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Exploring the interplay between HIV and AIDS treatment discourses and subjectivity in South Africa

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A thesis submitted to the Faculty of Humanities, University of the Witwatersrand, Johannesburg, in fulfillment of the requirements for the degree of Doctor of Philosophy.

July, 2017

DECLARATION

I declare that:

Exploring the interplay between HIV and AIDS treatment discourses and subjectivity in South Africa

is my own unaided work. It is being submitted for the degree of PhD in Psychology at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at another university.

Signed: _____

Date: ---------- of ---------- 2017

DEDICATION

Nosipo Sipamla, you are my mother and father. My gratefulness, appreciation and love for you are immeasurable.

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All praise, glory and honour to God.

I have so many people to thank for their input, guidance and support throughout my journey in the last few years.

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GENERAL ABSTRACT

This thesis explores the rearticulation of subjectivity in the context of the struggle for antiretroviral therapy in South Africa, and also in the contemporary era of treatment accessibility for HIV and AIDS. Two sub-aims are investigated: the first concerns exploring how, and with what consequences, subjectivity was deployed in the contestations that characterized the South African 'AIDS war'; the second concerns inquiring into the intelligibility of subjectivity in public and everyday consciousness in the post-AIDS war period. Integrating qualitative analyses with the theoretical lens of an analytics of governmentality, the data set includes policy-related archival materials, a popular HIV advice column and interviews with people living with HIV and on antiretroviral therapy.

The thesis brings into sharp focus the adumbration of the right to health with rational decision-making, dignity and autonomy. Much more than a way of organizing interests, advocating for the right to treatment - to prevent the transmission of HIV from mother to child and to slow-down HIV spread - was a strategy of effecting a rationality-cum-affective transfiguration of a widespread helplessness and despair into self-reliance and hope. At the level of public and everyday consciousness, self-government on antiretroviral therapy lies at the intersection of knowledge, self-care and self-management. However, such a subjective positionality is not adopted unproblematically, or even sustained indefinitely, owing to the relative weight of other disparate requirements upon oneself from day to day.

What emerged out of the epic battle for antiretroviral therapy, undergirding the prevailing current public and policy orientation to antiretroviral therapy care, was the combination of an optimistic rationality and a hopeful affectivity for the potential of fashioning an HIV-positive

subjectivity, contiguously responsibilized and self-responsibilizing. At the experiential level of living on ARVs, where autonomy is synonymous with self-regulation, the thesis demonstrates that self-responsibility is also an unpredictable and fluid undertaking of navigating the affective tumult of hopefulness, uncertainty, sacrifice and tension.

Key words: Governmentality; Antiretrovirals; Subjectivity; Rationality; Self-Government; Affectivity

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CHAPTER ONE

Prelude

Drawing upon some of the events and public debates around the struggle for antiretrovirals or ARVs, as well as social and policy developments in the era of treatment accessibility, the study presented in this thesis explores the limits or contours for constituting and transforming HIV-positive subjectivity engendered by the magnetic promise and availability of effective treatments for HIV/AIDS.

To be sure, the objective at stake in both the initiatives and experiences investigated here is primarily the improvement of physical and psychological health outcomes among people living with HIV (PLHIV). However, as will be demonstrated in the analysis and discussion throughout the thesis, accounting for their subjective implications provides a much needed alternative perspective able to represent the reciprocal or mutually reinforcing relations between being on HIV therapy and its productive dimension of accordingly *reshaping* or *refiguring* HIV-positive self-understanding, realization and lived experience.

Even with other emerging or recent health or social crises around the world - for instance, the recent Ebola disease outbreak in West Africa of 2014 to 2015 - the ongoing HIV/AIDS pandemic presents a vexing public health and socio-political challenge for developing and emerging countries.

In its recent *AIDS by the numbers* update, UNAIDS (2015) estimate that, by the end of 2014, as many as 37 million people globally were living with the virus - indeed, the sub-Saharan African region accounted for over two thirds of the cases, with the number of AIDS related

deaths globally totalling 1.2 million. Undeniably, the virus has left no region of the world unscathed, but the spread of HIV/AIDS has been most unrelenting and severe in impact in the African region, and more specifically in the Southern African sub-region.

In South Africa, for example, a recent HIV/AIDS surveillance study (Shisana *et al*., 2014) recorded a prevalence rate of 12.2%, translating in actual numbers to 6.4 million people, out of a total population estimate of just under 55 million (StatsSA, 2015).

Meanwhile, innovations in HIV biotechnologies, including advances in HIV testing or monitoring diagnostics, and also, most importantly, in HIV therapy - with the introduction of combination therapy in the mid-1990s - have heralded a new course and prospects for the fight against HIV/AIDS globally (see Carpenter *et al*., 1998; Johnson & Gerber, 2000; Nguyen, 2005; Mykhalovskiy & Rosengarten, 2009).

In contrast to monotherapy, a single class option, combination therapy or Highly Active Anti-Retroviral Treatment (HAART) is more effective in reducing the mutation of the HI-virus in the body of a person with HIV. HAART consists of a combination of classes of drugs, including 'Nucleoside/Nucleotide Reverse Transcriptase Inhibitors', 'Non-Nucleoside Reverse Transcriptase Inhibitors' and 'Protease Inhibitors', which are prescribed on account of indicators of immune system functioning and the level of the virus in the body - for example, viral load, disease or illness symptoms and the CD-4 cell count (see WHO, 2006).

In the case of preventing vertical transmission of HIV or PMTCT, HIV therapy is prescribed to secure the health of the mother and to prevent transmission to the infant or child (see WHO, 2010).

HAART quickly became available in the global West and rapidly changed the course of the epidemic (d' Adesky, 2004). However, even by the early 2000s, access to HAART in the developing and emerging world remained very limited (see Official Call from the TAC and Health-Gap, 2000; Hodes & Holm-Naimak, 2011; Mbali, 2013). Against this backdrop, a global campaign arose to repudiate and rebalance the situation.

Connected to contemporary transnational initiatives for human rights, key strategies and tactics of the campaign encompassed a whole range of activities. The most significant of these activities was to rally PLHIV to lobby pharmaceutical companies to lower the costs of anti-HIV drugs and demand universal access to ARVs.

Faced with a situation in which these medicines were largely out of reach and unaffordable for many people in the developing and emerging world, AIDS activists, in some cases acting in partnership with states and leveraging national as well as international networks, advocated for the removal of barriers to more affordable drugs, such as limiting the restrictions of international patent laws to make way for analogous importation or local production of cheaper generic ARVs (see Biehl, 2007a; Iqbal, 2009; Nguyen, 2009; Geffen, 2009, 2010).

In South Africa, the campaigning and struggle for ARVs was very politically polarized, owing largely to differences over HIV/AIDS policy between AIDS activists and the state. Perhaps most importantly, through the campaign and the politics of identity it mobilized, PLHIV were able to draw attention to their collective challenges - from the obstacles and hostility they face in accessing health services to discrimination in their communities and

their lack of access to ARVs and other essential medicines for managing HIV (see Schneider, 2002; Schneider & Fassin, 2002; Fassin, 2007; Mindry, 2008).

Equally, or maybe even more significant, as constitutional law experts and other writers have observed (see Budlender, 2001; Kistner, 2003; Johnson, 2004; Nattrass, 2007; Heywood, 2009), PLHIV mobilized and demanded dignity, respect and recognition but also the right to healthcare services afforded to every South African in the provisions of the constitution[1].

Therefore, as tragic and as "horrific a period of South African history" the battle for ARVs represents, it is also, in the words of Geffen (2010, p.11), "ultimately a story of hope and the restoration of dignity."

Today more than ever, to paraphrase Biehl (2007b) and Abraham (2010), the prevailing response to HIV/AIDS globally, not least in developing or emerging countries, is driven by both the increased 'pharmaceuticalization' associated with the mainstreaming of ARVs and the patient specific interventions required to optimize their benefits for PLHIV. Without doubt, progress in addressing the blockages to coverage has radically improved accessibility to ART in the African region, from a very low base of less than a million in 2003 to close to 12 million by the end of 2013 (WHO/UNAIDS, 2015).

Research suggests that, with the expansion of access to combination therapy, there is a resulting reduction in AIDS related deaths and illnesses, as well as a remarkable impact in positively transforming social perceptions and the experience of living with HIV/AIDS (see

[1] See also The Constitution of the Republic of South Africa, 1996.

Selwyn & Forstein, 2003; Palella *et al*., 2006; Persson & Newman, 2006; Granich *et al*., 2015).

Arguably, much of the still inchoate but potentially 'game-changing' social and individual level shifts attributable to HAART revolve around the implications of its availability for altering the view of HIV as potentially fatal to repositioning it as a chronic disease, which is also linked to expanding the possibilities for aligned and tailored HIV management programmes, clinical practice and related health services for individual patients (see Bennett & Donovan, 2009), although this is not without problems.

While there has been an exponential increase in ARV-related research, there has been little focused research within the sub-Saharan African regional context, not to mention in South Africa, specifically exploring the constitutive implications of being on ARVs for what it means to be HIV-positive or for the construction of HIV-positive individual subjectivity (Nguyen, 2005; see also Burchardt, 2013).

In a reading that situates the recasting of HIV-positive subjectivity within historic political and social developments that fundamentally changed South Africa's landscape for access to HIV/AIDS treatments, the research presented in this thesis offers an account of the set of conditions associated with constructing a subjectivity anchored in the promise of ARVs to restore health, dignity and freedom.

Aims

The broad aim of the research reported here is to explore the rearticulation of subjectivity in the context of the struggle for ARVs in South Africa, but also in the post-ARV struggle

period. It scarcely needs saying that one can presume that the subjectivity generated during the struggle for ARVs, including its language of representation or stylization, figures strongly in policy practice with implications for the popular imagination in the post-ARV struggle period. As Mbali (2013) intuited, with reference to the South African context of the struggle for ARVs, its enduring consequences are writ large on the contemporary 'HIV/AIDS treatments landscape', perhaps even the broader public health landscape.

This doctoral research primarily features two sub-aims deriving from the broad aim. First, the thesis is concerned with describing how, and with what consequences, subjectivity was deployed in the contestations that characterized the South African 'AIDS war' (Kistner, 2003) or the struggle for ARVs. In other words, the thesis investigates the placing of subjectivity into public discourse during this struggle.

As chapters three and four of this research demonstrate, accounting for the deployment of subjectivity in this context involves exploring the processes of its politicization, but also the corollary affects that animated the politicization itself.

Brown (1994, p.53) has suggested that such forms of politicization and their emotive effects can be viewed as entailing the reversing of "the very production as marginal, deviant…" into "semiotic, political, and psychic gold." The foregrounding of the South African 'AIDS war' thus offers an important window into the emergence of particular kinds of subjectivity for PLHIV, with particular poignancy for the analysis of HIV-positive subjectivity in the current HIV/AIDS treatment landscape in South Africa.

For Budlender (2001), Friedman and Mottiar (2006), and also Heywood (2009), the emblematic struggle for ARVs marked a significant and momentous turning point towards bolstering South Africa's fledgling democracy, including, of course, a further strengthening of a human rights culture. The second sub-aim of the thesis is therefore concerned with exploring how subjectivity is made intelligible in the post-AIDS war period, particularly in view of the emphasis on human rights to which the existing policy on the HIV/AIDS treatment or therapy programme makes recourse. Policy here is conceived less as a response than a tool for creating the reality that must be managed by means of policy proposals (see Bacchi, 2000), not to mention enlisting the actors constituent of that reality.

As such, the third published section in chapter five of this thesis develops an account of the terms of installing subjectivity in public consciousness via the medium of the HIV advice column. Of interest here are forms of guidance on the conduct of enrolling or being on ARVs, including managing viral load and the CD 4 count, disseminating public opinion and popular accessing expertise.

For the second component of the sub-aim in chapter six of this thesis, the cumulative consequences of the existing policy on the HIV/AIDS treatment or therapy programme are tracked through juxtaposition with everyday experience of living on ARVs. This is accomplished through an analysis of interviews conducted with PLHIV currently on antiretroviral therapy. After all, both the fight and enactment of a policy on ARVs comes full circle through the everyday fabric of existence, even if the outcomes may or may not work out as fated or anticipated.

Research questions

The main research question concerns exploring the limits or contours for constituting and transforming HIV-positive subjectivity prompted by the promise and availability of effective treatments for HIV/AIDS, which have eased, encouraged, and to some extent guided the transition to a 'post-AIDS' era[2]. In terms of scope, the question is addressed to key focal historical points, some of the events and public debates around the struggle for ARVs, as well as subsequent policy interventions and popular forms of guidance on the conduct of enrolling or being on ARVs propagating within the public sphere.

The main research question "*How is subjectivity reimagined with the promise and availability of effective treatments for HIV/AIDS in the South African context?*" is thus divided into three sub-questions. The first is: "*What terms of rearticulation are foregrounded in the struggle for HIV/AIDS treatments?*" Most consistently, the literature shows that, over and above the pressing need for restoring physical health, one of the primary motivations for the struggle for ARVs involved the cause of redefining or renewing the meaning of being HIV-positive, and with it, enabling psychological empowerment.

In her sweeping portrayal of South Africa's battleground for ARVs, Nattrass (2007, p.167) described it as "a major cultural project over how best to understand health and healing", that is to say, "a form of consciousness-raising." As such, what is worth investigating is how in this context subjectivity was deployed for advancing the cause of preserving life and averting death from HIV/AIDS.

[2] Following Dowsett and McInnes (1996), as well as Mazanderani (2012), the use of the term 'post-AIDS' in this thesis indexes the shift in the approach or armoury for treating HIV ushered in by the introduction of HAART in 1996 (the so-called 'protease moment'), at the XI International Conference on AIDS in Canada.

The second sub-question is "*How is subjectivity made intelligible in view of the existing HIV/AIDS treatment programme in the public health sector?*" This sub-question shifts the focus to the post-ARV struggle period in advancing the intent of gauging the cumulative consequence of the struggle for ARVs in shaping public policy on HIV/AIDS treatments, particularly with respect to how this policy enjoin PLHIV to constitute themselves in relation to achieving and maintaining healthier outcomes through ARVs. What is explored here is the way that HIV-positive subjectivity is both represented and refashioned within South Africa's post-AIDS policy landscape.

Finally, in all this, what is being asked is "*What modes of self production are prompted among PLHIV?*" Implicit in the third sub-question is that the struggle for ARVs bequeathed to the ARV programme certain kinds of ethicalizing of HIV-positive personages. This proposition, along with the question being raised through it, is explored in the thesis via self-help advice for PLHIV occupying contemporary public life or social consciousness in South Africa, as well as through the lived experiences of PLHIV. The tracking of both 'public opinion' and experiential accounts in this way offers a way to unravel the fundamental values on which the ARV programme rests, or as Heywood (2009) has contended, albeit in slightly dissimilar terms and for different ends, an avenue for disentangling the implicit agreement underlining both the claims and obligations of PLHIV within a democratic South Africa.

Making the case for the research

Over the last 20 to 25 years, research in the socio-medical sciences all around the world has been attempting to get to grips with the significance of ARVs for PLHIV, albeit in myriad of ways that do not always overlap with each other. The often applied and normative emphasis

of this work is generally triggered by a well-intended concern to isolate both supportive and aggravating factors, subjective or otherwise, to heighten the health benefits of ARVs.

With reference to the South African context, the research reported in this thesis makes a valuable and original contribution to this work by mapping the ways and terms upon which subjectivity is articulated with use of ARVs.

As shown in the thesis, this perspective clarifies how ARVs have significantly redefined strategies for mitigating HIV/AIDS, while, most importantly, fostering a change of expectations or obligations of HIV-positive self-evaluation and enactment. Before expanding on the form of the contribution entailed in the mapping task undertaken in this thesis, it is useful to outline the state of play of research on ARVs.

a) Lining up socio-medical research on ARVs

With a few notable exceptions (see Nguyen, Ako, Niamba, Sylla & Tiendrébéogo, 2007; Nguyen, 2009; Hodes & Holm-Naimak, 2011; Mfecane, 2011), the majority of existing work on ARVs or HIV treatments in sub-Saharan Africa is conducted from an explicitly normative stance directed towards interest in patterns of ARV use. In pursuance of this end - the elimination or reduction of resistant strains of the HI-virus - target subjects are enjoined to act on themselves.

This thrust or orientation is perhaps most clearly illustrated in the interest on ARV adherence research, which is distinguishable along three key tracks or lines of inquiry as sketched below.

The first line of inquiry on adherence to ARV treatment is to identify behavioural markers of adherence or non-adherence. An example of this kind of work would include studies (see Nachega *et* al., 2009; Kagee, 2008; Uzochukwu *et al.,* 2009) that measure the pattern of treatment intake within a specified time period (for example, daily intake in the last month) to determine adherence or non-adherence patterns in a specific group of patients. This is to help identify how the treatment could be modulated to suit the patient and accordingly reorganize healthcare practice within a context that acknowledges and respects patient autonomy and personal preference.

The focus on adherence within the first line of inquiry is legitimated by the danger presented by non-adherence to halting the spread of more resistant and virulent strains of the HI-virus, in a way that promotes certain modes of acceptable behaviours to reduce, if not eliminate, the epidemiological threat.

The second line, most common in developing and emerging countries, centres on identifying situational or structural variables (see Ware *et al.,* 2006; Tuller *et al.*, 2010; Johnson, Dilworth, Taylor & Neilands, 2011; Kagee, Remien, Berkman, Hoffman, Campos & Swartz, 2011) that may impact on treatment practice. Examples of this type of work include studies that examine the impact of factors such as difficulties in accessing health facilities and poor health systems on adherence practice.

Other studies that fall under the second line of inquiry investigate the role of social environmental factors - such as stigma - in shaping people's adherence patterns to treatment (see Skhosana *et al*., 2006; Peltzer, Friend-du Preez, Ramlagan & Anderson, 2010). In the context of the growing availability of ARVs in developing and emerging countries, this

research is frequently harnessed for intervening to control for the situational and structural factors driving individual adherence behaviour and decision-making. In this way, then, subjectivity constitutes a key site for managing the impacts of external constraints on ARV adherence.

The third line of inquiry on adherence research, which is growing in scope in sub-Saharan Africa (see Gilbert & Walker, 2009; Kyajja, Muliira, Ayebare, 2010; Miller, Ketlhapile, Rybasack-Smith, Rosen, 2010), is nonetheless more prominent in developed countries - owing to their relatively longer history with ARVs. The research trajectory of the third line of inquiry is associated with exploring the link between the varieties of practices of using ARVs and the way users position themselves subjectively in relation to them (see Meystre-Agustoni, Dubois-Arber, Cochand & Telenti, 2000; Persson, 2004, 2005; Kagee, 2008; Tim-Wong & Ussher, 2008; Newman *et al*., 2015), or alternatively, (see Kitshoff, Campbell & Naidoo, 2012) inquiring into the links between psychological or mental health and adherence to ARVs.

What the third line of inquiry has demonstrated is that ARVs are constructed and used in ways that relate to the users' own views of themselves as certain kinds of people. As a result, varied treatment practices are consciously enacted, reinforced or terminated. This line of research represents a substantial advancement in locating adherence practice outside of markers that can be predicted, measured or even manipulated.

One of the weaknesses with the first two lines of inquiry discussed above is the tendency of overlooking or downplaying the significance of how ARVs are represented is mediating of change in conduct or subjectivity. Because of this oversight, this unintended omission, the

first two lines of inquiry put more stress on generating through research the creative individual and structural solutions necessary for improving adherence to HIV therapy. The consequence is that the nexus between representations of ARVs and subjectivity has nothing to contribute to the work of maximizing adherence to ARV therapy.

Moreover, in the case of all three, not enough attention is dedicated to analyzing the socio-political conditions upon which representations of the significance of ARV treatment for subjectivity emerge or are made possible. This, in effect, is the space within which the research reported in this thesis seeks to make a contribution to South Africa's socio-medical and related cognate research on the significance of ARVs for PLHIV.

b) Foregrounding of subjectivity

The crystallization of the idea of an HIV-positive subjectivity capable of self-transforming implicit in the three dominant lines of inquiry discussed above needs to be viewed within a series of historic political and social developments related to the specific circumstances of their distribution in different countries - not least in South Africa.

Indeed, the introduction of HAART in the mid to late 1990s is significant for working HIV-positive subjectivity into South African politics, AIDS activism, policy development processes and public opinion, via a discourse whose reason, affect and moral vision accentuates a self that *can* and *should* work on itself (see Robins, 2004, 2008; see also Bawa, 2005; Cameron, 2005; Geffen, 2009; 2010; Mbali, 2013; Decoteau, 2014).

As most published accounts (see Heywood, 2003; Friedman & Mottiar, 2006; Robins, 2004, 2008; Geffen, 2010; Mbali, 2013) have demonstrated, much of the delay in upscaling ARVs

or PMTCT in public health facilities in all of South Africa's nine provinces - more especially after the significant drop in cost for a drug such as Zidovudine (AZT), the introduction of its affordable generic equivalent, Nevirapine, and price drops for other anti-HIV drugs - was largely a tragic consequence of the confusion caused by the prevailing influence of AIDS denialism on South Africa's HIV/AIDS policy in the late 1990s to the mid-2000s.

At the apotheosis of the 'AIDS crises', South African HIV/AIDS policy's denialist drift was most explicitly marked by the disavowal of a singular causal link between HIV and AIDS (see Geffen, 2009, 2010; Nattrass, 2012), an opinion ostensibly embraced and advocated by Mr Mbeki, South Africa's former deputy president and president from 1994 to 2008.

Another aspect of the puzzling sway of AIDS denialism, especially during Mr Mbeki's tenure as president, which proved very costly in terms of the lives that were lost to the disease at the time, was also manifestly evinced by a negative attitude towards ARVs by some executive officials of the state and a dissenting minority within the scientific community.

Despite overwhelming evidence to the contrary, Mr Mbeki, the former Minister of Health, Dr Mantombazana Tshabalala-Msimang, and a very small number of medical professionals or scientists, argued against the use of ARVs for treating HIV or for PMTCT on the pretext that their scientific efficacy had not been proven or adequately tested (see, for example, Fassin, 2007; Robins, 2009). Ironically, they also seemed to regard the demand driven soaring share of the distribution of ARVs in sub-Saharan Africa as a form of 'biocapital imperialism' or 'neo-colonialism' (see Comaroff, 2007; Mbali, 2013).

AIDS denialism in South Africa has been analyzed from a range of perspectives, not least by calculating its role in 'the lost benefits' of ARV use (see Chigwedere, Seage, Gruska, Lee & Essex, 2008) or tracing its transnational origins, history and evolving nature (see Nattrass, 2012). For Schneider and Fassin (2003), much like Posel (2005) and Bawa (2005), AIDS denialism in South Africa, particularly during the years 1996 to 2003, reproduced from a policy standpoint an African nationalist response to the problem of South Africa's HIV/AIDS epidemic. In their view, this reaction to both the intensity and manifestation of the HIV/AIDS epidemic in the sub-Saharan African region, but in South Africa in particular, meant that for its advocates its resolution and management required solutions that are uniquely African linked to the post-independence historical vision to promote intra-regional political, socio-cultural and economic integration.

In terms of the historical sequence of events, the earliest call for PMTCT is found in the National AIDS Plan or NAP of 1994 (see NACOSA, 1994), post-apartheid South Africa's first national HIV/AIDS policy. Indeed, it is also significant that the NAP's call in this respect articulated with the provision for free medical care to children under the age of six prescribed in the *Reconstruction and Development Programme* (see Ministry in the Office of the President, 1994)[3], the socio-economic policy framework enacted by the African National Congress (ANC) regime of Mr Nelson Mandela.

The NAP's development was facilitated through the National AIDS Committee of South Africa (NACOSA), which was set up alongside the multiparty negotiations for a democratic

[3] The RDP was replaced, in 1996, by the more neoliberal or conservative *Growth, Employment and Redistribution* (GEAR) policy, introduced while Mr Mbeki was still the deputy president before he took over the presidency, in 1999, from Mr Mandela.

South Africa by anti-apartheid and AIDS activists and representatives from the national department of health of the outgoing apartheid regime (see Schneider, 2002; Fassin, 2007).

The successive National AIDS Control Programme, adopted in 1997, and the HIV/AIDS and STI Strategic Plan, for the period 2000 to 2005, prioritized the objectives of behavioural change, protecting the human rights of PLHIV, mass-media and community awareness initiatives, but were very silent on PMTCT or ARVs (see, for example, Zungu-Dirwayi, Shisana, Udjo, Mosala & Seager, 2004). Also different was that leading up to their adoption, there was less consultation with some organizations involved in the national response to HIV/AIDS, such as the Treatment Action Campaign (TAC), owing to their indignation and very vocal assailing of the former president's views on HIV/AIDS and their obstructive impact for developing and enacting a policy for PMTCT or ARVs based on the most credible evidence on the science of AIDS (see Schneider, 2002; Schneider & Fassin, 2002; see also Nattrass, 2007).

For Budlender (2001), the efficacy of the reasoning behind the struggle for PMTCT or ARVs more broadly against the prevailing AIDS denialism, including its related discourse of the African Renaissance, is to be found in its appeal to the socio-economic rights guaranteed by the Constitution to every South African citizen and in making a direct linkage between the political, the social and the personal. Indeed, this proposition or idea derives from a perspective on subjectivity that conceives of it within the understanding of "the social formation as a complex, over-determined" set of discursive practices "in which the human subject is constituted" (Adlam, Henriques, Rose, Salfield, Venn & Walkerdine, 1976, p. 46).

Assessing for the effects in the assembling or alteration of subjectivity in the context of the struggle for ARVs and in the contemporary era of treatment accessibility for HIV and AIDS involves critically examining 'the discursive soil being tilled', by way of a repertoire of reflections, rhetoric, arguments, imagery and representations of subjectivity circulating in political, social and public life (see, for example, Ingram, 2010, 2011), including through the everyday practices of the most banal and ordinary situations, their challenges as well as opportunities. While the importance of this link between discourse and subjectivity cannot be overstated, neither can its partiality. Indeed, what is most crucial to emphasise, or perhaps worth underscoring, is that how we are positioned in discourse is constitutive of how we think, feel and relate to ourselves in the various ways that we do (see Rose, 1999; see also Campbell, 2010; Gill, 2014).

Thus, more than anything else, I show in the thesis that the 'ARV subject' is not a species that is distinct in terms of being entangled in the discourse that enables and constrains ARV-related behaviour, as well as more general subjective understanding and realization among PLHIV.

Indeed, many accounts of the struggle for ARVs in the South African context, including analysis of its likely consequences for PLHIV, have been offered in related 'popular' and academic literature (see Kistner, 2003; Cameron, 2005; Nattrass, 2007; Robins, 2004, 2008; Mbali, 2013). These vary in the manner of attention or analysis of subjectivity. By and large, subjectivity is explored as an expression of self-definition anchored in some or other form to a constitutive discourse with both 'individualizing' and 'collectivizing' dimensions (see Robins, 2004; 2009; Decoteau, 2014; Pienaar, 2016).

Among the parts of the recasting of subjectivity identified with the struggle for ARVs, those that markedly stand out include dignity or self-worth, the capacity for a meaningful exercise of individual choice and responsibility and action. Also, from the perspective of popular literature, most eloquently captured by South Africa's reputable HIV-positive Judge Cameron, the politics of the struggle for ARVs seemed to virtually connote a potentiality for PLHIV to undergo a change from unalloyed submission to HIV/AIDS to gaining dominion over it. This call to conquer can be apprehended as follows (Cameron, 2005, p.214):

"…We cannot escape our grief or the losses we have experienced or the suffering that has been. But we can act to minimize those occuring now, to prevent further deaths, to open our hearts and hold in them those who, now, are afflicted with illness and its isolation. Our grief is there…But we cannot allow our grief and our bereavement to inflict a further loss upon us: the loss of our own full humanity, our capacity to feel and respond and support. We must incorporate our grief into our everyday living, by turning it into energy for living, by exerting ourselves as never before. AIDS is above all a remediable adversity…"

The quote illustrates how the debates in South Africa over the provision of ARVs contributed to rewriting and adapting HIV-positive self-understanding according to the unfolding new normal of living with HIV ushered in by HAART. In a lot of ways, then, the thesis investigates many of these familiar themes or problematics of the struggle for ARVs outlined in the literature above, as well as some of the transformations related to the 'winning' of this struggle. However, an additional impetus of the thesis is both to enlarge on the scope and expand our understanding of the renewing of subjectivity within South Africa's evolving ARV programme. Therefore, together with analyzing the events prior to or around the roll-out of ARVs, the thesis moves beyond to map subjectivity in the mutually constitutive policy

and public terrains in which we need to understand the currently developing ARV programme.

Perhaps more importantly, in contributing to previous literature on our understanding of the deployment of subjectivity in the context of the ARV programme, the perspective espoused in the thesis pace Butler (1997), Rose (1999), Ahmed (2004 a,b), Foucault (2000, 2008) and Massumi (2004, 2015a,b) is distinctive for accounting particularly for the reasoning, emotive and 'ethicalizing' constituents of the discourse linking the developments prior to and following the roll-out of the programme in South Africa's public health system.

Much more remains to be done before full accessibility to ARVs or parity is actually achieved in sub-Saharan Africa - particularly in view of the scale of the epidemic and the greater need for HAART, its demographic and socio-economic implications for the region. However, it is encouraging that, as of the end of 2014, an estimated 2 623 271 people are enrolled for HAART in the public healthcare system in South Africa, followed by Nigeria at 639 397, Uganda at 595 175, Mozambique at 497 455 and Botswana at 223 506 (see WHO/UNAIDS, 2015).

What is even more uplifting or heartening is that the rates of adherence to ARVs in sub-Saharan Africa, as a number of recent studies have shown, appear to be considerably higher than in the developed world. For instance, a meta-analytic study comparing adherence rates in North America and sub-Saharan Africa found rates of 55% and 77%, respectively (Mills *et al*., 2006). At the time, of course, in many African countries ARVs were still either not available at all or had just been introduced.

In this thesis, making sense of this success in achieving such relatively high rates of adherence to ARVs is approached from the perspective of exploring the terms upon which subjectivity is constructed for the undertaking of handling HIV with ARVs. This angle, with its emphasis on shifting the focus beyond investigating only the patterns of ARV usage, grapples with the implications of ARVs for "representations of the disease, and in turn, the subjectivity of those who are able to access them" (Nguyen, 2005, p.143).

Above all, in the context of the history and progression of South Africa's ARV programme, the research reported in this thesis is justified within the opening space of accounting for the possibilities and constraints of an emerging discourse consisting of a knowledge or rationality type, intermingled or inflected with affective and ethicalizing properties. What I demonstrate in the thesis is that emerging from it is the constitution of a version of HIV-positive subjectivity increasingly positioned ever more resolutely to working on itself.

Organization of the thesis

Chapter two presents the study's conceptual and methodological framework or plan of action. The results of the thesis are then presented, in chapters' three to six, as four discrete journal articles. This format necessitates some inevitable repetition. Chapter two has therefore excluded an extensive literature review in order to minimize repetition.

Chapters three and four wrestle with the historical context of the struggle for ARVs in South Africa. In chapter three, the published article critically examines the so-called denialist position of the previous ruling administration from the perspective of its implications for subjectivity, but, most crucially, as juxtaposed to the position of ARV treatment lobbyists. Worth noting even at this stage is that the two positions echo each other in some respects in

articulating a type of subjectivity for PLHIV that is subject to tutelary guidance as much as it is being enjoined to a self-defining relationship with itself. Of course, none of this ignores the differences between the two positions, especially over the question of how these differences of conceptions on governing HIV/AIDS resulted in very different consequences from a life and death perspective.

In chapter four, the focus shifts to the published article on the legal and social struggle for ARVs, with the battle for PMTCT serving as the case study under examination. In important respects, this particular battle could be described as definitive of the struggle for ARVs, for the cause itself was not only about highlighting the benefits of ARVs for transforming ways of thinking and living with HIV, but it was also the most emotional of moments in the struggle's history from the point of view of its concern with safeguarding the life and future prospects of the mother and her child in a post-apartheid or democratic South African dispensation. Perhaps more than any other case during the AIDS war, it also represented most forcefully the priorities undergirding the envisioned prospects of a reconstituted subjectivity for PLHIV in South Africa's developing post-AIDS landscape. This historical context, along with the principled vision that propelled it, has influenced a host of interventions for mitigating South Africa's HIV/AIDS epidemic, not least the policy concerns and objectives pertaining to upscaling enrolment for ARVs in the public health sector.

Chapter five offers a window of opportunity for examining what is at stake in instituting relations of self-care and re-invention of self with reference to achieving or maintaining a healthier physical and psychological state while living with HIV with the aid of ARVs. Attention is fixed here on the guidance offered in the specific case of one of many expanding forums - both in print and electronic forms - in the popular media for seeking advice on HIV-

related health matters. Analysis of a popular HIV advice column offers a perspective on HIV-positive subjectivity on the ground.

Chapter five delves into the installation in public consciousness of a kind of subjectivity whose very presupposition, emergence or stabilization is closely intertwined with the terms and imaginary underpinning of its deployment and constitution during the struggle for ARVs and its particular influence on the current policy course.

Chapter six examines the experiential accounts of three women and men enrolled for ARV therapy. The interviews are discussed in relation to the initial review of three well-known HIV/AIDS policy guidelines.

Chapter seven is reflects back on the aims of the study, thereby offering considered critical reflections on what it means to be HIV-positive at the present moment of ARV accessibility in South Africa.

Chapter eight consists of concluding remarks on the limitations and strengths of the thesis, including suggestions for future research.

CHAPTER TWO

Theory and method

A well-recognized challenge running through the various practices linked to the struggle and realization of the delivery of ARV care in post-apartheid South Africa is that reconstruction of oneself after HIV diagnosis involves a substantial amount of work on the self, including devising a new HIV-positive subjectivity, interiority and embodiment. Even in the current era of the upscaling of antiretroviral therapy in the public health sector, this is no less the case. With the contemporary individualization of HIV/AIDS programmes, self-government is increasingly the preferred modality for intervening with the epidemic, not least in the area of ARV care. How one might take up the interrogation of this line of intervening with HIV and AIDS that, although not entirely novel to HIV and AIDS programmes historically, ARV care has certainly amplified, constitutes the core of the research questions raised in chapter one.

Chapter two is therefore devoted to setting out the theoretical framework of the study, interwoven with unpacking the corollary principal method. The basic idea is to provide a thorough outline of the most fundamental theoretical and methodological assumptions upon which the study takes propulsion and unfoldment. This, in turn, is used to put forth an argument for abstracting HIV-positive subjectivity with the aid of the conceptual and empirical tools used in the research reported in this thesis, both in the context of the struggle for ARVs and rolling out of ARV care in public health facilities in contemporary South Africa.

At the end of chapter two, I offer closing thoughts tying together the discussion on the theory and methodology of the study. The goal here is to say a few words about how we might think

through questions of rigour and trustworthiness with respect to the method and theory utilized in the study for data collection and analysis. Countering limiting empiricist approaches to qualitative research, I stress the value of employing a mixed "top down", "bottom up", theoretical and empirical approach for optimizing research rigour and trustworthiness. A central aspect motivating the taking up of this approach is this: subjectivity is a moving target, although demarcated by discernible and examinable discursive boundaries.

In democratic discourses, with their strong emphasis on individual and human rights, the amplification of subjectivity is frequently posited as a solution to a range of social challenges, not least in the predilection for individualizing interventions to mitigate and control for the spread of HIV/AIDS evinced both in the developing world and elsewhere around the globe (see Hickel, 2012; Sangaramoorthy, 2012; see also Pienaar, 2016). If, as Foucault (1982) has observed, subjectivity is spawned from power relations, or as Butler (1997) has reiterated, is engendered through the operation of various forms of social power, my very broad goal in the thesis is thus to trace how the HIV-positive subject is formed and constructed in relation to the discursively inscribed political and social norms by which power relations are enwrapped, fortified and enacted.

This conceptual framing of the mapping exercise, specifically drawing upon the Foucauldian orientation or framework of governmentality, constitutes the primary mode of analysis in the thesis of the means, terms and outcomes of organizing subjectivity in the context of the struggle for ARVs in South Africa, but also in the post-ARV struggle policy and social landscape.

Laying out the framework for conceptualizing subjectivity

Following Foucault's (1982, 2000, 2008) conceptualization of governmentality, together with its interpretation or amplification by, for example, Dean (1996), Rose (1999) and Read (2009), this framework is used in the thesis for conceptualizing subjectivity. Broadly speaking, governmentality is "the practice of government" (May, 2006, p.153). "How ought government to be done, what are its proper roles, whose benefit ought it to seek and how?" (*ibid*: 153). Less concerned with political philosophy, the point of studying governmentality involves bringing to light the practices and forms of political reasoning or rationality of government (Foucault, 2000, 2008).

Much about governmentality is centred on subjectivity, conceptualized as both an 'instrument' and 'effect' of government (Cruikshank, 1999). Defining or conceptualizing the activity of government, from the perspective of governmentality this encompasses the various 'governmental' and 'non-governmental' initiatives involving "institutions, analyses and reflections, calculations and tactics" (Foucault, 1992, p.102) linked to leading, guiding and shaping conduct or behaviour towards achieving desirable conditions of social and individual existence or eradicating social and individual ills.

Instead of assuming the primary importance of the state, this view of government conceives of its role alongside other non-state agencies. In other words, government consists of "…a domain populated by the multiform projects, programmes and plans that attempt to make a difference to the way in which we live by a swarm of experts, specialists, advisers and empowerers" (Dean, 1996, p.211), working in tandem, beyond and even contra to the administrative roles and public service functions of the state.

Important to underscore here is that the framework of governmentality provides a tool "for identifying the rich complexity and hybridity of modes of governance" (Stenson, 1998, p.349). All in all, the activity of government, as Campbell (2010, p.38) has emphasized, rests on or is anchored around various forms of political rationalization, which are inclusive of the "discourses and knowledges that guide, advise and inform our ways of being in the world." For Foucault (1982, p.784), governmentality involves any activity that "...structures the possible field of action by others", what he called the "conduct of conduct", including developing the capabilities of those who are governed to govern themselves. Within this framing of government, the potential for exercising power over the actions of others has recourse to those others exercising power over themselves (Cruikshank, 1994), or as Butler (1997, p.6) has argued in her own inimitable way, the subject is moulded through "the effect of power in recoil" or "assuming a reflexive form."

The framework of governmentality thus offers a way of conceptualizing and assessing "…the contact point, where individuals driven by others is tied to the way they conduct themselves" (Foucault, 1993, p.203-04). In this thesis, the activities of organizing the needs, interests and actions of PLHIV to fulfil their potential and improve their health through ARVs, both in the context of the struggle for ARVs in South Africa and in the post-ARV struggle period, are thus viewed as modes of governing. That is to say, the various initiatives examined in this thesis are interrogated and conceptualized as constituting strategies of 'governing at a distance' (see Curtis, 1995; Bennett & Donovan, 2009; Shoshana, 2012) the health of PLHIV, including, most importantly, their concomitant or associated effects of these initiatives on their subjectivity. For example, in his analysis of South Africa's campaign for ARVs, particularly the implications of its politics of resorting to legal and protest action, but also community treatment literacy and mobilization initiatives, Robins (2004, p.665) has

suggested that it "created the space for the articulation of a radical democratic discourse on health citizenship" by stirring the "passion" among PLHIV for the fulfilment "of the 'cold letter' of the Constitution." In other words, what the struggle for ARVs achieved was to 'delineate' and 'bind' the individual interests of PLHIV, via passionate or affective attachments, for a common cause enunciated around the link between their human rights and their own individual well-being.

According to Nattrass (2012), Mbali (2013), and Decoteau (2014), the strategy of engaging both the 'mind' and 'heart', during the struggle for ARVs, sought to link a reconstituted subjectivity with a human rights response to HIV/AIDS, according to which, in the post-ARV struggle era, PLHIV are prompted to recognize and constitute themselves.

As all this suggests, the period of the struggle for ARVs rewrote the coordinates within which for PLHIV the ethics of caring for oneself, particularly in relation to attaining physical and psychological dynamism through ARVs, is imagined and articulated in South Africa's post-AIDS society.

To analyze the prevailing ethics of self-care or help in the current post-AIDS period, the conceptual model that is used in the research reported here derives from Foucault's approach to analyzing the governing practices of self-care (see Foucault, 1992, 1993; see also, Hamann, 2009; Scharff, 2016).

As demonstrated through the analysis and discussion in chapter five of this thesis, an ethics of self-care is understood to involve aspects of the self that can and should be worked upon, as dictated by historically or contextually specific forms of political rationality and their

associated moral codes of behaviour. Moreover, ethical relations of self-care include the modes of guidance and goals or purposes according to which self-care is undertaken (Davidson, 1990, 2005).

In the sense described above, then, ethics is defined or conceptualized as denoting relations of the self to itself, enacted around a set of guiding principles, pertaining to an ideal of regulation and control of oneself. As Foucault (1992, p.28) explained:

"…all moral action involves a relationship with the reality in which it is carried out, and a relationship with the self. The latter is not simply "self-awareness" but self-formation as an "ethical subject", a process in which the individual delimits that part of himself that will form the object of his moral practice, defines his position relative to the precept he will follow, and decides on a certain mode of being that will serve as his moral goal. And this requires him to act upon himself, to monitor, test, improve, and transform himself."

The crucial point to emphasize is that ethics understood as relations of the self to itself are not exterior to governmental and non-governmental relations, in the Foucauldian sense, but are immanent in the latter; they are, in other words, the effects of the various permutations of relationships of power through which we are led to govern or relate to ourselves. For Rose (1999, 2007), what can be observed through these and related kinds of processes is the merging of the personal with the political.

By way of illustration, Braude (2009) has noted of HIV/AIDS programmes in contemporary South Africa the mounting traction of an adjustable rationality of politics or governing

oriented to promoting individual agency, which is inevitably articulated through an ethics of individual rights and responsibility.

The study reported in this thesis therefore also engages with the modes of guidance for self-care or self-help circulating in the public domain, but against or through the background of the locomotive history of various South African policy related initiatives that have set off the terms upon which the HIV-positive self imagines, relates to and reconstitutes itself in the present in relation to securing physical and psychological well-being through ARVs.

Working mostly within Foucault's (1982, 1990, 1992, 1993, 2000, 2008) conceptual toolkit, the thesis in its entirety is concerned with the modalities of a 'pastoral' like power in its evolving expression as a frame of governing HIV/AIDS in South Africa, whose formulation of 'salvation' is perhaps best indicated in its quest for new forms of self-identification or re-creation for PLHIV.

Scaffolding the conceptual toolkit

In order to operationalize the framework of governmentality, together with the deployment of Foucault's approach to analyzing the ethics of self-care, the thesis has foregrounded an analysis of a range of texts as the data source. A textual approach - in the sense of working with text-based materials accessed from the public domain - offers a number of useful functions, purposes and advantages not only in relation to the application of the perspective of governmentality, but also importantly with respect to the questions that the research addresses, as outlined previously in chapter one.

Let us highlight at least three of these benefits that are most especially relevant for an analysis of the scripting of subjectivity during both the run up to the introduction of an ARV policy and the succeeding period in post-apartheid South Africa.

First, with the view that the term 'subject' or subjectivity is more "a linguistic category, a place holder, a structure in formation" (Butler, 1997, p. 10), the significance of employing a textual analysis from the perspective of an analytics of governmentality is that it serves as a tool for assessing the various thought processes, valuations and agendas associated with rendering many aspects of social or political reality governable, including subjectivity (see Ingram, 2010; Shoshana, 2011, 2012).

At a more general level, analysis of texts constitutes a method of working with 'naturally occuring' data generated outside of social science research (Potter, 2010), or without the researcher guiding its development, as would be the case, for example, with interviews or focus group discussions (Jowett, 2015).

Second, the value of working with texts for analyzing the ways of constructing subjectivity - to use Atkinson and Coffey's (1997) words - is that they convey 'social facts' insofar as one may surmise that they are prepared, assembled and circulated in socially meaningful or practically oriented ways. For example, certain forms of texts, such as manuals for compliance with drug regimens or for improving self-esteem, elevate through language a sense of purpose, meaning and the precepts for living in the transitive sense of conveying for 'enfolding' or internalization the values for evaluating, reforming and governing oneself (Dean, 1996). In part, this is a matter of their value and effect in reproducing or reinforcing

meaning and even possibly arousing emotion to the extent that they resonate and have an affinity with recognizable social beliefs, norms and practices (see Rapley, 2008).

The third usefulness of a textual approach relates to the prospects of working with different types of texts for the purpose of conducting an analytics of governmentality. Common examples from previous literature include analysis of popular or self-help literature (see Rimke, 2000; Fridman, 2014), educational, public and health policy (see Tikly, 2003; Fimyar, 2008; Teghtsoonian, 2009; Vallgårda, 2015), newspaper articles or clippings (see Burkitt, 2008), press statements, advocacy materials and position papers (see Bennett & Donovan, 2009), as well as other electronic and print related mediums for advice and self-scripting (see Mazanderani, 2012; Mazanderani, O'Neill & Powell, 2013).

From an analytics of governmentality perspective, programme specific, vision-led or educational textual materials are particularly useful for analyzing the political, social and cultural values, assumptions and practices informing 'typical' expectations, formulations and practices for intervening with a range of problems, including comprehending the ways subjectivity is enlisted in various programmatic and educational interventions.

The decision to work with textual materials via the application of the perspective of governmentality and Foucault's model on practices of self-care, thus makes sense from the point of view of investigating or inquiring into the constitution of HIV-positive subjectivity, both in the contexts of the struggle leading up to the institution of an ARV programme and subsequently.

The texts gathered and analyzed in the thesis are taken to represent data that could be examined for traces of the ways of thinking and acting addressed to PLHIV, particularly their subjectivity. As such, the materials or texts are viewed to index a set of realities, beliefs, norms, aspirations and visions around which PLHIV are enlisted to understand and act upon themselves and their lives. A textual approach thus facilitates a way of engaging the patterns of thinking and acting reflected through the concerns arising from the texts (Jowett, 2015).

One of the limitations often linked to an analytics of governmentality is inattention to the spontaneity and unpredictability of subjective life (see Burkitt, 2005; Weidner, 2009; D' Aoust, 2014). There may not be a subjectivity seamlessly constituted in discourse without the chance for interruption, which is mostly possible to investigate via texts that integrate the realm of the discursive with experientially oriented and situated tools of accounting for courses of subjective formation. A challenge is thus entailed in accounting for the unpredictability and uncertainty that accompany the stormy conditions from which subjectivity often arises.

In response to this recognition, interview texts are therefore also included as part of the data for the thesis. In conjunction with the advice column letters, they help to exhibit most frontally the mutuality of rationality and affectivity in the construction and gestation of subjectivity. Interview texts add a layer of complexity or nuance, without which, the scaffolding would miss an opportunity to take a view of the processes involved in subjectivity being primed into consciousness, including the unconscious dynamics that set in or enable resistance.

In sum, from the perspective of the framework of governmentality texts are tied to certain kinds of programmes and projects that among other objectives and goals endeavor to reorganize subjective understanding and lived experience.

Method

For the remainder of the chapter, an outline of the method used in the thesis is provided. An overview of the data gathering procedure is presented. For the purpose of clarity and, most importantly, as part of the justification, the materials accessed and selected for the study are contextualized from the broader perspective of the literature on the struggle for ARVs and its legacy in South Africa. At each point of the description of the data gathering procedure, commentary will be provided on how the materials were identified and chosen from the various sources consulted.

The analytic approach for the study is also outlined. Described in the analytic approach is how the theoretical framework of governmentality was employed to answer the study's research questions through the analysis of the materials forming the data for both phases one and two.

Data gathering procedure

The procedure followed for gathering data for the thesis proceeded in two stages. For the first stage, the data can be described as discursive in bent, in consideration of the fact that it consists of documents already available in the public domain. While the second stage also involved the collection of documents in circulation in the public sphere, it also incorporates interview data. With the discussion here, the objective is to provide an outline of the data gathering procedure: how the process unfolded, the type of the data collected, as well as why

and how the data was chosen. The ethical considerations applicable to different components of the two stages comprising the data gathering procedure are also discussed.

a) Stage one

In order to describe how, and with what consequences, subjectivity was deployed in the contestations over HIV/AIDS policy, a range of documents were collected related to archival material centred on the battle for ARVs, as well as the debates that accompanied this battle.

All the materials collected are publicly available and can be retrieved either manually or electronically. In terms of ethical considerations, permission from the organizations responsible for their publication to retrieve and utilize the materials was not obligatory.

Following the perspectives of the protagonists in this battle identified in the literature, chapter three presents an analysis of AIDS denialism premised on the proposition that some aspects this denialism of it articulate Mbeki's envisaged African Renaissance. An electronic search of the Cullen Library catalogue, at the University of the Witwatersrand in Johannesburg, using the key word 'African renaissance', threw up two edited volumes.

The first volume entitled *African Renaissance* was published in 1999. The relevance and significance of the volume is that it is South African; it features a prologue by former president Thabo Mbeki, the key advocate of the much maligned alternative conception of the cause and response to HIV/AIDS; and it was published in 1999, when Mbeki took over the presidency from former president Nelson Mandela of both the African National Congress, the ruling party in South Africa, and country. Sub-divided into six parts, the volume consists of thirty essays based on papers and speeches delivered by an assorted group of African

academics and business and civil society leaders, as well as their counterparts from the United States and Europe, at a conference convened in 1998 in Johannesburg, South Africa. The conference was organized under the auspices of the South African Broadcasting Corporation, in partnership with City Press, a South African English language Sunday newspaper.

The papers and speeches from the conference deliberated such focus areas as 'defining the concept of an African', 'building bridges and linkages among Africans' and 'ensuring the prosperity of the continent and its people'.

Beginning with Mbeki's treatise in the epilogue[4], engagement with the volume is centralized around ten papers in parts one and two[5]. Part one focuses on the context of the African renaissance, and part two offers papers addressing topics relating to moral renewal and African values. Mbeki's treatise, along with the papers in parts one and two, encompass perspectives reflecting on the state of relations of selves in the aftermath of colonialism and apartheid, with implications for ways of thinking about the reconstruction of selves within the horizon of the envisaged African renaissance.

The second volume identified in the Cullen library in response to the research is entitled *Ideologies of Liberation in Black Africa 1856–1970: Documents on Modern African Political Thought from Colonial Times to the Present*. It was first published in 1979. In contrast to the more scholarly *African Renaissance*, the second volume is more or less political polemic. It

[4] The epilogue is edited from Mbeki's opening address at the conference.
[5] The published paper in chapter three has cited: 1) Mbeki, T. (1999). 'Prologue'. In M.W, Makgoba (Ed), *African Renaissance*. South Africa: Mafube Publishing (Proprietary) Limited & Tafelberg Publishers Limited, pp. xiii-xxi; and 2) Mamdani, M. (1999). 'There Can Be No African Renaissance without an Africa-focused Intelligentsia'. In M.W, Makgoba (Ed), *African Renaissance*. South Africa: Mafube Publishing (Proprietary) Limited & Tafelberg Publishers Limited, pp. 125-134.

comprises eighty public addresses by a cohort of well-known political leaders in Africa made either before or after a number of African states had achieved independence from colonial rule. Two chapters in the second volume[6] stand out for directly linking the relation with oneself to the African renaissance.

In addition, a sample of quite well-known and controversial public lectures, speeches and position papers authored by Mbeki or distributed with his approval, whereby he draws links between HIV/AIDS and ARVs and colonial and post-colonial psychological, social and political circumstances, were also gathered. These documents were accessed on online, via organizational websites such as www.anc.org.za, www.sabc.co.za, www.nepad.org.za. The websites were identified either through a google search, using the key words "Mbeki", "AIDS" and "African Renaissance", or from the reference lists of existing academic literature (see, for example, Posel, 2002 Schneider & Fassin, 2002; Kistner, 2003; Robins, 2004; Kenyon, 2008). Mbeki's particular recapitulation of the vision of the African renaissance via AIDS denialism is discussed in chapter three based on this layout or framework.

The last point about the material included in chapter three is that making a cameo appearance is other well-known literary, polemical and academic literature[7]. Among a few examples, the title *The Wretched of the Earth* (1963) of Frantz Fanon is worth mentioning here for its psychologically inflected analytic of the socio-political order in colonial and post-independence Africa. One might say that Fanon's masterpiece, published a few years after his debut *Black Skin, White Masks* (1952), by offering nothing less than a probing of colonial and post-colonial African subjectivity, has acquired a structuring power over subsequent analyses

[6] The chapters include: 1) Touré, A.S. 'The Political Leader Considered as the Representative of a Culture' (pp. 601-616); and 2) Azikiwe, N. 'The Death Grip' (pp. 418-422). In J. Ayo Langley (Ed.), *Ideologies of Liberation in Black Africa 1856-1970: Documents on Modern African Political Thought from Colonial Times to the Present*. London: Rex Collings.

[7] Author names are referenced in-text and full are provided in the reference list.

of identity formation in Africa. The handbook is especially useful in view of its preoccupation with describing the processes of the transfiguration of African subjectivity. By illustrating the productive correspondence between historical, philosophical and socio-political conditions, integrating into the analysis this other literature enhanced the prospects of illuminating the possible linkage of reforming African HIV-positive subjectivity in the context of regenerating African subjectivity.

On a certain level, the differently conceived engagement with AIDS denialism in chapter three also opens the way to set it alongside the particular placing of subjectivity into public discourse as affected by the lobbying for ARVs. In chapter four, therefore, the landmark PMTCT case - *Treatment Action Campaign v. Minister of Health*, at the Pretoria High Court in 2001 - is revisited. Targeting of relevant textual materials was developed based on the criteria that, at the time of the court case, they circulated in the public domain to offer clarification on the value of PMTCT and to mobilize public sympathy for pregnant women living with HIV. A combination of two manually sourced and electronic archival sources were searched.

The first manual archive is a collection assembled by South Africa's AIDS Law Project (see *Appendix A* for a record of the specific box files in the collection consulted for document materials), which is housed in the Historical Papers Section at William Cullen Library at the University of the Witwatersrand in Johannesburg, South Africa. When the materials were gathered, from January to July 2014, the archive was still under the process of construction and systematic cataloguing, and thus only half of it was available, that for the period 1994 to 2004. Significantly, this period is when the debates over HIV/AIDS in South Africa picked

up and gradually grew more intense. Most of the materials were stored in a hundred and sixteen boxes[8], with most of them still legible and in good state.

A substantial portion of the archive comprised of various types of HIV/AIDS related policy briefs and position papers, advocacy and educational materials, such as protest declarations, memoranda, press statements, newspaper clippings, pledges, a small number of social scientific journal articles on topics such as human rights and ARVs and fact sheets on the various aspects of preventing HIV/AIDS or the benefits of HAART and PMTCT. The archive reflects the multidimensional or multipronged nature of the struggle for ARVs, including the diversity of stakeholders involved during the period encompassed by the struggle.

The second manually accessed archive, the Zackie Achmat, Jack Lewis and TAC Political Papers (see *Appendix B* for a record of the specific files in the collection consulted for document materials), in many ways helped to complement the first one. This archive is much smaller but more systematically organized. Most of the documents archived in the collection comprise very readable materials donated by Zackie Achmat, the TAC's founding director, to the South African Historical Archive (SAHA), an independent non-profit human rights archive located in Johannesburg, South Africa. The archive includes various advocacy and educational materials, spanning the period 1998-2004. In addition, included also are newspaper articles, press or media statements, as well as Zackie Achmat's personal notes or reflections mostly on the work of the TAC. This archive was accessed between February and April, 2015.

[8] For the box files consulted see *Appendix A*.

The two archives proved to be complimentary. First to be gathered from both archives was a sample of policy briefs and position papers for a sense of the policy proposals advocated for PMTCT.

To establish how PMTCT was publicly justified on scientific, social and political grounds, along with how public sympathy was mobilized, also collected for the purposes of the research project were educational materials and fact sheets on PMTCT, as well as advocacy materials, newspaper coverage and press or media statements circulated prior to and around the court case for PMTCT conducted in the Pretoria High Court in 2001.

The type of material that was selected for gathering reached a saturation point, for it became either repetitive or no materials with different information could be located across the two manually searched archives.

To complement the materials collected from the manual archives, an electronic search was undertaken for newspaper articles of the 2001 court case via the South African Media Database, which houses all indexed South African newspaper articles and reports from 1978 onwards. To limit the search for relevant newspaper articles and coverage, the search words 'Nevirapine' and 'Pretoria High Court' in '2001' were used in combination, producing a total of sixty nine results. Out of sixty nine newspaper articles and related coverage, only about twenty articles were considered relevant for the reporting around the court battle. The TAC website (see www.tac.org.za) was also instrumental in looking at contestation around access to treatment, especially for accessing the court affidavits that were presented to the court in favour of compelling the state and the minister of health to roll-out access to PMTCT beyond the designated research pilot sites. The court affidavits from pregnant women with HIV are

especially helpful with providing insights on women's perspectives on PMTCT and how its availability might affect how they see and feel about themselves. Excluding expert and founding affidavits, five affidavits compiled by pregnant women living with HIV were located.

Altogether, then, both the manual and electronic searching yielded a very substantial corpus of materials around the court case for PMTCT, with a range as diverse as the events or activities that were connected to it.

b) Stage two

Shifting to the subjective implications heralded by the introduction of ARVs in South Africa, the data collected in stage two represents an attempt to integrate the subjective aspects of the lived reality of engaging with ARVs.

In chapter five, HIV advice column letters were therefore gathered for data. Advice columns are simultaneously positioned as popular media, as expert opinion and as insider perspective. They, in a sense, offer access to analyzing the popular forms of subjectivity contrived for uptake, together with the type of selves disseminating in the public domain.

In the specific case of the advice column letters used in chapter five, the advice columnist is HIV-positive herself, adding a layer of first-person experience to the subject matter addressed in the advice platform that other advice columnists are not always able to offer. With the columnist's celebrated personal experience with HIV, the advice column stands out from other advice columns in terms of visibility. Under the tutelage of the HIV-positive advice columnist, the HIV advice column letters put together for chapter five ran for the period from

May 2009 to April 2014 in *Bona*, a popular monthly magazine aimed largely at black women in South Africa. The advice column is still published in *Bona* magazine, although with a different columnist who is not HIV-positive. As pointed out in chapter five, the special significance of the advice column is that it is organized around representing the predicaments faced, directly or indirectly, by those who are willing to speak out about their experience with HIV and solicit the guidance of expertise.

In addition to the *Bona* material, advice letters were collected for the period May 2009 to April 2014, sourced from the reference sections of two national libraries, in Pretoria and Cape Town, in Gauteng and the Western Cape provinces, respectively. Across this time-span, a total of 166 advice inserts, published in 71 issues, were sourced, with both the questions and answers included.

In line with the focus on ARVs, the letters included in the sample had to specifically reference ARVs[9]. Moreover, because of their strong connection to ARVs, letters referring to viral load and the CD4 count were selected for analysis. In total, out of the entire corpus, 55 advice letters were analyzed.

Still on the subjective implications of ARVs, in addition to the advice column analysis, a total of six PLHIV enrolled for ARVs were interviewed. (The actual breakdown is three women and men, respectively). While recruiting and interviewing more participants was unlikely to yield more information[10], the advantage that connects with interviewing six people is the opportunity to explore substantively into the issues that come up in each interview. Initial

[9] The basis for selection and inclusion of the relevant advice letters is more comprehensively outlined and covered in depth later in the thesis (see pg. 115-118).

[10] The study had initially set out to interview ten participants, broken down into five women and five men. Because of some difficulties securing the other four participants, the researcher and his supervisor felt that with the six participants interviewed data saturation had already been reached.

electronic communication with AIDS Consortium, an umbrella organization for HIV and AIDS non-profit HIV and AIDS organisations, was established to indicate intent (see *Appendix C*, see also *Appendix D* for AIDS Consortium's reply) and to request for assistance with the recruitment of participants. Upon agreement, AIDS Consortium affiliated organisations were contacted and provided with the participant information sheet (see *Appendix E*).

The interviews, which form the basis for the aspect of the study reported in chapter six, are set in relation to the initial review of three well-known HIV/AIDS policy guidelines, joining up the conjectural with the observable reality of the participants' own experience with ARVs. The three policy guidelines reviewed include the Comprehensive Plan for HIV and AIDS Care, Management and Treatment, adopted in 2003; the HIV/AIDS and STI Strategic Plan for South Africa for 2007-2011; and the National Strategic Plan on HIV, STIs and TB for 2012-2016.

Although available online, hard copies of the policy guidelines were obtained from the National Department of Health in Pretoria, South Africa. With their drafting and adoption coordinated via the South African National Council (SANAC), the three policy guidelines together constitute the national policy framework for South Africa.

For the interviews, a schedule, including probing questions, was developed and helped guide each interview (see *Appendix F*). All study procedures and protocols were reviewed and approved by the Human Research Ethics Committee (HREC Non-Medical) of the University the University of the Witwatersrand, Johannesburg (see *Appendix G*). After approval of the

study ethics protocol, fieldwork for the individual interviews commenced from the middle of October in 2011 until the end of November of the same year

The participants were recruited through the help of a key informant from one of the AIDS Consortium affiliated organisations, who was himself HIV-positive. In terms of the demographic or socio-economic profile of the participants, they represent a mix of patients accessing ARVs in public health facilities. They are either unemployed or in informal employment, which means that when they do have employment, it is often temporary or not very stable. The other demographic or socio-economic aspect about some of the patients is that they also to some extent often depend on state social grants for meeting some of their needs, most commonly for childcare through the child support grant. Not all the participants had finished high school.

Each participant was issued an information sheet (see *Appendix E*) about the study to inform them about the study and to keep for their own record. At the start of an interview, each participant was briefed about the study and their rights. These included: the right to either grant or refuse participation; the right to confidentiality and the right to terminate an interview at any stage should they feel like not continuing, without any negative consequences. This information is contained in the consent form (see *Appendix H*) that each participant was requested to complete before each interview began[11].

The researcher, who conducted the interviews, took care to inform the participants about how their identity would be protected throughout the study. Specifically, they were assured that their names would not be divulged to anyone other than the researcher of the research project.

[11] No potential participant recruited refused to be interviewed and audio-recorded.

In addition, they were also assured that pseudonyms would be used to disguise their real names in the final report and in other publications produced from the research. The interviews were recorded with the written consent (see *Appendix H*) of each participant. No participant demanded that any portion of the recording should be removed. Throughout the briefing process, before each interview began, the researcher invited questions from the participants. This rapport establishing exercise, revolving around a discussion of the participant information sheet (see *Appendix E*) between the researcher and each participant, was intended to ensure that each participant was as well informed about the study as possible. Moreover, the semi-structured nature of the interview style allowed for both direction as well as free flow from the participants.

Although no major or obvious risks were experienced in the interviews, participants were made aware that a list of free mental health services (see *Appendix I*) in Gauteng had been compiled and could be freely issued to them should they consider seeking the assistance of a mental health professional immediately after the interview or even at a later stage. No one requested the list, whether after an interview or at a later stage. All the interviews took place at the facilities of one of the AIDS Consortium affiliated community based AIDS advocacy organizations in Pimville, one of the twenty six cluster townships of Soweto in Johannesburg, South Africa. The youngest person to be interviewed was in her late twenties and the oldest was in her early fifties.

At the time of the interviews, all the participants were receiving ARVs from their local public clinic or hospital. With the exception of the one participant who had started a few months prior to the interview, most had been enrolled for ARVs for at least a period of three years or

longer. Out of respect for their right to anonymity, the names of the participants have been changed.

Data analysis

Analysis throughout the thesis proceeded by identifying coherent systems of meanings in the various documents collected, as well as the interview transcripts (Parker, 1992). This approach allowed for flexibility that accommodated the study's aims and questions. At the same time, it was also open to integrating the theoretical tools of the study. The analysis focused specifically on identifying the different meanings at work within the different sets of texts.

Even with a common set of principles driving the analysis, like the outline of the data gathering procedure, to account for any differences between the chapters, description of the analytic process is separated into two stages.

a) Stage one

The analytic approach that was followed therefore focused on reviewing and interpreting the documents selected for analysis for meaning and understanding from the statements in the documents analyzed presupposing or suggestive of an assumption of a preexisting a psyche, subjective or interior space that is governable by others to effect its own transformation or governability.

Across the various documents reviewed, analysis involved identifying and interpreting all kinds of statements that appeared to reveal how HIV-positive subjectivity is discursively articulated or conceptualized, particularly in the sense of what they throw up in relation to its

reshaping or transformation to enhance its exteriorized and interiorized governability (see Foucault, 1982, 1992).

The analysis encompassed in the thesis integrated some aspects of pattern recognition and the organization of categories, as would be undertaken more broadly with a qualitative thematic analysis (see Braun & Clarke, 2006; see also Rapley, 2008), with specific reference to the ideals advocated for reimagining HIV-positive self-understanding and enactment. In each case, the analysis involved isolating the specific political, social and personal goals and the associated key terms implicated in the way that the internal life or subjective world of PLHIV is mobilized or primed towards an idealized state of HIV-positive self-understanding, constitution and existence.

With the general analytic frame presented above, let us now move toward delineating its application from chapter three to six.

Starting with chapter three, the proposal advanced here argues for the idea of linking the task of (re) constituting HIV-positive subjectivity to the vision for renewing African subjectivity in order to make sense of Mr Mbeki's AIDS denialism from the perspective that encompassed the claim discussed in chapter one that the former president's position on HIV/AIDS and ARVs encompassed a political rather than only a strictly anti-scientific underpinning.

Importantly, an argument is presented for transposing Mr Mbeki's reflective views on HIV-positive subjectivity into his frame for reinventing African subjectivity in the context of the normalizing discourse or vision of the African Renaissance. Via a critical analysis of both the

problem and vision animating Mr Mbeki's perspective on African subjectivity, key terms for intervening and reformulating HIV-positive subjectivity are identified and discussed.

In chapter four, two interlinked themes emerged as very relevant for the tactical moves analyzed around the battle for PMTCT. These were identified from a close reading of previous literature on the struggle for PMTCT (see Heywood, 2003, 2009; Kistner, 2003; Klaaren, 2014). The first theme locates the struggle for PMTCT within a broader campaign for the realization of political and civic rights guaranteed by the South African Constitution adopted in 1996, two years after the country's first democratic elections. Such a thematic is beneficial in highlighting the interconnections between the right to PMTCT and the larger social and political system of governing inaugurated by the transition to a democratic South Africa. In the case of the second thematic, the literature situates the political and civic struggle to secure access to PMTCT within the democratic requirement for autonomous individuals to choose to take on the responsibility for their own lives (see Johnson, 2004; Robins, 2004, 2008; Decoteau, 2014).

The two themes were then applied to frame the analysis of the materials in order to ascertain the terms and senses in which subjectivity served as the impetus for envisioning differently the subjective prospects for pregnant women living with HIV, but also for other PLHIV more broadly, in South Africa's constitutional democracy.

The analysis ventured to demonstrate how the political and social struggle for ARVs inaugurated new ways to be HIV-positive, encompassing also associated affective registers. This entailed drawing upon previous literature to conceptualize the subjective conditions

preceding the articulation of a transformed internal life of living with HIV in the context of the struggle for PMTCT.

b) Stage two

The HIV advice column analysis followed two steps. As pointed out in chapter five, the analysis began by following Braun and Clarke's (2006) method of thematic analysis in order to generate initial themes. One of the advantages to this method of analysis is its flexibility and openess to integrating theory. Together with ARVs, the opening thematic analysis focused on the analysis of themes relating to viral load and CD4 count.

Given that the titles of the inserts draw attention to the query requiring a response, they proved important as the analysis progressed. The questions, of course, were very briefly or precisely posed, often focusing on key aspects of the query relating to the nature of the problem requiring a response.

Each query was therefore utilized as a prompt for what to analyze in each recommendation of the advice columnist. At first the content was analysed to determine the key preoccupations in the data. Theory-led questions were subsequently superpositioned to the advice inserts for analyzing the each query, as well as the corrective action recommended by the columnist.

The analysis focused on the ways that the virtues of self-evaluation and self-reliance were extolled in each response. Individually speaking, the key question was therefore how advice inserts enjoined the subjects of interest to relationships with themselves. On closer inspection, it appeared evident that these questions were appropriate for every advice insert, and that the call for self-priming and self-management was central to the advice column.

The second layer of analysis applied Foucault's (1992) approach to the ethics of self-care as discussed in chapter five. Here the context will not be revisited. However, it is important to say the application of the Foucauldian approach allowed the analysis to pursue a more directed analysis of the broader themes that were identified from the first layer.

To ensure quality control and a consensual analysis, both authors of the paper in chapter five independently reviewed the advice inserts. The data was also evaluated in relation to its fit to the theory to avoid an analysis that improperly imposed theory on the data.

Chosen because they are exemplary of the data, partial examples are presented in the paper in chapter five. While many other data extracts could have been similarly used, the examples presented are typical and more detailed rather than exceptional advice letters. Effective use of advice inserts as data must engage the advice column where it draws its power: in the resonance of the question asked with the columnist's response.

The analysis in chapter six is undertaken along a number of dimensions. Engagement with the policy guidelines generated a sort of synthetic review upon which to transpose the interview transcripts.

Terre Blanche, Durrheim and Painter (2006) have argued that qualitative analyses are useful for evaluating and synthesizing themes and trends around a specific area of interest under study about the social world. Coding of the interview data was conducted line-by-line and codes were subsequently grouped into significant themes or motifs.

The analysis was also open to adopting any new categories in the interview data (Yin, 2010). It helped to ensure that coding is not manipulated but is rather adapted to the realities or experiences relayed in the interview transcripts. This analytic approach was best suited to gather both a breadth and depth of understanding necessary of the experiences conveyed through the interview transcripts.

Rigour and dependability

If there is one way of portraying rigour and trustworthiness in the research reported in this thesis, it is that it was a matter of integrating breadth and depth throughout the data gathering and analysis. This is reflected in the ensemble of the data gathered and analyzed. To be sure, there are complications associated with this strategy. Worthy though this attempt is there are very likely limitations to the scope of breadth and depth that was achieved. After all, rigour and trustworthiness in research on social life is not easy to satisfy, in part owing to the fluidity and spectrality of the social world[12]. Moreover, researching subjectivity is complicated by time-related events and experiences underpinning its development.

For illustration, let us take the complex events around the debate over HIV/AIDS at the time of the battle for ARVs, one of the subjects of investigation in this thesis. The impassioned call for a policy to make ARVs available in the public health system in South Africa had not only a psychic value, it also encouraged PLHIV to renounce their trepidation about their right to dignity, replacing it with a conviction for legal and social justice. In contrast, the state's policy on HIV/AIDS emphasized the link between HIV/AIDS and poverty over ARVs (see, for example, Mbali, 2013; Pienaar, 2016). The other explanatory factor for the state's opposition to ARVs was the logic of advancing an African nationalist response to the

[12] See Shenton, 2004 for her discussion of the four criteria for assessing rigour and trustworthiness in qualitative.

HIV/AIDS crisis in South Africa - one based on promoting traditional medicine, reclaiming Africa's social, political, economic and scientific independence, as well as mobilizing African solidarity (see, for example, Butler, 2005; Kenyon, 2008; Noyoo, 2015).

Strictly speaking, then, the 'AIDS war' over ARVs pivoted around an assemblage of desires - social, political, legal, ideological and psychical. Multiple agendas explain the debate over HIV/AIDS policy in South Africa, especially during the period 1994 to 2004, making an investigation into the processes of the construction of HIV-positive subjectivity at the time of the battle for ARVs an ambitious undertaking.

Another complication to truly satisfying rigour and dependability worth mentioning is that the dynamics of interiorizing a subjective positionality are liable to the fluctuations of individual affects and sensations related to an individual's everyday personal, cultural and social context (see, for example, Massumi, 2002). In relation to ARV usage, for instance, Tim-Wong and Ussher (2008) have demonstrated from their research with participants taking antiretroviral therapy that HIV-positive subjectivity is irreducible to a singular form of self-relation. Instead, HIV-positive subjectivity in the context of ARV dependency, in Butler's (1997) terms, will most likely consist of various permutations in psychic reconstruction propelled by the dynamic temporal and spatial exigencies of social and cultural life. In other words, to only investigate the discourses of HIV and AIDS treatment interfacing with the construction of HIV-positive subjectivity, without taking account of the possible variability of subjective positionality while living on ARVs, would have compromised both rigour and dependability in the case of the research reported here.

The research strategy adopted in the present study consisted of gathering a variety of textual types, converging into an assorted repertoire of discursive and experience-related forms of data for analysis. My view, although more based on my own intuition rather than an educated opinion, is that the extensity and diversity of the materials gathered maximized the likelihood of working out the key constitutive elements of the discourse of subjectivity enjoined in the context of the debate over ARVs in South Africa, as well as in the aftermath of the roll out of HIV and AIDS treatment in the country's public health system. Helping to improve the credibility of the documents gathered and eventually analyzed, I was assisted by archivists with the knowledge of the relevant archives to excavate in the four sites mentioned in the discussion of the data gathering procedure: Historical Papers at the University of the Witwatersrand, South African History Archive, as well as the national libraries in Pretoria and Cape Town. In this thesis, the archival data is utilized mainly in chapter three, four and five.

As already discussed in the description of the data gathering procedure for the interviews, identifying and recruiting participants was facilitated through the umbrella organization AIDS Consortium (see *Appendices C* and *D*) and also via the help of a key informant from one of the AIDS Consortium affiliated community-based organisations working with PLHIV in one of the townships in Soweto. While I conducted the interviews, regular consultative meetings with the research project supervisor helped with sharpening interviewing skills in order to obtain the most out of each interview. Moreover, research project supervision provided a forum to debrief and evaluate each interview. The interviews are included in the discussion in chapter six. The final data for the study, then, is reasonably extensive both in terms of adequacy and profundity.

In the configuration of data created from the study, each level of analysis unfolded in a kind of symbiotic relationship with the others (see, for example, Morrow, 2005). Along the maze of discursive pathways charted theoretically via analysis of policy advocacy materials, for example, HIV advice letters or individual interviews offered deeper and reflexive personal insights on the 'situatedness' of subjectivity in everyday life. Departing or improving on the prevailing modes of empirical analysis of governmentality, discourse and subjectivity, the inclusion of advice letters and individual interviews demonstrated to be valuable for elaborating the uneasy and ambivalent manner of subjectivity, or the under-recognized complex 'feeling-thinking' duality[13] of the constitution of subjectivity.

Therefore, the research strategy of deploying a combination of a top down and bottom up approach - moving between discourse and experience - has not only demonstrated the credibility of the theory utilized in this thesis, specifically the idea that the governance of subjectivity is encompassed in many arenas, spread out across the public to the private space of self-government. In a way that is articulated with the 'directed approach' described by Hsieh and Shannon (2005), the research strategy of integrating various textual forms enhanced the development of a thematic content analysis grounded in theory.

[13] For an extended discussion of the 'feeling-thinking' duality of the constitution of subjectivity of subjectivity, see Massumi, B. (2015a). *The power at the end of the economy*. Durham and London: Duke University Press.

CHAPTER THREE

Governmentality, subjectivity and AIDS[14]

Abstract

Our aim in this paper is to examine the South African state's discursive deployment of the African renaissance discourse to prompt a particular kind of HIV positive subjectivity, during the years 1996 to 2003. We interrogate this connection along two axes. Firstly, the paper offers an analysis of the state's nudging of a new African subjectivity. Secondly, we examine the state's representation of a new African HIV positive subjectivity. In this way, the representation of a new African subjectivity - and subsequently a new HIV positive subjectivity - and the realisation of the African renaissance discourse of a reconstructed Africa were mutually supporting. A critical analysis of the state and the treatment lobby group's representational practices implicates both in prompting the formation of an HIV positive subject who is rational, dignified and free.

Key words: African renaissance, Discourse, HIV, Subjectivity, Representation, Treatment.

[14] This chapter's status: Nkomo, N., & Long, C. (2014). Governmentality, subjectivity and AIDS. *Subjectivity*, 7 (4), 411-431.

Introduction

The discordant response that preceded the roll-out of South Africa's antiretroviral (ART) treatment programme in the public health sector in 2003 reflects an assorted and conflictual discursive field through which various actors enjoin the conduct of South Africans.

The complex contestations that took place prior to 2003 between the state and the treatment lobby group were characterised by much legal wrangling and disputes between the ruling African National Congress (ANC) under Thabo Mbeki (former deputy president and president of the ANC and the country, 1994 - 2008) and the TAC (a coalition of people living with and affected by HIV/AIDS, medical and legal practitioners, and trade unionists, gender and sexual rights activists, many of whom had credentials in the anti-apartheid movement and in lobbying for equal rights for lesbian, gay, bisexual and transgendered people).

These disputes mobilized legal and scientific discursive systems, with the state both responding to legal action and maintaining a position that challenged the legitimacy of Western science and medicine (so-called AIDS denialism). Through both court and protest action, the TAC succeeded in compelling the state to make ART available in the public health sector. As Geffen (2009) has argued, this victory affirmed the view that civil society can move the state to progressively realise the socio-economic rights enshrined in the South African Constitution of 1996. In equivalent terms, these events brought into play the ANC's own 'Freedom Charter', which advocates equal rights and prospects for all South Africans (ANC, 1955).

Much scholarly attention has rightfully been directed to examining the activities of the treatment lobby group in the run up to the adoption of the 'Treatment, Care and Support Act'

of 2003 (see Robins, 2004, 2005; Bawa, 2005; Cameron, 2005; Fassin, 2007; Nattrass, 2007, 2012; Geffen, 2009, 2010; Mbali, 2013). In turn, the policy position of the state was the subject of considerable and intense debate, with some writers arguing that this position was responsible for an effect akin to genocide.

By one account, as many as 330 000 people lost their lives as a result of the state's prevarication to introduce a programme for those in need of treatment to prolong their lives and to prevent the transmission of the virus from mother to child (Chigwedere, Seage, Gruskin, Lee & Essex, 2008). The juxtaposition between the work of the treatment lobby group, which ultimately saved lives, and the position of the state responsible for lost lives, is stark. In this paper, we revisit this foundational moment from a different perspective.

Accordingly, we first consider how both local and global dynamics affected how events between the state and the treatment lobby group unfolded. This discussion centres on a period, approximately between 1996 and 2003, of intensified and highly mediated concern with the epidemic, both locally and internationally. Drawing on the work of Foucault on governmentality and subjectivity (1982, 2000 and 2008), we focus on the state's discursive deployment of the African renaissance discourse to prompt a particular kind of HIV positive subjectivity.

We interrogate this connection along two axes. Firstly, the paper offers an analysis of the state's nudging of a new African subjectivity. Secondly, we examine the state's representation of a new African HIV positive subjectivity. In this way, the representation of a new African subjectivity - and subsequently a new HIV positive subjectivity – and the realisation of the African renaissance discourse of a reconstructed Africa were mutually

supporting. In closing the article, we posit that a critical analysis of the state and the treatment lobby group's representational practices implicates both in prompting the formation of an HIV positive subject who is rational, dignified and free. .

Clash of the titans

Alongside the multiparty negotiations for a democratic South Africa before the elections in 1994, the recently unbanned ANC, other key players who were part of anti-apartheid lobby groups and the soon-to-be reconstituted national health department forged a common vision that to most observers offered the promise of a strong and unified response against the then nascent epidemic (Schneider, 2002; Johnson, 2004). Encapsulated in the 'Maputo Statement on HIV and AIDS in Southern Africa' (1990), this vision prioritised prevention and support programmes for people living with HIV/AIDS (PLWHA).

In addition, it recognised the need to secure and protect the rights of those infected and affected by HIV/AIDS. The establishment of the National AIDS Committee of South Africa or NACOSA, as well as the formulation of the draft National AIDS Plan that was subsequently adopted by the new ANC administration in 1994, were the result of this participatory process (Schneider, 2002; Johnson, 2004).

Participation continued post 1994, albeit to a limited and declining extent. The first signs of strain in the collective project emerged with the controversy generated by the funding of the AIDS musical 'Sarafina II' in 1996 (Schneider, 2002; Posel, 2005; Mbali, 2013). Ironically, the 11th International Conference on AIDS in Vancouver, Canada was held in the same year. This conference represented a watershed moment in the history of the fight against the global epidemic, with the ushering in of ART combination therapy.

What made the 1996 Conference especially significant was not only the shift in ART strategy from the less effective mono to a three drug cocktail therapy, but also the catalyzation of a global health campaign (an assemblage of states, aid agencies, AIDS activist organizations, and so on) whose primary goal was to mobilize and push for treatment access in poor countries mired in poverty and with high prevalence rates. Specifically, this campaign mobilized and framed its stratagem within the principle of the right to healthcare, including access to ART and other essential medicines beyond the reach of PLWHA and the poor (Johnson, 2004; Nguyen, 2005; Cataldo, 2008; Iqbal, 2009).

In an exemplary move, in 1996 Brazil became the first developing country to introduce ART in the public health sector. Capitulating to pressure from civil society groups representing PLWHA, the Brazilian state was prepared to use the threat to issue compulsory licences to allow for parallel importation of generic ART equivalents, effectively inducing concessions from the pharmaceutical industry (d' Adesky, 2004; Biehl, 2008).

By contrast, in South Africa there was little or no productive cooperation between the state and the ART lobby groups. As Schneider (2002, p. 145) observed: "public debate on AIDS has been dominated by a series of responses and counter-responses in which actors have competed to set the agenda for AIDS in South Africa."

The notable exception to this animosity was during the court case that was instituted in 2001 by the Pharmaceuticals Manufacturers Association (PMA) against the state and the Minister of Health (Schneider, 2002; Robins, 2004). The PMA sought to prevent the promulgation of the 'Medicines and Related Substances Control Amendment Act' – an Act intended to reduce

the price of essential medicines like ART and, where possible, make way for parallel importation or local production of generic medicines still under patent protection (Heywood, 2003; Johnson, 2004; Mbali, 2013). This case drew immense negative publicity and mobilisation against the multinational pharmaceutical industry, both locally and internationally. The PMA eventually withdrew the litigation as a result of this negative publicity.

In a rare show of unity, the TAC joined the state and the health ministry as a friend of the court and also organised protest action outside the court and beyond in support of the state and the introduction of the Act. Yet, as the events to follow would demonstrate, this unity was short lived.

Disagreement over consolidating a policy for treating HIV/AIDS in the public sector was by far the most vociferous of any of the debates at the time in the new post-apartheid dispensation. The following brief chronological account adapted from Schneider (2002), Schneider and Fassin (2002), Geffen (2009, 2010) and Mbali (2013), among others, outlines the course of the ART debate.

The first disagreement generated in 1997 when the state and health ministry provided support to South African researchers who claimed to have discovered treatment for AIDS called 'Virodene', which turned out to be nothing more than an industrial solvent. Following this, there was the call, first made around 1998 by organisations like the TAC and the National Association of People Living with HIV and AIDS (NAPWA) for the introduction of a Prevention of Mother to Child Transmission programme (or PMTCT). (NAPWA subsequently parted ways with the TAC in support of the state).

The call for the roll out of PMTCT in state facilities emerged after trials in both Thailand and Uganda demonstrated the prophylactic benefits of a single course of either zidovudine or nevirapine for reducing the transmission of HIV from the mother to her unborn child. (The prophylactic benefits were as much as 47% to 50% at the time).

Subsequently, the hosting, in 2000, of the first major AIDS Conference in Africa, in the city of Durban in South Africa, intensified two processes that were already in motion both in South Africa and internationally. The first is the amplification of the challenge against the World Trade Organization's 'Trade-Related Intellectual Property Rights' agreement. International ART lobby groups (including the TAC) argued that the protection of patents afforded by agreements with mostly Western pharmaceutical multinational companies made it unaffordable for many in the developing world to access ART.

In addition, in the aftermath of the conference the struggle for ART accelerated in South Africa and internationally. The picture of the emaciated 11 year old HIV positive 'Nkosi Johnson' during the conference in 2000, splashed across the front pages of both local and international newspapers, would become a potent and galvanizing symbol of the struggle for ART in developing countries.

After the Durban conference, the South African state did approve the piloting of PMTCT in a few limited sites, a decision that the ART lobby group successfully challenged in 2001 in the High Court. The following year, the state filed an appeal at the Constitutional Court against the High Court ruling, arguing in its defence that costs and the 'inconclusive evidence' on

nevirapine's efficacy necessitated a gradual approach to extending PMTCT in the public health sector.

In presenting its ruling, the Constitutional Court argued that "the policy of confining nevirapine to research and training sites fails to address the needs of mothers and their new born children who do not have access to these sites" (Minister of Health v. Treatment Action Campaign cited in Heywood, 2003, p.278). Ultimately, it ruled that the state should take measures to extend PMTCT in the public sector.

This legal victory and the defiance campaigns of the ART lobby group that followed intensified both local and international pressure on the South African state to approve a broad based ART programme. In 2003 the state capitulated and moved to promulgate the 'Treatment, Care and Support Act'.

This battle, ultimately won by the ART lobby group, took place in the context of a discursive battle in which the state argued for the epidemic in Africa to be understood and approached in a distinctly African manner. It is to the state's position that we would like to now turn. However, before we do so, it is constructive to conceptually and critically engage the relation of governmentality and subjectivity upon which we base our re-appraisal of the state's position and the kind of HIV positive subjectivity it nudged into play.

Governmentality and subjectivity

Foucault (2000) first articulated the notion of governmentality in his series of lectures in 1978 to 1979 at the Collège de France. In the lecture series entitled 'The Birth of Biopolitics: Lectures at the Collège de France' (see Foucault, 2000), he would use the notion to

reconstruct the history of government from Ancient Greece to modern liberalism and neo-liberalism (Lemke, 2001; Read, 2009).

The most notable aspect in his use of the concept of government is that he advanced a critique and expanded current limiting associations of government with only the administrative functions of the state (such as security, health or education). Indeed, in his genealogical account of 'the modern state' he argued that it is only from the 18th century in the modern West that the concept assumed its current meaning and close link with the notion of the state and its functions (Rose & Miller, 1992; Lemke, 2001).

Up until the 18th century, government encompassed a whole range of activities centred on the management and promotion of the productive forces, wealth and health of populations. From Foucault's perspective, government entailed not only functions that in the modern sense unify within the state, but extended to consist of reflections and practices that bear on the government of such problems as "self-control, guidance for the family and for children, management of the household, directing the soul" (Lemke, 2001, p. 191). Government was the thematic focus of philosophical, legal, religious, pedagogical, political and medical reflections and practices (Foucault, 2000).

The relevance of this historical reconstruction of government is that Foucault used it to demonstrate, as Rose and Miller (1992, p. 272-273) point out, that the modern state retains "neither the unity nor the functionality ascribed to it", but instead "has assumed a particular place within the field of government." In these terms, the modern state is an important but by no means the only stakeholder with an interest in administering "the lives of others in the light of conceptions of what is good, healthy, normal, virtuous, efficient or profitable" (Rose

& Miller, p.273). In this way, then, government is an ensemble conveying the "dreams, schemes, strategies and manoeuvres of authorities that seek to shape the beliefs and conduct of others in desired directions by acting upon their will, their circumstances or their environment" (Rose & Miller, 1992, p.273).

In order to clarify the applicability of this perspective for this article, it is useful to highlight two other significant dimensions about government. The first, as Lemke (2001, p.191) points out, is that government "pin-points a specific form of representation…a discursive field in which power is rationalized…the specification of objects and borders, the provision of arguments and justifications etc."

Government enables the interrogation of a problem to be addressed - or its intellectual processing - and selection of strategies, programs and technologies to be used to manage it (Ingram, 2010, 2011). Second, government indicates the very close link between power relations and processes of subjectification (Read, 2009; Fournier, 2011). For Foucault (1982, p.789), government is the "conduct of conduct", or more specifically, ways of "acting upon an acting subject or acting subjects by virtue of their acting or being capable of action."

Thus, it is within the perspective of government as 'form of representation', 'a discursive field in which power is rationalized', and importantly, as the 'conduct of conduct' that we situate our understanding of subjectivity. For us, subjectivity is both mobilized for and results from government (Cruikshank, 1999). In this paper, we employ an analytics of governmentality to interrogate subjectivity as both 'instrument' and 'effect' of government.

A few comments about the constraints of using governmentality to theorize subjectivity are worth pointing out. Most frequently the governmentality approach accounts for discourses that endorse certain aspects of subjectivity – for example, a responsibilised, self-regulating and rational subjectivity – without being able to determine whether in fact these aspects will be interiorized or enacted (Weidner, 2009). As a result, it may be difficult to determine if the discourse being examined has actually worked (whether it forms or modifies subjectivity) or precisely how it has worked (the actual mechanisms at work in the formation or transformation of subjectivity).

Similarly, an analytics of governmentality focused on accounting for the subjective effects of the discourse being analyzed risks precluding the role and purchase of other discourses in supporting the effects being observed (Tie, 2004). A good example is a practice like the confessional, which is associated with both the psychological and religious discourses. The tendency in governmentality research is to subsume forms of subjectivity to the singular effects of a discourse that may derive its hold and strength because it partially resonates with the established beliefs and practices of another discourse.

This approach also frequently implies a discursive orientation that is unable to account for the experience and variability of subjectivity or subject positions in everyday situations (Blackman, Cromby, Hook, Papadopoulos & Walkerdine, 2008). Indeed, what this 'textual' preoccupation misses is the complexity of subjectivity "as situated, agentive and temporally grounded in conducts of everyday life - a fact which largely disappears behind descriptions of the rationality of specific logics of government" (Binkley, 2011, p. 84).

What, then, does an analytics of governmentality bring to an analysis of subjectivity? We have no difficulty in accepting the critique that beyond the 'authoritative' power of discourse there must be some way to account for the mechanisms whereby a discourse, even in conjunction with other supporting discourses, is effective in constituting or transforming subjectivity.

Furthermore, we have no difficulty in granting that subjectivity is highly situated and differentiated in everyday situations, that it would be an overstatement to privilege a uniform or singular characterization of it (Burkitt, 2008). While both these critiques have merit, what they understate and partially ignore is *why* we come to think, feel and experience ourselves the way we do, even when it is recognized that this is highly differentiated or situated in everyday life (Rose, 1998; Gill, 2008).

By contrast, an analytics of governmentality recognizes the explanatory potential of investigating the modes of thought or rationality "encapsulated in discourses and knowledges that guide, advise and inform our ways of being in the world" (Campbell, 2010, p.38). What an analytics of governmentality enables is an analysis of the epistemological bases within which subjectivity is formed, modified and negotiated (Ingram, 2010; Shoshana, 2011, 2012).

As such, it is in the discursive realm that subjectivity is made thinkable, practicable and governable. Broadly speaking, then, the notion of governmentality expresses the ways of thinking or mentalities supporting attempts to modify or shape the actions of others, including by modulating the way a self comes to understand, constitute or modify the self. Hence, the strength of using an analytics of governmentality is that it makes it possible to analyse the forms of rationality used to problematize, direct and govern subjectivity.

To this end, we develop two key aspects for thinking about the state's representation of HIV positive subjectivity using an analytics of governmentality (Dean, 1996). First, we focus on the manner that the state problematized HIV positive subjectivity for governing. In other words, we critically assess the areas of HIV positive subjectivity that the state delineated for governing, together with the arguments it deployed for thinking about HIV positive subjectivity as a problem for governing.

Second, we examine the purposes or objectives - or as Dean (1996, p. 226) puts it, the 'telos' of government - for which the state enlisted HIV positive subjectivity for governing. We describe the valuational justifications that the state marshaled to support the objectives for which HIV positive subjectivity is enjoined for governing. In a polyvalent discursive field of government, both these aspects might offer a way to understand *differently* the state's discursive deployment of the African renaissance discourse to represent a new HIV positive subjectivity.

Hailing a new African patriot

In the middle of 'Wretched of the Earth' Fanon (1963) makes the following critical observation: "…reclaiming the past…triggers a change of fundamental importance in the colonised's psycho-affective equilibrium…the colonised intellectual who decides to combat these colonialist lies does so on a continental scale" (p.148-150).

While it might be wrong to look for a trans-historical analysis in a work which is primarily written for a specific period in Africa's evolving post-colonial history, it is worth pointing out that this observation could almost have been made with reference to Ahmed Sékou Touré,

Nnamdi Azikiwe and Thabo Mbeki. (Touré, Azikiwe and Mbeki are first and second presidents of post-independence Guinea, Nigeria and South Africa, respectively). Important to observe about the three leaders is that they prioritized developing and enacting their perceived mandate around Africa's social, political, economic and historical renewal (Vil-Nkomo & Myburgh, 1999).

For the purposes of this article, we selectively extract from speeches and public lectures made by these leaders in order to demonstrate points of agreement and identification between them that partially capture the consolidation of what we call the African renaissance discourse. In doing so, we hope to distill some of the discursive outlines of the African renaissance discourse and explore the exhortation of a new kind of African subjectivity within the context of a socio-political and economic programme to renew Africa. This will set the stage for the discourse's juxtaposition with HIV positive subjectivity in the following section.

A key feature of the new African renaissance patriot concerns self-surveillance of the mind. Touré, for example, suggests the project of creating a particular kind of internal state, 'mentality', in his citizens as crucial to their further development: "For the first twenty years, we in Guinea have concentrated on developing the mentality of our people. Now we are ready to move on to other business" (Touré cited in Lamb, 1983, p.211).

In equivalent terms, the historical articulation and growth of this African renaissance discourse is synonymous with the advancement of the creation of a particular kind of 'mentality' and consequently self-governance as a pre-condition for Africa's reinvention post-colonialism and post-apartheid. Around the mid to late 1990s, Mbeki and others articulated a vision to reconstitute sub-Saharan Africa socially, politically, economically and

historically (Posel, 2005). This was encapsulated in the *re*-call of the African renaissance discourse that served as the impetus for the establishment of 'The New Partnership for Africa's Development'.

The grand bargain that was to be struck was that external donors should provide financial support in exchange for sound economic and political governance in Africa. Other institutional mechanisms subsequently established for the elaboration of the African renaissance include the 'African Peer Review Mechanism' in 2003 and the inauguration of the 'Pan-African Parliament' in 2004, hosted in South Africa (Ndlovu-Gatsheni, 2014). These institutions have moved beyond their early conceptual base, but are yet to function to their full capacity.

Perhaps most important, the conceptual impetus for the establishment of these institutions is the call to action of Africa's renaissance, and with it presumably the psychological enablement of Africans.

The discourse of Africa's renaissance has been a feature in African political thought since as early as the mid-19th century (see Ayo Langley, 1979). In particular, the founding of the international pan-Africanist movement in the late 19th century and Francophone Africa's literary and ideological movement in the 1920s and 1930s appear to be early signs of the development of this discourse (see Campbell, 2006).

However, with Ghana's shift to autonomous rule in 1957 and the formation of the 'Organisation of African Unity' (OAU) in 1963, precursor to the 'African Union' (AU), the African renaissance increasingly consolidated a vision for a new Africa post-independence.

For instance, just after Guinea gained its independence from France in 1958, Touré (1979, p. 613) delivered a speech in the country's capital Conakry, arguing that "Africa… is to-day totally committed to the road of its freedom, its dignity and its complete rehabilitation."

The common thread that runs through this and other such formulations, including Black Consciousness' celebration of the African personality and pre-colonial African history in the 1970s, is to reconstitute African subjectivity in such a way as to act upon subjective self-understanding, and in doing so, to empower (Biko, 1996).

As Mbeki (1999, p. xx) would elaborate forty years after Touré on the work to be undertaken to govern African subjectivity: "An enormous challenge faces all of us to do everything we can to contribute to the recovery of African pride, the confidence in ourselves that we can succeed as well as any other in building a humane and prosperous society…it cannot be that successive periods of slavery, colonialism and neo-colonialism, and the continuing marginalization of our continent could not have had an effect on our psyche and therefore our ability to take our destiny into our own hands."

It was within this framework that Mbeki (1998, par. 35-36) had argued that: "The beginning of our rebirth as a Continent must be our own rediscovery of our soul…such a people can and must be its own liberator from the condition which seeks to describe our Continent and its people as the poverty stricken and disease ridden primitives." Within this formulation, liberation and resistance are inextricably linked to the recovery of an experience of pride and the rediscovery of an essentially African soul.

What to make of this injunction to rediscover the 'true' psychology or psyche of Africans? More importantly, what is envisaged by rediscovering the psychology of Africans and the associated idea that Africans must assume responsibility for their own psychological, and in turn their social, political and economic empowerment? Mbeki envisions a restored and perhaps redeemed African subject to anchor the African renaissance.

The African renaissance is a call to action constructed upon the assumption that every African will enlist and engage with their own psychological empowerment. Rose (cited in Shoshana, 2011) notes how empowerment becomes a technology of subjectivity, simultaneously individualizing, legitimating and including certain subjectivities, whilst excluding others.

Mbeki (1999, p. xxi) elaborates: "In the end, what we are speaking of is the education, organisation and energisation of new African patriots who, because to them yesterday is a foreign country, join in the struggle to bring about an African renaissance in all its elements." In this account, the realisation of the vision of the African renaissance demands a 'true' elaboration and unearthing of the African psyche and the constitution of the African patriot who will consequently be enlisted into a regional socio-economic and political project.

Thus, Africans can become governable when they internalize the objective of Africa's renewal, a renewal that in turn depends on a new African subjectivity. The discourse of a new African patriot locates the hope of Africa's renewal in the psychological state of African people or individuals. The history of the African renaissance suggests that self-governance is a condition of Africa's regeneration.

How is the objective of a reconstituted African subjectivity to be realised? Mbeki and Azikiwe provide a clue in their public speeches (Azikiwe, 1979; Mbeki, 1998, 1999): by reclaiming the past in order to rewrite the present. If 'government' designates "the way in which the conduct of individuals or of groups might be directed" (Foucault, 1982, p. 790), the solution to Africa's developmental obstacles is discovered in the capacity of Africans to act upon themselves, guided by the African intelligentsia in rediscovering their true history. "Among other things, what this means is that we must recall everything that is good and inspiring in our past" (Mbeki, 1999, p.xxi).

Mbeki's call to subjects is to situate themselves in relation to history – interestingly, both as a "foreign country" to be left behind in the search for the future and as "everything that is good and inspiring in our past" (p.xxi) with its implications of reclamation. As Azikiwe (1979, p.422) had argued before Mbeki, "let the African know that he had a glorious past and that he has a glorious future…Teach the African to know his capabilities and his role in the scheme of things". History is therefore linked to the reconstitution of subjectivity.

Within this discourse an empowered African patriot demands a positive sense of history. This discourse effectively arose in opposition to the historical misconceptions that have shaped how the world and Africans see themselves. An African with 'dangerously desiring' habits - as Mbeki was to argue in a public lecture that he delivered at Fort Hare University in 2001 in the Eastern Cape - is inconceivable within a reconstituted African subjectivity with a sense of a "good and inspiring past" (Mbeki, 1999, p.xxi).

So, the turn to the discourse of an empowered and differentially historicized African patriot is a response to predominantly Western misconstructions "in everyday discourse or in

ostensibly scholarly narratives" of Africa as "the very figure of the strange", a "mediation that enables the West to accede to its own subconscious and give a public account of its subjectivity" (Mbembe, 2001, p.3).

Both Mbeki and Touré call for an intellectual investment in undoing the historical misconceptions that have shaped how the world and Africans see themselves. Touré (1979, p.601) observes that "this intellectual decolonization, this decolonization of thoughts and concepts may seem infinitely difficult. There is, in effect, a sum of acquired habits, of uncontrolled behaviour, a way of living, a manner of thinking, the combination of which constitutes a sort of second nature which certainly seems to have destroyed the original personality of the colonized."

Presumably, for Touré, African subjectivity was so beaten down by centuries of subjugation under colonialism that one could attribute a kind of intractable psychologized bondage to colonialist 'thoughts' and 'concepts'. In this sense, the African renaissance intervention into subjectivity denotes a form of resistance against a previous colonial form of subjection and subjectivity, or as Foucault (1982, p.781) has argued, it illustrates a form of opposition "against that which ties the individual to himself and submits him to others in this way."

In addition to the centrality of a new mentality, African pride, a positive relationship to history and a rejection of characterizations of Africans as 'dangerously desiring', the new African patriot is constructed as an intellectual. Taken together, these characterizations of the new African patriot, while resisting or deconstructing colonialist discourses, also reconstruct a new kind of African subjectivity.

In these characterizations the rationality of subjectification implicated "responds to stronger 'demand' for individual scope for self-determination and desired autonomy by 'supplying' individuals…with the possibility of actively participating in the solution of specific matters and problems" (Lemke, 2001, p.202). Comparing this kind of subjectivity to an African HIV positive subjectivity, however, foregrounds the extent to which subjects are enjoined to monitor themselves and create themselves anew.

Rewriting African HIV positive subjectivity

In his keynote address at a conference to deliberate on the African renaissance in 1998 Thabo Mbeki proclaimed that, "we must ask the question - where are Africa's intellectuals today... Africa's renewal demands that her intelligentsia must immerse itself in the titanic and all-round struggle to end poverty, ignorance, disease and backwardness" (par 27-30). Although not referring to HIV/AIDS but to the African renaissance, this quotation holds clues to the state's response to the treatment lobby group as well as to Mbeki's AIDS denialism.

More importantly, the quotation indicates that the state's response cannot be understood without juxtaposing it against the discourse of a new African patriot. Phillips (2004, p. 35-36) has argued that in the history of epidemics in South Africa it is "not without precedent…for those in authority or their agents to adopt a position of denial, at odds with mainstream medical opinion, for reasons more political, economic or ideological than medical and scientific." Indeed, the initial response to the advent of the epidemic in sub-Saharan Africa by a coterie of African heads of state articulated with long standing post-colonial efforts aimed at resisting mystifying and denigrating representations imposed on Africans.

This link, between HIV/AIDS policy and resistance to colonialist discourse, is key to understanding the terms upon which HIV positive subjectivity was viewed as a problem that deserves governing. Mbeki's assertions in the ART debate are irradiating: "And thus does it happen that others who consider themselves to be our leaders take to the streets carrying their placards, to demand that because we are germ carriers, and human beings of a lower order that cannot subject its passions to reason, we must perforce adopt strange opinions, to save a depraved and diseased people from perishing from self-inflicted disease" (2001, par. 42).

In order to resist colonial renditions of the HIV positive subject, then, Mbeki foregrounds and valorizes rationality, reason and dignity above poverty and disease. As the African patriot is a figure of pride, so too is the African in relation to HIV/AIDS. In this way, the governing of the figure of the African patriot and the African in relation to HIV/AIDS represents "a movement of truth from an older, discredited and proven 'untrue' self, to a new self - revealed to possess a new truth" (Binkley, 2011, pg. 87).

Likewise, holding in mind the African patriot as an intellectual sheds light on the relationship between reconstituting a new kind of African subjectivity and the subsequent reconstitution of a new kind of HIV positive subjectivity. Attention to Mbeki and Touré's ideas on intellectuals and their contribution to the African cause suggest two points of congruity that potentially explicate this relationship.

First is their skepticism of Western science. Touré (1979, p. 603) argues that "the imperialists use scientific, technical, economic, literary and moral cultural values in order to maintain their regime of exploitation and oppression. The oppressed peoples equally use cultural values of a contrary nature to the former, in order to make a better fight against imperialism

and to extricate themselves from the colonial system." He maintains that "if scientific knowledge, modern techniques and the elevation of thought to the level of higher human principles for the perfecting of social life, are necessary for the enrichment of a culture, they none the less retain the capacity of being used for contradictory purposes". Touré's assertions problematise scientific knowledge and offer it as potentially appropriable.

A similar formulation is evident in the anonymous document 'Castro Hlongwane, Caravans, Cats, Geese, Foot and Mouth and Statistics: HIV/AIDS and the struggle for the Humanization of the African'. Circulated widely in the ANC, the document's electronic signature was linked to Mbeki (Posel, 2005). The document specifically refers to HIV/AIDS science, and defiantly asserts that Africans will no longer "accept as the unalterable truth that they are a dependent people… and that is victim to a self-inflicted "disease" called HIV/AIDS. For centuries we have carried the burden of the crimes and falsities of 'scientific' Eurocentrism" (Anonymous, 2002, par. 43). In this formulation, then, the African patriot is set up in opposition to dependency and victimhood.

In order to appropriate or reject Eurocentric science, however, HIV/AIDS is also rejected. The African patriot is enjoined to reject the "disease" because of its associations with dependence and victimhood. The second point of agreement is evident in the call for intellectual allegiance to Africa. For example, Touré (1979, p. 608) counsels that the intellectual needs "to free himself intellectually from the colonized complex", to "discover our original values", and to "serve the African cause". Similarly, Mbeki (1999, p. xxi) speaks of the "great burden that rests on the shoulders of Africa's intelligentsia" and "the enormous brain power which our continent possesses" that "must become a vital instrument in helping

us to secure our equitable space." For Touré (1979, p.608) intellectuals "have no values unless they really concur with the life of the people."

Implicit in the African renaissance discourse is the notion of 'African solutions to African problems', or what Mazrui (1967) has called 'Pax Africana'. In this discourse, exclusive recourse to 'Eurocentric' solutions to the HIV/AIDS epidemic presents the danger of perpetuating racist scientific practices "to save a depraved and diseased people from perishing from self-inflicted disease" (Mbeki, 2001, par. 42), a perception associated with the early years of the epidemic.

As Comaroff (2007, p. 197-198) argues from an alternative vantage point, in the early years the epidemic confounded scientific expertise and "Western self-images of reasoned control" such that "the disease was deflected onto Africa as primal other, Africa as an icon of dangerous desire, Africa as the projection of a self never fully tamable."

It seems the African renaissance preoccupation with scientific knowledge has less to do with reinventing wholesale a new system of scientific knowledge, but more about making use of it 'for contradictory purposes': to revitalize the African continent by valorizing and prompting a subjectivity bereft of preconceived notions of an 'unscientific' and 'unreasoning' continent "doomed to an inevitable mortal end because of our unconquerable devotion to the sin of lust" (Mbeki, 2001, par. 44).

African renaissance approaches to HIV/AIDS, then, have less to do with the government of sexuality (Burchardt, 2013) and more to do with the 'government' of African pride and patriotism. Resisting prejudiced views about HIV positive Africans constitutes a form of

elaborating and constructing a new kind of African patriot, which in turn implies a new kind of HIV positive subject. This perspective also centralizes the role of the African intelligentsia in generating solutions to 'African problems', aptly characterized by Mamdani (1999, p. 130) when he notes: "This, surely, is…why the driving force of every renaissance is inevitably the intelligentsia… Intellectuals are central to the process of identity formation…The locus of identity formation is not just political, it also cultural and academic."

The "anti-science" or "pro-intelligentsia" stance appears to reflect the idea that knowledge can only be derived from the West as patronising. For this reason, HIV/AIDS knowledge allows for continued projections of depravity, and understandable resistance to this. As Comaroff (2007, p. 202) critically observes, "small wonder that the disease animates traumas which invert the phobias of the West…suspicions that it was inflicted on black populations by genocidal racists, by careless experimentation, by the CIA, or by drug companies and their craven sidekicks".

Butchart (1990, p.174) has noted "some of the fantastic, geometric, pitiable, docile, dangerous, risky, anatomically dissected and subjectified configurations" that have invested the African body and mentality in South African socio-medical discourse in the late 19th century through to the 1960s.

The African renaissance response to HIV/AIDS, then, simultaneously resists such powerful western discourses of otherness and propagates a discourse of a self-governing HIV positive subject as rational, dignified and free. Holding the juxtaposition of the African patriot discourse of a new African subjectivity and a new African HIV positive subjectivity in mind offers a different perspective on the juxtaposition between African HIV positive subjectivity

and the subject invoked by the treatment lobby group. In the remainder of this article we turn to this comparative critical perspective.

A comparative HIV positive subjectivity

In re-examining the state's discursive deployment of the African renaissance discourse to nudge a particular kind of HIV positive subjectivity, we hope to have elucidated the social and political conditions of its crystallization in South Africa's history in the fight against the pandemic. Although the state's response was the object of ridicule and cynical interpretation by many theorists and activists, it is not our intention either to advance its defence or to engage further in this form of criticism. Rather we seek to make a meta-theoretical argument about the reproduction of subjectifying power in different forms, even by those who would view their engagement as liberatory.

We pose the question as to whether the envisaged HIV positive subjectivity cobbled together from the correlative new African patriot is fundamentally different from the HIV positive subjectivity of the ART lobbyists. This is an important question to pose in terms of governmentality and subjectivity, since the two sets of antagonists in the debate have been represented as so diametrically opposed.

It is our contention that there are few fundamental differences between the two discourses in the way they engage subjectivity, despite their wide divergences. After all, that the debate even arises may suggest that there are overriding sets of conditions that make it possible for the two discourses to emerge. There are at least three arguments to support our suggestion that there are few fundamental differences in the HIV positive subjectivity associated with the African renaissance and the treatment lobby discourses.

Firstly, in propagating an HIV positive subjectivity which "shall no longer permit control by a colonial mother who claims for herself the right unceasingly to restrain" (Anonymous, 2002, par. 44), the African renaissance discourse is complicit in the creation of an HIV positive subjectivity that is its own "overseer, exercising surveillance over and against itself" (Butchart, 1997, pg. 104). The question then is whether this is intrinsically any different from the responsibilised and active subject of the treatment lobby discourse? It has been suggested that ART discourses support disease surveillance (Sangaramoorthy, 2012) and call into being subjects who are expected to be autonomous, self-regulated individuals (Adam, 2006).

We suggest that at stake in both discourses is the constitution of a self-governing subjectivity within a democratic constitutional framework. Just as the African renaissance HIV positive subjectivity was articulated through and within a discourse that enjoins an independent and self-determining subject for a renewed Africa, so similarly the ART lobby discourse also presupposed a subject with individual rights and agency (see Robins, 2004, 2005).

Within both discourses, a self-governing subjectivity is presented as a social and political responsibility: in both cases subjects may learn to recognise themselves as subjects of either a program to mobilize PLWHA to demand access to ART or as advancing Africa's renaissance. As Foucault (1982, pg. 781) has argued, there are two meanings of the word subject: "subject to someone else by control and dependence" or "tied to his own identity by a conscience or self-knowledge."

Both discourses posit independent subjects who are prompted in specific and powerful ways within these discourses. Indeed, both discourses reveal a subjectifying form of power in attempting to modulate the way a subject self-acts to constitute or modify the self (Hook,

2004a). We could say that "this form of power… subjugates or makes subject to" (Foucault, 1982, p. 781) in linking the way self-action to constitute or modify the self takes place within the purview of a socio-political programme or discourse, the realisation of which depends on the subjects recognising themselves as targets addressed and consequently enrolling in such a programme, be it consciously or unconsciously (Dean, 1996).

Secondly, what appear evident in both discourses is their implicit assumption of an ahistorical, primal or pre-existing subjectivity subject either to the repression of its true essence and potential or requiring empowerment from dependence, subjugation and a sense of inferiority.

Both discourses presume a pre-existing personality that was corrupted either by colonialism and apartheid or by a diagnosis of a potentially fatal and socially 'contemptible' disease. In other words, both discourses work from the implicit assumption of the existence of an interior space that could be acted upon to free it from any 'psychological complexes' that prevent it from fulfilling its potential. For this reason, in attempting "to alter the visible person by acting upon this invisible inner world" (Rose, 1998, p. 1), both discourses endeavor to enlist their subjects to recognise themselves as certain forms of possible subjects as opposed to others. Interestingly, both discourses draw upon the idea of struggle, so linked to apartheid discourse.

Both the African renaissance and the treatment lobbyists alike have "reformulated…historical exclusion as a matter of historically produced and politically rich alterity" (Brown, 1995, p. 53). Within the African renaissance discourse, the subjective and cultural effects of a history of racism and oppression under colonialism (and particularly 'apartheid') on African

subjectivity demanded a reconstitution of a positive 'knowledge of the past' as a significant pre-condition in the constitution of a new African patriot.

Likewise, reference to history was part of the treatment lobby discourse, even if in a different way. It was in large measure out of the history of discrimination against PLWHA that the ART lobby discourse could construct and marshal the substance of their argument for mobilizing for ART access (see Schneider & Fassin, 2002; Robins, 2005; Nattrass, 2007, 2012; Geffen, 2009, 2010). Both discourses, then, tactically appeal to a history of exclusion – the historical marginalization of Africans geopolitically and the historical discrimination against PLWHA both regionally and globally - in order to enlist their subjects.

Thirdly, both the African renaissance and treatment lobby discourses centrally cohered around the significance of knowledge and the status of science. While there were significant differences between the African renaissance and the treatment lobby discourses in relation to positioning themselves with regard to science, these differences from 1994 materialised in the context of "significant policy exercises…undertaken to study and reshape the science system to resonate with the new realities of a free but deeply divided South Africa" (Bawa, 2005, p. 610).

Inarguably, the African renaissance discourse was at variance with the scientific system. One significant point of difference is that there was the perception that the scientific system was "underpinned by Western scientific norms and knowledge systems and that it positively discriminated against other knowledge systems, in particular what have come to be known as indigenous knowledge systems" (Bawa, 2005, p. 610).

Despite these differences, though, the status of science was significant for both discourses (see Robins, 2004; Bawa, 2005). If science can be construed as part of "the ensemble formed by the institutions, procedures, analyses and reflections, the calculations and tactics, that allow the exercise of this very specific form of power, which has its target population" (Foucault, 2000, p. 219- 220), for both discourses alike science was also about 'who we are' and 'who we can become'.

For the African renaissance discourse, a reconstructed scientific system would entail "helping us to secure our equitable space" (Mbeki, 1999, p. xxi) both in the sub-Saharan Africa region and globally. The idea that 'African problems' demand 'African solutions' can be understood within this framework. Following a different argument but not necessarily different logic, the treatment lobby discourse centralized the right to the benefits of science as a global public good. Arguably then, both discourses claimed science as a medium for juxtaposing 'who we are' in light of 'who we can become' and for claiming psycho-political space.

The analysis offered in this paper is not intended as a comprehensive representation of the African renaissance discourse. We recognise that it is neither a cohesive nor a unitary discourse. Instead, our analysis is an argument for the possibility of a link between some elements associated with it and the type of HIV positive subjectivity enlisted therein in the period before the promulgation of the 'Treatment, Care and Support Act' in 2003. We also do not see this discourse as a dominant mode of thought currently in the ANC, or even historically. African nationalist thinking has always wrestled with other ideological positions - for example, 'Marxist' and 'Workerist' thinking - within the ANC (see Gumede, 2005; Erlank, 2012; Gilder, 2013).

As Pogrund (1990) has documented, the formation of the Pan-Africanist Congress in the late 1950s can be partly attributed to the rejection of the 'Africanists' in the ANC. More importantly, it is not our assertion that the ideal of a rational, dignified and free African subjectivity and the correlative African HIV positive subjectivity was the preserve of the African renaissance discourse.

On the contrary, it can be argued that the work of the treatment lobby group had centralised the African HIV positive subject in their struggle for Africans to have as much right and access to global public goods (such as access to lifesaving medicines) as people in the more developed world (see Heywood, 2003; Geffen, 2010; and Mbali, 2013 for an extensive coverage of the global treatment lobby movement and the impact of the work of the TAC on South African and global health politics).

While the African renaissance discourse represented African HIV positive subjectivity through an attempt to govern African subjectivity, the treatment lobby discourse represented African subjectivity through African HIV positive subjectivity (see Heywood, 2003; Geffen, 2009, 2010; Mbali, 2013). Indeed, what was rightfully understood as different discourses at the policy level were not necessarily that different in the way they both problematized HIV positive subjectivity.

In both discourses the manner that HIV positive subjectivity was problematized appears to have cohered around the following themes: shifting subjectivity from dependency to self-regulation; liberating an oppressed subjectivity; and the appropriation of science and knowledge as a tool for imagining a new and reinvigorated subjectivity.

Furthermore, the purposes for which both discourses enlisted HIV positive subjectivity for governing seem to converge on the creation of a rational, dignified and free subjectivity. While this analysis is admittedly partial, it illustrates some of the potential benefits of reading post-liberation politics through governmentality and subject formation.

CHAPTER FOUR

Bearing the right to healthcare, autonomy and hope[15]

Abstract

In this article, I discuss the significance of understanding within the context of the campaign for affordable and accessible HIV/AIDS treatments in South Africa, the transformational effects of the interplay between political rationality and affect for HIV-positive subjectivities. The article focuses on the policy tactics, in 2001, of the lobbying for a policy to prevent mother-to-child-transmission of HIV. A close reading of the lobby groups' rationalization of healthcare as a fundamental human right reveals a strategic attempt to recast a sense of helplessness into self-responsibilization, which concurrently involved nourishing hope in the preferred future for women with HIV to be afforded the right to individual choice associated with self-determination. Therefore, the struggle for a policy to prevent mother-to-child-transmission of HIV - an exemplary initiative to reconstitute HIV-positive subjectivity - maneuvered within both rationalizing and emotive spaces. Ongoing engagement of the broader campaign's contribution to redefining being HIV-positive thus also necessitates accounting for the effects of the convergence of political rationality and emotion in its tactically emancipatory project.

Keywords: South Africa; Political Rationality; Affect; HIV/AIDS Treatments; Mother-to-Child-Transmission; HIV-Positive Subjectivity

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Introduction

Vituperative policy related debates over appropriate and effective forms of treating HIV/AIDS between the South African government and AIDS treatment lobby groups have been the most unfortunate and disconcerting feature of the fight against the pandemic in post-1994 South Africa. Certainly, as Nattrass (2008: 157) has observed of the impasse in South Africa, this historic and foundational moment was at once the "defining feature" and "greatest tragedy" of the early post-apartheid dispensation.

The complex contestations between the state and treatment lobby groups owed much to the legal wrangling and public disputes over the legitimacy of Western science and medicine in setting the terms for responding to the escalating HIV/AIDS crisis in the country (Bawa, 2005). These disputes mobilized legal and scientific discursive systems, with the state both responding to legal action and maintaining a position that was antithetical to a scientific and biomedical approach to HIV/AIDS (so-called AIDS denialism).

Indeed, the battle the lobby groups waged against both the state and pharmaceutical industry is notable for having marshalled a convincing legal, political, economic, moral and, most prominently, scientific argument that successfully mobilized support for affordable HIV/AIDS treatments and the right to access a state funded programme to treat HIV/AIDS in the public health sector (Schneider & Stein, 2001; Fassin, 2007; Geffen, 2010; Decoteau, 2014).

What is most important, undergirding the politics of South Africa's HIV/AIDS treatments advocacy campaign, was the formidable force of its tactic of substituting the idea of individuals constituted as separate entities with conflicting interests for rearticulating self-

interest within a shared legal, moral and biomedically informed prerogative. Considering this observation we might ask about the form of HIV-positive subjectivity promoted in the impetus for access to anti-HIV medicines in South Africa's public health facilities.

This is a question I engage with here through the "intensely emotional" and highly publicized events around the legal and "political battle" for access to PMTCT, in 2001, launched by South Africa's HIV/AIDS treatments advocacy groups against the ministry of health and the state (Cullinan, 2001, p.1).

Indeed, the confrontation most captured the attention of the country and the world on the ruling administration's problematic HIV/AIDS treatments policy (see Swarns, 2001). This battle, ultimately won by HIV/AIDS treatments lobby groups, laid the foundation for the decisive push and pressure on the state to provide a broad range of HIV/AIDS treatments in the public health sector, which was finally realized in 2002-2003 with the promulgation of an operational plan for the care, management and treatment of HIV and AIDS.

In this article, I offer an analysis of the tactics of this campaign that interrogates the effects of the conjunction of political rationality with emotion in advancing not only a reorientation of policy, but most importantly, a transformation of HIV-positive subjectivity or subjective individuation. In undertaking this analysis, I draw on previous literature, which reveals two lines of argumentation for understanding the struggle for access to HIV/AIDS treatments or PMTCT in South Africa.

The first argument positions the wider campaign within the much broader struggle for socio-economic rights in post-apartheid South Africa (see, for example, Budlender, 2001;

Heywood, 2003 2009; Cameron, 2005; Nattrass, 2007; Klaaren, 2014). In the second argument, the literature draws a linkage between the battle for access to either HIV/AIDS treatments or PMTCT in South Africa and the realization of individual human rights (see, for example, Robins, 2004; Heywood, 2009; Geffen, 2010; Mbali, 2013; McLaren, 2014; Klaaren, 2014).

This article complements these arguments in two ways that are interlinked. Firstly, I suggest that Foucault's perspective on governmental power or, more precisely, governmentality, offers a useful framework for delineating the links between political rationality and the corresponding ethical values of HIV-positive subjectivity implicated in the policy tactics for PMTCT.

Secondly, I also propose that in augmenting this perspective with Ahmed's work on the cultural politics of emotion, it is possible to offer a possible account for the intermingled catalytic effects of political rationality and affect in constructing pregnant women with HIV as capable of governing themselves and of acting in their own interests in solidarity with others.

Therefore, taking a few examples linked to the policy moves in 2001, the point is made that 'modes of subjection' work on both ethical values and emotions in aligning forms of self-recognition to normative or governmental principles (Foucault, 1992). To make good on this intervention, it is constructive to outline the conceptual framework and how it is utilized in the discussion.

Governmental Power and Emotional Life

Most generally, the term governmentality indicates the forms of 'governmental' and 'non-governmental' tactics, strategies, calculations, reflections and programmes brought to bear on the government of individual and collective conduct (Lemke, 2001).

Governing in this sense comprises both being governed by others and governing oneself - in the sense of "the ethical work that one performs on oneself…to transform oneself into the ethical subject of one's behaviour" (Foucault, 1992, p.27). In this way, the act of governing is therefore encompassed in the schemes and practices through which our conducts are enlisted by various types of authorities in the pursuit of social, political and economic objectives (Rose & Miller, 1992).

The point is that the government of individuals or populations for the purposes of achieving or sustaining their health, efficiency, productivity, security, general well-being and so on, preoccupies various 'authorities of truth' and a range of 'regimes of conduct' (Dean, 1996). Indeed, the benefit of this conceptualization of government is that it demonstrates, as Rose and Miller (1992, p.272-273) have argued, that in most cases the state retains "neither the unity nor the functionality ascribed to it", but instead "has assumed a particular place within the field of government."

Take, for instance, the way in which the enactment of HIV/AIDS programmes across much of the developing world have been constituted through a range of public-private collaborations, the relation between AIDS activists and scientific authorities, as well as a range of strategically positioned projects - from awareness raising and prevention interventions, through to empowerment and self-help initiatives (Biehl, 2007; Nguyen, 2009;

Mbali, 2013). Underlying these practical measures, initiatives and programmes is a social and political imperative centred on shaping beliefs, attitudes, behaviours and emotions in more health realizing and maintaining directions.

As a mode of critique, then, the perspective of governmentality allows for a conceptual engagement of all kinds of strategies, practices and systematically organized activities implicated in directing and mobilizing the subjectivities of autonomous individuals, based on clearly identifiable social, political, moral and scientific values, principles and knowledge claims (Foucault, 2008).

Central to the recruitment or application of the perspective of governmentality is to understand or uncover the political rationalities of governing associated with these strategies of guiding behaviours and affecting subjectivities. Dean (1999, p.11) defines a rationality as "any body of systemic thought about the nature of things." In effect, political rationalities of government are "encapsulated in discourses and knowledges that guide, advise and inform our ways of being" (Campbell, 2010, p.38) or in modes of thought and systems of political beliefs or values implicated in the production of subject positions. For instance, for classical liberalism, "the free, rational, individual is the very foundation of the state, that which grounds and limits legitimate government" (Dean, 2008, p.48).

Contemporary neoliberalism, by contrast, is associated with the distribution of the economic or market logic to all spheres of society (Murray-Li, 2014), and typically, the neoliberal subject is "a free subject who rationally deliberates about alternative courses of action and bears responsibility for the consequences of these choices" (Brown, 2005, p.44). The framework of governmentality thus enables an evaluation of these political rationalities or

systems of thought in terms of their political, social and psychological implications for political and social structures, as well as for individuals (Hilgers, 2012).

Yet in their analysis of the contribution of specific forms of political rationality in affecting subject positions, most studies deploying the framework of governmentality are inclined to delineate mostly the modes of political beliefs, thoughts or values underpinning the moral quality of individuals (Tie, 2004; Binkley, 2009). Consequently, the effects of discourse in generating the emotions that are central in the formation of subjectivities are for the most part underexplored, if not altogether neglected.

My wager here is that the discourses associated with specific forms of political rationality disseminate both the systems of thought or political values and emotions that anchor the way individuals come to understand themselves. To this end, Ahmed's work on the cultural politics of emotion is proposed for reading emotion in discourse - rather than as a distinct theory of the subject - to extend on Foucault's diagram of the interaction of government, power and the subject.

In the text *The Subject and Power*, Foucault (1982, p.220) emphasized two fundamental aspects of the constitutive role of power in producing subject positions. The first aspect is that, as "a total structure of actions brought to bear upon possible actions" (p.220), power renders specific forms of behaviours possible as it organizes the values underlying the actions considered appropriate.

Basically, then, power is intricately linked to governance. In relation to the second aspect, he gestures towards the contributory role of emotions in suggesting that power "incites, induces

and seduces other actions" (p.221). In this manner, as Burkitt (2005) has observed, power elicits the emotions that prompt actions.

Thus considered, the rationalities by which individuals are motivated into action and to assimilate subject positions are inseparable from the affiliated feelings, emotions and affects stirred. One of the ways that power embeds itself is through discourse, which encompasses the socio-political and moral principles constituting our beliefs and feelings of the world (Rose, 1996; D' Aoust, 2014). Therefore, alongside evaluating rationality, a critical engagement of discourse implies also taking account of the emotions that work in conjunction with, or in fact, are produced by it.

One of the features of emotions or affects that Ahmed (2004a, p.11) has highlighted is that they "are not a property…something that I or we have." Instead, as she has elaborated, "the objects of emotions circulate" and "as they move through the circulations such objects become sticky or saturated with affect, as sites of personal and social tension or contestation, as emotions are made" (p.11). This way, emotions are neither inside nor outside subjects, but emerge through relational processes, both actual and imaginary, between individuals in ways that generate feelings and "embody meaning and belonging" (Scheer, 2012, p.196).

To be clear, from this angle, emotions "are shaped by, and even take the shape of, contact with others…" (Ahmed, 2004a, p.12). Ahmed's work on the cultural politics of emotion contributes in this article the concept that emotions are created through relational experiences and interests, with the potential effect of aggregating collective bodies.

In short, the usefulness of Foucault's perspective of governmental power for the discussion in this article is that it offers a framework for analyzing the implications of the political strategies pursued through the campaign examined here for the discursive construction of the subjectivity of pregnant women with HIV.

At the same time, in proposing the integration of Ahmed's work on the cultural politics of emotion with the perspective of governmental power, the aim is to explore how emotion featured as a strategy for reinscribing the individual interests of pregnant women with HIV, with the potential effect of discursively articulating a transformation of their subjectivity, within the collective interest of securing access to PMTCT in state run health facilities.

Overall, in proposing the integration of Foucault's and Ahmed's work in offering an alternative but partial reading of the campaign for PMTCT, I argue that its organizing principle was both a means to secure lives and a strategy of government. However, before I do so, it is helpful to contextualize the events leading up to the campaign.

Preventing Vertical Transmission and the Struggle for Human Rights

South Africa's campaign for PMTCT or prevention of HIV vertical transmission was engendered by the biopolitical threat that HIV/AIDS poses to the country's efforts to build a prosperous and sustainable future (see, for example, DoH (2002), a report of the department of health's routine surveillance of HIV/AIDS, which recorded an increase of 25% in 2001 from less than 1% in 1990, among pregnant women attending public health clinics for antenatal care).

Briefly, the notion of biopolitics refers to endeavours "to rationalise the problems presented to governmental practice by the phenomena characteristic of a group of living human beings constituted as a population" (Foucault, 1997, p.g 73). More generally, as Rose (2001, pg.1) has noted, biopolitical initiatives involve a range of authorities "taking on the task of the management of life in the name of the well-being of the population as a vital order and each of its living subjects."

Comaroff (2008, p.198) has suggested that the escalation of the HIV/AIDS crisis in South Africa not only brought into stark relief "pathologized publics" - note the savage and brutal killing of the AIDS activist Gugu Dlamini, in December 1998, by some members of her community for declaring her HIV status publicly - but also threatened to overwhelm the new democratic dispensation.

Accordingly, much of the legal wrangling and disputes that preceded access to HIV/AIDS treatments in South Africa's public health sector - in this case, through the roll-out of PMTCT - was staked upon the health and well-being of the country's population and securing a constitutional, democratic and human rights order.

Prior to 2001, one of the enduring priorities identified by AIDS treatments lobby groups was the provision of AZT for PMTCT. (In the South African context, PMTCT is a package consisting of HIV testing, provision of antiretroviral medicine to pregnant mothers with HIV and formula milk). Therefore, even as early as 1994, the National AIDS Plan (NAP) had provisioned for steps to be taken to facilitate the introduction of AZT for PMTCT (NACOSA, 1994).

Yet, safely administering AZT for PMTCT was "still a matter of intense scientific debate" (see "Ministry reluctant to use anti-AIDS drug", The Star, 1994, p.5). Moreover, for many women in the developing world AZT was unaffordable and beyond reach. As a result, most research efforts was expended on improving on the path breaking results of AZT, first reported in 1994, by developing more safe, less complicated and inexpensive ARVs to also benefit mothers living with HIV in the developing world (for comprehensive discussions of the history and arguments for AZT see, for example, Kleinsmidt, 1998; McIntyre & Gray, 2002; Heywood, 2003).

It was also around this time that the Treatment Action Campaign or TAC was launched, which became the most prominent AIDS treatment lobby group in South Africa. (The other key group that worked very closely with the TAC during these years is the National Association of People Living with HIV/AIDS or NAPWA, which as the tussle for HIV/AIDS treatments intensified, parted ways with the TAC in support of the state).

Not until the election of the second democratic administration in 1999 did tension and conflict come to dominate AIDS policy in South Africa. Prior to these elections, there was mostly agreement between AIDS groups and the ministry of health or the state on provisioning for AZT for PMTCT, lobbying pharmaceutical companies "to unconditionally lower the price of all HIV/AIDS medications", and that "affordable treatment for HIV/AIDS and all medical conditions is a basic human right" (TAC, 1999, p.1). At this stage, for all the stakeholders involved, there was strong agreement that facilitating access to AZT is in accordance with affirming or enshrining South Africa's constitutional principles of the right to dignity, life and healthcare services.

Thus, once media reports circulated about a research study in Thailand, in 1998, which validated the efficacy of a single dose of the anti-HIV drug Nevirapine for preventing MTCT, the prospect of a free and state instituted preventative programme became a realistic prospect (Heywood, 2003; Mbali, 2013).

However, this development coincided with the disintegration of the consensus on provisioning for PMTCT between South African AIDS activists and the ministry of health or the state. At issue for the treatment lobbyists was the state's delaying of registration of Nevirapine with the Medicines Control Council or MCC (for a more nuanced discussion of the political and scientific debates surrounding the delay in the registration of Nevirapine with the MCC see, for example, Nattrass, 2008), and the subsequent limiting of the provision of the medicine to only 18 pilot sites within and across the nine provinces in South Africa, for reasons political or ideological rather than scientific or financial.

In this context, when articulated, the critique levelled against the policy of limiting access to a few sites in particular was that, "denial of treatment for HIV/AIDS affects women disproportionately because of social, political and economic inequality", and therefore "all women with HIV/AIDS have an equal right to treatment, care and support" (TAC, 2000, p.2).

Consequently, the TAC and other organizations - including, for example, Save Our Babies, an organization consisting primarily of pediatricians concerned with HIV/AIDS in relation to its impacts on children - launched an application with the Pretoria High Court (from here on, the High Court) in 2001 to compel the state to change its policy on Nevirapine.

Here onwards, the discussion focuses on the formation of policy through a critical examination of the interaction of political rationality and emotion in the context of this highly publicized court case and other events surrounding the battle.

More specifically, the article unpacks how this clash called upon a certain type of what Foucault (1992, p.26) has referred to as "ethical substance" or the way in which pregnant women with HIV should constitute themselves "as the prime material" of their own "moral conduct". In the context of this clash, what emerged as 'prime material' was the 'telos' or pursuit of a personal ethics of individual autonomy and choice, and simultaneously, the politicized emotional work of cultivating hope in the potential of PMTCT to restore self-determination.

Organizing Autonomy

In essence, the High Court litigation action challenged two aspects of the state's programme (for an outline of opposing arguments by the ministry of health see, for example, Heywood, 2003). The first aspect was the policy of denying PMTCT to pregnant women living with HIV who give birth in the public health sector, "where in the judgement of the attending medical practitioner this is medically indicated" (Founding Affidavit of the TAC, 2001, par. 20).

In the second place, the TAC wanted the court to clarify the obligation of the ministry of health within the law to "set out clear timeframes for a national programme to prevent mother-to-child transmission" (par. 21), in effect challenging the policy's deferment of a decision on rolling-out PMTCT once the two years of the pilot research had been completed. However, as the snippets cited below demonstrate, it was the absence of individual choice,

and the sense of hopefulness intermingled with it, that was most closely associated with the lack of access to PMTCT.

Optimizing Individual Choice

In one of the pamphlets distributed nationwide to galvanize support for the litigation action, the TAC declared, "The Constitution says that the government has a duty to respect and preserve human life. It also says that all women have a right to make choices about bearing children" (TAC, 2001, p.1). One of the most significant aspects about the declaration is in articulating the goals of the campaign within the South African Constitution.

However, the declaration did more than to identify what is codified in law. In effect, it was also productive in the sense of engaging in a kind of imagining of the obligation of the state to life and the responsibilities of the women to themselves and their babies or children. After all, the South African Constitution is postulated on an achievable and aspirational future, which nonetheless requires action in the contemporaneous to fulfil the obligations, rights and responsibilities prescribed in it (see Budlender, 2001; Heywood, 2009; McLaren, 2014).

These obligations, rights and forms of responsibility, identify aspects to be worked on or prospects to be realized. My aim here is to pick up on the declaration's point on affording women the right to make choices in relation to their bodies and bearing children.

The advancement of individual choice in the campaign for access to PMTCT suggests a new way of organizing the way pregnant women with HIV relate, evaluate and act on themselves. In neoliberal terms, individual choice as a marker of subjectivity links up with the idea of an ideal society as constituted by rational and calculating individuals (Lemke, 2002; Foucault,

2008). In this sense, from a neoliberal perspective choice enables individuals to think of themselves as consumers of commodities, ideas and services, including public services (Read, 2009).

However, from another perspective, it is also interesting that even as most of their advocacy initiatives involved collective action, individual choice was both a key tactic of the TAC and its allies' mobilization and a central argument in their rationalization of access to PMTCT. For example, in their founding affidavit, they had suggested that they were acting "on behalf of pregnant women with HIV/AIDS and women of reproductive age, who are being or will be treated in the public health sector", as the women are not in a position to "act in their own name because of poverty, stigma, discrimination or a lack of knowledge of their HIV status or of the risk to their infants to be born, or of what can be done to reduce this risk" (Founding Affidavit of TAC, 2001, par. 30.2).

Thus, by characterizing itself as a representative of pregnant women with HIV who lack reproductive rights and control over reducing the risk of vertical transmission of HIV to their babies, the TAC and its partners sought to optimize their "individual scope for self-determination and desired autonomy" (Lemke, 2001, p.202).

In this case, access to PMTCT for pregnant women with HIV - along with optimizing their prospects for individual choice - would mean improving their sense of control in shaping their relation to HIV in all facets of their everyday life, including reducing the chances of vertical HIV transmission to their babies. The founding affidavit also alluded to personal risk reduction or management, which is another key ethical or moral quality of subjectivity linked with neoliberal or market rationality (Ericson, Barry & Doyle, 2000). In this way, then, a

pregnant mother with HIV with access to PMTCT will not only be free to choose among the best alternatives, but she will also be in control or responsible for reducing the risks of HIV transmission to her baby and to her health.

Altogether, the potential of access to PMTCT was viewed as a catalyst for building a bridge from "stigma, discrimination or a lack of knowledge" and marginalization (par.30.2) to inclusion or participation, but it also meant the prospect of substituting a sense of helplessness for individual choice, risk control and responsibility.

This, then, is the line of thought that underpinned the campaign for PMTCT - that an unconditional right to healthcare would entail the potential to make it possible for stigmatized, discriminated and marginalized pregnant women with HIV to gain the freedom to make choices in relation to their health and that of their babies that other South Africans are afforded in the constitution.

My point here is that for the TAC, its partners and pregnant women with HIV, access to PMTCT in the public health sector suggested the possibility to enable ever more options for individual self-management and governance. As Dean (1999) has conjectured, this articulation of subjectivity fits squarely within the neoliberal calculus that the moral quality of individuals is contingent on their ability to weigh the costs and benefits of choosing between various alternative actions and assume personal responsibility for their choices and actions.

Stressing the inflection of neoliberal thinking in this vision provides a perspective as to how this system of thought was tactically appropriated to bolster both the effectiveness of the

policy moves of the HIV/AIDS treatments lobbyists and maximize the potential to mobilize a new or transformed HIV-positive subjectivity.

However, this raises the question of how the pregnant mother with HIV stood in as a receptacle of the lobbying's prioritization of individual choice as an important element of reconstituting HIV-positive subjectivity.

I want to suggest that the foregrounding of the argument for individual choice by the TAC and its allies was correspondingly linked to a politics of hope (among the many emotions or affects at work during the campaign) mobilized by the potential of PMTCT to afford pregnant mothers with HIV control over their health and in protecting their babies from HIV infection. In this manner, the materialization of the collective suffering body of the pregnant mother with HIV unable to prevent HIV transmission was instrumental in stimulating the desire for hopefulness.

This, I argue, encouraged receptiveness to the idea that self-governance is an ideal personal and ethical quality of HIV-positive subjectivity.

Politics of Hope

It is significant that, even before 2001, the TAC working in partnership with Medicins Sans Frontieres or MSF (Doctors without Borders) and the Western Cape Province had already commenced with an independently funded PMTCT trial in the Western Cape's township of Khayelitsha. In the context of the litigation, the success it had achieved served to demonstrate that a clear framework existed for rolling-out PMTCT in the public health sector nationwide (Robins, 2009; Mbali, 2014). At inception, in 1999, the initiative's treatment package

consisted of administering AZT to pregnant mothers with HIV and provision of substitute baby milk. When Nevirapine entered the fray, it replaced AZT (see, for example, Meerkotter, Bullington, Young, Swawr & Heyes, 2001 and Geffen, 2010 for more details of the initiative).

Indeed, providing his assessment of the treatment trial in the Western Cape, the Minister of Health in the province had argued that the partnership with the TAC and MSF "…in the Mother-to-child transmission programme in Khayelitsha" had offered pregnant women with HIV "hope beyond HIV-positivity", and the result was that "HIV-positive women are better able to face the challenges of living with HIV disease and AIDS" (Western Cape Minister of Health, 2001, p.9). His hope was that, "if the role of MSF in the Khayelitsha project is successful and shown to be feasible, it could become a model for South Africa" (p.9).

With temperatures already at boiling point between the parties to the litigation, which kicked off at the end of November in 2001, it is important to understand that the Western Cape health minister's remarks were intended to lend an authoritative voice to the legal case to compel the ministry of health and the state to extend the PMTCT programme beyond the pilot sites accommodated by the policy.

In developing the argument from the previous sub-section further here, I am guided by two observations about the links between this initiative in the Western Cape and the broader campaign for access to PMTCT. The first postulates that the new and transformed subjectivities exemplified by this initiative legitimated the argument made in the broader campaign that access to PMTCT enables pregnant women with HIV to make the kind of choices that will be in both their interest as well as their babies. In effect, the argument was

that allowance of access to PMTCT in the public health sector will ultimately empower pregnant women with HIV to take responsibility for themselves and their babies.

The second observation is that there was an intimate association between this way of rationalizing the campaign for access to PMTCT and the initiative's actual demonstration of the hope that PMTCT affords pregnant women with HIV to make choices that will assist them to take responsibility and control of their lives and prevent HIV vertical transmission.

In pursuance of the first observation, one of the aspects to be noted about the Western Cape initiative is that here, as Cruikshank (1999) has argued from an alternative vantage point, power had as much to do with a relation of guidance by another or others through the treatment trial and its educational value as it was a real and desirable or fostered relation of self-constitution.

Meerkotter *et al.* (2001) and Cameron (2005) have noted that, in addition to testing or demonstrating the feasibility of PMTCT, the Western Cape initiative was successful in empowering participants or beneficiaries with a set of techniques and skills to assist them to manage their HIV condition in their everyday life - including equipping them with the knowledge of the science of antiretrovirals and methods of self-managing adherence to them. This, invariably, involved imparting to the beneficiaries the requisite techniques and capabilities that include understanding, feeling and, in Foucauldian terms, 'elaborating' the ethics of self-constitution differently in relation to the choices and control that access to antiretrovirals affords.

Thus, this initiative, and the power relations it encompassed, epitomized "the way in which the conduct of individuals or of groups might be directed" towards productive ends (Foucault, 1982, p.221). However, this leads to the second observation or problem of how to situate hope as affect or emotion within this discourse of individual choice and self-responsibility.

In Ahmed's perspective (2004b, p.119), one of the ways of reading emotion in discourse is to understand that "emotions do things", particularly in relation to mediating "the relationship between the psychic and the social." The example of the Western Cape initiative, along with the other activities to secure access to PMTCT, represented a symbolic space occupied by pregnant mothers with HIV tied to each other by an agonizing physical predicament and disaffection arising from a policy that limited access to treatment that will enable them the choice to assume responsibility and control for their own health and in reducing the risk of MTCT.

Much like the treatment testimonies of grassroots South African AIDS activists that Robins (2009) has documented elsewhere, the affidavits that were presented during the High Court proceedings helped to materialize this shared actual and potential dilemma for women living with HIV. As one of the deponents indicated, the most distressing and "painful" aspect of the lack of access to PMTCT was not only not knowing "whether my baby maybe HIV positive", but that it also entailed that women "like me" or "other women with HIV" do not "have the right to take steps to try to protect our children" from contracting HIV (Supporting Affidavit of SH, 2001, par. 16-17).

Yet, in addition to being materialized by their predicament, more importantly, the women were held together and surfaced by the hope of gaining control through PMTCT of the

hazards of HIV vertical transmission. In this case, the group or sub-population of pregnant women with HIV that the TAC and its allies represented was constituted by actual and prospective sufferers of a shared predicament who were hopeful that through access to PMTCT the choice to prevent these risks is possible.

Thus, the potential of accessing the anti-HIV drug had signaled to pregnant mothers with HIV the hope of improving or, at the very least, achieving a certain level of self-regulation of their health condition and health risks to their babies. Echoing Ahmed's (2004a, p.12) formulation that "what moves us, what makes us feel is also that which holds us in place, or gives us a dwelling place", I am suggesting that the connection of pregnant women with HIV to one another was partially consequential from the hope invested in the efficacy of PMTCT to enable personal responsibility in preventing HIV vertical transmission.

In the High Court, for instance, one of the beneficiaries of the Western Cape trial had testified that though she had "volunteered to be tested for HIV" when she was pregnant, and had been counseled, "it was very difficult to cope" (Supporting Affidavit of Bongiwe Mkhutyukelwa, 2001, par. 4). She continued: "It was like going mad because I had to think about my health generally and about this HIV and I also had to think about the health of the child I was carrying" (par. 5-6). In an expression of her conviction that PMTCT is effective, she impressed upon the High Court that "antiretrovirals can be a solution because they showed a difference to me while I was pregnant" (par.7). Thus, in her closing remarks, she stressed that "mother-to-child transmission prevention programs are very effective and can restore hope", and underscored that she had "proved it" to herself (par.8).

In the general context of the campaign for access to PMTCT, hope and individual choice were therefore coextensive within a space marked by a desire for some degree of control in shaping the conditions and terms of life.

Certainly, this desire was not merely wishful thinking or fantasy, but a legitimately incandescent and realistic hope that the success of the Western Cape initiative had established or 'proved'. Of course, as Ahmed (2004a) has pointed out of how emotions circulate, it cannot be assumed that it was a desire that necessarily held sway for every pregnant woman with HIV or anyone else in the same way.

Still, hope in the preferred future for women with HIV to be afforded the right to individual choice associated with self-determination arguably had a substantial framing and impelling effect on the policy tactics of the campaign for access to PMTCT. The TAC collected and submitted as evidence many such supporting affidavits from mothers with HIV.

Geffen (2010) has noted that the point of the submission of the affidavits was both to strengthen the challenge against the state's policy on PMTCT and to provide women with HIV an opportunity to air their views and desires in relation to living with HIV. The High Court upheld the challenge brought by the TAC and its allies, and ruled, most significantly, that the state should immediately take steps to "effectively and comprehensively roll-out a national programme for Nevirapine" (Constitutional Court, 2002, p.3). The state subsequently filed an appeal against the ruling with the Constitutional Court the following year, and it was rejected with costs.

South Africa's AIDS treatment lobby's initiatives for PMTCT exemplify the construction of a form of biological or biomedical citizenship, the desired outcome of which is a rational, calculating and responsibilized health subject (see, for example, Robins, 2004, 2009; Decoteau, 2014).

In its deployment in the South African context, as elsewhere in the emerging and developing world (see Biehl, 2007; Nguyen, 2009), biological or biomedical citizenship captures elements of the forms of citizenship that have been galvanized in response to the HIV/AIDS crisis. Among others, these consist of an array of endeavors to capacitate PLHIV with the scientific and biomedical knowledge of HIV/AIDS, including also the multiple activities around participation by PLHIV in treatment trials, in lobbying for HIV/AIDS treatments, and the communities or groups that have mobilized on the basis of shared experiences, predicaments and hopes for HIV/AIDS (see Robins, 2004; Mfecane, 2011; Decoteau, 2014).

Perhaps even more fundamentally, the South African campaign for access to PMTCT embodied what Rabinow and Rose (2006) have referred to as 'emerging biopolitics', whereby mobilisation by citizens - for example, social, environmental or medical activism - increasingly influences an array of social, political and medical practices.

My argument here is that the deeply intersecting confluence of the discourse of the right to individual choice with a politics of hope was instrumental in rallying support for the campaign to the right to access PMTCT, and in concomitantly articulating the 'ethical substance' and 'telos' of transforming HIV-positive subjectivity.

Put another way, my proposition is that it was within this rationalized and yet emotionally intense moment in the struggle for HIV/AIDS treatments in South Africa that an emergent rights bearing and neoliberal self-governing HIV-positive subject was most clearly articulated, and more importantly, crystallized, fostered and bequeathed.

Concluding remarks

In some ways, the analysis developed in this article contradicts most critiques of neoliberal rationality (see, for example, Brown, 2005; Dean, 2008), which tend to associate it with the withdrawal and privatization of state or public services, market fundamentalism and the increased burden on individuals that is attendant with individual choice and self-responsibility. After all, when health is recast as a matter of individual choice or 'positive' emotion, the risk is that the socio-political and economic circumstances that either hinder or facilitate its achievement could become irrelevant in the long run (see Comaroff, 2008; Decoteau, 2014).

Yet, the case for access to PMTCT demonstrates a different application or appropriation of neoliberal rationality. More than anything else, the claims that animated the struggle offer the clearest example of a strategic deployment or appropriation of neoliberal rationality and discourse for liberatory or emancipatory purposes (Ferguson, 2011). As others have noted (see Ferguson, 2009; Hilgers, 2012; Murray-Li, 2014), perhaps this attests to the degree that neoliberal or market rationality has 'naturalized' and permeated most political, social and economic spheres in most societies around the world, not least in South Africa.

However, the South African battle for PMTCT demonstrates the productive potential of certain forms of power relations - implicated or encapsulated in the rationalities of governing

– to incite, induce and ignite interest for the realization of democratic principles of freedoms, fundamental rights and self-determination (Appadurai, 2001).

Moreover, the struggle for PMTCT was also staked upon the concomitant emotion of hope, in the sense of enabling a grasping towards a more hopeful future for the pregnant mother with HIV to attain reproductive self-direction - a prospect nourished by the possibility of bodily restoration that ARVs such as AZT and Nevirapine portend. The article has therefore attempted to argue that the rationalities of conduct underlying power relations tend to have their greatest effect when intermingled with emotion.

The analysis or discussion offered in this article only partially captures the events centred on access to HIV/AIDS treatments, before and also during 2001. However, the case of the battle for PMTCT illustrates the potentially empowering effects of strategically deploying a combination of logics of conduct and emotion towards emancipatory ends.

Thus, ongoing engagement with the campaign's input in recasting HIV-positive subjecthood involves not only understanding the consequences of its tactics in winning over or reforming minds, but in equally understanding its affective effects in invigorating HIV-positive subjectivities.

The strategies of the treatment lobby have doubtless had a significant impact on what PLHIV believe and feel about being HIV-positive. This is especially the case considering that public health interest litigation and advocacy conducted mostly on scientific and moral terms - including tactically appropriating or appealing to certain forms of political rationality and emotion for emancipatory ends - increasingly command enormous respect and deference in

most democratic societies. It is in this sense that we can begin to read anew the impact of the South African campaign for HIV/AIDS treatments, and also to understand its likely effect in transforming HIV-positive subjectivity.

CHAPTER FIVE

HIV advice in the media: Implications for reinventing subjectivity[16]

Abstract

Working within a Foucauldian approach to governmentality and the ethics of self-care, this article analyzes the implications of the values upheld for caring and governing oneself in the HIV advice column of Criselda Sambeso Dudumashe, publicly HIV-positive herself. The analysis reveals that the central thrust of the advice advances the principle of investing in oneself and taking responsibility for one's physical and psychological health. Careful self-evaluation for self-improvement, however, means expending time and energy monitoring viral load, CD4 count and physical health. Likewise, monitoring one's adherence to HIV therapy requires careful evaluation of one's psychological state, including personal anxieties and fears, as well as the willingness to pursue qualified assistance from experts. Such self-government, it is argued, conjures up a subjective formation whose own discretion on how to gain control of HIV is oriented toward engaging with the best scientific practices and expert advice for its consolidation. In view of the emerging role played by similar platforms on and off line, an exploration of how the self is set in relation to itself, and how self-improvement is governed, offers insight into the contours of subjectivity in the post-AIDS era of treatment possibility.

Keywords: HIV advice, self-regulation, Foucault, ethics, governmentality, viral load, CD4 count, HIV therapy

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Introduction

In her introductory advice column, in May 2014, for South Africa's long-standing, popular and widely distributed weekly *Drum* magazine, appropriately entitled *Beyond Positive*, Criselda Sambeso Dudumashe (née Kananda) provided an account of her own personal journey with HIV.

She mainly addressed her grim experience with disclosing her HIV seropositivity for the first time, during a period in South Africa when not many people were educated about HIV/AIDS. Prior to the relocation of her column to *Drum*, her HIV advice column appeared in *Bona* (a SeSotho, IsiXhosa and IsiZulu word meaning "to recognize"), a popular monthly magazine that caters mostly but not exclusively to young and middle aged black women's consumer and lifestyle related issues.

In addition to her advice column, website and facebook page, Criselda also hosts a weekly radio talk show programme. As described on the radio show's website, she uses the platform to deliver a message of "hope by educating simple ways of living a Positive Life with HIV by encouraging individuals to focus on personal revolution" (see Metrofm.co.za, 2015). Having declared her HIV-positive status publicly, she is today a paragon figure in the HIV community, arguably the most easily recognizable South African living openly with HIV.

For Criselda, the process of disclosure of HIV status takes on many forms, which are not always predictable. Acknowledging that disclosure of HIV-positive status can result in negative consequences, she expressed the view that the decision to disclose is a personal right that South Africa's constitution protects in its bill of rights. For her, "disclosure is a very personal and individual decision", one that takes into account "all relevant personal

circumstances" (Drum, 8 May 2014, p. 42). Therefore, the decision to disclose is a deeply personal one; "it's not a decision you make to please others or because Criselda did it … do it because you acknowledge that it's the right thing to do - for you" (ibid: 42). In the rest of her account, Criselda continued to present an approach for working out disclosure under different circumstances, conditions, and to different people.

In the advice she offers in her introductory column in *Drum*, as with her advice previously in *Bona*, investing in one's HIV health is framed as involving the "right" personal attributes, attitudes and conducts. Of course, for Criselda, the answer to the question of what makes possible the development of the right traits and practices in relation to managing HIV is that it depends on the willingness to capacitate oneself with the information and skills required to make the choices that are in one's health and rational self-interest.

Thus, if this introductory example is any guide, it is that the capacity to act independently, with all the work that this implies, is understood to be of normative and immense significance in managing life with HIV.

At the most general level, in thinking about a way of characterizing the terrain within which Criselda or other advice columnists operate in the various traditional and contemporary social media forums, Foucault's notion of "new pastoral power" offers a useful analytic construct. From this viewpoint, advice oriented magazine columns, internet blogs and televised broadcast programmes function within a general economy of "salvation", except that here salvation designates expertise led guidance that no longer revolves around "leading people to their salvation in the next world but rather ensuring it in this world" (Foucault, 1982, p. 221).

Therefore, in its secularized deployment, the new pastoral power and its related "redemptive" character denotes an arena of confessional and increasingly "popular" therapeutic avenues for seeking and providing help or advice, spanning a range of areas of social functioning and disciplinary fields (see Wilbraham, 1996; Asera, Bagarukayo, Shuey & Barton, 1997; Rimke, 2000; Binkley, 2009; Beatty & Lambert, 2013; Mazanderani, 2012; Mazanderani, O'Neill & Powell, 2013).

In their incarnation in popular print, broadcast and social media, "practitioners" of the new pastoral power, particularly in the mold of the self-help genre - whether they be health advice columnists, psychologists, social workers or financial advisors - are linked with knowledge, professional skill and/or life experience driven expertise geared to assisting help-seekers to live physically, mentally, socially and financially healthy and enriched lives (see Fridman, 2014). That is, whether it is HIV, health or relationship advice, counsel on the subject of thrift or managing one's personal finances, there is no shortage of tutelary forms of expertise or life's coaches in the "globalized" public or social sphere to offer pedagogic and corrective guidance.

Indeed, in the work of the new pastoral expertise more generally we can gather the prevailing value systems, rationalities, conventions and "rules of the game" under which we are expected to function within the various dimensions that make up our everyday life, not least in relation to dealing with our own health.

As experience with the spread of the HIV/AIDS epidemic in sub-Saharan Africa in the late 1980s, throughout the 1990s and into the early 2000s has shown, people living with HIV (PLHIV) were the most vocal advocates for solutions for HIV/AIDS based on existing

scientific knowledge and biotechnologies, particularly those PLHIV who had participated in the early workshops on the science of the disease organized by aid agencies, global and national non-profit AIDS organizations (see Nguyen, 2005; Robins, 2004, 2005).

Within this context, a type of citizenship revolving around HIV took shape - what in the literature has been variously termed biological, biomedical or therapeutic citizenship. The notion captures the various efforts associated with capacitating PLHIV with specialized forms of scientific and biomedical knowledge to assist them to manage life with HIV, including the establishing of forums primarily serving to facilitate the sharing of resources, knowledge and personal experiences with HIV (see Rabinow & Rose, 2006; Rose, 2007; Mfecane, 2011; Decoteau, 2014). Through dialogue, research, advice, technical assistance, and training, these initiatives have helped create a community of practice, with global, national and local reach.

It might be argued that an HIV advice column represents an exemplary popular form of expertise, enmeshed within the various levels of an HIV/AIDS community of practice, deriving its authority, in Criselda's case, from the columnist's own personal and intimate experience with HIV. In a sense, the advice columnist personifies the scientific knowledge and life experience upon which a widespread and affect-infused hope of salvation and managing life with HIV is projected.

Moreover, we see the HIV advice column as a space for negotiating ways of understanding, relating and acting on self-identity on the basis of living with HIV. Criselda's HIV advice column is one of a kind in South Africa; she is a highly recognizable figure whose column has high readership numbers. The column potentially offers a prism through which the

workings of governing oneself can be explored. This article thus marks an attempt to analyze the case of Criselda's HIV advice column with *Bona* magazine as a popular self-help practice founded on the promise of offering its subjects direction for enabling self-understanding and self-improvement in relation to dealing with HIV.

We first inquire into the values or norms propagated for living with HIV in Criselda's HIV advice column, especially in connection with concerns about HIV biomarkers such as stabilizing the viral load and CD4 count, as well as initiating and adhering to ARVs.

With the shift to the so-called 'post-AIDS era' (Dowsett & McInnes, 1996) - an allusion to HIV becoming a chronic condition thanks to the availability of ARVs and the development of more effective diagnostic tools for monitoring HIV, such as the viral load test - the topic of HIV biomarkers and their relation to a person's everyday experience with HIV has proven to be of considerable academic interest (see Persson, 2004; Persson & Newman, 2006; Sangaramoorthy, 2012; Newman et al, 2015; van Loggerenberg et al, 2015).

This article seeks to build on this research by interrogating the popular technology of an advice column as a platform for self-help and undertaking health. Our second aim, not unrelated to our first, is to illustrate how target subjects are encouraged to understand and act on themselves. More specifically, we explore the form and nature of the self-regulation the advice column advances for readers who hope to attain the ideal of improving well-being.

With both these aims, our main interest is to understand the manner that the advice column acts as a productive and transformative technology in relation to constituting one's

subjectivity and accomplishing health or avoiding illness. But first, to make good on this intervention, it is constructive to outline the conceptual framework underpinning the analysis.

Inscribing and governing subjectivity

The article draws upon Foucault's approach to analyzing the ethics of self-care, combined with the perspective of governmentality. To a large degree, Foucault's work on the ethics of self-care in Greek and Greco-Roman antiquity during the latter part of his life extended and complemented his previous research on the connections between governmentality and subjectivity.

In fact, as Dilts (2011, p. 131) has sympathetically observed, this undertaking could be viewed to reflect Foucault's "subtle but radical response to the rise of neoliberal subjectivity" in the late twentieth century in the developed countries of the West, but also globally. For Veyne (1993, p. 2), Foucault's recourse to ancient ethics of self-care helps him to account for the resurgence, although under a different conception of morality in the current neoliberal era, of the "…self working on the self, an aestheticization of the subject…"

Foucault (1992), but also others (see Dean, 1996; Rose, 1999; Campbell, 2010) who have drawn upon his approach, delineated four elements to representing and analyzing the implications of ethical edicts for self-care and self-governance: the "*ethical substance*" or aspect of the self recognized or determined for ethical scrutiny and cultivation; the "*mode of subjection*" or the way a particular aspect of the self is positioned for constitution or change in relation to a prescribed or recommended ethical or moral directive; an outline of the "*ethical work*" that the self is to perform on itself to accomplish transformation into an ethical subject in view of an avowed ethical directive or dictum; and, lastly, "*the telos of the ethical*

subject" or the "*mode of being*" that the self is determined to accomplish in following the propagated moral and ethical directive or imperative.

Indeed, the approach Foucault (1992, p. 28) adopted in his analysis presumed that "there is no specific moral action that does not refer to a unified moral conduct; no moral conduct that does not call for the forming of oneself as an ethical subject; and no forming of the ethical subject without 'modes of subjectivation' and an 'ascetics' or 'practices of the self' that support them". Monitoring and constituting one's self, then, is always a moral and ethical endeavour. In turn, morality and ethics are always located in technologies of power. This shift in his approach allowed Foucault to consolidate both his interest in technologies of power and technologies of the self.

Foucault's pivot to ethics, or the self's relation to itself, is directly connected to his work on governmentality, what he described as the "contact point" between technologies of power and technologies of the self. For him (cited in Davidson, 2005, p. 127), "relations to oneself" organize around "the government of the self by the self", especially "in its articulation with relations to others … as one finds it in pedagogy, advice for conduct, spiritual direction, the prescription of models of life …"

Therefore, the question of the self's relation to itself corresponds to how the self should govern itself: this is what Foucault implies by the term "governmentality". Most generally, governmentality refers to the various "governmental" and "non-governmental" modes of governing rationalities, tactics, strategies, calculations, reflections, practices and programmes bearing on the government of conduct, including government of the self by the self (see Dean, 1996; Lemke, 2001, 2002; Collier, 2009).

The implication of the theory of governmentality, then, is that we are not governed by external factors. Instead, we are enjoined to govern ourselves through a complex and discursively loaded web of practices and programmes. An advice column may be one point where the subtle workings of governmentality can be more easily seen.

Governmentality is the "conduct of conduct", or more specifically, a power relationship entailed in "acting upon an acting subject or acting subjects by virtue of their acting or being capable of action" (Foucault, 1982, p. 220-221). Materialized through a constellation of often related programmes, initiatives, campaigns and strategies, the notion captures in one sense all the work undertaken by an array of authorities, experts and individuals to steer relations of humans with their selves and with each other in order to achieve particular ends, including maintaining the health of populations and of oneself (Lemke, 2015).

In another sense, governmentality reflects the ways of thinking and moralizing underlying the setting and demarcation of duties, obligations, sentiments and habits accompanying the governing of relations both with oneself and others.

For instance, drawing on lessons from the epidemic in the West, across sub-Saharan Africa HIV/AIDS prevention and treatment programs have revolved around reifying and calling forth the calculating, self-regulating and self-interested subject of neoliberal governmentality, in tandem with the framing of the epidemic within discourses of community mobilization, socio-economic development and social justice (see Robins, 2004, 2005; Comaroff, 2007; Nguyen, Yapo Ako, Niamba, Sylla & Tiendrébéogo, 2007). Within this call, anchored as it is

around western notions of self-help, HIV-positive individuals are enlisted to work on themselves accordingly by undertaking measures to improve or gain control over their health.

This emerging turn in HIV/AIDS programmes worldwide, even with the variations across different countries, calls upon individuals to govern themselves. The enterprising PLHA becomes one who undertakes self-improvement in order to maximize personal gain. This strategy is reminiscent of Foucault's (2008, p. 242) concept of a "generalization of the enterprise form", in which the neoliberal emphasis on profit and loss - of economic enterprise - is generalized to the ways in which individuals should calculate and maintain their own personal value, psychological life and, in this case, physical health.

Therefore, as with market initiatives of prompting or spurring consumer buying behaviour in the marketplace, health promotion campaigns in the current and global neoliberal milieu focus increasingly on cultivating self-management capabilities as a strategy for securing the health of individuals and the general populace (Ayo, 2012).

By stressing the imbrication of personal conducts or habits and public health initiatives, the current trajectory of health promotion fosters the shaping of individual agency through the various mechanisms by which human biological-cum-social life is rendered governable (Rose, 2007). This trend, especially as it applies to HIV/AIDS prevention campaigns or the rolling out of ARVs to PLHIV, has been noted in South Africa and around the world (Biehl, 2007; Finn & Sarangi, 2008; Mindry, 2008; de la Dehesa & Mukherjea, 2012; Hickel, 2012).

Ethics, understood through a Foucauldian lens as the relation of the self to itself possessed of the capability for moral agency, are therefore embedded in the relations of power through

which we are either made governable or self-governable. Our subjectivity is shaped by governmental initiatives, at least partly because these initiatives promote self-governance and self-regulation (see Hunter, 1996; Davidson, 2005).

Subjectivity and ethics are embedded in the relations of power through which we are either made governable or self-governable. Subjectivity is thus consequential and critical to achieving the interspersing ethical and governmental aims linked to the countless social, cultural, political and economic strategies of governing societies undertaken by a range of institutions and agents. Personal empowerment or self-governance are equally the channel for constructing subjectivity and its most desired outcome (Cruikshank, 1999).

Indeed, as Cousins (2015, pg. 150) has noted of HIV/AIDS initiatives in the post-apartheid period, "the relation between the parts and the well-being of the whole" constitute the objects of concern of the various activities undertaken by different public and private authorities to control, mitigate and manage the epidemic's consequences. As will be shown in this paper, the type of self-formation Criselda's HIV advice column upholds for health undertaking practices draws upon many elements we link with the trope of neoliberal subjectivity in its characteristic valorization of the credo of individualism.

Method

Sampling decisions

Of the many popular advice columnists and experts found in South Africa's print, broadcast and online media, offering psychological, relationship, financial and general health advice, Criselda stands out for her first-person experience with the subject of her advice platform. In

fact, most people know her more for her bravery in living openly with HIV than for her professional training as a nurse.

She is one of the most well-known "agony aunts" in terms of her public profile and has many achievements, including numerous awards in recognition of her advocacy work to destigmatize HIV, her own radio programme on HIV/AIDS on a prime time slot broadcast to Metro fm's listenership of over six million people who tune in each week (News24, 2015), and her regular guest appearances on various South African radio and television talk shows to reflect on her experience of overcoming her diagnosis with HIV.

With the growing spread and adoption of social media at the macro and micro levels of everyday life, she is set to develop her "brand" online, whether by accruing friends on Facebook or by participating in public debates on various issues via Twitter. A quick glimpse into her online footprint, for example, shows a steady upward trend, with approximately 19 000 and 95 000 followers on Facebook and Twitter, respectively.

Aside from her influential public profile or persona, three key reasons have therefore motivated us to embark on the analysis of Criselda's HIV advice column. First, at the time the magazine issues were collected for the research we report in this article, it was the only advice column platform in South Africa to offer guidance specifically on HIV/AIDS related issues. Other platforms - for example, "health24.co.za", "Sis Dolly" in *Drum*, "3 Talk" (2002-2015) and "Hello Doctor" on SABC 3 - mainly provide general health, relationship and dating advice, and they do not focus exclusively on HIV/AIDS. Criselda's advice column is organized around representing the predicaments faced, directly or indirectly, by those who are willing to speak out about their experience with HIV and solicit the guidance of expertise.

Second, even though her readership in *Bona* consists largely of black women, we felt the need to place it within a developing trend both here and globally of resorting to multimedia self-help forums for self-inspection, self-correction and self-empowerment. (The magazine is largely purchased by middle class Black women, but it is likely that it is passed on and read by those who cannot afford to buy it and by men).

Because the column is written by a black woman and largely for black women, it is addressed not to a Western subject but to an African subject. The broader trend of multimedia self-help is very strongly situated in Western neoliberal values, and so the analysis of this advice column offers the possibility of analysing self-help directed specifically to an African subject. Because of Criselda's similarities to her readers, her HIV advice column probably has a special appeal for this audience owing to its own columnist's widely celebrated courage to stare into the vertiginous face of HIV at a time when it was viewed as fatal and much stigmatized.

Third, the choice to use this advice column is motivated by its potential to throw up the more general and contemporary workings of the relation between knowledge, expertise and subjectivity. Advice columns are explicitly simultaneously positioned as popular media, as expert opinion and as insider perspective. They are both intimately personal and resoundingly public. For Foucault (1992), these "textual forms", often pedagogical in style and expert-driven, also enjoin people to evaluate their self-conceptions and behaviours in order to identify aspects requiring improvement or modification.

Analysis of an HIV advice column offers the possibility of examining both how and to what ends PLHIV are called upon to remake themselves with respect to shaping the course of their health or illness. An advice column therefore offers an avenue for assessing both the values and justifications for current modes of constituting and transforming how PLHIV subjectively relate to their condition.

Criselda's HIV advice column spanned a period of almost five years with *Bona*, from May 2009 to April 2014, when she moved to *Drum*. Collecting advice inserts across this time-span therefore allowed us to gain significant insights into the general thrust of how the self should relate to itself. All 166 advice inserts, published across 71 issues, were sourced, and both questions and answers were included. The sample was further narrowed down in line with the central focus of the broader research project (of which this paper is a part) to focus on letters specifically addressing the issue of living on ARVs.

All letters were reviewed and included in the sample if they made direct reference to ARVs. Because of the strong association between ARVs and viral load and CD4 count, letters were also included in the sample if they made reference to either of these terms. The final sample therefore consisted of 55 advice inserts.

Approach to analysis

Analysis followed two stages. We began by following Braun and Clarke's (2006) method of thematic analysis in order to generate initial themes. Braun and Clarke (2006) specify that one advantage to their method is the flexibility it offers, particularly because it allows the superimposition of theory. The initial thematic analysis began with analysis of themes pertaining to viral load, CD4 count and ARVs. As the analysis progressed, it became clear

that the titles of the inserts draw attention to the experience encompassed in each case - for example, *"ARVs make me look fat and pregnant"*. The questions were very briefly or precisely posed to highlight key aspects of the nature of the problem faced by the advice-seekers' pertaining to their viral load, CD4 count and ARVs.

We used each question asked as a prompt or a guide for what to evaluate in each recommendation advanced in response to the query. Initially the content was analysed, and this revealed that ARVs, viral load and CD4 count were indeed central preoccupations in the data. Theory-led questions were then applied to the data so that we could analyse how each query was framed and what remedial action each answer suggested. Importantly, we focused our attention on aspects about self-improvement and self-evaluation implicated in each response.

The overall guiding question was therefore how advice inserts accentuated the relationship one has with oneself. It became quickly clear that these questions were appropriate for every advice insert, and that the question of self-improvement and self-evaluation was central to the advice column.

A second layer of analysis applied Foucault's (1992) approach to the ethics of self-care as discussed previously. We asked the following questions of each advice insert and its recommendation: a) what ethical substance or aspect of the way the self relates to itself is identified for adjustment or reconstruction; b) how or what reasons are advanced or upheld - the mode of subjection - for obligating the self to adjust or refigure itself; c) what ethical work or particular task by the self is to be performed with reference to changing the way it views and acts on itself; and d) what telos of the ethical subject or overarching goal is

presented for aspiration or accomplishment? This allowed us to pursue a more directed analysis of the two broader themes that were identified.

In order to ensure quality control, both authors independently reviewed the advice inserts in order to generate a consensual analysis. We also evaluated the data in relation to its fit to the theory, so as to avoid an analysis that inappropriately imposed theory on the data. This helped us to refine the central guiding question in relation to self-improvement, self-evaluation and the relationship of the self to the self, since these questions were centrally important in the advice column. In some of the extracts below, it is clear that these concerns, of interest theoretically in this paper, are voiced in colloquial ways in the advice columns.

Although limited examples are presented in this paper, they have been chosen because they are exemplary of the data: many other data extracts could have been similarly used. We have therefore presented typical rather than exceptional data inserts. In order to facilitate the resonance of our analysis with readers, we have chosen fewer extracts that have been presented in more detail rather than more frequent but briefer extracts. This is particularly important since it is both the question asked and Criselda's answer that is of relevance to the analysis.

Two main themes emerged from the analysis. First, advice-seekers, and by extension, the readership of the magazine following the advice column, are nudged to enfold the principle of investing in self-affirmation involving the responsibility of expending time and energy acquiring the capacity for risk-management for viral load increase or reduction to the CD4 count.

Second, the undertaking to overcome the barriers to commencing with or adhering to HIV therapy is constructed in terms of the willingness to pursue qualified assistance on one's remedial options in the event of side effects. Each of these themes will be presented in turn, and illustrative extracts from the data will be discussed.

Investing in oneself in facing down HIV

An overriding point of view gleaned from the advice column is that successful reform of practices related to HIV health requires changing one's mind-set and habituating oneself to self-regulation. More specifically, readers are exhorted to place value on investing in oneself as an ethical virtue constitutive of an independent-acting subjectivity. This is promoted as a desirable state of living with HIV.

Understood this way, investing in oneself for the goal of living positively with HIV designates the sort of actions, measures and initiatives concomitant with a self-caring approach to enhancing personal health, with the assistance or tutelage of medical expertise. The ability to be self-caring, as Foucault (1990, 1993) has shown, is itself lodged in one's capacity to acquire knowledge of the ways of improving oneself for the fulfillment of a desired state of being, happiness and satisfaction.

There is strong emphasis in the advice column on taking responsibility for looking after personal health and productively managing HIV. Readers are encouraged to do this by keeping watch over their HIV biomarkers and their psychosocial correlates of adjustment or resilience, which entails acquiring the information or capability to keep them in check.

Consider the example of an anonymous advice seeker who asks Criselda to explain "*the difference between a CD4 count and a viral load*", as well as "*what should an HIV-positive person eat*" to keep healthy (Bona, September, 2010, p. 104).

Taking up the perspective and principle of investing in self-care, Criselda's response focuses on prodding the advice-seeker to take care to pay close attention to the role or influence played by the combination of emotional and psychological state on the course of the viral load and CD4 count as the most reliable bodily markers of the extent to which HIV is under control:

"*The two most important blood tests for assessing how well your body is managing HIV are the viral load test, which measures the quantity of HIV in your blood, and the CD4 count, which is a measurement of your body's resistance. If your health is balanced, the viral load will go down or remain stagnant and usually, your CD4 count will rise. There are specific targets set for viral load changes that will tell your doctor if you need to be on ARVs - CD4 count should not be less than 350 and viral load less than 100 000 copies … A healthy immune system would mean a proper healthy functioning body from eating well, treating each and every minor illness, maintaining a healthy mind that is fed positive and realistic thoughts, which will involve educating yourself about all you need to know about HIV*" (Bona, September, 2010, p. 104).

An important aspect for managing HIV, this advice suggests, entails ensuring that the CD4 count is not below the target point and that copies of the virus in the body do not multiply to the extent of overwhelming one's health. The advice links enhancing the immune system's strength and vitality with the determination, disciplining and control of self facing HIV.

Medical facts flow seamlessly into careful monitoring of the body ("*each and every minor illness*"), and then of the mind: feeding the mind healthy thoughts is directly equated with a healthy immune system.

As Criselda's intervention signals, improving the strength of one's resistance to HIV requires a keen sense of awareness and interest in regulating one's emotions. That is to say, investing in the ability to stabilize the CD4 count, viral load and emotions is important for confronting courageously the egregious consequences of being HIV-positive.

What the advice in the extract mobilizes for uptake or self-consciousness, as Sangaramoorthy (2012) has shown through her work on the constitution of a 'numeric subjectivity' with PLHIV, is the perspective that self-representation is a measurable or quantifiable experience inextricably linked to emotions.

The advice emphasizes self-adjustment and self-scrutiny in the quest for physical well-being, and gestures towards the obligation of learning to take responsibility in controlling HIV. This is to be accomplished by acquiring knowledge of the crucial determinants of HIV health, including the impact of both emotions and biomarkers in hindering or facilitating the on-going experience of living with HIV.

Such an investment, as Criselda's advice to the anonymous advice-seeker above evinces, can have instrumental benefits if, for example, knowledge of the nutrients upon which a healthy body for also controlling the fluctuations of HIV biomarkers is adopted into a way of life. On the other hand, the benefits can be of a psychical nature or form, if they result in cultivating the capacity for the personal determination required to independently manage a life with HIV.

Take, for example, Sindiswa's case. She started on antiretroviral therapy in 2012, and initially, her CD4 count increased "*from 126 to 646*", though when she wrote to Criselda in 2013 it had dropped (she did not mention how far it had dropped). Her doctor changed her medication, but what she finds most distressing is that **"***people are starting to comment about my weight loss…this is stressing me because I eat a very balanced diet*" (Bona, November, 2013, p. 90). In her response to Sindiswa, Criselda starts by drawing attention to the value of taking individual responsibility for one's health in paying Sindiswa a compliment for discussing her concerns with her doctors and "*having them change your medication to suit your needs*" (ibid: 90).

For Criselda, what is important for Sindiswa to bear in mind is that for any person living with HIV "*your CD4 count changes with your emotions; when you are happy your CD4 count is happy and vice versa*" (ibid: 90). In offering her guidance to Sindiswa, Criselda advises her to "*figure out what's stressing*" her and to "*do something about it*" (ibid: 90), which as she points out, will help her manage how she feels about herself as an HIV-positive person.

The ethical work of adjusting oneself that Criselda suggests involves careful scrutiny of body and mind in order not only to be a good subject but also in order to increase CD4 count. Sindiswa is congratulated on enlisting the help of doctors in her quest for self-surveillance.

One consequence of the advice just outlined is that it marks off the distinction between the imaginary and what is realistically possible in dealing with the day-to-day complexities of living with a disease that is a repository of external and internalized positive and negative projections, stereotypes and suspicions (Campbell et al, 2005; Gilbert & Walker, 2009; Cama

et al, 2015). In her advice, Criselda goes so far as to present growing to accept oneself as preceding the actualization of taking responsibility for preserving one's life with HIV: "*You went down a size and that is not always a bad thing. Embrace your new weight; use the mirror to say the things you want people to say to you: I am beautiful, sexy and classy. Say these words with faith until you believe them. It all begins with a thought and thoughts become things, meaning what you say you are, you become*" (ibid: 90).

From the standpoint of the advice Criselda offers to Sindiswa, nurturing the inclination to value oneself enables the ability to muster the affective resolve for valiantly navigating the day-to-day experiences and demands of living with HIV.

The advice discussed above advances the principle of self-acceptance or affirmation, which is expressed through the call for investing in oneself. It thereby links subjective constitution and reconstruction to both power relations and self-governance. Stated differently, developing the capacity to be self-managing emerges out of a confrontation with oneself to seek professional assistance and to capacitate oneself for gaining control of HIV.

Taking our cue from Foucault (1982, p. 220), two aspects about a relation of power make self-governance possible: "that the 'other' (the one over whom power is exercised) be thoroughly recognized and maintained to the very end as a person who acts; and that, faced with a relationship of power, a whole field of responses, reactions, results, and possible inventions may open up."

The "relationship of power" in this case is between Criselda and the PLHIV seeking advice from her; "the whole field of responses" that the relationship "opens up" involves the

possibility of transforming, recasting and optimizing the potential of each advice-seeker to act to manage HIV, including by resorting to specialized help for further assistance.

Indeed, one of the most significant aspects of the voluntary relationship of power between Criselda and the advice-seekers is that it is motivated by an expectation by both the advisor and the advised for change. The potential for change is embodied by the weight or force of the example of Criselda's own journey from HIV diagnosis through trials and tribulations to self-affirmation. In her example, advice-seekers come to see that the prospect of internalizing possession of the power to take charge or govern oneself is a realistic possibility.

Most importantly, as the next extract vividly illustrates, the relationship between Criselda and the advice-seekers works to model and perhaps naturalize the principle of growing to accept oneself through self-ownership and the freedom of choice to act independently to seek professional guidance:

"*Dear Criselda: I have been to the doctor several times trying to increase my CD4 count but it keeps dropping. I'm doing my best to eat and stay healthy. What am I doing wrong? Sy, Kwa-Thema*."

"*Dear Sy: Your CD4 count increases and drops according to your emotional state. It will be at its lowest when you are stressed, anxious, depressed or scared. You know your life and circumstances better so try and identify what could be causing the above, seek professional help and deal with it. Focus on living a better life, treat minor illnesses as they occur, address any fears and perceptions you might have about living with HIV*" (Bona, April, 2011, p. 84).

In this advice, to think of HIV health as an activity involving decision-making is concomitant with the willingness to seek out expert assistance, medical or otherwise, in order to obtain guidance and develop the capability to deal independently with the on-going experience of living with HIV.

Moreover, the advice to Sy that "*your CD4 count increases and drops according your emotional state*" is startling for what it accomplishes: it elevates the implicit logic that improving one's body is contingent on improving one's mind, and therefore promotes psychic government as a crucial aspect of managing one's health. In Criselda's 'pastoral-like' lexicon, the ideal form or measuring rod of what it means to be HIV-positive depends upon the possibility of becoming responsible for one's health.

This advice suggests that working to improve one's resistance to HIV by boosting the immune system's strength and vitality in all the ways necessary or possible constitutes a desirable psychical dividend; it entails the possibility of cultivating a better view of oneself as a person living with HIV.

In the next section, we examine a similar ethical call to self-improvement and self-evaluation in relation to the theme of dealing with the side effects of starting with and adhering to HIV therapy.

Stepping up to personal anxieties, fears and barriers to HIV therapy

The analysis above highlights the extent to which, from the perspective of Criselda's advice column, negotiation of life with HIV is viewed through the personal or individualistic

investments so characteristic of contemporary neoliberalism. To borrow Rose's (1999, p. 256) apt and very useful phrase, the privileging of the logic of personal development typical of neoliberalism is all the "more profound because it appears to emanate from our autonomous quest for ourselves, it appears as a matter of our freedom."

Furthermore, as Hamann (2009, p. 54) has observed of the proliferation of neoliberal rationality in the social, political and cultural spheres, "the imposition of market values" invariably leads to "the evisceration of any autonomy" or neat separation "among economic, political, legal, and moral discourses, institutions, and practices." In other words, for personal empowerment or investment to properly operate as the productive force it is, it needs to capture its subject's ethical imagination and turn it into an aspirational model or ethos of self-practice.

According to Brown (2005), neoliberalism as a governing rationality or an ethical regime of relating to oneself inscribes almost all of social and political reality with a market sensibility, whereby developing and improving on present capabilities maximizes "future value" or prospects.

Binkley (2009) has argued that neoliberal self-government as anchored around increased freedom and privatization therefore centrally involves investing in oneself, in a similar way to the neoliberal subject's habit of investing money, time, or even affection for oneself in anticipation of a desired present or future return.

For example, as the next extract from Criselda's HIV advice column illustrates, investing in oneself - maximizing one's value - involves the ethical work of orderly, sensibly and

moderately conducting oneself to reach the objective of overcoming one's fears or anxieties to commencing with HIV therapy:

"*Dear Criselda: Is it true that you can start behaving in a crazy way when you start with taking ARVs? I rent a backroom and am about to start treatment. I can't afford to go around acting like a crazy person. Please help! Sophie, Kwa-Guqa.*"

"*Hi Sophie: I would not quite refer to this as going mad or acting crazy. There are, however, some side effects to certain antiretroviral medication, which includes suffering from hallucinations (seeing things that aren't really there). But not all antiretrovirals have this as a side effect. Before you start treatment, talk to your doctor about your fears and concerns. Ask questions that will give you as much information as possible and help you to deal with any possible consequences of taking your medication … Well done for asking about this myth and for not taking it as the gospel truth*" (Bona, February, 2011, p. 82).

Much like a worker in the labour market enjoined to invest in the development of the skills, knowledge and abilities "that increases the capacity to earn income, to achieve satisfaction" (Read, 2009, p. 28), in Sophie's case, acquiring the knowledge to manage the side effects of HIV therapy promises gains for her health and for the psychic income of freely exercising responsibility for her well-being.

Beyond asking her doctor the types of questions that empower her to deal with the frightening consequences of starting with HIV therapy, as important for Sophie is psychic and bodily capacitation to enable her to reduce the social attention that side effects could draw to her. Persson (2004, 2005) has shown with her participants who reported a range of

body shape changes owing to their long-term use of HIV therapy that ARVs hold both the possibility of both resurfacing and concealing HIV status, depending on the commensurability of the medication with the person.

Thus, if the willingness to attain information on side effects produces the capacity to start with ARVs, this itself would be an accomplishment for Sophie; in learning to govern herself by investing in her own health, she will normalize or adjust to HIV therapy. Mobilized through a form of 'economic rationality' or 'grid of intelligibility' (see Foucault, 2008), Sophie is told that reducing the costs of the side effects of initiating ARVs - or increasing the opportunity gains of HIV therapy - is a personal responsibility.

Living productively with HIV is possible through acquiring the requisite knowledge and also the psychical skills and capabilities required. For this reason, the problem of negotiating the side effects of ARVs is all the more challenging in view of the necessity of stepping up to the anxieties or fears of commencing with or adhering to the therapy.

In a globalized culture already streaked with the tendency for psychologizing all manner of social problems (see Hook, 2004b; Rose, 1998, 2008; Rutherford et al, 2011; Scharff, 2016), for Criselda, the initiative of gathering the information to help one manage the side effects of starting with HIV therapy is itself rooted in an imperative to overcome personal anxieties, fears and barriers.

Indeed, the reader's worry about the possibility of side effects (referred to by Criselda as a "*myth*", although side effects are indeed possible) is addressed by applauding Sophie's bravery and focusing on the pursuit of autonomy and knowledge. A concern about the

physical becomes solved through psychic work. That way, one is enabled to pursue the deep and very personal transformations that are needed to combat life with HIV.

In encouraging its advice-seekers and readers to be little more than self-interested subjects with the potential to optimize their choices, as the following extract shows, the advice column draws on a particular type of psychological discourse. The personal adjustment and development required for solving the physiological problems of HIV is championed through the work of capacitating oneself from a psychological or emotional point of view:

"*Dear Criselda: I am an HIV-positive person, but I refused to take the treatment because of their side effects, especially body disfigurement (severe body changes). But since the government announced that as of April this year there will be only one pill to treat HIV, I will start the treatment. What are the side effects of this new pill? Maureen, via email*".

"*Dear Maureen: …You are not alone; everyone is worried about side effects before they start treatment…Many people put up with side effects when they could change to another treatment and this is not good. Before starting treatment, learn about the side effects that can occur with the drugs you are going to use. Ask your doctor, nurse, or HIV pharmacist about how likely they are to occur. Ask how many people stop treatment because of them (usually very few). Even rough estimates will give you a good idea of what to expect. Ask other people taking the drugs for their experience. This way you will know what to look out for. Taking ARVs can never replace counselling to help deal with fear, anxiety and other health challenges. Ask your doctor questions that would help you deal with your fears. No need to fear; information gives you power*" (Bona, March, 2013, p. 51).

Self-help, here, means that expertise intervenes to produce a relationship of help in the self's relation to itself; self-help implies asking experts for advice. Within a Foucauldian perspective, as Butler (1997, p. 3) has noted, "the form this power takes is relentlessly…a turning back upon oneself or even a turning on oneself." While the relationship is initiated through expertise, it is dependent on those seeking help investing in their bodies, minds and emotions in bringing about their own self-transformation.

In the exchange between Criselda and Maureen, the potential for self-help builds a bridge between the specific issue of tolerating side effects (when one "*could change to another treatment*") and the much larger issue of substituting helplessness for individual empowerment. The psychological work involved in achieving this ideal involves dealing with one's "*fear, anxiety and other health challenges*" related to commencing with HIV therapy. By aspiring to overcome the anxieties, fears and barriers to beginning ARV treatment, PLHIV are enlisted to take responsibility for reducing the risks of non-adherence to anti-HIV drugs.

This ideal arguably serves not only their own individual health, but also the vision of a South African society pushing back the HIV/AIDS epidemic. Criselda's recommendation to Maureen to "*learn about the side effects that can occur with the drugs*", and to ask health practitioners about the likelihood of their occurrence, is also a broader call to adhere to ARV treatment and to undertake personal risk reduction and risk management. This link of risk management to personal investment is constitutive of subjectivity: taking personal responsibility is offered as a way not only to reduce health risks but also to take back control of personal destiny (see Ericson, Barry and Doyle, 2000).

National and global HIV/AIDS treatment guidelines (see SANAC, 2011; WHO, 2012; WHO, UNICEF, UNAIDS, 2013), with their attempts at espousing and cascading the best scientific practices, are filled with expressions of "indicators", "benchmarks" and "objectives" as a way of highlighting the collective risk of ARV side effects and resistance for PLHIV. Criselda draws on this language too in her column.

For example, Nobenani's HIV-positive brother has been on ARV treatment for two years, but "*now he feels healthy and strong*" and "*wants to stop the treatment*" (Bona, July, 2012, p. 110). According to Criselda, "*ARVs are currently regarded as a lifelong commitment, as per the World Health Organization's guidelines…Scientists advise that when a person stops treatment they risk having resistance to drugs should their health deteriorate and ARV's are once again necessary…once the decision is made, it's for life*" (ibid: 110). Perched on the absolute certainty of scientific guidelines the advice to Nobenani also serves to promote self-responsibilization, thereby individualizing the responsibility for adherence, and to encourage recourse to expertise.

In the sweep of Criselda's advice to Nobenani, a special responsibility is constructed for her audience to proactively manage personal risks to their health. Taking responsibility when commencing with or adhering to HIV therapy is linked to the personal benefit of averting the problem of ARV treatment resistance in the long term. Indeed, not only the individuals who write to Criselda but her audience in general are enjoined to reactualize their selves through a subjective formation of self-governance, self-improvement and self-evaluation.

Concluding remarks

In this article, we have presented an appraisal of Criselda's popular platform for seeking HIV advice and its implications for reinventing subjectivity. This popular advice column, we have argued, offers a potential lens for interrogating the possible ways in which subjectivity is rearticulated in the post-AIDS era of treatment possibility and self-management. For Criselda, the key to rising above the threat posed by an unmanaged life with HIV lies in the principle of personal investment.

Investment in the acquisition of knowledge and skills is insufficient without concomitant self-affirmation and self-monitoring, including of one's psychological state. Resorting to expert knowledge and guidance provides an opportunity for realizing self-control by acquiring the capability to successfully monitor key indicators of HIV progression, and by commencing with and adhering to ARV treatment.

In effect, this advances a subjective vantage point from which to survey the ethical imperatives of gaining control of HIV and curtailing its risk for society. Crucially, a subjective vantage point is offered from which to monitor the self. From this position, overcoming HIV is a choice like any other and, armed with facts and professional assistance, it is possible to start managing it.

To the advice-seekers and Criselda's broad readership, the HIV advice column offers the promise and hope that, by taking its message seriously, PLHIV can succeed on their own, even against the sometimes debilitating and burdensome obstacles of living with HIV and the demanding work encompassed in plodding through the side effects of using HIV therapy.

Moreover, the advice columnist's own exemplary battle against HIV suggests that becoming self-governing is and should be the greater objective for PLHIV.

There are necessarily limits to the extent to which the analysis offered in this paper can explore implications for reinventing subjectivity. An advice column by definition allows access only to a questioning voice and to Criselda's answer. What is not available for public scrutiny is how advice seekers respond to her advice or how the broader readership accepts or rejects her position. How people engage with the advice Criselda offers will be mediated by the complexities of their life circumstances, contexts and already multiply constituted subjectivities.

The self-help genre is itself located in a very specific context that may foreground Western rationalist approaches to personhood. For many PLHIV in South Africa, a plurality of value systems and rationalities exist, along with their accompanying discourses for representing selfhood, including African 'moral-aesthetic' views about personhood and their implications for perspectives on health and illness. The public form of the advice column, however, offers an important lens on how selfhood is shaped and governed.

The analysis offered in this article suggests a strong emphasis on the individualization of responsibility, the value of expertise and the imperative to improve and monitor the self. A very normative and self-governing subject is presented as the ideal, and in the process other kinds of subjectivities are potentially devalued. A critique of Criselda's advice column suggests important possibilities for resisting self-entrepreneurialism and for undermining the seemingly rational processes of self-governance.

At the same time, however, in the face of challenges to HIV adherence that risk lives, it is important to conclude by considering the potentially transgressive or transformative possibilities. For us, her advice column - as with similar platforms and the typical solutions they offer for thinking and acting on oneself - presupposes, and thus constitutes, a certain aspirational space that lies between knowledge, expertise and subjectivity.

Most especially, they take the form of demystifying and democratizing the nexus of knowledge and expertise in ways that promise to unshackle subjectivity from its own inhibiting characteristics, processes and vices that limit its ability to realize its potential for assuming agency over life and the future. Equally important, they also simulate actual supportive gathering forums enabling their audience to be encouraged and learn from one another or from those who are willing to articulate their private but most likely shared health and illness predicaments or trajectories.

The challenge perhaps is to simultaneously undermine and embrace this aspirational space so as to both unsettle and explore the reinvention of subjectivity in the post-AIDS era.

CHAPTER SIX

HIV/AIDS policy and the governance of everyday experience on antiretrovirals[17]

Abstract

This article critically examines the juxtaposition of HIV/AIDS policy with the everyday subjective experience of living on antiretrovirals. A cursory review of three policy strategies in South Africa, spanning the period 2003-2016, highlights the merging of a rights-based approach with the advancing of individual accountability, including personalized risk management, for successful enrollment onto antiretroviral therapy. Correspondingly, an in-depth analysis of three respective accounts of women and men enlisted for antiretrovirals in public health facilities reveals that assuming greater personal responsibility is identified with self-realization, achieving personal wellness and restoring self-worth. This is not, however, to say that uptake unfolds seamlessly. With the taking of antiretrovirals necessitating unwavering psychological and affective resolve, often amid other competing daily demands upon oneself, adherence setback is not beyond the bounds of possibility. Self-responsibilization on antiretrovirals is therefore inherently in-flux, not always determinable, owing to constantly evolving everyday circumstances.

Key words: HIV/AIDS Policy; Subjectivity; Antiretrovirals; Individual Accountability; Risk; Public Health

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Introduction

In thinking about interventions for HIV/AIDS both in South Africa and elsewhere, it is striking how much they have evolved since the discovery of the epidemic in the early 1980s. Arguably, the development in the 1990s of more effective HIV treatments - especially the introduction of several antiretroviral medicines deployed either to decelerate the rate of HIV replication or prevent vertical transmission of HIV from mother-to-child - has significantly improved the life prospects of many people living with HIV (PLHIV) and altered the course of the epidemic around the world (see Heywood, 2009; Mykhalovskiy & Rosengarten, 2009).

Though coordinated global efforts and lobbying to scale-up access to antiretroviral therapy or ART in low-and-middle-income countries prevented an estimated 4.2 million deaths between the years 2002 to 2012, HIV treatments were at first out of reach for most PLHIV in sub-Saharan Africa and many other regions of the developing world (WHO, UNICEF & UNAIDS, 2013).

In part, the reasons for lack of access included the high costs of the medicines, the limiting restrictions of international patent laws to make way for the production of more affordable generic antiretrovirals, and the absence of the political wherewithal or commitment to fostering a credible response to HIV/AIDS (Biehl, 2004; Geffen, 2010; Mbali, 2013). Still, there were countries that endeavoured tenaciously to overcome these barriers.

Soon after the introduction of highly active antiretroviral therapy (HAART) or antiretrovirals (ARVs) in 1996, for example, Brazil introduced an HIV treatment programme in the country's public health system, a decision that managed to curtail considerably its rate of HIV infection and mortality (Iqbal, 2009). Brazil's very rapid move in this direction was a

very clear sign of the high level of political commitment to universal healthcare by the country's political leadership, especially during the presidential tenure of Fernando Henrique Cardoso, from 1995 to 2003 (Galvão, 2005).

More specifically, such a stance initially involved the country importing generic anti-HIV drugs from India and Thailand, even at the risk of violating international patent agreements, but later also undertaking to develop its own capacity to produce the drugs (see Biehl, 2007; Cataldo, 2008). Thus, "this policy of biotechnology for the people", as Biehl (2004, p. 105) aptly described it, was embraced as an exemplary approach for other developing countries to emulate and emerged at the time as "an important component of international medical activism".

Within sub-Saharan Africa, Uganda and Botswana stand out for their early initiatives to introduce ARVs in their public healthcare systems, with the former enacting a plan to prevent the transmission of HIV from mother- to-child or PMTCT in the late 1990s, and the latter, in 2001, introducing a programme to offer a general ARV programme in the public health system (d' Adesky, 2004).

By contrast, in the prolonged and very conflictual South African chapter of the transnational battle for affordable and accessible HIV treatments, it was only in 2002, after a number of successful legal and civil campaigns by AIDS lobby groups, most notably the Treatment Action Campaign (TAC), that the government, under the stewardship of former president Thabo Mbeki, announced an operational plan for the care, management and treatment of HIV/AIDS. Of course, this decision was preceded, in 2001, by the Pretoria High Court ruling

compelling the ministry of health and the state to extend and provide PMTCT in the public health sector (see Kistner, 2001; Heywood, 2003, 2009; Nattrass, 2007, 2008; Mbali, 2013).

In fact, with the delays in rolling-out PMTCT and provision to people who are eligible but too poor to afford HIV treatments, as one study estimated, as many as 330 000 of these people died between the years 2000 to 2005, with 35 000 babies born HIV-positive (Chigwedere, Seage, Gruskin, Lee & Essex, 2008).

With the conflict now arguably settled or resolved, South Africa continues to make progress in rolling out ARVs to PLHIV. Currently, over 2.7 million people are on ARVs, making the country's public HIV treatment programme the largest in the world (DoH, 2015). The upscaling of ARVs in South Africa has along with it spurred a rise in research prioritizing mitigating the risk of anti-HIV drug resistance, most clearly evinced by the burgeoning number of studies researching the barriers and facilitators to ARV adherence (see Bartlett, Hornberger, Shewade, Bhor & Rajagopalan, 2009; Kagee, Remien, Berkman, Hoffman, Campos & Swartz, 2011).

More than recasting the response and research on HIV/AIDS in South Africa, or elsewhere in the world, the availability of ARVs has transformed the very nature and measure of value for PLHIV (Pollack Petchesky, 2003), reconfiguring their ethics, anxieties and aspirations (Venkatapuram, 2011). Yet, there has been little empirical research that looks across public policy on ARVs and the evolution of subjective experience of living with HIV.

This article critically examines the juxtaposition of HIV/AIDS policy with the everyday subjective experience of living on antiretrovirals. In taking this approach, the article is

attempting to add to the still nascent analyses of public policy discourse about ARVs in shaping its subjects.

Such an undertaking arises from the premise that the contours of subjectivity are set or demarcated by social discourses (Butler, 1997), or alternatively, the prescribed voluntary relations of rule linked to the ways we constitute and relate to ourselves (Cruikshank, 1999). Moreover, as Binkley (2010) has previously recounted, swayed by the twists and turns of lived day-to-day experience, the substance of subjectivity is dynamic and shape-shifting, not least unrestrained and unpredictable.

The conceptualization of subjectivity formed and unleashed discursively, while dynamically experienced and expressed in everyday life, encapsulates both the aspects of governability and self-governance (see Rose & Miller, 1992; Foucault, 2000). As this article attempts to demonstrate, this 'governmentality' framework offers an alternative way of comprehending what is at stake, whether from the viewpoint of reason or emotion, for PLHIV in deciding who they are or who they want to be with respect to enrolment or living on ARVs and with HIV.

Using governmentality as a conceptual tool

In this article, I take the approach that subjectivity has an instrumental role in enabling power relations, in so far as the potential to be spurred into action by others, including driving oneself, is underpinned by the idea of our own freedom to act independently (Foucault, 2000).

On the one hand, this approach conceptualises all the facets that make for subjective conception and enactment as constituted through the nexus between power and knowledge. On the other hand, from this perspective subjectivity is the interiorisation, or as in Dean's (1996) adaptation of the Deleuzian concept of the 'fold', the 'enfolding of authority' comprised in the manifold discursive positions made available through the various institutional and programmatic activities or initiatives based on the underlying rationale of securing human and population well-being (Rose, 2008).

But more significant is the view that public policy makes intelligible the forms of obligations to be nurtured, instilled and enacted in advancing human life and the qualities that sustain it (Rose, 1999). Such a perspective indicates that public policy has implications for the assignment or allocation of the rights, duties and responsibilities of the people associated with its materialization into practice, more especially its beneficiaries. In other words, public policy enframes a larger apparatus of public, private and not for profit programmatic initiatives that help form our beliefs about ourselves, actions and our world.

The perspective adopted in this article, therefore, is that subjectivity is produced, transformed and lived according to a set of rationalities and directives, not least exemplified by public policy, laying out and expressing codes of conduct or action. Subjectivity is an instrument and effect of mentalities of government broadly defined, or 'governmentality', encompassed in all kinds of reflections, analysis, initiatives and programmes linked to advancing and protecting all things material and non-material pertaining to human existence (Lemke, 2015). According to Swyngedouw (2005), mentalities of government have their most effect and visibility in the production of selves that are governable, including their impact in spurring or driving self-governance.

For Foucault (1993, p. 203), such a conceptual and ultimately analytic standpoint is mainly about accounting for the structure of self-determination or agency, or how "technologies of domination of individuals over one another have recourse to processes by which the individual acts upon himself", with the acting individual "integrated into structures of coercion or domination."

Here one might ask what constitutes a structure of self-determination, and what its constituting effect is. For Adlam et al., (1976, p. 46), for example, "the human subject is…constituted in the intersections of a determinate set of discursive practices which take their particularity from the totality of practices in which they are articulated". Similarly, for Rose (1998, p. 172), it is through the linkage of these discursive practices that subjects are constituted "as desiring selves, sexed selves, labouring selves, thinking selves, intending selves capable of acting as subjects" (1998, p. 172).

More important for the discussion in this paper is that these practices encapsulate, if not constitute, ideas on appropriate and effective means of mitigating or managing social and political problems, with the aim being to improve the overall standard of living and safeguarding 'life itself' in all its dimensions (Vallgårda, 2015).

In this article I position the policy guidelines or strategies analysed here within the wider apparatus for controlling and managing South Africa's HIV/AIDS epidemic, including the encoding of ideal modes of beliefs and conduct expected or encouraged among those to benefit from the distributing and upscaling of the ARV programme that was rolled-out from 2003 in the public health system (see Robins, 2004, 2008; Mbali, 2013). In this sense, the

notion of subjectivity as both related to the working of government and its outcome, at least from a Foucauldian perspective, presupposes a relationship with oneself premised on being directed by others as well as the self turning on governing oneself (see Burchell, 1993; Cruikshank, 1993, 1994).

To be sure, the framework of governmentality has limitations, the most important of which is that it pays attention mostly to a textual or discursive rather than an experientially grounded account of subjective formation, reconstruction and enactment, particularly in relation to everyday living (see Burkitt, 2005; Weidner, 2009; D' Aoust, 2014).

For the most part, the framework largely offers a way to understand or think about the modes of rationality, valuation or ethicalization within which subjectivities are imagined and constructed (Dean, 1996), while tending to overlook the way selves are actually lived out across space and time (see Binkley, 2009,a,b; Murray-Li, 2014).

More often than not, in most governmentality studies subjective life appears as wholly enwrapped by and an effect of discourse. Such accounts, however, fail to recognize that discourse is also appropriated by subjectivity, hence subjective life may move in directions unexpected or surpassing the constitutive discourses by which it is produced (see Butler, 1997).

Here we might also consider that the penchant for archival or document based sources of most studies utilizing an analytics of governmentality often results in very oversimplified formulations of the transmission mechanisms between governmental rationalities and subjective life. For Brady (2014, p.13) such "deterministic" and "linear" approaches overlook

the role of "multiplicity and context" in anchoring any form of constitutive discourse in subjectivity. In other words, the power of a discourse to effect subjective constitution or transformation is contingent on the context or circumstances of appropriation.

One way out of this conundrum is to work with a range of data sources, beyond purely textual readings of formal and informal documents (see Scharff, 2016). Combining archival or documentary and interview texts, for example, allows for an analytics of governmentality that accounts for the forms of rationality, discourses or rules bounding and anchored in subjectivity, while also delving into the varying ways that appropriation translates into modes of subjective constitution and performance in everyday social life. This approach to using governmentality as a conceptual tool enables the article to explore the juxtaposition of the often policy based adamancy of the importance of ARVs and the everyday experiences linked to taking them.

Method

Selecting the data for analysis

Two aims motivated the analysis reported in this article. First, drawing on the framework of governmentality, the analysis endeavored to explore South Africa's post-2003 HIV/AIDS policy guidelines for the public health system for the kinds of terms that cluster around the self when enlisting for and living on ARVs. Indeed, the policy guidelines are addressed to a range of stakeholders, including PLHIV, the general South African public, healthcare professionals in the public and private healthcare systems, community organizations and so on.

This review specifically aimed to develop a schematic outline of the register mobilized for thinking and constituting oneself in preparation for enrolling and sustaining a life lived on ARVs.

Second, to add a dimension beyond merely a reading of the terms the policy guidelines advance for envisioning and acting on oneself upon enrollment onto ARVs, the analysis undertook to analyze the interview narratives of six women and men accessing antiretroviral therapy from the public health system. With the terms set out in the policy guidelines, the first-person accounts open the window to exploring how they are reproduced daily in quotidian personal strategies for living on ARVs, indeed their anchoring in subjectivity.

Three policy documents were reviewed: Comprehensive Plan for HIV and AIDS Care, Management and Treatment, 2003; HIV/AIDS and STI Strategic Plan for South Africa, 2007-2011; and National Strategic Plan on HIV, STIs and TB, 2012-2016. These three documents were selected because they offer a reasonably representative outline of the core policy choices, values and rules set to drive the devolution of HIV/AIDS care in public, private and civil society sectors in South Africa.

Accessed from the national department of health in Pretoria, their drafting, development and adoption was mainly coordinated through the South African National AIDS Council or SANAC, a voluntary association initiated by the cabinet of the South African government, in 1994, to synchronize a multisectoral response to HIV/AIDS. The documents are intended to guide a multisectoral response at the national, provincial and local level. However, it is not so much the prospects of a multisectoral approach in crafting an effective response that I draw

attention to in this article, but rather how the response itself and the involvement of PLHIV is rationalized.

The three policy documents epitomize a sort of melting pot or constellation of the normative standards, schemes, ideas, strategies and envisioned practices through which various officials, social and private agents, experts and so on endeavor to formulate an effective response to HIV/AIDS, but one depending on enlisting or changing the beliefs and behaviours of South Africans. They are both part and constitutive of the apparatus to emerge in response to South Africa's HIV/AIDS, in view of their coalescing of "strategies of relations of forces supporting and supported by, types of knowledge" (Foucault, cited in Hook, 2004a, p. 240).

Looking back at South Africa's victorious struggle for ARVs, they are as much a product of the scientific know-how brought to bear for formulating guidelines on an adequate response to HIV/AIDS as the inputs of other stakeholders, including groups representing PLHIV, state institutions, trade unions and business. After the fight for ARVs, the basis of their normative authority and ability to shape the cascading of HIV/AIDS care stems from their underpinning values that uphold the constitutional rights of PLHIV.

Shifting to the first-person accounts, the sense of being HIV-positive and the reality or presence of living on ARVs, semi-structured interviews were conducted with three women and men who volunteered to take part in this study. This interview method or technique was chosen because it allows the participants to bring their understanding or reflection upon the experience being investigated (Babbie & Mouton, 2001). The participants were recruited through the help of a key informant who was himself HIV-positive. Conducted by the author, all the interviews took place at the facilities of a community based AIDS advocacy

organization in Pimville, one of the twenty six cluster townships of Soweto in Johannesburg, South Africa. The youngest person to be interviewed was in her late twenties and the oldest was in her early fifties. At the time of the interviews, all the participants were receiving ARVs from their local public clinic or hospital.

With the exception of the one participant who had started a few months prior to the interview, most had been enrolled for ARVs for at least a period of three years or longer. Out of respect for their right to anonymity, the names of the participants have been changed.

Procedure for analysis

While to derive a formal method of analysis for the kind of study presented here would be misleading, speaking rather roughly, it is possible to identify a number of dimensions along which the data was analyzed. Terre Blanche, Durrheim and Painter (2006) have argued that qualitative analyses are useful in enabling researchers to evaluate and synthesize themes and trends around a specific area of interest under study about the social world. With both the policy guidelines and interview transcripts, the analysis revolved around working out their thematic content on ideas relating to living on ARVs (Braun & Clark, 2006).

However, with the policy guidelines, identifying the central thread was supplemented by an attempt at distilling the sets of more conceptual or valuational arguments running within each document and across all three. In effect, then, the envisioned outcome from the analysis of the policy guidelines was partly to generate a sort of 'discursive prose' upon which to juxtapose the analysis of the interview transcripts.

In more practical terms, with both the policy guidelines and interview transcripts coding was conducted line-by-line and codes were then subsequently grouped into significant themes and motifs. Predetermined categories, mostly drawn from the most informative and significant existing South African literature (see Robins, 2004, 2009; Decoteau, 2014; Pienaar, 2016), were used to search through both sets of texts.

The existing literature was especially helpful in clarifying the emergent themes relating to the struggle for ARVs and in the post-struggle or in the so-called 'post-AIDS' (see Dowsett & McInnes, 1996) landscape with respect to the significance of ARVs in altering socio-political and personal attributions around the experience of living with HIV. However, with especially the interview transcripts, the analysis was also open to adopting any new categories that were coded from the two sets of texts (Yin, 2010). This assisted in ensuring that coding is not manipulated but is rather adapted to the realities or experiences relayed in the interview transcripts.

In light of the two aims undergirding the investigation, as discussed above in the outline of selecting the data for analysis, this analytic approach was best suited to gather both the breadth and depth of understanding necessary from the policy documents and interview transcripts analyzed.

Findings and discussion

In the first part of the analysis and discussion I offer a broad representation of the terms underlying the way enrollment onto ARVs in the public health system is rationalized or envisioned in the policy framework analyzed. The discussion pays attention to the types of persons conjured up for enrollment onto ARVs.

In the second part, turning to the actual lived or everyday experiences of people enrolled for ARVs through the public health system, attention shifts to the six first-person accounts on personal strategies for living on ARVs. Here focus is expended on the kinds of persons materialized by enrollment onto ARVs, including the dilemmas faced in cultivating the related constitutive capacities.

Mobilizing self-responsibilization

One of the underlying rationalities of a response to HIV/AIDS, particularly in the context of providing treatment for HIV in the public health care system in post-apartheid South Africa, is the constitutional and legal imperative to ensure that the implementation of the programme is geared towards the democratic goals of human rights and socio-political equality (see Budlender, 2002; Heywood, 2003, 2009; Mindry, 2008; Klaaren, 2014).

Indeed, in the three documents' lexicon, the right to ARVs in public health facilities is afforded the most prominence. For example, in the *Comprehensive Plan for HIV and AIDS Care, Management and Treatment* (hereinafter, *Comprehensive Plan*), for instance, we learn that "at the stage at which ARVs are required to maintain health, medication should be made available and accessible through a coordinated programme across levels of the public health care systems including primary care clinics, community health centres, district hospitals, and regional and tertiary care institutions" (Comprehensive Plan, 2003, p. 54). This move seems aimed at spiriting a present and future compelled by a recognition and respect for the claim to ARVs as a public good, one linked to the constitutional right to healthcare (Budlender, 2001).

The *HIV/AIDS and STI Strategic Plan for South Africa, 2007-2011* (hereinafter, *NSP, 2007-2011*), highlights that "between 1994 and 2007 South Africa developed a sophisticated legal framework for dealing with health", one "which has respect for human rights at its centre" (NSP, 2007-2011, p. 49). After noting that "the principles guiding the implementation of the NSP (2007-2011, p. 55) are in keeping with the imperatives of the Constitution", it argues that PLHIV are entitled to access "all essential commodities, including prevention technologies and medicines". However, the right of access to ARVs and other related services is linked in the document to the "meaningful involvement of people living with HIV in all aspects of the national response" (NSP, 2007-2011, p. 55-56). The right to ARVs and other associated HIV/AIDS care services is thus set out in conjunction with active participation by PLHIV in pushing back against HIV/AIDS.

Under what terms do the policy documents start to articulate constitutional or individual rights with placing more responsibility for taking ARVs on PLHIV as part of a national strategy against HIV/AIDS?

In the three documents there is also a construing of the ARV programme in terms suggesting the objective of generating the most sustainable good with the utmost technical efficiency of implementation and standardized calculability of delivery. The Comprehensive Plan (2003, p.61), for example, gestures towards the need for measures to build "accountability" and ongoing "independent evaluation" into implementation and delivery processes of the HIV treatment programme in the public health care system.

Simultaneously, both the NSP documents prioritize such indicators as "costing and financing", "financial sustainability" or "sustainable financing", "auditing of programmes"

and the "costing of best practices", in the evaluation of the public HIV treatment programme (NSP, 2007-2011, p.64; NSP, 2012-2016, p.73). In addition, the two NSP documents require South Africa's ART and PMTCT programme 'targets' to be benchmarked to international standards. For instance, the NSP, 2012-2016, alludes to the obligation to align these targets to among others, the WHO's *Health Strategy for HIV and AIDS 2011-2015* and UNAIDS' *2011-2015 Strategy: Getting to Zero*. While the operationalization of these terms would mean enhancing the chances for achieving present and future success of the ARV programme, they also pave the way for constituting and putting into action the self-management capabilities of PLHIV enrolled for ARVs.

The three documents call upon a type of selfhood to be reprogrammed along the lines of what Foucault (2008, p.226) has described as "an entrepreneur, an entrepreneur of himself", a responsibilized subjecthood. While there is very little doubt that their underlying organizing principle around reconstruction of HIV-positive personhood is restoration of human dignity and equal rights to health care services for PLHIV, there is also an apparent move to couch responsible ARV use in terms of attaching a social or psychological kind of value to it.

One of the manifestations of this discursive move in the Comprehensive Plan (2003, p. 62) is demonstrated in the Comprehensive Plan's enjoining of PLHIV starting or already on ART "to make a lifelong commitment…which may require not only education to gain understanding of potential side-effects and importance of adherence", but also "well informed and engaged patients" that can be counted on to be "successful with adherence to therapy". The commitment of PLHIV on ARVs "to adhering to treatment over the long term" (2003, p. 64) should constitute the normative standard of delivering treatment services, and just as important, it is behaviour that must be actively fostered or encouraged among PLHIV.

It is worth noting that in order to facilitate the realization of this strong emphasis on responsibilizing PLHIV starting or already on ARVs, the Comprehensive Plan (2003, 73-74) encourages "drug-readiness" and constant "training…to enable individuals to take ownership of their own health and prolongation of their lives."

The argument being advanced in the Comprehensive Plan is that for PLHIV on ART adherence is ultimately "essential to maintain long-term health benefits" and for avoiding the "development of drug resistance" (2003, p. 74). The document notes that the possibility of giving effect to responsible ARV use by PLHIV involves improving their knowledge and skills, specifically in such areas as positive living techniques, options for "care and treatment for HIV and AIDS", ARV-related "side effects" and ways of improving adherence to ARV regimens (Comprehensive Plan, 2003, p. 74). Within the perspective of the Comprehensive Plan, the ability of HIV-positive individuals to conduct themselves freely and rationally is precisely what will enable the HIV treatment programme in the public healthcare system to function optimally.

In fact, in prescribing the tasks of active self-responsibility for PLHIV starting or already on ARVs, the Comprehensive Plan aligns an adherent HIV-positive patient to the governing goal of minimizing the burden for the public healthcare system and the risk for the larger population of PLHIV of the virus mutating into strains that overwhelm current treatment regimens. In similar fashion, the NSP (2007-2011, p. 56), suggests that "every person in South Africa has a responsibility…to know their status and seek appropriate care…" This, then, is consistent with the view that, after all is said and done, as Teghtsoonian (2009, p.31)

has argued elsewhere, "good citizens who take responsibility for making choices…do not burden the healthcare system."

Another way that PLHIV starting or enrolled for ARVs are implicated in the policy framework is through the emphasis on keeping watch of the roll-out of the ARV programme. As part of attempts at molding the way enrollment for ARVs is to unfold, the Comprehensive Plan (2003, p. 85), for example, provisions for "ongoing monitoring and evaluation…in the context of an integrated and comprehensive team approach to healthcare" to improve "the chance for treatment success." One of the methods for enabling 'ongoing monitoring and evaluation', as described in the NSP (2007-2011, p. 85-86), would involve enacting measures "to actively trace people on ART who are more than a month late..." for follow-up, and in its own words, for "psychosocial education, intervention and support".

The Comprehensive Plan and NSP, 2007-2011 frame the problem of adherence as requiring PLHIV to take responsibility for adhering to ART. Likewise, the NSP, 2012-2016, envisages that the roll-out of a comprehensive package for HIV treatment involves encouraging PLHIV to participate in positive living workshops, counselling for adherence and ART literacy programmes, which all require one to work on oneself and involve the obligation of taking ownership for one's health. On this point, I am arguing that all three documents shift the responsibility for the potential social and public health ramifications of drug resistance into "the domain for which the individual is responsible and transforming it into a problem of self-care" (Lemke, 2001, p. 20).

Indeed, in the two NSP documents, the constitution of the self-directive HIV-positive individual in the context of ARV care is envisioned to unfold under the general guidance of

health professionals, community health workers and a host of other actors implied in the 'continuum of care' approach to delivering ARV services advocated in the foundational Comprehensive Plan.

Approaching the policy plans from the perspective of governmentality, in particular as 'conduct of conduct' (see Foucault, 1982) living on ARVs, what emerges is that they encourage the development of compulsions of self-government and responsibility. To be sure, they do not constitute the only basis upon which people on HIV therapy act or think of themselves. Instead, in the Foucauldian sense, they aim to align both self-understanding and action in the direction of maximizing the benefits of HIV therapy and minimizing the costs to the public healthcare system of anti-HIV drug resistance (see Foucault, 1982). In recasting the problem as one of self-care and an obligation to oneself, the three documents do more than individualize accountability for being on HIV therapy.

Much like various health promotion initiatives the world over in the current neoliberal dispensation that place a strong emphasis on modifying health beliefs, developing self-discipline and promoting enlightened rational action (see Ayo, 2012), the political and social imperative of preventing the development of more virulent strains of the HI- virus turns into an issue of professionally guided but ultimately personalized care and responsibility.

Taken together, the requirement the policy framework advances locates the solution to the public health risk of anti-HIV drug resistance in improving the self-governing capacities of people on HIV therapy. However, to the extent that living on ARVs requires unflinching self-disciplinization or individualizing risk management, it cannot be divorced from the psychosocial dynamics of day-to-day goings on. I turn to this presently.

A Janus-faced culpability

From the perspective of the first-person accounts, the six women and men interviewed were keenly aware and appreciative of the benefits of ARVs for their physical health, as well as for improving their chances of living long and healthier lives, unhindered by the ravages of HIV. Importantly, their acknowledgement of the substantial difference that ARVs have made to their health and subjective outcomes was in no small measure underpinned and strengthened by the break that they have ushered in from a life that previously seemed meaningless and without any hope.

For Vista, an HIV-positive gay man who was in his mid-30s when he was interviewed, "in those days…there wasn't a difference between HIV and AIDS." Indeed, for him "you immediately just told yourself that you've got AIDS...you just told yourself that 1, 2, 3, you're dead", in a way conveying a resignation to an impending death - the physical, psychological and social death of oneself. As he continued with the representation of that time in his life: "...I didn't love myself. I hated myself. I started doing bad things…I gave in to alcohol. I never used to drink, at all. I never smoked...I gave in to alcohol…So…eish (emotional pause)". Here, then, we can say that fatalism to all that was associated with having HIV morphed into self-abjection, lack of self-regard and self-care.

Most significantly, it is amplified by the personal circumstances of HIV diagnosis, which in Vista's case, was due to a form of "corrective rape" (see Nel & Judge, 2008) that he endured as a gay man that led to his sero-conversion in the late 1990s. Now, what is crucial to note is that this alignment of HIV with a foreclosed life in the present and the future for some of the participants who now felt themselves, in a way that is very personal, to be more visible also involved the imagining of restricted mobility. For instance, after "those two weeks I got my

results" during a routine test for HIV when she was pregnant in the late 1990s, Pheto who was in her early 40s at the time of the interview felt not just that when "I looked at myself I did not understand…I wanted full proof that yes I was HIV positive", she also described feeling "as if I had been written off - as if everyone in the taxi knew my status" as she travelled back home on the day she received her test results.

In the way that both Vista and Pheto accounted for their lives before their enrolment onto ARVs, a diagnosis of HIV conferred an injured self-identity, shame and psychic dread, with respect to self-understanding, how one is likely to be viewed by other people and the ability to envision possibilities for personal growth in the future.

While an HIV diagnosis did constitute an event that generated an immense sense of self-identification related vulnerability and spoilation (see Parker & Aggleton, 2003; Rohleder & Gibson, 2006), as both the cases of Pheto and Vista have particularly demonstrated, accessing ARVs provided the grounds for its resignification, hope and re-invention of oneself when living with HIV.

Coming into contact with healthcare providers as regularly as they do, for the participants the one value that is indisputably beyond reproach for taking ARVs is that of personal accountability. Indeed, as the accounts demonstrate, with enrolment onto ARVs, lack of self-regard and self-care for some quickly evolved into an opening of hope for living, self-determination and self-responsibilization. As Mary put it, "…I do not see how I will fail with taking ARVs for a life time. After all, I want to prolong my life, for my sake, for my children' sake and my family…"

Mary was in her late 40s at the time the interviews were conducted, making her the oldest participant to be interviewed. She had discovered her HIV seropositivity while pregnant. For Mary, ARVs have allowed her to regain control over her life for not only her own sake, but also for that of her children and family.

For her the turning away from helplessness when living with HIV entailed identifying unequivocally with the responsibility of using ARVs properly: "They said at the clinic that if I take these pills today, for instance, I will know the following day how I respond to them. Should I feel uncomfortable about them the next day, I should return them and get them changed." In other words, what we learn from Mary is that reassuming control of HIV is accomplished through the small-scale struggles of the everyday realities of living with HIV.

Moreover, Mary's casting of responsibility to herself, children and family was mediated by her identification with the collective accountability of PLHIV on ARVs. This turning toward a form of collective solidarity could be understood as reflecting her own way of gauging her accountability to herself, even when confronted by the unpredictable effects of ARVs. Later in the interview, she expressed this well: "Many people just sit with their discomforts and think the pills are somewhat being effective, when they are not. No, it is not that they are not effective, but that there is something wrong with them. So, people sit with them, making them dizzy and so on without going to the clinic. And you go the second time for treatment, but you still don't raise the issue and the side effects become worse. Had you highlighted these effects, they would have done something about the pills. The people at the clinic know how these pills work."

For Mary, the enactment of such responsible behaviour should be a matter of routine everyday living, built into a way of understanding, assessing and acting on oneself when enrolled onto ARVs.

In this way, then, a self-driven containment of HIV and the effects of ARVs is both a responsibility to oneself and a way of demonstrating one's commitment to his/her family, immediate community, other PLHIV and the general South African population. Such a view is based on the unstated presumption that enrolling onto ARVs does not automatically guarantee the prospect of prolonging one's life, in and of itself, unless it is augmented by a sense of personal responsibility and due diligence.

More specifically, it is through the imperative to take personal responsibility that the shift to ARVs as a strategy for reviving the hope of living long with HIV becomes more meaningful and justified. Such a formulation on the part of the participants, much as reflected in the three policy guidelines reviewed above, stands as a provocation for diligently following the instructions for enrolling onto ARVs and also a caution against non-compliance with the prescribed regimen. Vista's response was that**,** "if you're supposed to drink them at eight, four hours shouldn't pass if you forgot to drink them at that time…to this day, I still do that." Here, adherence to ARVs is understood as non-negotiable, if not unconscionable.

Indeed, for Vista this kind of self-discipline or stoicism becomes a way both to elevate "my CD4 count, which is currently very high", and of boosting "my immune system." After all, as he argued later in the interview, "without your immune system, you're nothing". In fact, "when your immune system is high, that's when you feel as if you're succeeding in life. To be honest, ARVs have given people life, especially those who are like me with positive

minds. They also decrease your clinic visits as you are not sick as often as you were before. You become healthy and go back to square one, before you fell sick. That's what made me realise that ARVs are the best." We might also note here that this perspective sets out clearly the criteria for differentiating those that are 'good' from those that are 'bad': courageously and actively struggling against regressing to a state of helplessness, whereby visits to the clinic become a regular feature. Most of all, it is in terms of the prospect of assuming control over health outcomes that ARVs have raised personal accountability as a criteria of judgment in the struggle against HIV/AIDS.

Yet, as Minkler (1999) has observed about responsibilization with respect to personalized health management, actions that are individually responsible do not always automatically produce desirable aggregate outcomes. The emphasis on personal responsibility pervading the policy guidelines reviewed above, or as depicted by the participants' narrative accounts above, is far from extraordinary. Indeed, what it demonstrates is an attempt at producing or normalizing self-management as an imperative for navigating everyday life on ARVs. We might note as well that the understanding of enrolment onto ARVs as a personal responsibility aligns the production of a subjectivity so inclined with the imagined population of PLHIV staking a claim to their right to life and healthcare.

Nevertheless, as some of the narratives show, the commitment to personal responsibility while on ARVs is not unwavering or cast into subjective consciousness indefinitely. Though for some it is a principle they have endorsed and live by, it does not always align comfortably with the other demands or expectations of daily life.

Like all the participants, in his account Ojay was very clear that he is devoted to taking ARVs responsibly. A father of three children who was in his mid-40s at the time of the interview, he was diagnosed with HIV in 2000 after a persistent cough that would not go away. For him, a diagnosis of HIV was less disheartening than it had been for some of the other participants that had been interviewed, maybe owing to the fact that he was immediately enrolled onto ARVs after first being on treatment for tuberculosis and his kidneys were subsequently compromised.

Ojay clearly recognized the huge importance of ARVs for his well-being: "No, there are things I can forget, not them. Sometimes though, 8:30 am passes without my taking them and then I would drink them at 10. True, I would have forgotten to take them at 8:30 am, but then I would take them eventually." When he was asked about what ARVs mean for him and his sense of living with HIV, without equivocation, he gave the response that "They saved my life a lot."

However, as he later noted, "Once I stopped taking them for a week, just to see what would happen. After a week I began to cough a lot, and then lost weight." When the interviewer probed him for an explanation for this decision, he admitted that "the thing is...it is like this, my brother when your CD4 count is less than 200, (and you know there are no jobs now) you could go and register for a disability grant, you see. And then you get it. Then you can support your child and you yourself can eat, you see. Now, if the CD4 count is more than 200, you get no grant. But you have to take these pills, and these pills you take for life. Now you have no job…So I thought I should stop taking these pills, to reduce my CD4 count. That's why I had stopped taking these pills."

His narrative hence suggests that it is the danger of not being able to provide for himself and his children that makes him discontinue ARVs. In this instance, he constructs a life-long commitment to ARVs as portending the risk of taking away his only means for gainful welfare, which is a compromised CD 4 count leading to HIV illness.

Within his narrative account, there is also recognition by Ojay that, "Looking at it carefully, it hurts to reduce your CD4 count for the sake of money." However, for him it is also "painful to take these pills without food…because of unemployment." He noted that the "the issue is complex…" for when he has attempted to look for employment in order to sustain his enrolment onto ARVs, "they ask you how old you are and when you are above 30, they don't take you." Moreover, "when you go register for a disability grant, they say you don't qualify. You then go and see the doctors, they say "stay on that treatment, permanently."

Posing a rhetorical question in concluding his response, "but how do you take these pills when you have had no supper", he seemed to suggest that at times he feels tethered to a powerless position between continuing with his ARVs or compromising his health in order to receive a disability grant. If there is a choice between the two options while he is still unemployed, he seems to be suggesting, it is economic or financial, even at the risk of bearing with the consequences of discontinuing with ARVs.

Everyday and scientific discourses certainly construct enrolment onto ARVs as involving cost/benefit trade-offs, with implications for constraining economic, social or aesthetic choices (see Persson, 2004, 2005; Mfecane, 2011). In other words, in such ways of understanding the processes of negotiating a life-long commitment to ARVs, there will inevitably be complex compromises entailed in enlisting for ARVs and sticking to prescribed

regimens. However, rather than seeing the difficult choices, such policies as reviewed in this article and their related programmes place more emphasis on physical survival, often underplaying the real fears and concerns on which delays to enrolment and inadequate adherence to ARVs thrive. As a result, for some people there may be a felt pressure that unyielding commitment to ARVs is the one and only choice. This is not to say that there should ever be a toning or scaling down on the imperative for an absolute dedication to ARVs. Rather, we can consider its implications as fraught with feelings of ambivalence on the part of those to whom it speaks to or is directed.

Take, for instance, the case of Hlali, who was around his late 20s when he was interviewed. Also diagnosed with HIV in 2000, when he had a recurring skin problem, he was very clear that ARVs have made a world of difference for his general well-being and particularly his skin condition. While the fear of stigma or discrimination was less of a challenge for him having disclosed his HIV seropositivity to everyone he knows, he still admitted to the psychical ambivalence that comes with depending on ARVs for managing HIV.

More specifically, for him the challenge is that while at the clinic "they do mention the fact that you should not drink alcohol whilst you're on ARVs, but as you know, you're still young you want to hang out with the guys." In these terms, for him being on ARVs feels like being "caught" between acknowledging his sense of youthful vibrancy and checking its potential for disruptive effects on his condition of living on ARVs.

Indeed, the incongruity for Hlali is aggravated by the feeling relayed through his depiction that, "it's as if you're living on them, it's hard". Also in play in all this is the uncertain issue of how to be himself with his friends, even with their knowledge and acceptance of his HIV

seropositivity: “Sometimes you’re hanging out with someone in your shack and its 21:00 and you have to drink them, now you have to hide yourself. I have to make excuses to be able to drink them. It’s tough...it’s tough. It’s difficult living with the fact that at a certain time there are these pills you have to take.”

In the end, however, he conceded that “but this is your life, there is nothing you can do, you have to take the pills.” Thus it is that, for some, the choice to live with the limits to personal autonomy when on ARVs is a less pressing issue when it is only a matter of readjusting a social lifestyle than one also layered on top of economic destitution or precariousness. This ambivalence is evinced also by fears over the prospect of experiencing the egregiousness of anti-HIV drug side effects, which may lead to delays in enrolling for ARVs, if not disruption of adherence.

For example, Nondumiso, who was in her late 20s when she was interviewed, valiantly postponed starting on ARVs until she had absolutely no choice. Unlike the other women participants interviewed, she discovered that she is HIV-positive when she became very “seriously ill” in 2002. In her words, diagnostic test results showed that “my CD4 count had dropped to 164. I told them at the clinic I would not take them. I did not have a child then. Better that I die than take ARVs, I had thought, you see.” However, she was compelled to start on ARVs when she became pregnant “for the sake of living for my child”, but even then, she noted that she “still remained stubborn” and “procrastinated”. Indeed, she felt that she “was not ready” until she became very “sickly and no longer enjoyed life.” At this stage, her ambivalence about ARVs overpowered any knowledge or vicarious experience she had of the value of ARVs for her HIV seropositivity.

When probed for clarification of her resistance to starting on ARVs, this was her response: "People were saying these pills make you mad; that they change your shape; people would say so and so's shape has changed because of these pills." In their association with a non-idealized, non-normalized or undesirable psychical and bodily state (Persson & Newman, 2006), the possibility for ARV iatrogenic effects seemed to evoke for Nondumiso a return to a form of unwelcome visibility of HIV seropositivity, perhaps not unlike that described by Mary earlier when she reflected on her experience of discovering that she is HIV-positive.

In fact, for Nondumiso, as later her depiction illustrated, enrolment into ARVs signaled for her the prospect of an unwelcome and undesirable body shape change, an issue that we see in her response would eventually erode in significance for her with the passing of time and enfolding of know-how about ARVs: "someone told me that her shape has changed owing to these pills…when I looked at her body, I also noticed that it was out of shape. So I preferred dying to having my shape change. At that time, I was still interested in possessing a good shape. But then I changed my attitude and accepted the treatment, only because I did not have a choice. I took the treatment, and experienced none of the shape related side effects." Nondumiso's account highlights most forcefully the importance of another fear about the effects of ARVs - disintegration of a valued body image of oneself.

The last three cases thus illustrate in their various ways the powerful effects of already ingrained subjective positionalities, even when one's prospect of achieving health is at stake. Taken together, however, all six accounts suggest that ARV enrollment and the responsibility attached to it is a binding and lifelong choice, with both the potential to be fulfilled but also far more ambiguous than the logic of the policy framework upon which it is based allows.

Concluding thoughts

The HIV/AIDS policy framework discussed above sets up antiretrovirals enrollment as connoting a claim to citizenship; after all, the battle for ARVs was waged on the basis of the premise that the right to healthcare and dignity should be extended to all, whether HIV-positive or not (see Cameron, 2005; Geffen, 2010; Mbali, 2013).

Even more important, it determines that the ARV programme is contingent on the capacities and actions undertaken by individuals. To effect this transformation, to bring about the willingness for self-governance, the subjectivity of people living on antiretrovirals is recast as a central mechanism for achieving success with ARVs. With no apparent coercion, voluntary self-government is represented as an important tool for ensuring a well-functioning programme for ARVs and enhancing the everyday experience of living with HIV. It is envisioned that the ARV programme will work well only when individuals living on ARVs exercise self-discipline and personal and social responsibility. While its traction or hold is not without fault, as some of the accounts from the interviews demonstrate, this perspective is for the most part endorsed by the participants as it allows for greater control and capability over HIV (Venkatapuram, 2011).

What then is the lesson to take from this? From the perspective of this article, in order to understand how it might be possible to produce subjectivities more inclined to follow the routine of living on ARVs, it is necessary to inquire into the norms underpinning the constitution of subjects capable of self-responsibilization.

Moreover, it is important to acknowledge that such constitution has effects that are contingent rather than permanent as a consequence of the unpredictability of everyday experience. In

other words, living on ARVs as an everyday experience is a strategic field that is never closed but always open to outcomes that may work in alignment but also against the standards upon which it is constituted, thus making responsibilization on ARVs a state in flux, not a fait accompli.

Together with analyzing the rationalities associated with the governance of ARVs enrolment, a comprehensive governmentality inquiry needs to take account of the multiple features of lived reality, including making visible the role of uncertainty in personal lives, not least when living with HIV.

CHAPTER SEVEN

Critical reflections

In this penultimate chapter, it is useful to revisit chapter three to six in this thesis to draw out some of the more important threads, insights and concerns with a bearing on the conclusion that follows in the next chapter. With this general schematic in mind, the discussion that follows below is intended to do more than provide a summary. Steered by the aims outlined in chapter one, it is also important to offer purposeful and considered critical reflections on what it means to be HIV-positive at the present moment of ARV accessibility in South Africa.

While not in any way exhaustive, the research reported in chapter three to six presents us with a possible framework in which to begin to better understand the contours of HIV-positive subjectivity today and maybe to even imagine the future direction they are likely to take as more HIV biotechnologies are introduced and made accessible.

In undertaking the research reported in chapters' three to six, the hope was that the thesis would make both a theoretical and empirical contribution to understanding the various ways that political, civil and individual claims and rights in post-apartheid South Africa have influenced ongoing public health initiatives aimed at angling the response to HIV/AIDS towards impelling the self-governing capacities of PLHIV. An analysis of the transformation wrought by the introduction of ARVs in post-apartheid South Africa goes some way in drawing out the making of an HIV-positive self-governing individual taking shape in the current moment.

The advent of ARVs, alongside related developments in diagnostic and prognostic technologies, has certainly propelled the struggle for equal recognition of PLHIV before the rule of law and in society. Simultaneously, a governmental rationality advocating rational and responsible individual behaviour in ARV care has taken root, with implications for HIV-positive subjectivity. If we consider Robins' (2004) point, recapitulated by Decoteau (2014) and Pienaar (2016), the emblematical 'rights bearing' HIV-positive subject of the lobbying for ARVs is also one encouraged to command him/herself.

To take up both the theoretical and empirical implications of the aforementioned governmental rationality, the studies reported in the thesis have analyzed the link between the collective claim to the basic right to healthcare for PLHIV - as exemplified in the struggle and the ensuing attainment of access to ARVs in public health facilities - and the spotlighting of subjectivity as the focal point for (re)constituting who the HIV-positive subject is or should be. Once human beings are thought of in terms of possessing a subjectivity that is intervenable, the conclusion is that they could be encouraged or made pliable for intervention for the good of everyone.

If there is one value that stands out consistently from the studies reported in the thesis, it is that of personal responsibility and the related terms that converge around it - for instance, individual rights and empowerment, as well as self-determination. It is in the language of personal responsibility that the struggle for access to ARVs in the public health sector in South Africa was a topic or issue of contentious debate, with the parties involved differentially and in disagreement setting the terms upon which it is to be understood, experienced and evaluated with respect to the rights already afforded by the South African

constitution to every citizen. For those who rallied behind the cause for ARVs, it was important that this did not preclude PLHIV.

The more general standpoint of the thesis is that the way matters of fact are rationalized, verified and even hotly debated, provides insight into political, social and moral imaginaries, most particularly for who we believe we are and could be. After all, it is around an 'affecting' hope placed upon the prospects of personal responsibility for restoring self-worth and dignity that PLHIV are encouraged to understand and experience living with HIV in the era of ARVs. In short, emerging from the studies reported in the thesis, the rights bearing HIV-positive subject of ARV enrolment is one constructed to be in possession of the capability of taking personal accountability.

The Foucauldian framework of governmentality (see Rose, 1999, 2008; Foucault 2000; 2008; Shoshana & Samimian-Darash, 2014) helped with conceptualizing the power heralding the making of a self-governing HIV-positive subjectivity as an effect of either a hoped for and shared feeling for access to ARVs or actualized enrolment with the upscaling of the ARV programme. For Cruikshank (1999), as a form of subjectivity, taking personal responsibility is often set in motion by obligations to internalize the power to command oneself.

The thesis started with the sub-aim of investigating the placing of subjectivity into public discourse during the struggle for ARVs. Chapter three and four, for example, analyzed the conflictual debates between the state and AIDS lobbyists over the prospects of a self-governing HIV-positive subjectivity. The political significance of the debates was in exalting to public discourse the role each individual with HIV could play in his or her governance.

In chapter three the analysis that was carried out expands on the most common analyses of the debates (see Schneider, 2002; Schneider & Fassin, 2003; Heywood, 2003, 2009), with their emphasis on their political and legal implications. Instead, the analysis centred on a Foucauldian analytic of power and subjectivity. Not claiming to offer completely new insights, the deployment of the analytic nonetheless opened up a way for rethinking the important role of subjectivity in the disputes.

Departing from previous analyses, chapter three was developed around linking AIDS denialism with the discourse of the African renaissance. Underscoring the important point that the struggle for ARVs centred on securing the equal right to health and dignity for PLHIV, drawing upon existing literature (see Kistner, 2001; Robins, 2004, 2005; Cameron, 2005; Nattrass, 2007; Geffen, 2009, 2010; Mbali, 2013) including on the work of HIV/AIDS treatment lobbyists, it was possible to draw out a comparable outline of subjectivity from the viewpoints of both the stakeholders in the conflict.

The discussion will only highlight a few of the main points about how the coupling of AIDS denialism with the vision of the African renaissance weighs up in view of the transformative work of ARV lobbying for HIV-positive subjectivity.

The subject of discretion, in a Foucauldian sense, is called upon to exercise her or his own government. Likewise, the two sets of antagonists in the debate rightly represented as so diametrically opposed, illustrated the way they engaged subjectivity demonstrated the mode that power takes when it structures possible actions rather than enforcing outcomes. For the antagonists self-governability entailed a presumptive capability for independence of mind, along with action. In their varying ways, for the antagonists psychological life was the object

of governability and the medium for producing self-governability. An individual is either a victim or survivor of personal, social and historical circumstances, both of which involve a particular fracturing of the mind. Indeed, both sides seemingly approached the potential for mental transcendence through setting free the mind from the repression of all kinds of social, physical and psychological vagaries that make living with HIV odious, threatening and precarious.

Extending on a similar point made by Posel (2005) and Bawa (2005), the combination of the AIDS denialist and the African renaissance perspective projected the liberation of PLHIV onto the ideal of a new African subjectivity (as discussed in chapter three, Mbeki's so-called 'new African patriot') articulated with the vision of the African renaissance.

For their part, echoing both Cameron (2005) and Geffen (2009, 2010), it is argued in chapter three that the ARV lobbyists conceived of their share of their kind of escape from the pain wrought by HIV/AIDS for PLHIV in sub-Saharan Africa and the developing world as tied to attaining access to the best that medical science has to offer, including ARVs and other related treatments for HIV.

All in all, this puts a whole new perspective on the antagonists' very divergent views on the potentiality having knowledge offers as a pathway for autonomy and psychological emancipation. Of course, knowledge as a tool for salvation and cultivating a social conscience meant very different priorities for the antagonists.

While ARV lobbyists maintained a much clearer and commendable focus on saving lives through the deployment of biomedical scientific knowledge, the state's policy was a source of

a great deal of confusion[18]. If the attempt to make a linkage stands up to critical scrutiny, and here the argument presented is particularly indebted to both Butchart (1997, 1998) and Phillips (2012), the assortment of AIDS denialism and the African renaissance discourse drew on disaffection with colonialism, apartheid and the history of scientific racism during both periods to discredit a western scientific view. However, the consequences were as perilous as they were callous to the cause of many suffering from HIV/AIDS.

As is well-known, the deadlock drew to an end through a number of court verdicts against the state, the most significant of which, the PMTCT case, was addressed in chapter four of the thesis. We might say, then, that for both the antagonists something about having the power to act independently, being your own master, encapsulated their view of restoring self-worth to PLHIV. Significantly, in terms of the actual consequences for PLHIV, the work of ARV lobbyists was more effective in generating a positive discourse of self-government.

What strengthened the discourse of self-government under the aegis of the lobbying for ARVs? Still working with the sub-aim of investigating the placing of subjectivity into public discourse during the struggle for ARVs, chapter four tackled this aspect.

Taking cue from Foucault (1982) in *The subject and power* and Butler (1997) in *The psychic life of power*, alongside Tie (2004), Campbell (2009) and Kiersey (2014) in their respective attempts to incorporate an analytic of affectivity into an analytics of governmentality, chapter four takes account of the idea that the form that power takes generating subjectivities is not only discursive but also affective.

[18] For an extended and very compelling account of AIDS denialism and the resistance marshalled against it, especially from both a scientific and political economic perspective see Nattrass (2007, 2012).

More specifically, chapter four presented the argument that the activities waged to advance the adoption of a policy for issuing and upscaling ARVs in the public health system in South Africa were not singular in their productive capacity and action. Beyond the way the argument for PMTCT was politically, morally and scientifically rationalized, the lobbying for PMTCT also entailed galvanizing collective affectivity, with individual interests merging to produce what is in the interest of all PLHIV.

With the application of the combination of an analytics of governmentality combined with Ahmed's (2004a, b) insights on the *Cultural politics of emotion*, in the context of the discussion in chapter four, a case is made that the desire for self-governability was both formed and reinforced via the binding social ties anchored around a democratic civic virtue, social and political solidarity.

Aided by the constitutional prerogative and guarantee of the right to reproductive health (see Budlender, 2001; Heywood, 2003, 2009), the lobbying for ARVs made common cause with pregnant women living with HIV to be afforded the autonomy to take measures to protect their babies from HIV transmission. Along with the demonstrable success of a pilot programme for PMTCT instituted by ARV lobbyists in the Western Cape (see Meerkotter, Bullington, Young, Swawr & Heyes, 2001; Geffen, 2010), the court victories in 2001 and 2002 were a portent symbol of the prospect of self-determination for pregnant women living with HIV and other PLHIV.

The analysis, owing inspiration to Ahmed (2004a, b), is that the form of despair that intensely or passionately 'moved' many to mobilize for ARVs on behalf of pregnant women living

with HIV should not be equated with passivity. Rather, it served to ground the hope for autonomy for all PLHIV. Additionally, it is argued in chapter four that the mobilization for PMTCT was aimed at making PLHIV politically active and capable of self-government. In other words, the everyday individual predicaments mixed with the hopes of PLHIV constituted the foundation of the political activism for ARVs.

The activation of political activism driven by the desire for self-government, as Robins (2004, 2008), Mindry (2008) and Geffen (2009, 2010) have also hinted, appears to point very strongly to the significant lesson that individual autonomy might be rearticulated for a vision constructed around social justice.

To be sure, chapter three and four offer partial analyses of inarguably very complex disputes over HIV/AIDS policy. The hope, however, is that the analysis undertaken helps to shed some light on the kinds of encouragements, expectations and obligations placed upon subjectivity at the present moment of ARV roll-out.

Chapters five and six were guided by the second sub-aim, the concern with exploring how subjectivity is made intelligible in the contemporary moment, in view of the emphasis on human rights to which the existing policy on the HIV/AIDS treatment or therapy programme makes recourse. Today, as during the apex of the struggle for ARVs, when people speak about the rights of PLHIV, it is usually from both the implicit and explicit understanding of their right to self-government.

In chapter five, the theoretical combination of an analytics of governmentality and Foucault's (1990, 1992, 1993) approach to the ethics of self-care framed the thematic content analysis of

a well-known HIV advice column in one of the popular South African magazines. As pointed out in chapter one and two, the choice to sample an HIV advice column is in keeping with the idea of tracking public consciousness on HIV related subjective reflexivity in the aftermath of the struggle for ARVs.

Indeed, what immediately stands out from the analysis is that knowing and caring for oneself is not an obvious subjective posture for every individual living with HIV and enrolled for ARVs. In a certain way, it is an exercise in learning to govern oneself and to be 'free', whereby one could choose to live responsibly.

In the HIV advice column, knowledge and self-care is advocated as a choice to make, a value or an ethical choice, in the sense of Foucault's (1992) definition of ethics as 'the self's relation to itself', that is amplified in plausibility and tenacity by the lived example of the advisor, publicly HIV-positive herself and well-known for her work to normalize HIV/AIDS in South Africa. For those seeking advice on enrolling for ARVs, or even interested readers of the advice column, the ethical directive to knowledge and self-care implies acting responsibly and optimally to achieve the end of curbing HIV. Countering HIV, it is generally advanced in the HIV advice column, demands knowledge of options and regularity of self-care.

The value of knowing and caring for oneself implies that reaching HIV physical and psychological health, as well as making the most out of living on ARVs, is up to each person and that PLHIV need to take their freedom and use it wisely, or responsibly. It is as if, as a choice to make, enabled by accessibility to ARVs, equipping oneself with detailed knowledge coupled with the willingness to take care of oneself opens the way for achieving the utmost

HIV physical and psychological health outcomes. To underscore the point differently: knowing and caring for oneself is presented in the HIV advice column as the most moral of choices to make for oneself and perhaps even for others who may be affected by the choices one decides on.

Linked to eligibility or risk criteria for ARVs, including the advice on stabilizing viral load or improving the CD 4 count is also crucial if we are to gain a tangible grip on the subjectivity conjured up in the HIV advice column analyzed in chapter five. Self-government, here, is stressed by presenting psychological self-management as a strategy of stabilizing viral load and improving the CD 4 count.

Psychological self-management constitutes personal risk management. In Sangaramoorthy's (2012, pg.) words, "risk…is treated as an inherent part of the individual, alluding to an internal state of vulnerability." Likewise, for Persson and Newman (2006), the link between personal risk and psychological self-management with respect to ARVs, viral load and the CD 4 count contributes one axis alongside other ways in which subjectivity is rendered governable and self-governing.

To clarify this last point, it is important to consider that there is also something to be gained by recognizing the significant role affectivity plays in the kind of subjectivity the HIV advice column maps out for uptake. This aspect, it could be argued, has often been overlooked by South African and international researchers (see Wilbraham, 1996; Asera, Bagarakayo, Shuey & Barton, 1997; Binkley, 2009; Beatty & Lambert, 2013) who have examined advice columns and other self-help forums. Indeed, it could be insisted, the constitutive power of a self-help forum such as an HIV advice column is both pedagogical and affective.

Consider one of the examples from the HIV advice column on the feeling of disenchantment linked to "I started ARVs last year…my weight is very unstable…I worry about my image…" The response from the columnist is equally revealing of the elicitation of affectivity encompassing the HIV advice column: "embrace your new weight…it all begins with a thought and thoughts become things". Central here is to understand the power of the medium to produce an alternative thought and feeling about HIV or ARVs.

According to the HIV advice column knowledge and self-care come together, ultimately, with the willingness to seek out professional assistance. Not ready for ARVs? The most likely response from the advice columnist is that "many fear ARVs based on hearsay", and then to also "encourage you to speak to health professionals about your fears." The implication is that the potential for rational calculation of options for ARVs or just facing down HIV comes with individual empowerment by rational persuasion from expert guidance.

Thus far, the connecting thread in the thesis is the persistence of the discourse of self-government as largely equated with taking personal responsibility. However, it is in chapter five and six that we start to see that self-government is an acquired and sometimes unsteady disposition.

Therefore in chapter six, the juxtaposition of a schematic analysis of three sets of HIV/AIDS policy guidelines with lived accounts of ARVs yielded interesting insights about the actual implications of the principle of rational and responsible choice underlying enrolment for ARVs. An analytics of governmentality was utilized for developing the schematic analysis

and a thematic content analysis was applied to the lived accounts. Between the HIV advice column and HIV/AIDS policy, the latter is more indirect in organizing subjectivities.

Revealing a governmental rationality of economization, or as some (see Brown, 2003; Ferguson, 2011; Hickel, 2012) would say, neoliberalization, the three set of guidelines advocate the principles that delivery of ARVs in the public health system, as with other HIV/AIDS services they address, should run efficiently, transparently and accountably. Monitoring and evaluation is also prioritized, along with the importance of benchmarking the national ARV programme to international 'best practices' and guidelines.

At the individual level, the principles translate to enjoining PLHIV to make responsible and rational choices. They imply that taking personal responsibility is synonymous with the right to ARVs, self-preservation and restoring dignity. To be sure, the guidelines varyingly raise such interventions as psychosocial preparation to be coupled with enrolment for ARVs, or making follow-ups of people lost to ARV treatment services for provision of psychosocial guidance. Nonetheless, the main thrust of the criteria is anchored around fostering self-management capability.

The central point which chapter six tries to convey in examining the guidelines is that their recognition of the individual rights of PLHIV and their undergirding penchant for promoting self-government cannot be held apart. They reinforce and amplify one another, echoing each other, while shoring up the prospects for PLHIV to act responsibly and rationally with regard to enrolling for ARVs.

However, taking up or sustaining a rational and responsible subjective posture to ARVs is still only probable. After all, each day for PLHIV can present both undesirable challenges and consequences for living on ARVs. Let us expand on this from the point of view of lived accounts of people enrolled on ARVs.

The transition from one self to another is not straight forward. Between actuality and possibility lies a host of contingent decisions with unpredictable outcomes. Decision-making entails the capacity for rational choice but there is also an affective dimension to it. This is especially the case when the choice involved pits self-understanding as currently construed against a differentiated idealized self not yet attained. Juxtaposed with the policy guidelines, living on ARVs is affirming and raises hope for overcoming HIV, yet it is also saturated with sacrifices, tensions and uncertainties.

In chapter six, it is noted in relation to the lived experience of ARVs that taking adherence seriously may be valued for its proven potential to restore physical health, and social and psychological dignity. Nonetheless, adhering is still a decision to be made amidst the twists and turns of everyday life. The point is that choosing a course of action "is unconditionally, irreducibly, non-transferrably referred to an infra-individual zone of indistinction with affect" (Massumi, 2015a, pg. 9). In other words, deciding on a course of action might entail a form of psychic battle, which at its most conflictual for an individual produces contradictory affective states, say, resistance or ambivalence and the contrary feeling of hopefulness. Until a decision is made, each affective state can equally define the course of action.

This point is evinced in some of the lived accounts, revealing that the ability to sustain adherence to ARVs is always in-flux. In at least half of the cases, there are hints that

sustaining adherence may encompass sacrificing financial security, an uninhibited sociability and an idealized body-image, with affective dissonance being the probable underlying instigation of such concerns but also the consequence. In turn, behavioural inconsistencies relating to ARV treatment adherence are more likely to occur, although also reversible. Here the point is that, even when equipped with the right knowledge and the wherewithal to be self-caring, living on ARVs may sometimes be affectively and behaviourally precarious.

Perhaps what is different about the analysis in chapter six with respect to previous research (see Leclerc-Madlala, 2006; Nattrass, 2006; Uzochukwu *et al*., 2009; Peltzer, Friend-du Preez, Ramlagan & Anderson, 2010; Kagee, 2008; Kagee, Remien, Berkman, Hoffman, Campos & Swartz, 2011) is the acknowledgement that the range of sacrifices entailed by living on ARVs are heightened by the affective agitation of having to decide on a course of action each day and strongly being enjoined to cultivate a particular kind of subjectivity.

Ultimately, for subjectivity, the implications comprise the knowledge that adhering to ARVs is a sensible and wise choice for oneself. At the same time, the feeling of uncertainty may loom large over the decision to act, owing to the personal sacrifices acting on the knowledge will require from oneself. Tension and anxiety is therefore inseparable from making the responsible choice of following ARV treatment regimen. In short, uncertainty is part and parcel of living on ARVs. The decision and action to live on ARVs involves making sacrifices and substituting the rational and responsible choice of adherence for existing health risking propensities. Such tradeoffs may arouse tension. Returning to Massumi (2015a, pg. 11), affectivity and rationality "reciprocally determine each other", and they are concurrently constitutive of subjectivity and action.

Now let us return to where the reflections took up speed and sum up the main thoughts on the force of this dynamic of the making of subjectivities both influenced, and in turn, self-ruling in the context of the opening made possible by the availability of ARVs.

Starting from the struggle for ARVs, the thesis has assessed the rapid transformation towards individualism that HIV-positive subjectivity has undergone until the contemporary period. It is not, of course, that the bent or shift in HIV/AIDS mitigation strategy towards individualization is altogether new in the history of the global struggle in relation to HIV/AIDS. Indeed, information, prevention and awareness interventions virtually from the time of the discovery of HIV/AIDS in the West, including its rapid and virulent proliferation in the developing world over the course of its history in the last thirty five years or so, have almost always cohered around fostering or promoting individual responsibility.

While the Western world led and modeled the turn to individualization of HIV/AIDS information, prevention and treatment (see Nguyen, 2005, 2009; Nguyen, Yapo-Ako, Niamba, Sylla & Tiendrébéogo, 2007), the inclination towards the individual gaze has been no less important in sub-Saharan Africa and other underdeveloped countries of the world ravaged by HIV/AIDS.

Even with the prominence stressed upon a strategy such as community mobilization, cohesion and empowerment, which in sub-Saharan Africa especially was the most preferred and even valuable option for designing and enacting HIV/AIDS programmes, it was often operationalized together with and also inside the underpinning of intervening to bring change to subjectivity. In occupational or community settings in South Africa (see Kalichman & Simbayi, 2003; Setswe, Herman, Mokwena & Ram, 2005), for example, interventions aiming

to reduce HIV have often proposed solutions focused on individual behaviour change. The best testament to this is taking responsibility for being tested for HIV.

Innovative advancements in HIV biotechnologies, such as ARVs and related tests for HIV viral load and the CD 4 count, have arguably deepened the spotlight on subjectivity and the individual body as an important axis of intervention for managing HIV/AIDS. Knowledge, self-care and self-management: the triad undergirding and intensifying the predilection to individualization that comes with ARV accessibility.

The papers presented in the thesis reveal that the implication of the dynamic triad at the level of the fabric of everyday existence encourages a reassertion of individual agency and cautious exercise of personal choice. In the context of the ongoing upscaling of enrolment for ARVs in South Africa, the most rightly valued view of exercising freedom of choice prizes making educated and health sustaining choices. Taking care of oneself makes it possible to continue to benefit from ARVs.

In theorizing the kind of subject formation emerging from both the struggle and introduction of ARVs in South Africa, the thesis is indebted to Foucault's formulation of the regime of individualization in the contemporary epoch of neoliberalism in his lectures at the Collège de France in 1979, *The Birth of Biopolitics*. He theorized that neoliberal subjectivity is self-entrepreneurial, "a form of relationship the individual has to himself, time, those around him, the group, and the family" (Foucault, 2008, pg. 242). A self-entrepreneurial subject invests in himself for an anticipated income - monetary, psychical or otherwise.

Here is the central argument of the thesis: with ARVs, a self-entrepreneurial HIV-positive subjectivity has its sights set on a physical and psychological return for investing in its well-being. In other words, self-entrepreneurialism is taking personal responsibility for ARVs in pursuit of physical, social and psychological dignity and longevity.

Like any discourse of individual empowerment or psychological emancipation, the discourse of personal responsibility for ARVs is grounded, in the final analysis, on a collectivizing or biopolitical imperative. What it achieves, to appropriate Robins (2004, 2008) and Pienaar (2016), is to join what PLHIV choose and accomplish in their own individual capacity to broader public health goals of curtailing or mitigating HIV/AIDS or even eradicating the problem of ARV drug resistance. In this way, then, what is individual is simultaneously social (Rose, 2001, 2007).

The effects are twofold. First, improvements or reversals at the individual level accumulate at the social level. Implicitly or explicitly, this is always the implication of the call to rational action with respect to living on ARVs. The second effect is that cumulative social achievement or failure has a bearing at the micro-level of the individual. Any reversal at the macro-level is a blow to the hard won gains of the struggle for ARVs for individuals at the micro-level.

What emerged out of the epic battle for ARVs, undergirding the prevailing current public and policy orientation to ARV care, was the combination of an optimistic rationality and a hopeful affectivity for the potential of fashioning an HIV-positive subjectivity contiguously responsibilized and self-responsibilizing. However, at the experiential level of living on ARVs, where autonomy is one with self-regulation, self-responsibility is an unpredictable

undertaking of navigating the affective tumult of hopefulness, uncertainty, sacrifice and tension.

CHAPTER EIGHT

Closure

In this final and brief chapter, the limitations and strengths of the research reported in the thesis will be discussed, together with possible directions for future research.

The analytic approach utilized in the thesis may be described as encompassing the combination of a theoretical and empirical lens, with the former having a much stronger presence since the research reported advanced, for the most part, theoretical analyses.

With the exception of chapter three - which developed a summative exegesis of the debates around ARVs through the register of public addresses, lectures and the existing literature - the main chapters of the thesis included analysis of empirical data. The data from chapter four to six included court affidavits, advocacy materials, advice column letters, policy guidelines and interview data. In each case the analysis was grounded on the solid qualitative methodological principles of a thematic content analysis. The breadth and scale of the data is a particular strength of the thesis.

In the thesis, the dominance of a theoretically driven abstraction over an empirically developed or oriented analysis, however, has perhaps resulted in the research tending to lean more on theory rather than conducting a ‘naturally occuring’ analysis of the gathered empirical evidence. Since the theoretical framework has driven the research in this thesis; future research utilizing a more inductive approach may offer additional insights and levels of analysis.

Taking into consideration only the views from chapters three and four, one might easily conclude that the analysis of the emerging contours of HIV-positive subjectivity in the post-apartheid democratic dispensation in South Africa is perhaps more sweeping, aphoristic and even repetitive than is probably the case in reality for PLHIV.

As a counterweight, the strength of chapters five and six is the introduction of an appreciation of complexity entailed in the composition of HIV-positive subjectivity, taking into account the lived realities of PLHIV. With the addition of these chapters - although in different ways - of an analysis of the experience of living on ARVs, they both manage to tame a teleological representation of subjectivity as described in chapters three and four with the ambivalence inherent in lived reality with its possibilities and challenges.

There is a clearly a lot to be said in favour of a 'truth' driven approach based on a rigorous empirical grounding and analysis, yielding more systematic evidence. Unlike a purely theoretically grounded analysis, empirically based approaches offer more concrete than abstract explanations (see Braun & Clarke, 2006), and also allow either for the testing of causal claims or richer and deeper analysis of phenomena than is perhaps possible with theoretically driven research (see Terre Blanche, Durrheim & Painter, 1999).

The analysis undertaken in the thesis has admittedly rested more on theoretical descriptions, even with the inclusion of empirical analysis and evidence. Perhaps condensed too thinly over a very large surface, consisting of both the period during and after the struggle for ARVs, the analysis might be said to be schematic and to lack the kind of immersed engagement that might allow for more nuance and deeper insight into the very complex

policy related events and social practices, as well as personal experiences analyzed in the thesis.

Still, the integration of a diversity of materials has perhaps validated the analysis of HIV-positive subjectivity developed in the thesis. Following existing global and local literature (see Bawa, 2005; Nguyen, 2005; Biehl, 2007), one can be fairly confident that the HIV-positive subjectivity sketched in the thesis is a useful outline, even if the argument can be advanced that the details constituting the often very different experiential realities of PLHIV must be treated individually and contextually.

However, if the very process of providing or upscaling ARVs requires enlisting subjectivities for its success, from the perspective of the thesis it also made sense to inquire into the constitution of subjectivities capable of self-governance. In effect, chapters three to six focused on the productive nexus between power and subjectivity, as well as policy and individual subjects.

In the thesis, power is understood as widely dispersed - simultaneously constitutive of subjectivity and materialized by it (see Butler, 1997). Within an analytics of governmentality (see Foucault, 1982, 2000), power encompasses both the aspect of governability and self-government, with subjectivity the remit around which they rotate.

Accordingly, in analyzing mainly some of the 'macro' events around the struggle for access to ARVs, social practices and everyday experiences after the introduction of a policy for upscaling ARVs in the public health sector in South Africa, it became possible to understand the transformational value of enabling ARV accessibility for HIV-positive subjectivity.

South Africa is still only a short distance down the line from the struggle for ARVs, but has also moved some way down the road away from the almost complete helplessness and dejection that may be said to have characterized a life with HIV for the many impoverished PLHIV before the introduction of ARVs into public health facilities.

Between the combination of the spirit that drove the courageous lobbying for ARVs and the legacy it bequeathed to HIV-positive subjectivity is a commitment to equality of access for everyone to common public goods, in addition to transforming the subjectivities of PLHIV. Indeed, some existing literature (see Budlender, 2001; Friedman & Mottiar, 2006; Mbali, 2013; Pienaar, 2016) has addressed extensively the heritage of the struggle for ARVs in the currency of a gained achievement for social justice and equality of access to public healthcare services for PLHIV.

The placing of responsibility at the personal level that the thesis has sketched is not without the consequence of overlooking the reality that there is, in fact, a co-composition between the structurally occurring and individual experience. As van Loggerenberg *et al*. (2015) have found in their study in South Africa, personal encouragement and assuming responsibility to adhere to ARVs is possible only if you also take note that this rests on and is augmented by the availability or accessibility of public healthcare services, a compassionate and caring public health workforce, as well as a political and social ecology accepting of ARVs.

To put it briefly, subjectivity is embedded: dependent on power for production, it is plied through the complex interaction between structural and social formations constituting lived experience.

During and after the battle for ARVs, a key pillar related to the end of achieving equality of access to public healthcare services for PLHIV was and continues to be the attention afforded to the constitution of self-governing HIV-positive subjects. If it is judged purely on this criterion, the thesis has managed to the extent that it has to throw light on some of the discursive and affective processes related to the anchoring of power in HIV-positive subjectivity, a tropological placeholder for a wide-ranging and even complex set of individual experiences with ARVs for PLHIV.

Three points stand out in terms of implications for the direction of future research:

1) For a number of authors (see Tie, 2004; Burkitt, 2005; Murray-Li, 2009; Brinkley, 2009, 2010; Brady, 2014; Scharff, 2016), working within the framework of an analytics of governmentality, understanding how power is enabled and materialized by subjectivity would require unraveling how it is both temporally and spatially enacted in everyday life - with all its complexity. At the level of the fabric of everyday existence, with both its promises and challenges, the subjective prospects for rational behavioural choices and action can turn out to be either optimistic and habituated or pessimistic and unpredictable.

What the thesis has demonstrated is the operation of a governmental rationality of cultivating self-government capacity undergirding the struggle and scaling up of ARVs in South Africa. Shifting preferences from day to day, however, may complicate the capability for adopting and sustaining self-government. Even when equipped with the ability for self-awareness or having the willingness to be self-caring, enabled by the acquisition of the knowledge for achieving successful outcomes on ARVs, acting optimally does not follow automatically.

If the interface between power and subjectivity established in the thesis is any guide, the implication to be drawn is that combining an extraction of the types of rationality and transformative affective mechanisms in play in the organization and actualization of subjectivity opens up the opportunity to offer meaningful descriptions of the experience of living on ARVs.

2) In an attempt at bridging the public with the personal, drawing upon the framework of governmentality it was possible in the thesis to outline the discursive and affective threads during and after the battle for ARVs with implications for the founding or conversion of HIV-positive subjectivity. The bridging conducted in the thesis thus needs to be more explicitly conceived as openness to triangulation in the gathering of data.

The utilization of triangulation in the thesis has enabled a more extensive picture of how the discursive terrain interfaces with the subjective. Very rarely have any related studies attempted to do this. In most cases, studies have relied exclusively on individual interviews with PLHIV on ARVs, drawing linkages with broader discourses only from the interview material. Future research could triangulate more and perhaps play with balance of different data sources.

3) The act of making an educated and responsible choice on ARVs for the obvious interest of keeping oneself away from impairment by HIV is susceptible to unpredictability and fluctuations of stability and instability. Although often summed up by indicators of barriers and facilitators of ARV adherence (see Ware *et al.,* 2006; Skhosana *et al.*, 2006, Johnson *et al.,* 2011), what precedes the summation is a subjective life churned by the likely alloying of

the desire to be responsible with uneasiness and ambivalence. Understanding demands constant vigilance grounded on an ongoing gathering of evidence.

Nothing is ever settled, not least subject formation in relation to ARVs. Past, current and future selves may be as varied from each other as two different people. To ponder on the interaction between living with HIV and the well-recognized life altering undertaking of enrolling and living on ARVs is thus to acknowledge the prospects for locating future research in the reconciliation of the relation of a fabricated subjectivity and the individually and contextually aligned specifics of its incarnation in everyday life.

In conclusion, let us now return to Nguyen's (2005, pg. 143) claim, rehearsed earlier in chapter one, about the ostensibly life changing potential inherent in ARVs for "representations of the disease, and in turn, the subjectivity of those who are able to access them." While the significant interest in ARV adherence is understandable in light of the epidemiological threats of high non-adherence rates, it does run the risk of diverting attention away from other equally significant areas of investigation.

One unfortunate consequence of developments in ARVs is that they have re-inscribed the dominance of behavioural and health sciences research approaches in HIV and AIDS interventions (Mykhalovskiy & Rosengatern, 2009). This has been at the cost of more dynamic and theoretically engaging research. The focus on treatment adherence certainly exemplifies this trend. Without a doubt, these dominant approaches have yielded very useful insights that have not only strengthened the lobbying for cheaper and accessible HIV/AIDS treatment for developing countries but also the treatment programmes that have been subsequently instituted.

These approaches, however, are also limited. The research reported in thesis has perhaps represented an attempt to move away from this emphasis towards the interconnection of power and subjectivity in which the prospects of experience are engendered, although they are also clearly fluid and open to adaptation in everyday life.

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A1C ACHMAT ZACKIE, 1999-2006

New York Times article on ZA and his refusal to take ARV's, May 2003; Speech by Achmat at Microbicides conference , April, 2006 -"Make truth powerful- leadership in science, prevention and the treatment of HIV/AIDS; "We can use compulsory licensing and parallel imports - a SA study" by ZA for the Conference "Increasing access to essential drugs in a globalized economy , held in Amsterdam, Nov 1999; Various articles and photos; John Foster lecture delivered by ZA on "HIV/AIDS and human rights " a new SA struggle; Article written by ZA about Ronald Louw, a friend living with HIV but who was in denial, undated; Invitation to ZA from world Bank to meeting on ARV treatment in June 2003.

M1A MEDICINES CONTROL COUNCIL (see also DRUGS)

M1A.1 2000

Biozole generic for fluconazole (diflucan); Delay in registration of (No Suggestions); ; TAC press release responding to attacks on TAC by MCC, Oct 2000 re Biozole and Pfizer; Memorandum of meeting between Helen Rees, MSF and TAC, Feb year? on use of section 21 by MCC; Declaration of doctors to MCC re Biozole generic for fluconazole (diflucan see and response from Helen Rees; Memorandum from TAC to MCC, 24 Nov, 2000; Record of meeting with Helen Rees and MH, 27 Nov ; Response from MCC re Biozole applicate on behalf of Brooklyn clinic; MCC grants a conditional exemption for importation of generic fluconazole (section 21) 30 Nov 2000; Participation on Fluconazole working group by MH, Nov 2000.

M6 MOTHER TO CHILD TRANSMISSION

Mother to Child Transmission Constitutional Court case (handed down in July 2002) including what happened after case in Constitutional Court see also Medicines Control Council and also C4.16.

M6.1 Various documents

Including: 2000; WHO new data on the PMTC transmission of HIV, 2004 - report warned of severe reactions, Houston Chronicle; 2005; Safety and tolerability of Zidovudine - a review of literature.

M6.1.1 1998-2000

MH - Possible legal arguments on the issue of access to AZT to prevent MTCT, 1999; Letter to Glaxo welcome, April 1999 " AZT for pregnant women with HIV" from Peter Busse and Sharon Ekambaram, Gauteng TAC co coordinator.

M6.1.2 2001

Side effects; Adv. Geoff Budlender 2002 April, amendment to Nevirapine affidavit July 2001 by ; Availability of Nevirapine for patients in the public health sector , letter from DOH to Adv. Budlender; Offer from Boehringer Ingelheim , Donation programme' offer of free Nevirapine made in July 2000 to developing economies for prevention of MTCT(2001); Anita Kleinschmidt The constitutional rationale for provision of AZT to pregnant women with HIV, "working paper to provide the basis for the discussion of a legal strategy seminar at the ALP"; "Taking responsibilities seriously- the role of the SA state in preventing Transmission of HIV from Mother to child", Jonathan Berger, 2001 for the Univ of Toronto.

M6.2 2002

Statements by ANC Youth League on order to provide Nevirapine, March 2002 and SA Communist Party on (No Suggestions) statement criticising the roll out of Nevirapine in Gauteng, Feb 2002; Transcript of interview with Ayanda Ntsaluba with Freek Robinson, April 2002; New application by TAC in Nevirapine case, Jan 2002; Circular Minute (from government)on prevention of MTCT wrt Constitutional Court's interim order, 16 April 2002; correspondence between Geoff Budlender and various provincial Health depts. after the Concourt case was handed down 6 July)as well as Dr Ntsaluba, DG of Health, July -September 2002.

M6.3 2003

Letter from Ntsaluba to Adv. Budlender "HIV/AIDS the prevention and treatment of opportunistic infections, (April 2003); TAC lodges complaint with the SA Human Rights Commission re contempt of court of the Concourt order by the Dept. of Health of Mpumalanga - letter from LRC (Adv. Budlender) to MEC for Health requesting reply from DOH, 2003 responding to request of April 2003; Letter to TAC from Adv. G Budlender re Manana MEC of Health, Mpumalanga) contempt application including letter from Office of the State attorney (20 March 2003); Affidavit of Nonkosi Khumalo, in TAC v MEC for Health, Mpumalanga, Case no 35272/02; Mark Heywood "Preventing MTCT in SA: background, strategies and

outcomes of the TAC case against the Minister of Health" in SA Journal on Human Rights, 2003; Briefing on a two-day visit to PMTCT programmes in Mpumalanga, May 2003 by Steven Robins.

M6.4 Congratulations to TAC/ALP re Concourt Case, July 2002

M6.5 Nevirapine

Registration of Nevirapine registration briefing by MCC, August 2002 in Parliament; Letter to the Minister of Health by Adv. Geoff Budlender (August 2003), - "What will happen if MCC withdraws approval of Nevirapine? - "the government will be obliged to make other provision for treatment to reduce the risk of PMTC transmission of HIV" correspondence with Medicines Control council re registration of Nevirapine, 2002.

M6.6 Articles and data on Mother-to-child-transmission in provinces from 2002 onwards.

N1 NATIONAL AIDS CONVENTION OF SOUTH AFRICA (NACOSA) 4 files 1994-1997.

N1.1 A National AIDS plan for South Africa; Draft constitution for NACOSA.

N1.2 Minutes of NCC meetings, Exec. Committee meetings and others 1995-97.

N1.3 Miscellaneous NACOSA documents 1994-1995 Includes Regional NACOSA Conference Feb 1995; plan for 1995-1996.; contact addresses.

N1.4 Miscellaneous NACOSA documents 1996-1997.

Includes: Report of the National Lobbying office to the NCC (May, Aug-Sep 1996).

Strategic planning workshop report (Oct 1996).

Proposal to the South African Rugby Football Union to adopt NACOSA for 1997 (Sept 1996).

Media statement by NACOSA on Sarafina 2 and the Public Protector’s report, 1996. correspondence

T2 TREATMENT ACTION CAMPAIGN (TAC)

T2.1 Documents

Constitution, Overview, background and introduction to TAC, minutes of NEC meetings, (2001-2002); documents relating to 1st congress March 2001 and Gauteng Provincial Congress, July 2003 ; discussion document on TAC work and structure until Oct 2002 Business plan and proposal for fundraising support.(2001) Also: Rationale and Proposal for a National HIV /AIDS prevention and treatment plan.

2002. TAC Memorandum: Defiance Campaign against patent abuse and profiteering. 1f 1999-2002; State, Civil society and the reconfiguration of power in post-apartheid SA by Ran Greenstein, August 2003, contains profile of the TAC.

T2.2 Treatment issues 1f

Includes TAC pledge, informative articles on nutrition, HIV fatigue, Antiretroviral Therapy , side effects, women with HIV (Treatment issues for women: Discussion document, prepared by Vicci Tallis for the TAC, 2002), clinical trials, Opportunistic infections etc. Issues of 'project inform' and 'wise words'.

National AIDS drug policy (Brazil)

T2.3 Miscellaneous documents, fact sheets , plans for Global March, July 2000

T2.4 Save our babies campaign'. 1f 2001

Messages of support from medical staff signatures for a petition, in a campaign to provide (No Suggestions) to pregnant mothers to prevent transmission of the virus

T2.5 Correspondence (emails) and other documents 2f 1999-2001

Correspondents include Zackie Achmat, Quarraisha Karim, Mark Heywood and others. Includes a letter to USA Vice-President Al Gore re pharmaceuticals, (1999) and a memorandum addressed to Jacob Zuma, to be presented during a march for AIDS treatment 2000.

T2.6 NAPWA-TAC 1f 1999

Correspondence and documents re campaigns (see also N2)

T2.7 Treatment Action Campaign vs Minister of Health

Notice of motion and other documents in a matter: 'Treatment Action Campaign vs Minister of Health' (2004). Also submission, and documents in response to the TAC submission, regarding the proposed merger between Glaxo Wellcome PLC and Smith Kline Beecham PLC 2000.

T2.8 Treatment literacy

Evaluation of 2004 TAC treatment literacy programmes; paper on the TAC treatment literacy programme, Funding request for financial years 2004/5 to 2007; Treatment literacy report - in various provinces ; Email correspondence between Sipho Mtathi (National treatment literacy co coordinator) and other TAC members re organisation of programmes 2004; SADC regional plan for treatment literacy (TAC, ARASA

AIDS and Rights Alliance for Southern Africa and CHMT Community Media Trust), report on TL mobile campaign in George; HIV and access to treatment, presentation to TAC treatment literacy workshop , 2003 by Marlise Richter.

T2.9 TAC/TAG workshops

SA and US speakers with agenda; 3 day "teach in" held in Durban, Johannesburg and Cape Town, Nov 2000.

T2.10 TAC Secretariat

TAC evaluation dated June 2005 by Jacqui Boulle and Tenu Avafia; Notes to contribute to a discussion on the reorganization of the TAC, Mark Heywood, May 2007; Overview of 3 provincial structures of the TAC, Eastern Cape, KZN and Mpumalanga, 2007, Teleconference minutes of 8 August 2007 and Agenda; TAC treatment programme strategy planning meeting minutes, 29-30 July 2007; minutes of TAC Women's reference group national meeting 1 August 2007; TAC National Executive committee meeting 20-21 September 2007 incl a report of the TAC provincial and district organisational review processes; Financial report for TAC, TAC minutes of the NEC meeting May 2007.

T2.11 TAC civil disobedience campaign see also Mbeki

TAC briefing document on Civil disobedience ,March 2003; Questions and answers on their civil disobedience campaign; Breaking the law - civil disobedience campaigns and strategies by Marlise Richter, 2003; Civil disobedience resource pack from TAC; Gene Sharp - 198 methods of non-violent action.

T2.12 TAC Treatment Project

Aim is to extend and improve the quality of life for treatment access activists in SA by making HAART available. Launched 2003. Funding proposal, Oct 2003; Work plans ; guide to patient selection; ARV treatment protocol by Dr Kwezi Matoti, June 2003; Work reports; TAC Treatment Project board meetings

T2.13 Mpumalanga TAC office - Workplan, budget ; Terms of reference for the evaluation of the TAC in Mpumalanga, 2006

N4 NOTIFICATION OF AIDS 3f 1998-1999 (see also Confidentiality, C3) plus 1999, 2000.

N4.1 Various documents

Including: Contribution by MH to, Disclosure and surveillance of HIV infection and AIDS UN 2000, also TAC submission to Health dept. 1999 on adding AIDS and AIDS related deaths to Schedule of notifiable conditions. correspondence with David Miller,(Psychosocial advisor, UNAIDS, Geneva,)also comments on document by Edwin Cameron, invitation to MH to International consultation on HIV/AIDS reporting and disclosure, Geneva, 20-22 October 1999; "conditions facilitating disclosure for PLWA" outline of presentation by Edwin Cameron made 20-22 October , Geneva and, Namibia August 1999, including:

Historical background to AIDS surveillance.

Draft document on AIDS notification (DOH, 7 Jan 1998).

DOH notice re notification of communicable diseases, government gazette no 19946, 23 April 1999.

'Legal implications of the draft notice declaring AIDS to be a notifiable medical condition', (K Barrett and A Strode).

TAC Submission to draft regulation relating to AIDS notification (government gazette no 19946, 23 April 1999) and fact sheet on the prevalence of HIV among women and the dept. of Health's proposed policy on notification of immediate family members and caregivers and letter from Lawyers for Human Rights, (Ann Strode) to the dept. of health and to MH on regulations (which want to make AIDS a notifiable condition, 22 July 1999.

Workshop report: 'Making AIDS a notifiable disease – the gender implications' (Commission on Gender Equality, 14 July 1999.

A review of the proposed regulations to the Health Act to make AIDS disease and AIDS death notifiable medical conditions. By L Forman.

Comments by Mark Heywood on Ron Bayer's report "Public Health and surveillance in the HIV epidemic" also included - "public health and surveillance in the HIV epidemic - the role of notification" by Bayer??

Article by Mark Heywood: "Reverse the decision to make AIDS 'notifiable' before it's too late" Undated.

AIDS notification, public health and human rights (ALP reading package).

Documents on international approaches to AIDS notification.

APPENDIX B: ZACKIE ACHMAT, JACK LEWIS PAPERS, AL3165

B1: Formation - 1998-1999

- Notes of Zackie Achmat (mostly handwritten).
- December 1998 Campaign.
- TAC activities in 1999.

B2: Defiance Campaign & Fluconazole Importation - 2000-2002

- Christopher Moraka Defiance Campaign Against Patent Abuse.
- Fluconazole Campaign.
- Press releases and news clippings.
- Discussion documents and agendas.

B3: Prevention Of Mother To Child HIV Transmission (PMTCT) - 2001-2003

- TAC v. Minister of Health (2001 case heard in the Transvaal High Court, 21182/2001).
- TAC v. Minister of Health (2002 case heard in the Constitutional Court, CCT 8/02).
- Background materials on PMTCT.
- TAC activities around PMTCT.

B5: AIDS Conferences - 2000-2004

- AIDS XIII (July 2000, Durban, South Africa).
- AIDS XIV (July 2002, Barcelona, Spain).

B6: Global Activities - 2000-2004

· National AIDS Treatment Advocacy Forum (USA).

B7: Partner Organizations - 1999-2004

· Congress of South African Trade Unions (COSATU).

· Faith Based Organizations.

· Medicin sans Frontiers (MSF).

B8: Community Education and Media - 1999-2004

· TAC Leadership School.

· Treatment Literacy Series.

· Phila newsletter.

APPENDIX C: LETTER OF INTENT TO AIDS CONSORTIUM

Dear Denise

Until early in 2008 I used to work and report to Professor (name deleted for anonymity) at the Human Sciences Research Council. After discussing with him this afternoon the nature of the project I am about to embark on he referred me to you.

Specifically there are two reasons I am writing to you. Firstly, I see this email as an initiative on my side to establish contact and a relationship with AIDS Consortium for the immediate and distant future. The broad thrust of my research interests is in HIV and AIDS related research, with a particular interest in the mental health/ HIV and AIDS nexus. In an attempt to improve the relevance of any research I am either currently or intend embarking on I believe it is important to establish contacts with organisations involved in service work. From this perspective, this email constitutes such an attempt.

Secondly, I am currently intending to undertake a research project for my Ph.D studies to speak to people over the age of 18 years who have been using ARVs for the last 3 to 5 years. The purpose of this project is to speak to them about what this treatment means to them. In order to do this, I will need some form of contact with AIDS service organisations registered with AIDS Consortium.

This could happen in one of two ways. One possibility is an invitation to attend a forum where I could meet representatives of different AIDS service organisations registered with AIDS Consortium. This will off course depend on whether this kind of forum is open to members of the public. The second possibility may be a direct request for a contact list of appropriate organisations registered with AIDS Consortium. Alternatively both options could also be considered. At this stage I would just like an indication of whether any of them are possible or whether AIDS Consortium would be able to assist.

I trust that you will find this acceptable and I look forward to hearing from you.

With kind regards,

Nkululeko Nkomo
Lecturer: Department of Psychology
School of Human and Community Development
University of the Witwatersrand
328 Umthombo Building
☎: +27 11 717 4542
🖷: 0865534929 ✉: nkululeko.nkomo@wits.ac.za

APPENDIX D: RESPONSE FROM AIDS CONSORTIUM

From: Denise Hunt

Sent: Thursday, September 02, 2010 11:17 PM

To: Nkululeko Nkomo

Cc: Rhulani Lehloka

Subject: RE: Greetings

Hello Nkululeko,

Thanks for your mail. We do have monthly meetings with AC affiliates, who are primarily CBOs working in HIV service delivery at grass roots level, some of which are HIV positive and on treatment themselves. This monthly 'bua@AC' meeting takes place on this Tuesday 12 – 3pm in Orange Farm. Please feel free to join us? Let me know if you are able and need more details.

Secondly, at that meeting, you could meet with Rhulani Lehloka, our Communications Manager, who is running a campaign on Stigma with identified 'Community Champions" who may be happy to chat to you. A number of them will be at the meeting too,

Warm regards

Denise

APPENDIX E: PARTICIPANT INFORMATION SHEET

Hello, I am Nkululeko Nkomo, a student at the University of the Witwatersrand in Johannesburg. I am asking people over the age of 18 years who have been using ARVs for the last 3 to 5 years to speak to me about what this treatment means to them.

From my understanding, a growing number of people in South Africa are using ARVs. These questions that I want to ask will hopefully help create better understanding of what the availability of this treatment has meant for people like you and others in a similar situation. Hopefully, the information you give to me will also help our government, non-profit organisations and other stakeholders to plan effectively from a more informed position.

Please understand that you are not forced to participate in this research and the choice whether to take part or not is yours alone, but I would really appreciate it if you do share this information with me. If you choose not to take part, you will not be affected in any way whatsoever. If you agree to take part, you can stop at any time. If you stop at any time you will also not be affected in any way. A list of free mental health services in Gauteng has been compiled and can be freely issued to you should you consider seeking the assistance of a mental health professional.

This interview will be confidential. What you share with me will stay between you, me and my academic supervisor. The information you provide will be written up into a report and scientific articles in order to share with other researchers, health practitioners, policy-makers and so on what living with HIV and AIDS and on antiretrovirals has been like for you.

I also ask for permission to tape record the interview. The choice whether to record or not, once again, is yours alone. Recording helps me to keep a record of everything you say. If you agree that I can record the interview, your name will not be mentioned on the tape recorder, and if you want the tape recorder switched off at any point during the interview, or you want something erased, I will do that. Direct quotes by you may be used, but they will not be identified with you.

The interview will last around 45 to 60 minutes. If you find this explanation acceptable, and you do agree to participate in this research, I would like to request that you are as honest and open as possible in answering the questions.

With kind regards,

Student: Nkululeko Nkomo
Tel: (011) 717 - 4542
Academic Supervisor: Professor Carol Long
Tel: (011) 717 – 4510

APPENDIX F: INTERVIEW SCHEDULE

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a) How did you find out about your HIV status?
b) What was this like for you at the time?
c) How did you find out about ARVs and when did you get on them?
d) What has your health been like since?
e) How important do you think your health is to how you see yourself?
f) What does being on ARVs mean to you?
g) How did it come to mean this to you?
h) Looking back to the time when you first found out that were HIV positive and what this meant to you at the time, how has being on ARVs changed your perspective on being HIV positive?
i) For a long time since the dawn of democracy there has been this rift between our government and other stakeholders on what the country's treatment policy should look like.
j) How did you view this disagreement?
k) How do you think it shaped your perspective on ARVs?
l) How do you think it shaped your perspective on being HIV positive?
m) What is your view on the changes in style in the country's policy on HIV and AIDS under the new leadership of the ANC and South Africa?
n) How do you think this will affect you as a person living with HIV?
o) How do you feel in general about the future for people living with HIV and AIDS in South Africa?
p) Do you have anything else to add?

APPENDIX G: ETHICS CLEARANCE CERTIFICATE

HUMAN RESEARCH ETHICS COMMITTEE (NON MEDICAL)
R14/49 Nkomo "

CLEARANCE CERTIFICATE: PROTOCOL NUMBER H100904

PROJECT TITLE: Exploring the interplay between HIV and AIDS treatment in discourses and subjectivity in South Africa

INVESTIGATOR(S): Mr N Nkomo

SCHOOL/DEPARTMENT: Psychology/Psychology

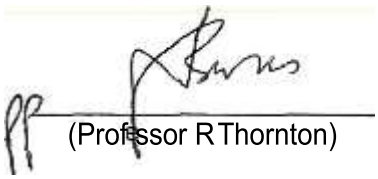
DATE CONSIDERED: 17.09.2010

Dc: VISION OF THE COMMITTEE: Approved unconditionally

EXPIRY DATE: 16.01.2013

DATE: 17.01.2011

CHAIRPERSON:

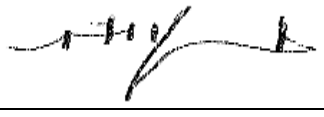


cc: Supervisor: Dr C Long

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and ONE COPY returned to the Secretary at Room 10005, 10th Floor, Senate House, University.

I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. l/We agree to completion of a yearly progress report.



Signature

APPENDIX H: INTERVIEW INFORMED CONSENT – PARTICIPATION AND RECORDING

I _____ consent to being interviewed by Nkululeko Nkomo.

I understand that:

- Participation in this interview is voluntary.
- That I may refuse to answer any questions I would prefer not to.
- I may withdraw from the study at any time.
- The recordings and transcripts will not be seen or heard by any person other than by the researcher and his supervisor.
- No information that may identify me will be included in the research report, and my responses will remain confidential.
- Direct quotes from me maybe used but will not be identified with me.

Signed _____
Do you give me permission to record the interview?

I _____ consent to being audio recorded in the interview with Nkululeko Nkomo.

Signed _____

APPENDIX I: LIST OF FREE MENTAL HEALTH SERVICES

Name of Organisation	**Contact person**	**Postal and physical address**	**Tel and fax**
South African Federation for Mental Health	Mr S Mokgata	P/Bag X 3053 RANDBURG 2125	T:011-781 1852 F: 011-326 0625
Northern Gauteng Mental Health Society		716 Fry Street Waverley PRETORIA	T: 012-332 3927 F: 012 332 3977
Depression and Anxiety Support Group (SADAG)	Ms E Matare	PO Box 652548 BENMORE 2010	T: 011-262 6396 F: 011-262 6350
Lifeline	Ms D Richards	PO Box 32201 BRAAMFONTEIN 2017	T: 011-728 1347/31 T: 011-715 2000 F: 011-715 2001
Schizophrenia and Bipolar Disorders Association of SA	Ms N Van Ginkel	PO Box 1450 CRAMERVIEW 2060	F: 011-507 5024 T: 011-463 9901
Alzheimer South Africa	Ms S Cooper	PO Box 73627 FAIRLAND 2030	T: 011-478 2234 F: 011-478 2251
Bipolar and Related Disorders Group	Mr J Clarke	39 Belgrano Rantkant Crescent CENTURION	T: 012-663 3452