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TITLE PAGE:

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ABSTRACT PAGE:

Identity and the body: narrative accounts of two HIV positive women with lipodystrophy in post-apartheid South Africa¹

Abstract

South Africa has the highest number of HIV-positive people in the world and also boasts the most comprehensive ART programme to date. Long-term ART adherence requires a range of identity negotiations in order for treatment success to materialise in the long term. However, some patients on ART develop a treatment side-effect known as “lipodystrophy” which is a condition that can severely undermine a person’s sense of self and identity given the bodily alterations that take place given notions of anticipated, felt, or internalised stigma. In this article, we explore two women’s narratives who suffer from this side-effect of ART. Their narratives are used as an “instrumental case study” (Stake 2000) inasmuch as these instances provide insights into wider phenomena. Both these women are black African, have limited means and resources, and already face serious everyday challenges despite their HIV infection and lipodystrophy. We subsequently conclude that this embodied experience is a reflection of individual and social realities of multiple layers of precarity that characterise the HIV/AIDS and ART landscape in South Africa. The article also emphasises the corporeal aspects of chronic disease which has not been amply studied in the context of HIV and ART, especially in developing countries where HIV infection is disproportionately high. Moreover, studying lipodystrophy interpretatively has also been largely neglected.

Keywords: HIV; South Africa; lipodystrophy, antiretroviral therapy; stigma; identity

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Identity and the body: narrative accounts of two HIV positive women with lipodystrophy in post-apartheid South Africa

Introduction

In South Africa, which is the country with the highest number of HIV-positive people in the world (UNAIDS, 2013), the pandemic has undergone various transformations: the most recent being its transformation from an acute crisis (and an almost certain death sentence to those infected) to a more manageable condition vested in the vicissitudes of chronicity. With this shift to chronicity comes a host of new challenges: from a clinical point of view there are preoccupations as to co-morbidities, side-effects and resistance to long-term antiretroviral treatment (ART) (Cysique & Brew, 2009; Lohse *et al.*, 2007)ⁱ. From a health systems point of view, there is the sustained pressure on public health care institutions that are already plagued by severe human resources for health shortages, as well as by the precarious position of guaranteeing a continued drug supply and being able to meet the challenges of future forms of resistance to ART (Hontelez *et al.*, 2012)ⁱⁱ. Besides these clinical and health systems aspects, HIV as a chronic condition also has a wide range of psychological and social ramifications – especially related to notions of stigma – “enacted” or “felt” (Scambler, 2009)ⁱⁱⁱ – which might potentially lead to real or perceived senses of loss, rejection, marginalisation, and powerlessness. The ramifications of stigma in the South African context are evident in the recent release of the 2014 Stigma Index that identified “internalised stigma” as a great concern (SANAC, 2015). It was found, in this study among approximately 10 500 HIV positive people, that internalised stigma affected more than 40% of respondents and that this sense of shame and inferiority also led to 11% of respondents indicating that they had experienced suicidal ideation, and 14% replied that they had relinquished sexual relationships and the prospect of marriage because of this internalised stigma linked to their HIV infection^{iv}.

A multitude of previous studies, not necessarily comparable in scale of the Stigma Index study, have shown that HIV as a chronic condition has an impact on an infected person’s identity: HIV and stigma have been studied widely (*cf.* Gilbert and Walker, 2010; Abrahams and Jewkes, 2012); HIV, being on ART and issues of sexuality and reproduction have also been investigated as important notions of identity (*cf.* Wekesa and Coast, 2013); as well as the influences and links

between HIV and masculinity (*cf.* Mfecane, 2012). As shown by many of these studies, an HIV infection and its concomitant treatment are often associated with an irrefutable change in taken for granted aspects of everyday life or notions of identity. Closely associated with this change in identity, HIV as a chronic condition equally impacts on social interactions (Russel and Seeley, 2010). These manifold ramifications of an HIV infection are still of a stigmatising nature to many people, and total disclosure is still not exercised by many PLWHA. This is partly done to preserve to some extent, some identity features that characterised the person before the onset of illness and its treatment. Also, even in poorer, highly affected contexts where state-of-~~the~~-the-art treatment is not as readily available as in richer parts of the globe, HIV is becoming a less visible condition because of hugely successful treatment programmes albeit not comparable to the feats experienced in HIV management in developed nations.

Despite these advancements, disclosure can be *inevitable*^v, especially when there is physical inscription of illness on the body as in the case with the lipodystrophy syndrome which is associated with a range of corporeal transformations in some HIV positive individuals who are on ART (Carr, *et al.* 1998). When suffering from lipodystrophy, excess fat can develop in areas of the body, most notably around the stomach and abdominal organs such as the liver, but also around the breasts and the dorso-cervical spine. It can also lead to fat loss or lipoatrophy of the face, limbs and buttocks. Not only morphological changes, but also metabolic alterations happen when suffering from this side-effect (Guaraldi *et al.*, 2008:153). Most significantly, these changes are mostly irreversible. Extreme forms of lipodystrophy may then be the cause of a *forced disclosure* of HIV diagnosis, and can lead to increased fears of adverse events related to HIV-treatment (Guaraldi *et al.*, 2008: 154). It has been proven that “disfigurement may cause stigma, erosion of self-esteem, and a decrease of desirability or attractiveness; it may also influence social relations, and lead to anxiety and depression” (Guaraldi *et al.*, 2008: 154). Curiously, it has also been shown to interfere with immune-virologic outcomes: at first it was noted that the likelihood of lipodystrophy was related to greater adherence, but this correlation has apparently diminished over time (Guaraldi *et al.*, 2008: 156)^{vi}.

As Asha Persson (2004) powerfully argues in relation to lipodystrophy in gay communities in Australia, its manifestation represents an:

awkward reminder of times past and [is] an ominous sign of shortcomings in the current, supposedly triumphant fight against AIDS. As the ‘new face of HIV’, lipodystrophy is swept under the social carpet, largely consigned as an individual problem rather than a collective or political concern. Its public presence

in the streets of gay neighbourhoods is not matched by any public dialogue of what lipodystrophy means, not just for those affected by it, but for communities as a whole. For something so invisible, lipodystrophy is strangely invisible (Persson, 2004:62).

Given this very visible sign of the ART regimen that manifests in some patients, we would like to reflect on the bodily aspect of HIV as a chronic illness in the South African context. This is something that is largely ignored in the study of HIV as a chronic illness in the developing world, including South Africa which hosts the world's largest ART programme (Finkelstein *et al.* 2015). Also, studying this phenomenon interpretively has been overlooked with the exception of a few studies (Persson, 2004; 2005; Gagnon and Holmes 2008; 2010; 2011). We would therefore aim to address this research gap and enquire into an important bodily aspect of chronic ART: lipodystrophy and its link with other aspects, namely social interaction (stigma) and identity.

Firstly, we will argue in this article that this visible inscription of illness on one's body can give rise to feelings of "felt" or "internalised" stigma as "stigma is typically a social process, experienced or *anticipated*, characterised by exclusion, rejection, blame or devaluation that results from experience, *perception* or reasonable *anticipation* of an adverse social judgement about a person or group" (Scambler, 2009: 441 emphasis added). We acknowledge that HIV infection can be a stigmatising condition for any affected person, but visible bodily transformations linked to HIV can be internalised by the afflicted person and can give rise to *notions of anticipated stigma*. This inevitably has consequences in relation to the afflicted person's identity as stigma not only refers to those attributes that are hugely discrediting, but also affects relationships (Goffman, 1968).

Secondly, and closely related to our first line of argumentation, we aim to contribute to the social theory of identity, by contextualising the conditions under which adverse HIV experiences – in this case, lipodystrophy – take place by emphasising "intersectional identities" which posit the overlapping forms of "marginalised identities" or the "intersection of vectors of oppression and privilege [that] create variations in both the forms and the intensity of people's experience of oppression" (Goodman and Ritzer, 2008: 479). This is also closely linked to a "realist theory of identity" (Alcoff *et al.*, 2006: 6) where it is conceived that "identities can be no less real for being socially and historically situated, and for being relational, dynamic, and, at times

ideological entrapments. Identities are markers for history, social location, and positionality (...)” This approach to “identity” is vested in the importance that our contemporary global context is strongly and decisively shaped by “*systems of inequality*” (Branaman, 2010: 143 emphasis added). Bryan Turner (1992) has extensively argued that Erving Goffman’s notion of the ‘presentation of self’ or the ‘social self’ was largely determined by and “presented through the social body” (Turner 1992: 44), and we argue that the presentation of the social body that we will discuss in this article is a manifestation of these systems of inequality.

Lastly, we aim to capture these mundane experiences of living with HIV and lipodystrophy through the use of two women’s narratives which are not necessarily focused on “repair and restoration” (Williams, 1984), but rather interested in Michael Bury’s emphasis on continued existential realities that people have to face living with and managing HIV as a chronic illness (Lawton, 2009). This is also relevant, given the unequal burden of HIV on women in terms of infection rates and care taking responsibilities. They are also more susceptible than men to experience corporeal transformations as a result of lipodystrophy (Galli *et al.*, 2003; Heath *et al.*, 2002).

South Africa, HIV-infection, treatment and lipodystrophy

In October 2003, after an extraordinary and much publicised struggle to make ART available in the public health care sector – an announcement was finally made that the roll-out of the drugs would start in April 2004^{vii}. Late in 2004, 25 000 people were receiving ART through the public health care system. That number gradually grew to 1 000 000 in December 2010, whereas at the same time, 5.5 million people were infected with the disease. In 2012, it was reported that 1.9 million people were receiving free ART dispensed at public health care facilities all over South Africa (Pillay, 2012). At the 7th South African AIDS Conference in June 2015, it was estimated that just over 3 million people were accessing ART in the South African public health care sector. Between 1998 and 2011, it is estimated that 2.5 million South Africans died because of the disease. The country hosts the world’s largest ART programme – a programme that is unparalleled in scale. Impressive results have been recorded after more than ten years of generalised access to ART which include increases in adult life expectancy (Bor *et al.*, 2013), as well as a declined risk of acquiring HIV in areas where there is high ART coverage (Tanser *et*

al., 2013). Mother-to child-transmission of HIV has also virtually disappeared as a mode of HIV infection.

Despite warnings that ART should not be considered a “magic bullet” to the HIV problem in South Africa, responses to the illness have become largely medicalised and “drugs have come to embody even more succinctly the means of life itself: the means to control qualities of body and mind and subject them to the terms of the market” (Comaroff, 2007:213). Treatment success and surprisingly good adherence, but also side-effects, co-morbidity, issues of long-term adherence, compliance, resistance, drug stock-outs, drug pricing and intellectual property legislation characterise the ART landscape of South Africa. Also, the limited means of the public health care system render patients’ complaints about less important issues – such as chronic pain, and bodily changes – trivial and insignificant in the greater scheme of things – thereby “delegitimising the illness experience” (Ware, 1992) of those who have these “secondary concerns”.

One of these “secondary concerns” is lipodystrophy which is a side-effect of ART and often linked to medication used in first line therapy, especially Stavudine or d4T, although it is also caused by prolonged use of ART. Updated guidelines of the clinical management of HIV that were accepted in April 2010 in South Africa (following the World Health Organisation’s recommendations) began to phase out the use of Stavudine (d4T) which is now replaced by the use of tenofovir (TDF). However, 14 of 52 low income countries are currently still using this line of treatment due to a variety of factors. These factors include financial constraints that prevent systems to change to a different line of treatment, lack of donor aid, uncertainty as to the manner in which phase-out should be prioritised, or the need to reduce already acquired stocks of d4T (WHO, 2013). The WHO acknowledges the fact that the use of d4T or Stavudine has, for many years, been mainly limited to resource-limited settings (WHO, 2013).

The commonly used term “lipodystrophy” which means “fat redistribution”, actually implies both “lipoathropy” (fat loss) and/or “lipo-accumulation” (an increase in fat). Globally, it is not known how many HIV positive people actually suffer from this treatment side-effect. In their study to ascertain its occurrence, Grinspoon & Carr (2005) estimated that this percentage can be in the widely variable range of 11% - 83%. This condition can apparently be linked to a host of risk factors related to patient characteristics (ethnicity, age, sex, lipids, nadir CD4+ count, level

of HIV), as well as to treatment regimens (type of ART and length of time on treatment). (Baril *et al.*, 2005). In the South African context, with the majority of people infected being black African, it can also be added that the concomitant scourges of increasing incidences of obesity and malnutrition exist among the HIV positive population. These lifestyle factors might also play a role in the manifestation of lipodystrophy. Also, there are no clinical guidelines to assess and manage lipodystrophy in South Africa, therefore it remains largely ignored and is often trivialised, even in developed countries' care contexts (Gagnon and Holmes, 2008; 2010; 2011).

This apparent “secondary concern” that is addressed, but often at too late a stage (or not at all) – has been shown to become problematic in the long term with regards to clinical outcomes as well as to psychological well-being. In a context where HIV is becoming increasingly invisible and manageable given access to ART, it is even more problematic that one's infection status can be detectable involuntarily by inexorable corporeal transfigurations.

The body and identity confronted with the visibility of illness

A chronic illness diagnosis does not automatically lead to a “construction of being ill”, but according to Joseph Kotarba (1977:272) the “primary definition of being sick comes from the person's body”. Erving Goffman's (1968 [1963]) seminal work on stigma established a solid relationship between the body which acts as a meaningful social symbol on the one hand, and the articulation of stigma, on the other. Questioning one's identity during illness originates from a very tangible fear that one is no longer exercising control over one's body and therefore becomes largely incapable of doing what one used to do before. This is also the case with HIV/AIDS, where it has been shown that the physical manifestation of the infection on the body is correlated with a sense of loss in terms of control and integrity over one's body and therefore, one's identity (Alonzo and Reynolds, 1995). Moreover, physical inscription of illness onto the body can also lead to a feeling of no longer understanding the body's language, which inevitably leads to a lack of trust as the familiar body now becomes fundamentally unfamiliar (Kotarba, 2009; Corbin 2003). In fact, Paul Ricoeur (1996 in Ferguson 2009) has indicated that we do not choose our bodies, or for that matter the changes that our bodies might undergo because of illness, treatment or mere ageing. Harvey Ferguson (2009: 106) thus alludes to the one-sidedness of the “existential focus on the ultimate freedom of self-identity” because of its “failure to acknowledge the ultimacy with which we are bound to our bodies”. Inevitably, there is an undisciplined nature

associated with our bodies and being able to control all aspects of the body is something that is largely out of our immediate manipulation. In illness, but more importantly, during the treatment thereof, *iatrogenesis* which means adverse effects and secondary pathologies, demonstrates the “non-mechanical quality of medical drugs *and bodies* alike” (Persson, 2004: 54), especially when these two entities meet in times of therapeutic interventions. We might accept and embrace biomedical regimes to cure and care for our bodies, but our bodies might not follow the rational, causal narrative or “pharmacomythologies”^{viii} transmitted by medical intervention. We might accept a specific biomedical regimen, understand its purpose, its capacity and its effects (Helman, 1990), but there can still occur unintended and unexpected consequences in the process of actually ingesting chemicals. Our quest for survival might come at an iatrogenic cost, which might require a whole new series of self-negotiation and identity reconfigurations.

Juliette Corbin (2003: 258) rightfully states that the “body and self are caught in a fateful embrace [because] what happens to either affect the other”. This idea of a body that surpasses mere corporeality has been important in demonstrating the intimate and necessary connections between body, experience and relationships, but also how these notions link up with identity. The onset and experience of chronic illness, or in the case of the ensuing narratives, the inevitable visibility thereof – could lead to a “loss of self” or a sense of diminished identity (Charmaz, 1983). In Gagnon and Holmes’ (2011) qualitative study on women with lipodystrophy, it was established that a strong link existed between “inability to regain control over the body and the distress reported by women who suffer from lipodystrophy”. (Gagnon and Holmes, 2011: 31). The perceived and real impact of bodily dysfunction or transformation can also have an impact on our wider social relationships. For Arthur Frank (1995), the body is therefore considered a “logical place to investigate subjectivity and identity for this is the site through which people experience life” and he further stipulates that a “condition for interpretation shapes a person’s own body as a medium and is a point of departure for narration”. In his seminal work, *The Wounded Storyteller*, Frank (1995) indicates that our bodies are not “mute”, but that they are “inarticulate”. He states that the body “does not use speech, yet begets it”. It is through illness stories that this voice is heard – especially the voice as heard from embodied experiences. It is also, however, that bodies express stories of medicine, or the interaction of bodies and medicine, and the manner in which “corporealities [are] produced when medicines meet living flesh” and the meanings that are borne out of this “biochemical encounter”

(Persson, 2004). Lipodystrophy results as a direct consequence of an adverse reaction to a specific life-saving medication. The manner in which lipodystrophy developed in poor areas of the world is often directly linked not to being on treatment for a protracted period of time, but because a specific first-line regimen (d4T) was the only option for those who were receiving free ART in the South African public health context. Asha Persson's (2004) remarks about *pharmakon*^{ix}, its unintended consequences and vested commercial and political interests in combination with its potential beneficial properties, are a stark reminder of a context in which resources are limited, demand is great, and people are desperate, after witnessing years of procrastination and too many untimely deaths as a result of AIDS. The first priority, in such circumstances, is often related to mere survival.

Site, sample and methods

The case study of the two women that is presented and discussed here, emerged as an interesting and unexpected theme in a larger research project titled "HIV and Identity" that we have been conducting in Bloemfontein, in the Free State province of South Africa since 2011. This research project draws upon a qualitative longitudinal study of the life transitions of HIV-positive people who are on ART in the Free State province of South Africa. We recurrently visit and interview 12 women and 12 men as part of this project. These participants were recruited from a previous study entitled the *Free State Effective AIDS Treatment Study* (FEATS), which was a prospective cohort study aimed to consider the impact of peer adherence and nutrition support on clinical outcomes in a sample of 655 HIV-patients enrolled in the Free State province's public-sector ART programme. Convenience sampling was used to select these 12 women and 12 men from the FEATS data set, with the convenience criteria being geographical spread (residing in Bloemfontein or in close proximity thereof) and a disposition to regularly participate in the discussions. These visits and discussions took place only after informing the potential participants about the rationale behind the research, the latent risks and benefits linked to their participation, their right to privacy and confidentiality, and the ongoing voluntary nature of their longitudinal participation. At each visit, we ascertain the ongoing consent of each participant, albeit not in writing as was the case during the first visit. We strongly believe that the consent procedure is ongoing and have replaced (and lost) some of the male participants in this study because of their tacit reluctance to continue. Overall, the interviews addressed a wide range of

subjects related to the experience of life with HIV and on ART in a high HIV-prevalence, resource-constrained setting. Each visit usually lasted about between 40 and 90 minutes. The interviews were recorded, while the field workers (one author and a field worker) took notes and immediately following the interviews wrote a short summary. The participants were provided with a token of gratitude in the form of a R100 voucher from a local supermarket. The study was approved by the Ethics Committee of the Faculty of Health Sciences of the UFS and we also obtained authorisation of the Free State Department of Health.

The choice to opt for a case study methodology materialised retrospectively as it was not intended at the onset of the research. Moreover, we wish to describe this case study an “*instrumental case study*” (Stake, 2000) inasmuch as the phenomenon under scrutiny (in this instance, lipodystrophy and the manner in which it afflicts two HIV-positive women in a particular context) provides insight into broader phenomena (inadvertent disclosure, impending stigma, testimony of deficient health care and generalised inequality and poverty). Although some men and some other women in our study also referred to corporeal transformations (change in skin colour, texture of hair, size and shape of the body, facial lipoatrophy), none of the others stood out as poignantly as the two narratives that we selected. In fact, the other participants paid scant attention to, or chose to ignore their altered bodily states. But for the two women below, their experiences of lipodystrophy occupied an important part of their lives.

The story of Sello’s wife

When contemplating a pseudonym for this 37-year old participant, we couldn’t help linking her to her now deceased husband. His enlarged ID-photo still decorates their wall; he was her first and only love and lover, the father of her two daughters of which the first was born when Sello’s wife was only 14, the source of her happiness after an unhappy childhood, but also the person who brought HIV to their home. He was a migrant labourer – earning an income for him and his family in Johannesburg, and according to his wife: “*he did things when he was there...*”

Sello’s wife has accepted her HIV-infection – in fact, being infected is not her “*biggest worry*”, but the fact that her body has changed is dramatically influencing her life. This occurrence then, had a serious effect on her identity as soon as she realised that her body was changing.

I have accepted my status and I am fine with it, but my only worry is my body. Summer is approaching and I won't be able to reveal my legs because of the side-effects. I am fine from here to here [indicating her upper body]. (...) This part of my body is always painful [touching her abdomen] and I want to do a pap smear. The pain is too strong (...)^x

So not only is she suffering from visible bodily transformations, but she also experiences a lot of pain, sleep deprivation and consequently a generalised sense of fatigue. She is also very uncertain as to her state of health and often reiterates how difficult it is to discuss her preoccupations with the medical personnel at her public clinic. In fact, it is near impossible to ask for a pap smear to be done in the context of the public health clinic. This is a classic example of deficient health care that is offered at public health facilities in South Africa.

My body is so painful... I only go to work because I really have to. (...) If it was up to me, I would rest. My body is in desperate need of rest...

In Sello's wife's case, her lower body has become much thinner than before. She wears multiple layers of towels under her skirt or more than one pair of trousers to give her buttocks more shape. She is aware of the fact that people start gossiping once they notice that someone is losing weight, and that women become unappealing and "suspect" when they are too thin, especially if they used to have fuller figures. She infers that her female body is thus under scrutiny of neighbours, acquaintances, and close friends and family, and feels very uncomfortable with their anticipated reaction – overtly but more importantly, covertly.

She is severely depressed about her body's altered state and does not feel healthy and energetic. However, she cannot risk being absent from work, as she does contract work for a cleaning company and can easily be replaced if her employers deem her unfit to fulfil the tasks at hand. She is responsible for the well-being of her two daughters and has limited financial means.

She was asked if she had ever considered terminating her treatment because of all the side-effects. Sello's wife is adamant that this idea has never crossed her mind, that ART is her life and her only hope of survival and that she will take whatever side-effects come her way in order to survive this infection. She has internalised the messages from the drug-readiness training^{xi} in relation to adherence and leading a responsible life: she does nothing that compromises her health like drinking, smoking, engaging in unprotected sex. She takes her medication religiously.

She epitomises the “expert patient” who has made ART part of her life, part of her identity, despite its severe side-effects in her case.

When asking her to show photos of herself before these bodily changes, she replies that she has destroyed most of her photos:

I tore my photos because I was angry and frustrated (...) I am disfigured.

She constantly alludes to the changed shape of her body, and during a subsequent visit, she repeats:

I used to wear shorts before, but now I can't wear them anymore because my calves used to be round, and now they are not anymore. (...) They are sculpted like I am doing a lot of gym (...) ^{xii}. I do not have curves anymore, and they told me that the pills are responsible for that, but I don't know...

Jean Comaroff (2007: 203) points to the usage of certain adjectives “like *fat* or *thin*, *sharp* or *sluggish*, *sallow* or *pumped*, [that] prime the delicate labour of framing identities and futures in the shadow of the epidemic.” Sello’s wife’s altered appearance – her being “thin” now - has led to changes in her everyday life: her present self-image is wholly incompatible with her possessing a valued self (Charmaz 1983), which in turn influences her social interactions. During one visit to her house, she indicated that she was not going to attend a funeral of a relative, given her changed appearance. She is afraid that people who know her will observe the drastic manner in which her body has changed. She does not even contemplate the possibility of an amorous relationship as her “*illness will complicate things*” as well as her now devalued appearance.

Rather, in the close intimacy of their home, Sello’s wife and her daughters find solace in one another. The oldest daughter who is 21 says that she does not have friends, to which Sello’s wife answers: “*We are each other’s friends*”.

Beauty’s story

Beauty’s illness identity has taken a different turn from other participants: she was diagnosed with non-Hodgkins lymphoma as a direct result of her HIV status. She uses her status and identity as a “cancer patient in remission” in concrete ways: she volunteers at the local Cancer

Association as a speaker especially to the African population who, according to her “sees cancer as a disease of White people”. She has also featured in the Cancer Association’s project “Moments in Time” where short biographies and life stories together with professional photos of cancer survivors are displayed in a calendar. Witnessing the radiant, attractive, confident 35-year old woman on the photos highlights the contradictions of her sustained failed attempts to lift herself out of unemployment, financial hardship and dependence. Her illness trajectory is one of redemption. She was not surprised when she learned about her status on World AIDS Day in 2003 – the very day the former president of South Africa, Thabo Mbeki (also known for his with AIDS denialism) was addressing a crowd of people a couple of kilometres away from the hospital where she received the news. She was a party girl and the positive test result made her change her lifestyle as she did not want to take ART when she was first diagnosed because she associated treatment with skin problems (dry and blemished skin) and other factors that might have changed her appearance, albeit not morphologically. Her CD4-count went up, which led her to “getting a big head” and she started partying again. Then the cancer hit and her CD4 count dropped to 16. For the better half of 2007 she received chemotherapy together with ART. The cancer experience made her change her life. Today she is a born-again Christian, her church and her new friends - “quality not quantity” friends - define who she is. Her friends know that she is taking medication, and she does so openly, because she simply pretends it is for the cancer and discloses her HIV status selectively. We asked her about her illness (HIV) and ART:

Interviewer: ... *and when you started your treatment, how did that change your life, the treatment?*

Beauty: *No...*

Interviewer: *Not?*

Beauty: *Wait! It changed my figure, oh Jesus! I developed these veins, calves... it ... my figure changed! My bum went smaller and my breasts got bigger. (...)*

Interviewer: *What did your figure look like before?*

Beauty: *I was fine, I was voluptuous, and I was OK...*

She then brings back a photo album to show us what she looked like before she got ill, during her treatment and afterwards. Most of her photos contain captions: “*I was dying there*”; “*shortly before I lost my hair*”; “*I was really fat*”. But Beauty often alludes to the fact that she likes her new shape: she can eat as much as she wants without getting fat (except around her stomach). She even sees it as a positive happening – to have lost weight – because she says: “*I used to be big...*” Over the time that we got to know her, she often refers to her body and her weight when she refers to her everyday life experiences. For example, when she got a job working odd hours, she tells us that she lost four kilograms in one week. During another visit, after she managed to do another job and earned some money, she went on a short trip with some of her friends. She tells us how happy she was – having had some money, going somewhere, away from the monotony of her everyday life, and being able to buy some new clothes and shoes. When referring to this time in her life, she says: “*I’ve been good, I’ve gained four kilograms*”. She explained that she is now the weight that she always wanted to be. However, when asked what her biggest fear is, she answered: “*what if I meet Prince Charming?*” The idea of disclosing her HIV status to a potential lifelong partner and the prospect of having children seems problematic with regards to this important anticipated relationship, an idea that she has largely given up on, because of her HIV infection.

Her treatment, despite the side-effect of lipodystrophy, she sees as her “friends”. She also internalised the biomedical messages of normalisation into her HIV identity. She equates HIV to other chronic illnesses, notably diabetes, and leads a responsible life, not taking any risks that might interfere with the functioning of her ART. She will also never become non-compliant, as she already experienced the consequences that this insubordination did to her body and her state of health. But she cannot help to utter from time to time that she would like to be cured of HIV...

Discussion

The meaning of treatment faced with lipodystrophy

These two narratives show us how complex and different bodily experiences of illness can be. In both cases, ART has been incorporated into these women’s identities inasmuch as they don’t foresee ever becoming non-adherent to their treatment even in light of the highly perceivable side-effect of lipodystrophy. This has been shown in other accounts, especially among

participants in the developed world (Persson, 2004). This predominance on survival in general and the relief to be among those fortunate enough to simply access life-saving treatment, in particular, cast other side-effects and complaints into the domain of irrelevance, especially in the contemporary South African context where resources are directed mainly to get those HIV-positive people who qualify onto ART and ensuring adherence and compliance and ultimate therapeutic success measured in terms of an undetectable^{xiii} viral load and a high CD4 cell count. The victory of *pharmakon* is viewed uniquely in its life-saving and life-enhancing capacity without making way to perceive the manner in which these pills can change, among other things, people's sense of self (Persson, 2004). The experience of lipodystrophy tends to “compound feelings of ‘difference’, of having a body already ‘set apart’ by medical management and by a socially stigmatised illness” (Persson, 2004: 52).

For Sello's wife, her altered body adds to the “social inefficacy” (Kleinman, 2009) and growing isolation that she is already experiencing to a certain degree – shaped by the traumatic memories of her childhood, the death of her beloved, constant pain and fatigue that are left untreated, overall dissatisfaction with her job that entails long hours and hard, physical labour which are all compounded by her perceived loss of identity because of severe lipodystrophy. Beauty, on the other hand, capitalises on her altered physical appearance: the fact that she has cancer however, serves as a counter narrative to the stigmatised notion of being HIV-positive, and she actually prefers her new appearance, as long as she can shape her narrative according to her own preferences – of which denying HIV infection is the greatest.

These two illness accounts can be read and understood as presenting “factions” – described by Michael Bury (2001) as including both “hybrid facts” and “fictions”. The term “factions” thus represents, captures and conveys the idea that rather than expressing “a form of unalloyed subjective truth, narratives take many forms, have many uses and serve many purposes” (Bury, 2001: 281). In terms of Goffman's “dramaturgical performance” of identity, Beauty acts to “maintain face” in the “front regions” (in front of the researchers, in front of her friends, in public spaces) whereas Sello's wife seems to have stopped performing, and has retreated to the safe space of her home and her daughters (“back regions”). They both anticipate forms of stigma (or reactions) related to their bodily alterations and remedy this perception by using these two strategies: Beauty's counter-narrative of cancer allows her to provide explanations for taking

medication as well as for her transformed body. Sello's wife simply withdraws to the safety of her home and her daughters, and when she leaves this safe space, she tries to partially hide her transfigurations by padding up her lower body and by avoiding too much contact with people who used to know her before the onset of these alterations. She resigns herself to living in a diminished world (Goffman, 1968) as it is too difficult to face acquaintances of her (anticipated) pre-stigma life.

Despite this, they both have expectations in terms of therapeutic efficacy. For both Sello's wife and Beauty are adamant that the most important outcome despite their transformed appearance is the fact that they will be given a chance at survival. In a ubiquitous context of death, but more importantly, *untimely* death linked to AIDS, this notion holds a lot of meaning. Also, the so-called "normalisation" of HIV in clinical settings, the message that HIV is like any other manageable, chronic disease if actions are responsabilised, and the ultimacy of ART in official discourses and at medical facilities, makes the acceptance of ART as a "magic bullet" widespread in the South African public health care setting. People with chronic conditions such as HIV and who opt for lifelong treatment adapt to biomedical technology, at times in ways that are foreign to them and to their culture, but nonetheless they persevere in order to "affect health" (Etkin, 1992 in Persson, 2004). These narratives tell the story of the "normalisation of iatrogenic effects" as survival is paramount (Persson, 2004: 58). It runs contrary to the findings of Gagnon and Holmes (2011) who show that the women in their study got to a point of "pathologising" lipodystrophy, as all of their participants, suffering from lipodystrophy, underscored the importance of exposing this side-effect as a "debilitating condition that permanently damaged their body and seriously reduced their chances of living a 'normal' life" (Gagnon and Holmes, 2011: 32).

Intersecting modes of effect: women, bodies and inequalities

Our corporeality is an all-encompassing element of the commodified reality in which we find ourselves today. Our body image (and not so much affect) is the main channel through which we view ourselves and consider others to view us. This physiognomic obsession is instrumental in how we perceive our status and our social acceptability and determines how we judge others (Featherstone, 2010), even in non-western contexts of deprivation and lack of resources, as cultural conceptions of bodies, especially female bodies, are also strongly affected by appearance

or “conspicuous corporeality” (Persson, 2004: 62). In direct line with these two narratives, we share Chris Shilling’s opinion that the body is a fundamental phenomenon that shapes the “modern person’s sense of self-identity” (Shilling, 2012) as these narratives contain elements of contemporary “Western” influences or the “distinctively modern activity promoting the self as image” (Sontag, 1991:29) and are reflections of the interlocutors’ “local moral worlds” or contexts (Kleinman, 2010: 1518). Both Sello’s wife and Beauty are intently aware of the important messages their bodies convey in their unique contexts. Lipodystrophy is an inscription on the body that cannot simply be treated in its pathophysiological dimension, given the importance of one’s body in the presentation of the self and its centrality in our interactions with others (Gagnon and Holmes, 2008).

Also, these narratives are examples of Turner’s (1992) “somatic society” inasmuch as this phenomenon is telling of a whole range of personal and political realities that shape these two women’s lives in the contemporary South African context inasmuch as “ways in which bodily change occurs are related inextricably to people’s social actions as well as to the wider social structures in which they live” (Shilling, 2008:1). Both Sello’s wife and Beauty suffer from lipodystrophy directly related to their HIV infection. This infection disproportionately affects black African South Africans, and especially young South African black women. This disproportionate prevalence reflects the explosive mix of a complex amalgamation of past injustices and present privileges that so characterises this country on the African continent (Fassin, 2006). In fact, these women’s stories are individually and collectively revealing of the “reconfiguration of the suffering body in the light of historical past and present” (Das, 1997 in Fassin, 2002: 66). The intersectionality of these two women’s vulnerabilities is writ large: both are “black” African and female, both have precarious employment potential, both are young and single, both lives are marked by precarity and generalised lack of financial stability and rely on unpredictable social capital from family and friends. Sello’s wife has the added vulnerability of having to singlehandedly bring up and to provide for her two daughters. Beauty might not have children of her own, but she is also responsible for looking after her younger brother and cousin. Also, they both get their treatment and medical attention at public health care facilities that are notoriously known to seldom provide optimal, negotiated care which is of paramount importance in the management of chronic conditions with potential unintended consequences^{xiv}. The majority of the South African population (mostly previously disadvantaged communities during

apartheid) has to rely on public health care, and pervasive inequities in health care still epitomise the lasting unequal distribution of privilege in the South African context.

The primary and irrefutable experiences and the immediacy of the body in these two narratives therefore contain elements that entangle the structural and the agentic in terms of shaping identity. The narratives of these women are indicative of more than simply bodily alterations despite the importance and immediacy of this treatment side-effect. It is a reflection not only of the ubiquitous inequality of the South African health care system, but also of systematic precarity, of dubious moral priorities, of gendered realities, but most tellingly, a moral commentary of embodied non-privilege.

Conclusion

The availability and access to ART in the South African public health care setting is an enormous victory to those who are HIV infected. However, the specific trajectory and context of ART access in South Africa have rendered the notion of survival paramount to those accessing this treatment, often at the expense of iatrogenic complexities: those physical and psychological effects that this illness and its *pharmakon* can have on people – in our narrative accounts evolving around lipodystrophy. Lipodystrophy is associated first and foremost with anticipated, internalised or felt stigma, a trend that was found to be disturbingly high among HIV positive individuals in South Africa after the recent Stigma Index study. Lipodystrophy should start occupying, together with other so-called “side-effects” (such as the experience of pain), more prominent attention by researchers, care givers and policy makers, given the long-term commitment in South Africa to the ART programme. Affecting women disproportionately, it should also be reiterated, as was done by Varas-Diaz *et al.* (2005) and Gagnon and Holmes (2008) that it is not merely an “unfortunate cosmetic consequence” of HAART. As Jean Comaroff (2007: 202) indicates, AIDS lays bare the sovereign control “not only of death but also of life”. This is all the more relevant in a context of chronic HIV management where increasingly complex side-effects and psychological consequences of life-saving treatment are neglected. This does not bode well for the world’s largest ART programme given the

permanence of this treatment in people's lives and its potential effects on people's sense of self in a context plagued with manifold concurrent challenges.

ENDNOTES:

ⁱ Common side-effects include: insomnia, nightmares, fatigue, memory problems, depression, chronic diarrhea, stomach cramps, nausea, vomiting, sexual dysfunction, nerve damage (peripheral neuropathy), rashes, hypertension, liver damage, heart disease, pancreatitis, bone diseases, etc. Patients can also suffer from fat loss (lipoatrophy) and fat accumulation, or fat redistribution (lipodystrophy) – bodily alterations that can also lead to other metabolic problems including insulin resistance and high levels of dangerous fats in the blood (cholesterol and triglycerides). This obviously increases the risk of some non-communicable diseases like diabetes and heart diseases (Carr and Cooper, 2000; Machon and Batrouney, 1999). The steady increase of non-communicable diseases in combination with the high incidence of communicable diseases in the South African context has dire public health consequences.

ⁱⁱ Currently, the South African government mostly provides first line ART regimens. Second line ART regimens are also free of charge in public health care facilities although not widely used as yet. South Africa has also been the first African country to have recently adopted third line regimens in the public sector for those resistant to the first two lines of treatment.

ⁱⁱⁱ “Enacted” stigma refers to overt discrimination against those with a particular affliction solely because of their social unacceptability, while “felt” stigma implies a sense of shame and the fear of being the victim of “enacted stigma” (Scambler, 1989 in Scambler 2009). In this article, “felt”, “anticipated” and “internalised” stigma are used interchangeably.

^{iv} This shows the fact that stigma is not a static concept, but rather vested in particular societies at specific points in their social development (Whitehead *et al.*, 2001). Enacted stigma used to overshadow all other forms of stigma in relation to those infected with HIV, especially in terms of discrimination and explicit “othering” of those infected.

^v Inevitable disclosure obviously challenges issues of “control, protection, privacy and integrity” (Collins *et al.*, 2000; Power *et al.*, 2003; Reynolds *et al.*, 2006 in Gagnon and Holmes, 2008: 237).

^{vi} Various studies have been conducted in the developed world to ascertain the impact of lipodystrophy. These consequences include: “a negative impact on adherence, body image, mental health, physical well-being, self-esteem, sexuality and intimacy, social functioning, quality of life, and the overall well-being of people living with HIV/AIDS” (Ammassari *et al.*, 2002; Blanch *et al.*, 2004; Burgoyne *et al.*, 2005; Corless *et al.*, 2005; Duran *et al.*, 2001; Huang *et al.*, 2006; Lenert *et al.*, 2002; Oette *et al.*, 2002; Preau *et al.*, 2008; Steel *et al.*, 2006 in Gagnon and Holmes, 2011: 25-26).

^{vii} South Africa is not only known for its high HIV prevalence rates and AIDS deaths, but also for its controversial political response to the illness in the late 1990s and early 2000s. This era of AIDS denialism has been studied elsewhere (see Fassin, 2006)

^{viii} Montagne (1996, in Persson, 2004: 55) coined the term “pharmacomythologies” to indicate the fundamental principles associated with medicines such as the omnipresent notion that treatments have one *main* effect, and that all other effects are secondary, incidental or “on the side” (i.e. a “side-effect”).

^{ix} The Greek word *pharmakon* has an ambiguous meaning inasmuch as it contains the double meaning of medicine that includes both its potential to act as a remedy but also as a poison. Jacques Derrida, (2000, in Persson, 2004: 49) in “Plato’s Pharmacy” ascribes this overlapping function of *pharmakon* as inherent to its existence. “Having no stable, definitive essence, *pharmakon* is indeterminate rather than predictable, contextual rather than causal” (Derrida, 2000 in Persson, 2004: 49). Like some other drugs and treatments, ART has the capacity to be simultaneously treating illness and causing side-effects; benefiting and causing harm - to the same person at the same time, as is the case of the lipodystrophy syndrome (Persson, 2004).

^x The redistribution of fat tissue apparently leads to increased physical pain of those who experience this phenomenon (Gagnon and Holmes, 2011: 33). In a personal communiqué with an HIV/AIDS specialist in the South African public health care sector, he indicated that it is a well-known fact that very limited pain management takes place when treating HIV/AIDS patients.

^{xi} The Drug Readiness Training (DRT) that all patients must undergo in the public health care setting before being eligible for ART conveys a strong message of normalising HIV and of rendering patients responsible for their well-being by adhering to treatment and to a specific lifestyle associated with good clinical outcomes.

^{xii} She is referring to the fact that the veins in her legs are showing much more prominently now and this is because of a loss of subcutaneous fat in the extremities which is a symptom of lipodystrophy.

^{xiii} Persson (2004) makes a striking point by hinting to the fact that an internally undetectable viral load (because of successful treatment) can, in the case of lipodystrophy, become “detectable on the surface of their body” (Persson, 2004: 52). Therefore, those on treatment might be healthy from a clinical perspective in relation to their HIV infection, but their social appearance of HIV, i.e. a manifestation of lipodystrophy, might make them and others think differently about being healthy (Persson, 2004).

^{xiv} Surprisingly, Gagnon and Holmes’ (2011) study revealed that women with lipodystrophy in Canada also expressed their distress with the manner in which health care providers, notably physicians responded to their transfiguration as a result of ART.

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