me, good. I was lucky, the guy I stayed with, we have been together for a year. He supports me and calls me all the time to check if I took my medication and my plans for the day. He is very supportive.

There is an implicit recognition by the women in the above extracts that they were 'lucky' to meet partners who have stayed with them even though they are HIV-positive. The partners are not always HIV-positive themselves. We see also that for someone like Lihle, her determination to live openly with HIV is due to her activist background. It is important to these women that despite the fear of being rejected that they give their partners the opportunity to make an informed choice if they are willing to expose themselves to the risk of being infected. Concealing a stigmatized illness, after all, curtails opportunities for social support while burdening the physical and mental well-being of the individual (Brener et al., 2013). Non-disclosure of a stigmatized status allows for the short-term protection of an individual's identity but continuing to hide the condition may be stressful and mentally taxing (Cama et al., 2020).

Anticipated and lived stigma

The previous theme shows us that societal meanings attached to HIV retain a profound effect on the way these women see themselves and how they consider others to evaluate them (Alexias et al., 2016). Beyond the concern expressed with forming or maintaining romantic relationships, there is general anxiety by some of the women they will be ill-treated should they disclose their HIV-positive status to others:

> Extract 9

> Ayanda: People are too judgemental and when you tell them they can run away and say you will infect them by eating together or sharing a bed, have sex with you, yet there are condoms, and my boss can find out, and I will lose my piece job. It would cost me so much because that little R200 I get enables me to buy diapers from the street and food for my child.
>
> Extract 10
>
> Lihle: I thought at home, they would reject me or tell me that they have told me so about men or I am forward, etc. I did not get that reaction; instead, they supported me and told me that 'I am not alone, and they will be with me every step of the way no matter what happens. On my first check-up at the Clinic, I went with my mother and brother, which is very rare.

Ayanda's and Lihle's anxiety is referred to as anticipated stigma: the expectation of aversive repercussions in the future. These are beliefs by PLWHIV that others will treat them negatively due to their HIV status (Turan et al., 2017). Ayanda anticipates people will judge or reject her. Imagining that her colleagues and employers would fear being infected by her, she thinks she might lose her job if they found out that she is HIV-positive. Likewise, Lihle anticipated rejection from her family when she disclosed to them that she is HIV-positive, and instead, they assured her that she had their support. We see with Lihle that disclosure had positive psychological benefits because her family's response was supportive, caring, and affirming. PLWHIV must take the risk of being met with stigmatizing reactions to gain the support necessary to cope with living with HIV (Stutterheim et al., 2011).

For other participants, their anticipation that they will be stigmatized is not unfounded based on actual past experiences of discrimination, devaluation, and prejudice from others:

> Extract 11
>
> Ayanda: I did not have any problems, but when I found someone who is HIV positive, I thought things would be different, but it is worse. He devalued and undermined me.
>
> Extract 12
>
> Sandile: Yes, people are like that. I thought people were informed about stigma towards people living on HIV treatment. But it seems like people do not have much knowledge about HIV. People are scared to be around me, and I thought they would

> change as time goes, but they are still the same. They stayed away from me and could never sit with me like we were seated. They still have no knowledge of how HIV is transmitted.

Brener et al. (2013) argue that higher levels of stigma are associated with lower social support and poor mental health. Stigma for women in this study is also related to lower social support, although some of the more egregious effects of stigma for them are mediated by the support of family members and friends:

> Extract 13
>
> Gladness: Yes, my family supported me. They did not isolate me. Remember, during those times, people thought that if you were HIV positive and you used a cup, then no one else should use it. So, you must have your own things, and they should only be used by you. They did not do that. We would just eat and do everything with anything.
>
> Extract 14
>
> Lungile: …but close friends and family were supportive. They would come to see me with fruits and vegetables or take me for a walk because I like walking. Fruits, vegetables, and boiled eggs were easy to eat; as I said, I did not have much appetite, and I would force myself to eat healthily, and eating healthily made me lose more weight.
>
> Extract 15
>
> Nobuntu: Some they do cut you out if you tell them your status. Some are supportive, some they are funny when they see you, and you can see a change in their reactions or interactions with you in family gatherings. However, my family is supportive; I do not want to lie.

PLWH often carry these internalized representations into their daily interpersonal interactions by self-isolating or avoidance of social situations that invite stares from other people (Turan et al., 2017). Participants also spoke about decreasing their social participation to avoid disclosing their HIV-positive status and the gaze of others. This was perhaps an attempt to contain their social world to avoid shame and humiliation from those who were already aware of their diagnosis and to prevent their diagnosis from being exposed (Ho & Goh, 2017) by isolating themselves and avoiding social interaction when they paradoxically need support from others (Kaplan, 2014).

Body evaluations in social situations

The side effects of ARVs are extensive and debilitating and include not only lipodystrophy but also weight gain and weight loss as part of a broad spectrum of body alterations (Gibson, 2012). While it is increasingly becoming rare for PLWHIV to experience visible symptoms reflecting an advanced HIV condition, visible symptoms related to the side effects of antiretroviral treatment, especially those related to lipodystrophy, weight loss, or gain, are common (Brener et al., 2013). Lipodystrophy causes fat loss in the buttocks or fat gain in the stomach (Kelly, Langdon & Serpell, 2009). These are areas of the body usually more valued than others, as Nyamaruze and Govender (2020) concluded from their research with HIV-positive women on ARVs in Durban. For their study participants, the 'ideal' body type is shapely and curvy, and thus a lack of a big "bum," for example, was a concern for them. A similar perception based on this beauty standard was picked up in this study as well. Ayanda feels she is being judged even if it is said in jest when people comment on how big her tummy or how flat her bum is. The challenge for her is to explain her body changes without disclosing that she is HIV-positive:

> Extract 16
>
> Ayanda: Yes, some they judge me and say, 'hey, your tummy is big blah blah blah, and your bum is flat .'I would respond by saying, 'this is how I am, and my tummy is big because of C-section,' but it does not bother me because they make the comments while laughing nothing serious.

For Ayanda, disclosure may become involuntary and no longer a personal choice, although she does try to explain the visible symptoms without disclosing her HIV status. Gagnon and Holmes (2012) have found that women on ARVs with lipoaccumulation must deal with the perception that they look pregnant when they are not and handle this reaction without revealing their HIV status. Prior research also indicates that experiencing lipodystrophy and other side effects of HIV medication can affect people's self-esteem, sense of control, social and sexual relations, and can contribute to demoralization, forced disclosure, and the decision to stop treatment (Kaplan, 2014).

The women in this study were not only concerned about their body shape but also with gaining weight:

> Extract 17
>
> Gladness: Sometimes, when I am out partying, and I bumped into someone I have not seen, for sometimes he/she will say, 'you look so fat, sometimes I do not feel good, and I feel like I must lose weight. But I am okay.
>
> Extract 18
>
> Nobuntu: Yes, I feel like something changed. People will tell me that I have gained weight. They will tell me 'yho your weight is worse now .'It hurts because I do not like the situation I am in. People will say I look bigger; it is not nice being told that (.). You found out at the Clinic, when they [healthcare professionals] weigh your weight, they would say 'yho you are more than 140 kg' and they say that in front of other people in the waiting area. They will shout, 'this person has exceeded the weight scale .'You feel like this person- if she knew what she is saying is hurting me because I do not like the way I am. They are not sensitive, and people are watching you. It is a joke now (.)

Sax et al. (2020) found an increasing prevalence of overweight and obesity in people living with the human immunodeficiency virus (PLWHIV) on antiretroviral therapy. In Extract 17, for Gladness, when people say she looks so fat in social interactions, she feels like she must lose weight. In extract 18, Nobuntu is hurt when people comment on her weight getting worse. She does not like her weight gain. Healthcare professionals do not help to boost her confidence either. They are oblivious to her weight. She recounted how she felt embarrassed by them once during a consultation when they loudly shouted that she exceeded the weight scale for everyone to hear, including the other patients at the Clinic. It hurt her feelings.

When for Nobuntu, weight gain is a problem for her; weight loss has been a common complaint among HIV patients (Badowski & Perez, 2016). Sandile, Nosipho, and Lungile, for example, dislike the social attention created by their weight loss:

> Extract 19
>
> Sandile: It happened this Sunday; a woman from my church said, ' yoh, you are losing so much weight,' you see. It turned out to be a conflict because I told my mother and my mother called her out. Some people would say 'no, this is not sliming; you are thin .'When I answer them, I come across as rude because they know I was sick. I tell them

> I was sick; how am I supposed to gain weight while sick? I lost appetite, and I easily got irritated.
>
> Extract 20
>
> Nosipho: I have friends, and they support me, but there was a friend of mine who was judgemental. She said, 'the way I have lost weight; I should eat power maize meal [eat maize meal to gain weight] .'I stayed away from her after she was also diagnosed with HIV. I spoke with my children and nurses from the Clinic, they all supported me. In my community, they do not judge me even if there is umgidi [is a joyous family celebration, welcoming a boy returning as a man from the sacred custom of ulwaluko – initiation] we all go.

HIV/AIDS is often associated with either being thin or losing weight and as a result, tpeople living with HIV (PLWHIV) have a desire to gain weight to fight stigma (Bosire et al.,2020). In this context, we can understand why Sandile, Nosipho, and Lungile do not want to be thin. They feel judged, as they suspect that in the comments on their weight loss, other people are pretending to care about them. Moreover, they feel the specter of stigma is behind these comments. Sandile's mother had to intervene on her behalf when a woman from her church remarked on her weight loss. The woman knows Sandile's HIV status, yet it was almost as if Sandile had to explain to her why she had lost weight. Nosipho was offended by the unsolicited advice from her friend that she should eat a power maize meal to gain weight. They are no longer friends. Both Sandile and Nosipho find these comments or advice to be very patronizing. The HIV/AIDS-related stigma attached to thinness obscures risk perceptions on being overweight result into attempts to gain weight to avoid stigma from others (Bosire et al.,2020).

HIV/AIDS stigma is associated with negative emotions like shame, guilt, fear, anxiety, and self-blame (Yuh et al., 2014). These emotions can prevent an individual from disclosing their HIV status and make the task of living with HIV a more negative experience than it should or needs to be (Hutchinson & Dhairyawan, 2017). Karabo's struggle with the questions generated by the dark spots on her body is exemplary. In her case, we see that stigma is concealed through apparently 'innocent' questions about her health condition:

> Extract 21

> Karabo: I was right. Maybe I was right because sometimes shame is eliminated by using alcohol. I was drinking too much; that is why I did not have shame. I remember I was at the Tavern wearing short sleeves shirt, and the dark spots were showing, and one of the men said, 'why you have so many dark spots? Are you sick?'I said, yes, I am HIV positive, and I am on treatment; I am better now. I was worse than this.

The irony is that the participants who did not have the bodily marker of HIV like weight loss or dark spots on the skin not only lived openly with HIV but felt less stigmatized even when they were questioned about their HIV-positive status. Disclosure of infection to family and friends, including the wider community, often takes a considerable amount of courage (Seeley et al., 2012). Self-acceptance plays a significant role in buffering their response to how others react to the disclosure of their HIV status. The next two extracts by Lihle and Nobuntu are illustrative:

> Extract 22
>
> Lihle: No, people asked my mother if I am HIV-positive, my mother said yes. They asked, 'why I am not distressed, why I have not lost weight, etc..' I am HIV positive; I am the boss, and I defy it. It is mine, and it is not for us. People treat me well and say I am brave.
>
> Extract 23
>
> Nobuntu: I am an open person; even in my family, there are members of my family that still hide their status. Recently, a cousin of mine died, and after the funeral, we were sitting as a family, and I told them about my status. My aunt was like, but you look well, you do not look like you are HIV-positive, and I asked her if it needed to be written on my forehead that I am HIV positive. I have accepted it, and it is up to you if you cut me out of your life or not; I do not care.
>
> Extract 24
>
> Lungile: When it comes to the stigma, it was a problem; I remember when I had TB and lost weight, the people who gossiped in my area saw me. They also gossiped about my husband when he passed away, and they said 'HIV is killing me faster than my husband' to me. When I come across people who speak badly about people with HIV- I have the… [name of the organization] t-shirt that is written with capital letters 'I am HIV positive- I would take my t-shirt, wear it and walk up and down the street.

> To show them that I know myself and I do not care. That is how I would deal with the stigma.

The three cases above also illustrate that visible symptoms of HIV may increase HIV-related stigma (Stutterheim et al., 2011; Brener et al., 2013). The sense of confusion that the two women's disclosure generates stems from the absence of visible symptoms of HIV in their appearance. HIV status can be hidden in the absence of noticeable changes in appearance, but when such alterations in appearance are experienced, they are seen as a mark of HIV status and illness and provoke negative treatment by others and a great deal of emotional distress for WLWHIV (Kaplan, 2014).

The promiscuous HIV body

Armstrong et al. (2014) has argued that women living with HIV tend to be slut shamed, discriminated against, and stigmatized because HIV is linked with promiscuity, a deviation from the sexual standard society prescribes for women. The link between HIV/AIDS and promiscuity is most problematic when it comes to negotiating condom use. Some of the women reported that they had partners who accused them of cheating when they suggested condom use:

> Extract 25
>
> Ayanda: I was HIV, and I told him we must go and get tested, but he is one of those men who do not want to get tested. It is less likely for men to want to get tested. I told him lets go and get tested, and he said he was alright. I was taking my pills and using a condom, so I did not care much about what will happen. I knew I would not infect him. That was before I found his appointment card. He was sleeping out with other women, so I was like, he will bring me sickness while pregnant. He said, 'I was insisting on using a condom because I was cheating,' and I asked, 'how can I cheat while staying with you in the same house.
>
> Extract 26
>
> Lihle: When we started dating, we used a condom, but as time goes, he started saying that 'I want to use a condom because I am not loyal to him... I decided to be submissive to the man because he was my partner. I live with him, he is my person, and soon we will stay together in our house and have kids. I did not have a choice.

Insisting on condom use, as the two accounts by Ayanda and Lihle demonstrate, can lead to accusations of infidelity. In their study, Dube et al. (2017) have found that condom use is associated with infidelity and lack of trust among married and cohabiting couples. It is interesting to note that Lihle agreed to have sex without a condom with her partner because she felt like she had no choice but to be submissive to her man. At other times resistance to practicing safer sex is through inconsistent use by men, underlining the difficulty for women with HIV to negotiate safer sex practices (Cicconi et al., 2013). Here are a few examples from the women interviewed in this study:

> Extract 27
>
> Karabo: Sometimes, he does not use it, to be honest. He is the one causing problems for himself because I told him how I am [her HIV status]. It is not my problem.
>
> Extract 28
>
> Sandile: We discussed that we must use a condom, but he is a Zulu man. Zulu men do not want to know a condom, but he understands because he uses it sometimes.

In a systematic review of recent South African literature, Fladseth et al. (2015) have demonstrated that women's relative disempowerment in relationships with men reduced their ability to refuse sexual advances and negotiate safer sexual practices, including condom use. Unequal power relations also play out through men's unwillingness to practice safer sex, with women portrayed as untrustworthy or unfaithful when they insist on practicing safer sex (Osuafor & Ayiga, 2016).

Sex with a condom as unenjoyable

There is also a personal dislike of condom usage by some of the women that were interviewed in this study. For them, condoms interrupt sex and lessen their enjoyment of sex. However, they still use them for their own and their partners' safety:

> Extract 29
>
> Gladness: When I use a condom, I do not feel good, but there is nothing I can do. It is like eating a sweet while it is still wrapped [laughing], but it is for my safety. I do not have a choice; that is all there is to it. I am used to it because before, I was just doing my own thing and not using a condom. My partner is also used to it; he has no stress.
>
> Extract 30

> Nobuntu: You must adjust because you cannot do the things you used to do before. When you are HIV positive, when you met a man and you were used to muffing [colloquial term for oral sex], he will fear muffing you [giving you oral sex]. You see, many things have changed, and you must be more careful now. You do not enjoy it because you must limit yourself, you are scared, and you need to be careful now. It is not like before where you used to be free and do whatever you wanted to do. Now, it deprives you of other things you used to do.

Gladness says that she does not feel good when having sex with a condom; however, she has no choice because it is for her safety. Before she was diagnosed as HIV-positive, Gladness used to have sex without a condom. In the interview, she described using a condom as like eating a sweet while it is wrapped. She had to adjust to it. Sex with a condom is also not the same for Nobuntu. As someone living with HIV, she feels extremely limited as she can no longer perform oral sex or feel free during sex. Nobuntu has to be more careful and adjust to limited sex. There is a perception of being contagious in Nobuntu's remarks, which limits her enjoyment of sex and makes her feel constrained to choose freely how to perform sexual activities (Carlsson-Lalloo et al., 2018). Sex for Nobuntu is no longer as enjoyable as before she has diagnosed HIV-positive. It is interesting that Gladness and Nobuntu spoke about their dislike of condoms. In the literature, this is infrequently reported. HIV-positive women are not afforded equal recognition in terms of their capacity to enjoy sex as much as HIV-positive men (Williamson et al., 2009).

An undetectable virus and not using condoms

Some of the women in this study do not use condoms frequently, not only because they dislike them. One woman decided with her HIV-negative partner to discontinue using a condom because she is undetectable. Another one reported that she does not use condoms consistently because she is undetectable, although she is aware that it is risky:

> Extract 31
>
> Lihle: To be honest, I do not enjoy sex with a condom. I know I am suppressed. I sat down with my boyfriend, and I showed him my results. He understands that I am suppressed, and we are both negative, so we do not use a condom, and every day he makes sure that I drink my pills.
>
> Extract 32

> Sandile: (.) using a condom is right, but I used not to enjoy sex when using a condom. But guess what, the person I am with, we do not use a condom, but every time he goes for HIV testing, his results come HIV negative. Obviously, when you are on HIV treatment, you are undetectable. It is not easy to infect someone, but it is a risk.

The effectiveness of ART has reduced the risk of transmission to a sexual partner (Carlsson-Lalloo et al., 2018). Lihle does not enjoy sex with a condom. She sat down with her boyfriend and showed him that her viral load was suppressed, and therefore she could not transmit the virus to him if they had sex without a condom. Sandile also does not enjoy sex with a condom, and her partner does not use condoms consistently. Her partner's test results always come back HIV-negative. She attributes his negative test results each time he tests for HIV to the ARVs she is taking and low risk of transmission when you are on them. Persson (2013) and Carlsson-Lalloo et al. (2018) have shown through their research with HIV patients on ARVs that a deeper understanding of their individual infectivity based on knowledge of their viral load seems to reduce their feelings of being contagious. Lihle and Sandile are both aware of the link between an undetectable viral load and reduced infectivity, and they have incorporated this knowledge into their sexual strategies.

Nevertheless, there is always uncertainty. Sandile still struggles to reconcile the idea that a person with an infectious disease could somehow become non-infectious, a concern that Persson (2013) also reported with her HIV-positive participants who are on ARVs. With a growing consensus that the risk of sexual HIV transmission to sexual partners is zero when the viral load is undetectable, engaging in sexual activity when you are using ARVs with an undetectable viral load is increasingly being recognized to constitute a highly effective form of safer sex within HIV serodiscordant partnerships (Patterson et al., 2017).

Conclusion

In this chapter, the phenomenological functional, affective, material, and social dimensions of embodiment were used to organize the themes. Under the functional dimension of embodiment, the following subthemes were described and discussed: sleep disturbance, nutrition, and the HIV-body and consciousness of the living body. The affective dimension themes included difficult emotions and difficult bodily sensations. The material dimension of the embodiment discussed the participants' experience of their body as uncontrollable and not normal, as well as their challenge of relating to a strange or unfamiliar body and the extent some of them were prepared to go to conceal any signs of ARV side effects in their body.

Lastly, the social dimension of embodiment focused on how participants spoke of how others relate to their bodies as frightening, diseased, and underserving, as well as contagious and promiscuous. The participants also accounted for how their bodies are evaluated in different social situations, their experiences with anticipated and lived stigma, and some of the complexities they are confronted with related to using or not using condoms.

CONCLUSION

Chrisler and Johnston-Robledo (2018) argue that women's bodies are often perceived as sex objects and as objects of beauty. Women's bodies are subject to continuous evaluation and judgment, making it more difficult for women living with HIV to attain a comfortable embodiment (Chrisler & Johnston-Robledo, 2018). It is crucial to explore women's experiences of their HIV-positive lived-body from their first-person perspective to understand how they experience living with HIV and the side effects of its treatment in their day-to-day life (Chen et al., 2013). Women experience more body changes due to ARVs side effects than men (Quatremère et al., 2017). Nevertheless, there is a gap in research on the embodied experiences of side effects among WLWHIV in Sub-Saharan Africa (Chen et al., 2013). Unlike other aspects of living with HIV, such as quality of life and treatment adherence, side effects have not benefited from the same degree of empirical and theoretical engagement (Gagnon & Holmes, 2016).

This research project aimed to explore how HIV-positive women experience their bodies, emphasizing the impact of side effects of being on antiretroviral therapy. The study's research question was how HIV-positive women on antiretroviral therapy (ARVs) experience their bodies. Within this question, this research explored the sub-questions of how they experience their bodies as a disruption or empowerment to engage in day-to-day activities, how they appraise and feel about their physical body, and in what ways they experience their bodies differently, strange, or familiar as well as how are they experience their bodies in social interactions. The research used the phenomenological framework to center their live-body experience, focusing on the women's first-person accounts of what it is like to be HIV-positive and live on ARVs. Phenomenological semi-structured interviews were conducted with eleven HIV-positive women who have been on ARVs for two years or more. Interviews were analyzed using the IPA. The findings showed that the disruptions evoked by the side effects of ARVs call for adjustments as the participants had to come to terms with their altered bodies, the deterioration of the bodies' capabilities, disruption of their embodied positioning to the world, including their capacity to engage in everyday activities. The following section summarizes the findings, discusses the limitations of the research project, and makes suggestions for future research.

Summary of the findings

This research showed that living with HIV affected the body's ability to freely be in the world and realize one's projects (Grīnfelde, 2018). Living on ARVs interrupts the ability to sleep peacefully without having nightmares, insomnia, and dozing off after taking ARVs. However, not all the women interviewed reported disturbances in their sleeping patterns. The speculation by one of the participants is that sleep disturbance might be connected to which company manufactures the ARVs someone is taking. It is unclear if sleep disturbance is related to the infection itself or to a particular type of antiretroviral drug (Lee et al., 2012).

Another disruption the women in this study highlighted is that they can no longer eat like they used to; eating is no longer effortless. It requires taking vitamins to boost the appetite and prevent unwanted weight loss. However, not all participants reported unpleasant reactions to food or must observe their dietary intake. The advice from health professionals most of the participants have received on meals that will guarantee optimal health include a diet high in vegetables, fruits, whole grains, and legumes, lean and low-fat sources of protein, limited foods with added sugar (Enwereji et al., 2019). However, most of the participants were unemployed or lacked a personal income at the time of the interviews to afford or maintain the healthy diet recommended by their health professionals.

The women that were interviewed reported that they could no longer cope in the work environment; their bodies were unable to cope with their work conditions, and they were concerned that remaining at work might increase their illness and death. It seems like living with HIV limits the work women can do, the body becomes an obstacle, and their attention centers on the body, making them conscious of how the work environment can deteriorate their physical well-being (Lape et al., 2019). However, a few of the women continued to work despite the limitations of their bodies.

Another physical challenge the women reported is waking up feeling tired, unable to do daily activities, and sometimes they force the body to perform everyday tasks. Gebreyesus et al. (2020) have found that fatigue is common among WLWHIV, and it affects their day-to-day activities, can result in poor quality of life, and can impose a burden on family and community by affecting patients' job desire and productivity level. The women in the study experienced a breakdown of the bodily certainty or the confidence to engage with the activities they used to perform before taking HIV treatment.

Most of the women not only experience their body as limited in terms of the possibility of action in the world but also experience disturbance in their feelings, mood, and bodily sensations (Grīnfelde, 2018). They shared that receiving a diagnosis of HIV was a journey consisting of a combination of fear of dying, shock, sadness, irritability, hurt, anger, and shame; however, these feelings have faded as they learned to accept their HIV-positive status. Others reported these persistent feelings that their mood and made them suspect that they might not be well emotionally and mentally, with one of the women reporting she has been placed on an anti-depressant. In a surveillance study by Damtie et al. (2021), their estimate is that 3.63 million PLWHIV have major depressive symptoms in Sub-Saharan Africa. HIV and its treatment, therefore, may cause a depressed mood which may transform the being-in-the-world of WLWHIV into a mood disorder (Svenaeus, 2013). In addition, the women in the study reported experiencing body sensations such as pain, itchiness, and dizziness. These findings suggest attention is needed on unhomelike emotional reactions, mood, and bodily sensations of WLWHIV. The home likeness of the health of WLWHIV dwells in the background and is rarely paid attention to until illness strikes them (Svenaeus, 2011).

WLWHIV reported experiencing continuous body changes, and as a result, they live in fear of what will happen next as they do not have control over what happens to their bodies. The changes the women spoke about is a medical condition named lipodystrophy syndrome (LDS) caused by an abnormal redistribution of adipose tissue in the body (Gagnon & Holmes, 2011). The women said the changes in their bodies were abnormal and acknowledged that ARVs are sometimes harmful to their bodies. They continue to take the treatment because it is a matter of life and death for them (Gagnon & Holmes, 2012). Those women in the study who have not experienced body changes felt more normal, almost as if they are HIV negative. As Renju et al. (2016) have previously observed, when PLWHIV are able to resume their daily activities, they tend to feel 'normal' again, and some even report feeling like they are 'cured.'

Crucially, the women in the study feel like themselves when their bodies are healthy, but when their bodies undergo a transformation due to either HIV or the side effects of ARVs, they experience a split between themselves and their bodies. They end up feeling different as if their bodies are no longer theirs. They feel helpless that there is nothing or very little they can do to reverse the body changes. A study conducted by Gagnon and Holmes (2016) also showed that the side effects of ARVs could heighten the feeling of being different as they redefine one's sense of normality. The possibility of being put on a new treatment of ARVs that effect less or nobody changes encouraged one of the women interviewed in this study to reconsider her decision to stop taking ARVs.

Some of the women in the study compared themselves to others living with HIV and wondered if their condition would also get worse. The comparison reveals their anxiety and uncertainty about the side effects of ARVs; they are unpredictable, and it is difficult to tell which one's people will experience. It is impossible to know if, when, and how they will manifest. As such, there is always a certain unknown and anxiety with every treatment regimen (Gagnon & Holmes, 2016).

Other women in the study tried to take control over their visible body changes by using beauty products, exercising, and making dietary and clothing changes to conceal the visibility of HIV or ARV side effects. This finding corresponds with the findings from the study by Gagnon and Holmes (2011) that some women manage the side effects of ARVs through making improvements in their physical appearance. Gagnon and Holmes (2011) also show that when these efforts do not yield the desired results, they could lead to despondency. In the current study, some women found beauty products that worked for them, and others were compelled to accept that they would have to live with the visible markers of HIV and its treatment.

Before the advent of ARVs, women living with HIV were perceived as a source of HIV infection (Lawless et al., 1996). The women in this study have faced rejection after disclosing their HIV-positive status, and that is why in their perspective, it is a challenge for them to form and maintain a romantic relationship. Some of them even questioned if they were deserving of happiness. Others seem to have internalized the very inaccurate perception that women living with HIV are more infectious than men living with HIV and need to remain single to control the spread of the infectious and deadly disease.

It is not easy for most women in the study to share their HIV-positive status with a potential partner. However, some have decided that regardless of the possibility that an existing partner or a partner-to-be might run away, they will disclose their status anyway. These women considered themselves to be lucky when potential partners stayed and supported them after HIV disclosure. This finding shows that sometimes the consequences of disclosure are less severe than anticipated, even though fears of the disclosure are valid (Visser et al., 2008). Not all the women in the study have disclosed their status to their partners or would-be partners. They fear the possibility that they might be rejected. These women mentioned that the HIV body still conjures up suspicion promiscuity, and it is rejected and hated by men. As Armstrong et al. (2014) have pointed out, WLWHIV is still likely to be slut shamed, discriminated against, and stigmatized as they are seen to be deviating from the sexual standard society prescribes for women. The link between HIV/AIDS and promiscuity is contributing to the elevated level of stigma and discrimination against women (Paudel & Baral, 2015).

With regard to how they feel about their bodies, some of the women in the study described feeling judged for some of the visible side effects of ARVs. They also described how these visible effects make them feel like they need to explain their body changes without disclosing their HIV-positive status. Previous studies (see Gagnon & Holmes, 2012; Persson, 2013; Alexias et al., 2016) have shown that this feeling is not uncommon with PLWHIV, who experience visible side effects of ARVs. Participants in this study expressed concerns with visible side effects like dark spots on the skin and whether they are gaining or losing weight. From their perspective, such body changes expose them to the gaze of others' intrusive questions and may also increase the chances of body stigmatization. It is worth noting that the women in the study with fewer bodily markers of HIV or ARV side effects were more likely to live openly with HIV and reported that they felt less stigmatized.

The women in the study spoke of both actual and imagined experiences of being stigmatized associated with the decision to disclose or not their HIV status. Some of them have had bad experiences after they disclosed their HIV status, and others have received support from family members and friends. Although disclosing a stigmatized illness can result in increased social support, which cannot occur with non-disclosure (Cama et al., 2020), there can also be drawbacks to disclosing an HIV-positive status (Brener et al.,2013).

Some of the women in the study reported that when they suggested condom use, their partners accused them of cheating. Their experience is that condom use in romantic relationships is interpreted as a sign of cheating or lack of trust. Other women in the study said that they agreed with their partners to use a condom; however, their partners were inconsistent with condom use despite knowing their HIV-positive status. This finding underlines the difficulty for women with HIV to negotiate safer sex practices (Cicconi et al., 2013). Some women in the study consequently had to let go of partners who refused to use condoms.

The participants' own feelings about condoms were discussed. They do not enjoy having sex with a condom, although they do acknowledge they have no choice for their safety. It seems like a strong commitment, and sometimes obligation, to always use a condom or other safe sex techniques constrains sexuality (Carlsson-Lalloo, 2016). Some of the women do not find having sex different with a condom than without it. For most of the women in the study, their perception of being contagious is experienced as being sexually limiting. They describe it through feeling like their opportunities to choose freely how to perform sexual activities are no longer as enjoyable as they used to be before they were diagnosed with HIV. However, an awareness of the link between an undetectable viral load and reduced infectivity can be incorporated into sexual strategies (Persson, 2013). One of the participants pointed this out.

Strengths and limitations of the study: Recommendations for future research

This study has contributed to exploring the embodied experiences of WLWHIV on ARVs; however, there is no research without its limitations. The sample of the study was small and purposively selected. This means that the findings cannot be generalized to the wider population (Willig, 2008). However, as Smith et al. (2009) has observed before, a small sample allows for a richer depth of analysis that might be inhibited with a larger sample. Purposively sampling also enables detailed data collection and analysis on specific groups of people with similar experiences (Roberts, 2013). By using phenomenology to give more weight to patients' lived experiences and overcome the constraints of a one-sidedly biological understanding of the illness (Klausen, 2021). This research design has flaws that require augmentation, if not correction. For example, phenomenology studies the experience of illness by focusing on first-hand accounts of what it's like to be suffering from a specific condition (Carel, 2015), but it is difficult to make any general assertions about these experiences beyond subjectivity into the realm of statistics and norms (Sholl, 2015). To address these limitations, medicine should pay attention to patients' experiences by recognizing and responding to subjective manifestations of illness and their impact on the patients' experience of being in the world, while also investigating the number of people affected and biomedical causes of illness, which are typically not accessible to the patient's own experience but are accessible in the realm of statistics (Klausen, 2021). However, this was useful as there is very little qualitative research exploring the embodied experiences of women living with HIV on ARVs in South Africa and elsewhere in the sub-Saharan African region. Purposively sampling can give insights into the lives of people whose voices might not have been heard otherwise or whose experiences might have been overlooked or framed in a different way (Charlick et al., 2016). Future research would benefit from studying the embodied experiences of PLWHIV, including men as well, with larger samples so that findings can be generalized. In the context of expanding ARVs programs in the sub-Saharan African region, more of this research is needed.

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APPENDICES

Appendix A: Information Sheet

Department of Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 450 Fax: 011 717 4559

Greetings

My name is Nontozamo Tsetse, a Masters student in community-based counselling psychology at the Department of Psychology at the University of the Witwatersrand. I am conducting research towards my research report. The study aims to understand how do HIV positive women experience the side effects of HIV treatment in relation to their bodies. A description of the experiences of being on HIV treatment as lived by the person will help in understanding the side effects of the HIV treatment in order to reduce potential negative effects on therapy such as reduced adherence to the treatment and improve quality of life of people who are living with HIV. I would like to invite you to take part in a research study. Before you decide you need to understand what the research is about, why the research is being done and what it would involve for you. Please take time to read the following information carefully. Take time to decide whether or not to take part. Thank you for your interest in the research. Please feel free to ask any questions once you have finished if you have any.

If you agree to participate in the research, you will be asked to take part in one interview session that will be recorded and each interview might take up to 90 minutes. You can withdraw from the interview at any time when you want to stop or feel uncomfortable. The session will focus on your life history in relation to living with HIV, details of your lived experiences of being on HIV treatment and reflection on the meaning of your experience. The interview aims to put your experience in context by asking you to tell the researcher as much as possible about your experiences of being on HIV treatment. Everything you tell the researcher will only be seen by the research team which is my supervisor and I (the researcher). For wider use identifying information such as specific location, dates, and names will be changed to ensure that no identifying information is linked back to you. Interviews will be conducted in English, isiXhosa or isiZulu. We will store the recordings on our computers that are password protected for five years. When this period has passed, we will destroy both the recordings and transcripts.

Taking part in this research is voluntary. Your participation or non-participation will in no way affect your relationship with the NGO. If you do not want to take part, you do not have to give a reason and no pressure will be put on you to try and change your mind. If you decide to participate, what you have to say is very important as it will help others better understand the experiences of being on HIV treatment. If you are comfortable, we will proceed with the interview. You may contact the researcher at any time during the research.

Contact persons for more information or interest in taking part:

Researcher: Nontozamo Tsetse
(nontozamo.tsetse@gmail.com)
0799742497
Supervisor: Dr Nkululeko Nkomo
nkululeko.Nkomo@wits.ac.za
0117174542

Free Counselling Services Contact Details

Lifeline 0117281348

Life Care Centre 011 788 4784

Emthonjeni Community Psychology Clinic 011 717 4513

Appendix B: Informed Consent

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 450 Fax: 011 717 4559

Consent Form (Interview)

I, ____, consent to being interviewed by Nontozamo Tsetse, for a study exploring experience of HIV positive women on antiretroviral therapy. I understand that:

- Participation in this study is voluntary. ☐
- I may refrain from answering any questions. ☐
- I may withdraw my participation and/or my responses from the study at any time before the research report is examined. ☐
- I may voice to the researcher any concerns I have about my participation in the study, or consequences I may experience because of my participation, and to have these addressed to my satisfaction ☐
- All information provided will remain confidential, although I may be quoted in the research report. ☐
- If I am quoted, a pseudonym (Participant A, Respondent B etc.) will be used. ☐
- None of my identifiable information will be included in the research report. ☐
- I am aware that the results of the study will be communicated in the form of a research report or journal articles. ☐
- The research may also be presented at a local/international conference and published in a journal and/or book chapter. ☐

Signed: ___________________________

Date: _____________________________

Appendix C: Audio Recording Consent

Psychology
School of Human & Community Development
University of the Witwatersrand
Private Bag 3, Wits, 2050
Tel: 011 717 450 Fax: 011 717 4559

Consent Form (Recording)

I, ____ give my consent for my interview with Nontozamo Tsetse to be audio recorded for a study exploring experience of HIV positive women on antiretroviral therapy. Please tick the relevant boxes. I understand that:

- The audio-recordings and transcripts will not be seen or heard by anyone other than the researcher and/or their research supervisor. ☐

- The audio-recordings and transcripts will be kept in a password protected computer. ☐

- No identifying information will be used in the transcripts or the research report. ☐

- Although direct quotes from my interview may be used in the research report, I will be referred to by a pseudonym. ☐

Signed: ______________________________

Date: ________________________________

Appendix D: Interview schedule

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IN-DEPTH SEMI-STRUCTURED INTERVIEW SCHEDULE

HISTORICAL CONTEXT

- Can you tell me about how you came to initiate HIV treatment?
- What are experiences have you had with HIV and the side effects of the treatment?

DETAILS OF EXPERIENCES

- **Questions on function embodiment**
    - Can you tell me about how the treatment interfere or helps with your ability to engage in certain activities?
        - Do you feel like you are able to do and not do certain things comparing before you had HIV and after diagnosis and initiated treatment?
        - What can you eat and not eat etc?
    - Please tell me about how living with HIV and the side effects of the treatment affect your reproductive body?
- **Questions on affective embodiment?**
    - How do the side effects of HIV treatment affect your sense of self in relation to your physical body?
    - What are appraisals and feelings about your body in relation to living on HIV treatment?
- **Questions on material embodiment?**

    - Can you please tell me a bit more about how are you experiencing your body differently or familiar?
    - Do you feel any different comparing to before diagnosis and living on HIV treatment?
    - Can you still relate to your body the way you used to before?
    - Do you see yourself differently?
- **Questions on social dimension?**
    - How do other’s reactions to your body affect your self-worth or sense of self?
    - Are you self-conscious in social interactions?
        - What makes you self-conscious about how you appear to others?
    - How do you think you would be if your body was not always in view and subject to the judgments of others?
    - Do you feel any pressure to engage in beauty work as the results of the side effects of HIV treatment?
        - Can you tell me more about the self-improvement activities you do as a response to side effects of the HIV treatment? If any.

REFLECTIONS ON THE MEANING

- How do you make sense of the questions I asked you?
- What meaning do you make of the side effects of HIV treatment in terms of engaging in certain tasks, feelings about self and interactions with others?