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‘SWIMMING IN CONFUSION’: A QUALITATIVE STUDY OF FACTORS AFFECTING UPTAKE AND ADHERENCE TO ANTIRETROVIRAL TREATMENT IN SOUTH AFRICA

Elizabeth Mills

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Elizabeth Mills is Deputy Director of the AIDS and Society Research, Centre for Social Science Research, at the University of Cape Town.

‘Swimming In Confusion’: A Qualitative Study of Factors Affecting Uptake and Adherence to Antiretroviral Treatment in South Africa[1]

Abstract

In 2007, less than one-third of all HIV-positive South Africans in need of life-extending highly-active antiretroviral treatment (HAART) are accessing it through the public health system. This ‘treatment gap’ poses a significant challenge to health practitioners and researchers given the complex factors that influence the provision (supply) and uptake (demand) of this public health intervention. This qualitative study, conducted in 2006, set out to explore some of the demand-side factors affecting uptake and adherence to HAART among a cohort of HIV-positive people living in the Western Cape. Two significant and interrelated findings emerged from the research: one, political equivocation influenced the use of lay and untested HIV remedies among the cohort, with lay remedies represented as ‘benign’ compared to the ‘risks’ of using biomedicine like HAART; second, psycho-social and physical factors, like hope, stigma and fear or experience of HAART’s side-effects, affected the respondents’ health seeking behaviour. This preliminary qualitative study suggests that political equivocation and national activism compound, and also obscure, nuanced personal responses to managing illness and securing health. In order for the hard-won HAART roll-out to succeed in reaching 80% of all those in need by 2011, as per the 2007 – 2011 HIV/AIDS and STI National Strategic Plan, researchers and practitioners need to consider and address both supply and demand-side factors inhibiting access and adherence to HAART in South Africa.

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[1] Busi Magazi was the assistant researcher on this project, and her contributions to the study are greatly appreciated. Thank you to Professor Nicoli Nattrass from the AIDS and Society Research Unit, at the University of Cape Town, for her comments and critical engagement on this paper.

Introduction

In 1991 Winstone Zulu became the first Zambian to disclose his HIV-status publicly. As his public status grew nationally and internationally, Winstone Zulu's intimate experience of HIV evolved. His internationally acclaimed condemnation of stigma did not preclude him from the local-level prejudice he encountered in Lusaka, and his promotion of 'positive' living became difficult when his physical health was compromised by AIDS-defining illnesses in 1996. At the time Winstone became ill in Zambia, a scientific breakthrough that would later extend his life, was presented at the 1996 International AIDS conference: triple combination antiretroviral treatment (Pickrell, 2006; Nattrass, 2007). With the support of international funding, Winstone moved onto this drug 'cocktail', hereafter referred to as highly active antiretroviral therapy (HAART). He was restored to full health within a month. Winstone viewed his dramatic physical recovery as evidence of HAART's efficacy, and embarked on a new public awareness campaign to promote access and adherence to HAART for Zambians (Nolan, 2007).

At a conference two years later, in 1998, Winstone noticed a group of AIDS denialists staging a hunger strike; his interest was piqued when he noticed that one of the protesters was a Nobel Prize-winning scientist, Kary Mullis. That a Nobel-Prize winning scientist could support AIDS denialist claims – including the claim that antiretrovirals caused rather than treated AIDS – intrigued Winstone. But when he learnt that Thabo Mbeki supported their stance, his engagement with the group was sealed: "Here was Thabo Mbeki, my hero – when Thabo Mbeki questioned it [HAART], I was sold." (quoted in Nolan, 2007: 232). This high-profile 'conversion' resulted in Winston being invited to join Thabo Mbeki's controversial Presidential Advisory Panel on AIDS in 2000.

After stopping HAART, Winston's health quickly declined. Eventually he could no longer deny the nature of his illness when he saw countless friends and members of his family die of AIDS. He also noticed that Mbeki's claim that AIDS was a disease of poverty did not account for the many well-educated and comparatively wealthy people who were dying of AIDS all around him. The combination of his personal loss of friends and relatives, and his realisation of the limits of Mbeki's claims, compelled Winstone to resume HAART. Within a month he was out of his wheelchair, and back to work as an AIDS treatment advocate (Nolan, 2007).

Winstone Zulu's story is unusual, but it is not unique. It is a story of AIDS treatment advocacy networks and health citizenship; of personal struggle masked by public 'positivity'; of new scientific technologies and concomitant hope, risk and uncertainty; of personal and political denial of science; of lives transformed by illness and by HAART. This article illustrates the deep resonance this story has in South Africa – the country led by Winstone's hero, Thabo Mbeki (1999 – 2009). South Africa is home to at least 5.6 million people living with HIV (PLWH); at 11%, South Africa has one of the highest population prevalence rates in the world (Dorrington, Johnson, Bradshaw and Daniel, 2006). Despite South Africa's high HIV prevalence rate, the national government prevaricated on the provision of antiretrovirals to prevent mother-to-child transmission (PMTCT) and then later, to provide HAART to people who were AIDS-sick. The government's prevarication on provision of ARVs for PMTCT has been attributed to a number of factors. The first is economic: the government claimed it could not afford to provide ARVs for PMTCT and it feared that provision of ARVs for PMTCT would force the government to procure excessively priced and patented ARVs for AIDS-sick people (Nattrass, 2007). Another set of factors include ideological concerns such as Thabo Mbeki's engagement with AIDS denialists, his questioning the link between HIV and AIDS, and concern that ARVs were toxic. The latter concern was taken up by his minister of health, Manto Tshabalala-Msimang, who called ARVs 'poison', and recommended that patients choose between a range of healing strategies, including untested HIV remedies and unproven nutritional interventions (ibid).

Civil society activists, most notably the Treatment Action Campaign (TAC), resisted these arguments and challenged the government on the streets and in the courts to provide ARVs for prevention and treatment. In October 2003, seven years after HAART was first presented to the international scientific community, the South African cabinet committed the government to providing HAART through the public health sector. However, the rollout was delayed until March 2004 and proceeded slower than planned over the next few years (Nattrass, 2007). By 2006, 711 000 people were estimated to be AIDS sick and in urgent need of HAART, yet only 225 000 people were accessing it (Dorrington et al., 2006). In late 2006, the government embarked on an unprecedented collaboration with civil society to develop the 2007 – 2011 HIV/AIDS and STI National Strategic Plan (NSP). This document set ambitious targets to improve the uptake of HAART through the public sector, reaching 80% of those in need of HAART by 2011. Ambition, however, has not been met with concrete and sustained action, and in 2007, the goal set for providing HAART to an additional 120 000 has not yet been reached.

The success of health care policy development and implementation, like the HAART roll-out, is influenced by both supply and demand-side factors. Contestation and debate over the provision of HAART in South Africa has focussed predominantly on supply-side factors inhibiting the roll-out, including (but not exclusively): international pharmaceutical companies' prohibitive pricing structures for antiretrovirals; political engagement with pseudo-science; and the inheritance of a poor health care infrastructure from the apartheid government (Buch, 2000; Geffen, 2000; Achmat, Mtathi and Heywood, 2001; Nattrass, 2004; Hassan, 2005; Nattrass, 2007). In addition to these supply-side factors, an important demand-side factor in the intervention's success lies in its ability to recruit members of the population to which it is targeted, and, especially in the case of HAART, to ensure high levels of adherence among its clients. One approach to securing good epidemiological outcomes in industrially advanced countries has been to follow a health systems model of 'responsibilised health citizenship' in which clients are encouraged to bear greater responsibility for ensuring their health. Recognising the structural limitations of this approach for South Africa, activists have called for slightly different approach that combines an effective public health system with community engagement and empowerment of clients through knowledge of health and health care (Robbins, 2005; Robbins, 2006). Drawing on qualitative research conducted with a group of HIV-positive South Africans in 2006, this paper suggests that even with knowledge and access to health care, uptake and adherence to HAART is constrained by a range of factors, including political equivocation on HIV treatment, and physical and psycho-social responses to illness and healing.

The findings are used as a lens through which to explore three related arguments in the discussion below. Firstly, the findings indicate that knowledge of, and access to, health care do not enable uptake and adherence to HAART. The respondents did not regard scientific fact as sufficient 'evidence' for the efficacy of biomedicine. Rather, this paper suggests that the transformative power (both positive and negative) of tested and untested treatments were constructed and evaluated, firstly, from personal experience and, secondly, from the attributions accorded to treatment by various social actors, like politicians, activists, health practitioners and community leaders. The findings and discussion consider the extent to which social actor attributions, particularly those of politicians and activists, have affected the respondent's knowledge of and belief in various HIV treatments. Secondly, although the respondents' understanding and adoption of various HIV treatments were influence by key social actors' attributions, the findings suggest that the respondents' health-seeking behaviour was fundamentally informed by their lived (physical) and felt (psycho-social) responses to HIV treatment. Experience of HIV-related stigma and HAART's side-effects, particularly lipodystrophy, played a significant role in informing the respondents' health-seeking behaviour; therefore knowledge of scientific fact was either confirmed or undermined by intimate physical and psycho-social responses to both HIV and its treatment. In addition to making active decisions regarding HIV treatment based on experience, the respondents asserted their own power to influence the effect of treatment on their illness; personal hope and faith in treatment were regarded as pivotal to the treatment's success. This paper suggests that there is a duality at play between individual responses to treatment and what they are told about the treatment by key social actors: political equivocation and personal experience of HIV treatment are mutually reinforcing. Theories of lay expertification (Epstein, 1996) and citizen science (Irwin, 1995) are explored in relation to the respondents' perception and management of health, illness and the relative risks and benefits associated with untested HIV treatment and new biomedical technologies, like HAART (Leach et al, 2005; Robins, 2005).

Recognizing the danger of political equivocation around AIDS science in both undermining provision and uptake of appropriate HIV treatment, activists and scientists have worked to foreground the benefits of HAART as a life-saving health intervention. A third facet of the discussion considers how, in this context of national activism and political equivocation, some of the subtle personal struggles entailed in taking up and adhering to HAART have not only been exacerbated, but they have also been obscured. The findings suggest that biomedical knowledge and positive experience of HAART's transformative power exist alongside deep and actively concealed fears that HAART was, indeed, toxic. This finding indicates some of the difficulties subsumed by the 'positive' HIV-positive identity promoted by HIV treatment activists. These findings challenge Robin's (2006) description of ritualised 'positive' HIV-positive activist identity within TAC, and his conception of linear transformation from 'bare life' to 'new life' in which activists testify to the 'Lazarus effect' of HAART. The effect of HAART is not uniform, nor is it unilinear in moving the HIV-positive person into health and social re-integration, as Robins (2006) suggests. The findings from this qualitative study suggest that the emphasis on the 'positive' affect of HAART, in part a response to the negative political emphasis on its side-effects, may mask some of the fears and painful experiences connected to HIV treatment.

This research does not aim to represent the views of all HIV-positive people living in South Africa, but to illustrate scope for future research into some of the conflicting responses to HIV treatments, and the complex political and biopsycho-social factors that affect the translation of knowledge into practice through uptake and adherence to HAART. The public and discursive struggle between science and pseudoscience in South Africa is both a consequence and cause of South Africa’s muddied AIDS leadership, compounding the respondents’ intimate physical and psycho-social responses to HIV treatment, leaving them ‘swimming in confusion’. This paper argues that in order for the HAART roll-out to succeed as a public health intervention, reaching 80% of all AIDS-sick South Africans by 2011, social research and analysis needs to move beyond the simplistic dichotomies of indigenous versus modern, science versus pseudoscience, political denial versus AIDS activism, to consider the grey areas of side-effects, stigma, fear and hope associated with HIV treatment in South Africa.

Research Objectives and Methodology

Busi Magazi and I conducted the qualitative research for this study over two months in 2006. The methodology was guided by four theoretical and analytical objectives: a) to understand the respondents’ experiences of HIV-related illness; b) to identify the various HIV treatments they had used over the course of their HIV-infection; c) to explore some of the factors that had informed their health-seeking behaviour; and d) to consider and critique existing theoretical explanations for health-seeking behaviour among HIV-positive South Africans. To this end, respondents with one or a combination of the following characteristics were identified for participation in the study: HAART compliant; defaulted or stopped taking HAART; utilised untested treatments with HAART; opted for untested treatments instead of HAART. Respondents from the first two categories were identified through purposive sampling from a panel survey, conducted in 2004 and 2006 by the AIDS and Society Research Unit, at the University of Cape Town. The survey was conducted with 225 HIV-positive people on HAART who lived in Khayelitsha, an urban informal settlement in the Cape Town metropolis[2]. Thereafter, a purposive and snowball sampling method was used to engage respondents from the last two categories.

In his research, Steven Robins draws on the ‘treatment testimonies’ of HIV-positive activists as they testified to the transformative power of HAART (2006)[3]. Similarly, Arthur Kleinman describes the value of ‘illness narratives’ as a means of understanding the connection between the personal and social ramifications of illness, also referred to as ‘social suffering’ (Kleinman, 1988;

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[2] The survey explored a range of topics including formal and informal employment, perception and experience of stigma, use of traditional medicine, myths associated with HIV transmission and treatment, and experiences of side-effects related to HAART.

[3] As discussed below, however, the notion of evangelical ‘testimony’ can obscure some of the more complex processes of denial, fear and hope.

Kleinman et al., 1997). This study employed qualitative research methods similar to Robins' (2006) and Kleinman's (1988) approaches to treatment and illness respectively (cf. Kleinman et al., 1997). The 'treatment narratives' of nine respondents were recorded, transcribed and then coded using grounded theory, which is sensitive to the implicit belief systems that emerge through the narrative (Strauss and Corbin, 1994; Corbin and Strauss, 1990). The narrative method was used in favour of a more structured interview style in order to allow for new perspectives on illness, health and treatment to emerge without the restrictions imposed by a formal and structured interview format. Written and informed consent was obtained from each of the participants, and for purposes of confidentiality, all the respondents are referred to using pseudonyms.

For reference purposes, the table below presents some of the demographic, household and employment details (at time of research) for each of the respondents:

	Age	**Gender**	**Family and household composition**	**Volunteer activities and sources of income at time of research**
Bongani	44	Male	Lives with parents.	Unemployed; has a disability grant.
Mangwanga	51	Female	Seven children; lives with husband.	Unemployed; collects and then sells second-hand clothes.
Monde	31	Male	Lives with wife and their son.	Makes coat-hangers; has a child grant; TAC volunteer.
Mzimazi	41	Male	Two children; lives with mother, brother and sister.	TAC volunteer.
Nocawa	34	Female	One child. Lives with husband and son.	Administrative assistant, NAPWA.
Nomvula	42	Female	Two children. Lives with mother, brother, sister, son and nephew.	Informal sales of clothes; community health worker.
Ntombi	43	Female	Lives with two children, sister and parents.	Unemployed; community health volunteer.
Sibongile	31	Female	Lives with husband and their son.	Administrative assistant, University of Cape Town; TAC volunteer.
Xolisa	32	Female	Lives with cousin.	Community Development Worker, NAPWA; former TAC volunteer.

Findings

Political Equivocation on HIV Science and Treatment

Three main political actors emerged in the narratives, including President Thabo Mbeki, ANC Deputy President, Jacob Zumu, and the Minister of Health, Manto Tshabalala-Msimang[4]. Of these actors, Tshabalala-Msimang was mentioned most frequently and hence perceptions of her political leadership and discourse of ‘choice’ were chosen as the main focus for this section.

Tshabalala-Msimang, like President Thabo Mbeki, has a track record of questioning the appropriate medical response to PMTCT and the efficacy of HAART, pointing to the toxicity of ARVs. In addition to questioning scientifically established information on the biomedical etiology and treatment of HIV, both Mbeki and Tshabalala-Msimang pursued a discourse of choice, which promoted the relative value of untested HIV treatments compared to the potential toxicity of HAART, for prolonging the lives of PLWH. For example, when Mbeki agreed to go ahead with the universal roll-out (in 2003), he agreed on the basis that HIV-positive people were given information to make them aware of HAART’s side-effects and the range of other treatment options available to them (Gevisser, 2007: 727 - 765). Manto Tshabalala-Msimang took up this discourse of choice through articulating, for example, that, “Yes, there are ARVs, but you do have choices and must be informed and look at options from vitamins, to traditional medicine, to nutrition.” Further, when she spoke to Reuters in 2005 she said, “When we talk about antiretrovirals, I will continue to educate people in this country about the side-effects of ARVs... I have no information that nutrition has side-effects ... your garlic, your lemon, your olive oil, your beetroot.” (Interview with Reuters, 5 May 2005). In addition to Tshabalala-Msimang’s promotion of this ‘nutritional diet’, her equivocation on HIV treatment has opened the door for lay people to promote untested mixtures, which they claim heals HIV-related illnesses (Nattrass, 2007). One such person, Dr Rath, conducts illegal clinical trials with HIV-positive people using vitamins that he claims treats HIV; he has close links with the Department of Health (DOH), and particularly with its funded ‘civil society’ organisation, the National Association for People Living with HIV/AIDS (NAPWA). The narratives discussed below point to three main and interrelated groups affected by

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[4] As reflected at the time of the interviews. Jacob Zuma was subsequently elected President of the ANC at the Polokwane Conference in December 2007. Thabo Mbeki and Manto Tshabalala-Msimang’s political positions remain the same (at the time of this paper’s publication).

Tshabalala-Msimang's discourse of choice, and her engagement with AIDS denialists: South African citizens in general; the respondents in particular; civil society organisations, like NAPWA, to which some respondents belong.

Firstly, with regard to the impact of Tshabalala-Msimang's discourse of 'choice' on South African's in general, the respondents asserted the danger of Tshabalala-Msimang's equivocation on HIV treatment. Mzimazi, for example, is a TAC volunteer, and his statement below reflects TAC's call for Tshabalala-Msimang to provide stronger AIDS leadership, and to recant her statements on the relative benefits of nutrition compared to HAART:

> "Being a minister of health to say something wrong to the nation was not acceptable because we are looking up to them as leaders to bring about good. We were expecting a lot from Manto [Tshabalala-Msimang], but she has confused many people. Many people have since died after taking this garlic and African potatoes she is telling us about. There are some who are still using these things because she has not said people must stop using them." (Interview with Mzimazi, 2007).

In addition to the expectation of clear guidelines on HIV treatment from Tshabalala-Msimang, Mzimazi calls attention to the fact that Tshabalala-Msimang has not withdrawn her statements on the relative benefit of nutrition compared to the toxicity of ARVs. Confusion generated by her ambiguous statements, as illustrated below, continue to affect people's decisions around whether or not to prioritise HAART over non-biomedical interventions like nutrition, Rath's mulitvitamins, other quack medicines and traditional medicine. Mzimazi goes on to state that Msimang-Tshabalala has a mandate, through her position as a leader in a government governed by principles of democracy, to provide unambiguous information on HIV treatment to South African citizens. Additionally, he notes that financial constraints are not, in his opinion, a reasonable excuse for the state's failure to procure and provide HAART in order to ensure that HIV-positive people can live long productive lives:

> "So Manto [must] think carefully, and lead us in the right direction, because we are free now. The government is ours, so I don't see why it is so difficult to use the money for HIV/AIDS, to give a better and long life to people. South Africa is not poor, it is rich… We see when they present the budget, I don't know what her problem is - why she can't to act to prevent many people from dying every day. That's why I am saying we don't really understand what is hindering Manto?
>
> …

> The confusion that Manto is causing is really affecting us. She is not sticking to one thing that is right… If a leader does not want to be straight and tell people the right thing, we are going to be confused. Our leader is not guiding us in a right way. That is the main problem we are faced with." (Interview with Mzimazi, 2006).

Bongani, an HIV-positive and unemployed male respondent, reiterates Mzimazi's assertion that Tshabalala-Msimang has generated confusion through her equivocation on HIV treatment options. He goes on to suggest that although her agenda is unclear to the general population, Tshabalala-Msimang may have a hidden agenda because she is a 'politician'. Additionally, Bongani attributes the Department of Health's failure to address a growing epidemic of extreme-drug-resistant TB (XDR TB) in Kwazulu-Natal[5] to Tshabalala-Msimang's 'evangelical' preoccupation with 'spreading the message' of nutrition:

> "The health minister has caused a lot of confusion in people's minds because the things she is saying people must eat are not new to us. Beetroot is not a new thing. Saying people must eat those was a big mistake, but you never know in politics - people say this while they mean that. They might have a hidden agenda.
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> So while she was spreading the message about nutrition, the XDR TB came… So we have learned that according to TACs research in KZN there were reports about XDR TB last year [2005] in March. So the question from TAC to the health minister was, 'how can Manto be surprised by the findings that there is MDR in KZN when she was told about it in March 2005?' (Interview with Bongani, 2006).

In addition to criticizing Tshabalala-Msimang's focus on nutrition, to the detriment of addressing the XDR TB crisis, Bongani, like Mzimazi, draws on his knowledge of TAC's activism, and its criticisms of Tshabalala-Msimang's focus on nutrition rather than on addressing HIV and concomitant diseases like TB.

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[5] Tuberculosis (TB) accounts for 25% of AIDS deaths worldwide, and nearly 40% of AIDS deaths in Africa (World Health Organisation, 2005). The rate of TB in a township near Cape Town has reached the WHO's definition of a health emergency, with over 4.381 cases per 100 000 HIV-positive people (Health Systems Trust, 2004). TB is particularly pernicious among destitute HIV-positive South Africans, and with the lack of new diagnostic and treatment facilities, the disease has mutated into multi-drug resistant TB (MDR TB) and extreme drug resistant TB (XDR TB).

Tshabalala-Msimang's discourse of 'choice' has also had a direct impact on the respondent's health-seeking behaviour firstly, through her equivocation on HIV treatment, and secondly, through her support and engagement with proponents of untested treatments and lay knowledge around nutrition and traditional medicine, for example. Mzimazi states his association of Tshabalala-Msimang with proponents of nutrition, and attributes his decision to use garlic to heal HIV-related illnesses because he had heard her talking about HIV and nutrition on television (TV):

> "A person I hear about sometimes on TV is this Manto Tshabalala [Msimang], the Minister of Health. I have heard that she is the one who is working with the people who say we must eat garlic and these potatoes of hers. They are not helping but killing us…. She is the other one who confused many people in South Africa, us. I don't want to lie I have used garlic before because I have heard her talking about it on TV and saying it helps heal HIV. I used to buy it and just cut it in pieces and take a piece. And many people were convinced and used the mixture Manto was talking about, so she confused people a lot." (Interview with Mzimazi, 2006).

In addition to his personal confusion around appropriate treatment for HIV, Mzimazi went on to discusses how members of his HIV support group, too, were confused. Concerned to address the opportunistic illnesses members of the group were experiencing, they drew on a range of tested and untested treatment; Mzimazi describes this 'trial and error' process as a means to evaluate the positive or adverse effect of different treatments had on the support group members. The excerpt below illustrates how the support group responded to a woman, Thea, who came down from Johannesburg to promote her 'unique' HIV remedy of fish oil and garlic (among other things). Like other white or foreign proponents of untested treatments (like Tine van der Maas and Mathias Rath), the example of Thea's fish oil and garlic remedy challenges the simple dichotomy of 'western' versus 'traditional' medicine, and draws attention to the opportunistic use (from both the supply and demand side) of various HIV treatments:

> "We previously had a white woman visiting our support group by the name of Thea. She showed a mixture of fish oil, garlic and other things. She said those things can heal HIV. So there were about five people in our support group who were using the mixture Thea was telling us about.
>
> But they died one after the other... So our support group leader said we must not use that mixture again because there are four people

> who died before us while they were healthy before taking that mixture…
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> Other people in the support often talk about these medicines but it's not easy for people to talk about the things they do on the side to treat themselves." (Interview with Mzimazi, 2006).

Thea's fish oil and garlic mixture is one example of a plethora of untested HIV treatments that are peddled to HIV-positive people in South Africa. Another example is Dr Rath, whose campaign has encouraged PLWH to stop HAART in favour of high doses of his untested vitamins. TAC has charged Tshabalala-Msimang and the Medicines Control Council with responsibility to stop Rath's illegal actions, claiming that Rath's trials have resulted in the premature deaths of people who moved off HAART onto Rath's unregistered trial[6]. In addition to the dangerous impact his vitamins have had on AIDS-sick individuals, Rath's campaign has also undermined the scientific authority of HAART's efficacy through its campaign to 'educate' the public on HAART's toxicity and the collusion of HAART advocates, like TAC, with large pharmaceutical companies[7]. The following extract from an interview with Sibongile, an HIV-positive women currently on HAART, illustrates the 'turf-wars' that have taken place between Dr Rath and TAC in Khayelitsha:

> Sibongile: Pamphlets were distributed [by the Rath Foundation], and newspapers were talking about Rath - how Rath is helping some people; they described how multi-vitamins help.
> Elizabeth Mills (EM): Where did they put the pamphlets?
> Sibongile: They gave them to the people. Some are displayed at bus shelters, lots and lots of them on all the bus stops in Khayelitsha. On the sides of the bridge from top to bottom and it was scary. The pamphlets had a baby that was very thin and looked like a skeleton, saying that the baby was destroyed by ARVs and the other baby was handicapped because the mother of the handicapped baby took AZT. … But TAC put up [new] pictures all over Khayelitsha.
> EM: Really? What did they put on the pictures?
> Sibongile: They put people who are taking ARVs over the posters.
> EM: And what do those people look like?
> Sibongile: Like normal people, they are healthy and they are fine. They are smiling and saying how many years they have been taking ARVs. (Interview with Sibongile, 2006).

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[6] TAC's Electronic Newsletter. Accessed on www.tac.org.za. 23 February 2006.

[7] The Rath Foundation. Accessed on www.dr-rath-foundation.org. November 2006 – October 2007.

Despite TAC's efforts to dispel Rath's claims that HAART was toxic, two respondents had opted to take Rath's vitamin treatment in place of HAART. Xolisa had stopped taking HAART altogether in favor of the vitamins, and Nocawa had decided not to start HAART although her CD4 count was below 200 and she was AIDS-sick. A number of factors affected these respondents' decision to take Rath's vitamins. Firstly, they both worked with NAPWA, an organization that is closely aligned with the DOH and the Dr Rath Foundation, and which has taken up Tshabalala-Msimang's discourse of choice, as illustrated below. Secondly, Xolisa and Nocawa expressed a range of concerns about HAART's side-effects, and the importance of living 'positively' without HAART until they were 'ready' to take on the side-effects and life-long commitment entailed in the HAART program. The latter is discussed in more detail in the following section. The promulgation of Tshabalala-Msimang's discourse of 'choice' by NAPWA is evident in Xolisa and Nocawa's narratives in which they view Tshabalala-Msimang's equivocation as consultative, and as respectful of local knowledge and practices.

> "Our position as NAPWA is that we must not focus on one side like TAC focusing on ARVs. We must tell people that there are options; people must choose whether to take ARVs or traditional medicine. People must have a choice they must not be forced into taking ARVs… There is a problem of side effects from … D4T: it changes the shape of the people[8]… Their stomach goes up and the arms and legs are getting too small. I think Manto is scared about these things." (Interview with Nocawa, 2006).

Nocawa's statement suggests a connection between her assertion that people should be given 'choices' and the dangers associated with ARVs, like lipodystrophy. She goes on to suggest that Manto (Tshabalala-Msimang) is concerned about these side-effects, and that this accounts for NAPWA's focus on giving people options to enable them to make choices with regard to HIV treatment. The following statement indicates the respondent's perception and support of Tshabalala-Msimang's approach as it validates local knowledge and lay responses to various illnesses:

> "I support her [Tshabalala-Msimang] because she is saying she knows that we used herbs; like there is a green herb that people take

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[8] D4T is an anti-AIDS drug that disrupts the replication of the virus, and also reduces the amount of the virus in the body. In 1997 it received full approval as an initial therapy for the treatment of HIV-infected adults with advanced immunodeficiency, when used with other HIV drugs. It has, however, fallen out of favour as a first-line therapy due to the increased risk of body fat side-effects, known as lipodystrophy (see www.aidsmap.com/cms1032406.asp). Nocawa's description of the body shape changes refers to lipodystrophy.

> when they have fever, so they have experience of that medication. That medication can also treat opportunistic infections. There are those who believe in that medicine, even I because at home they used to give me that medicine." (Interview with Nocawa, 2006).

Like Nocawa, Xolisa suggests that the nutritional foods Tshabalala-Msimang has promoted are basic food stuffs that should be incorporated into a healthy diet. Just as Nocawa represents Tshabalala-Msimang's discourse of 'choice' as a form of consultative equivocation that engages people and practices 'on the ground', Xolisa suggests that civil society organizations, like TAC, are 'up there' and neglecting the views of the people 'on the ground':

> "You see now, some are swearing and say the health minister is the minister of beetroot. Those foods are helping some of us. We grew up eating garlic, beetroot, spinach. Our grandparents grew up eating those things and you will never see old mamas go to hospital because they always eating healthy foods like pap, samp and cabbage. But now it's like people never heard about this.
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> …
>
> NGOs that are dealing with HIV and AIDS … are not focusing on people who are living with HIV and AIDS. They are up there and not hearing our views on the ground. They are supposed to ask us if we want we want sangomas, traditional healers, Dr Rath's drugs and ARVs. They are supposed to ask people on the ground: what is your view?" (Interview with Xolisa, 2006).

Tshabalala-Msimang's equivocal stance on the relative benefits of ARVs versus unproven alternative treatments has had a layered effect on the three groups discussed above. An indirect effect of Tshabalala-Msimang's equivocation on HIV treatment is perceived by Mzimazi and Bongani to have generated confusion around appropriate HIV treatment among South Africans in general. Secondly, and more specifically, Tshabalala-Msimang and her department's failure to shut down quacks, like Thea or Matthias Rath, as well as her engagement with lay knowledge and healing practices, has affected the respondents directly. Sibongile and Mzimazi, for example, both refer to their awareness of the availability of untested treatments in Khayelitsha, and in support groups. Mzimazi, too, refers to his attempt to become healthier by eating large amounts of garlic, as per Tshabalala-Msimang's nutritional recommendations. In addition to generating general uncertainty amongst South Africans, and specific confusion among the respondents, the narratives suggest that Tshabalala-Msimang's discourse of 'choice' has also been taken up discursively at an institutional level within NAPWA.

Physical and Psycho-social Responses to HIV Treatment

In addition to the uncertainty generated by Tshabalala-Msimang's discourse of choice, there are a range of interconnected physical and psycho-social factors that have influenced the respondents' health-seeking behaviour. The extracts below indicate that these factors include: fear of HIV-related stigma; the importance of having faith and hope in the treatment; fear and experience of HAART's side effects; and lack of care from and distrust in biomedical health practitioners. Physical and psycho-social responses to tested and untested HIV treatment are interrelated, and in some cases, they are also compounded by the political and discursive struggle between proponents of AIDS science and pseudoscience.

The convergence of HIV-related stigma, fear of HAART's side-effects and the importance of having faith in treatment is evident in Mangwanya's 'treatment narrative' below. Mangwanya, a 51 year old HIV-positive woman, initially described her decision to use traditional medicine because she had noticed that the people using HAART lost weight. Typically, when PLWH become ill they lose weight, and they gain it when they start taking HAART. Individual responses to HAART, however, are not consistent, as illustrated in Mangwanya's account of her HIV-positive sister's death while on HAART.

> "The reason I chose traditional healing is I noticed that the people who use these pills [ARVs] lose weight more and more. So I decided to take a different route and speak to this woman to help me with traditional medicine… It's easy to see the HIV positive people taking pills. I noticed from my sister who died; she was taking medication for HIV.
>
> …
>
> I never told anyone, no one knows, only this woman knows (her healer). I kept my status to myself for fear of being ridiculed in the community; I thought they will always refer to me as a person with AIDS…. So I told this woman behind closed doors, and said, you know I have a problem here. She asked what was the problem. I told her that I have AIDS... She gave a traditional medicine and I am not feeling sick now.
>
> …
>
> No one knows about my status except this mama [traditional healer]. I said to her she must never, never tell anyone because it's my secret. I think the fact that she came live next to my house was God's plan because I am not really into traditional medicine but

> since I met her I now use traditional medicine religiously. (Interview with Mangwanya, 2006).

Later in the interview Mangwanya went on to explain how she had felt before she was tested for HIV, and her fear that she would be stigmatized as a result of her HIV-status:

> "I started feeling tired, had no energy, lost weight and when I went to for a check-up in hospital I was told that I have this thing – AIDS… I used a calamine to cover my face, and did not want people to see the marks on my face. So this woman [traditional healer] helped. I decided to come to her because I knew that if I go to a medical doctor then people will know that I am HIV positive." (Interview with Mangwanya, 2006).

The concern that one may unwittingly disclose their positive HIV-status through clinic visits can extend to a concern that the medicines themselves can identify the individual's HIV status. I have written elsewhere on this (cf. Mills, 2004 and 2006), and was interested to see that this issue also emerged in these findings. Nomvula, a community health worker, described how some of her organisation's clients would attempt to disguise their ARVs in order to avoid disclosure for fear of subsequent stigmatisation:

> "There are those who are hiding the bottles, they are taking ARVs… You know there was a lady who was … taking pills out of a bottle; she crushed them and put them in a money bag. I mean once you do that you won't know the real measurements you are taking. [T]hey know that if you don't have HIV you wouldn't know those medicines. If you have HIV someone at home will know." (Interview with Nomvula, 2006).

In addition to the fear of stigma described by Nomvula and Mangwanya, one of the factors that compelled Mangwanya to use traditional medicine instead of HAART was the faith that she had in this particular form of medicine:

> "I know what has helped me - I mean some people may not have faith traditional medicine and have faith in western medicine, but I have faith in traditional medicine."

Later in the narrative Mangwanya describes how clinic staff, too, assert the importance of having faith and accepting one's HIV-status:

> "At the clinic they are telling us to accept the virus; if you have the virus you must take it into your heart because if you do not take it into your heart, the virus will eat you and you will look like a

> skeleton. So people must find it in their hearts to accept their positive status. So I am telling myself that I have accepted it and I need to have hope. You must have hope for what you are given to help you and tell yourself that this medication I am getting from this person is going to heal me." (Interview with Mangwanya, 2006).

The extracts above indicate Mangwanya's fear of being labeled as 'a person with AIDS'. This, combined with her perception that HIV-positive people who take ARVs, like her sister, become ill rather than healthier, contributed to her decision to use traditional medicine. The confidentiality ensured by the traditional healer is contrasted with Mangwanya's perception that if she consulted a medical doctor people would label her as HIV-positive. Mangwanya does not categorically dismiss 'western medicine' in favour of traditional medicine in general, but notes that it is important to have 'faith' in whatever medicine one uses, stating that although she had not previously believed in traditional medicine, she did believe in the traditional healer she consulted, and used her medicine 'religiously'.

Like Mangwanya, Bongani notes the importance of positive belief to ensure the health of those taking ARVs. He attributes a lack of hope in HAART as the key factor in the deaths of some of the members of his support group:

> "Some people were taking their treatment but you could see that they had no hope… What is important is, [as] with any other illnesses, people need to have hope and not just take medication because they are required to. It won't work if people don't have hope in the medication… For sure if you have doubts about it, it won't work." (Interview with Bongani, 2006).

In turn, the death of people who had taken HAART, had not fully adhered to it, or who had experienced severe side-effects had a significant impact on the general perception of the value of HAART. For example, Xolisa initially started HAART in 2001 on the recommendation of her doctor. 2001 was the height of Thabo Mbeki's public foray into AIDS denial, and HAART was not yet offered through the public health system (Gevisser, 2007; Nattrass, 2007). Perhaps these factors account, to some extent, for Xolisa's fraught and uncertain entry onto a privately funded HAART program, run by Medicins Sans Frontiers (MSF), based in Khayelitsha. She had heard many rumours about the negative effects of HAART, including liver damage and loss of eyesight. She said that although her doctor recommended that she start HAART, she was still afraid and did not feel ready to start HAART. Her fears were compounded when the person she had asked to be her 'treatment buddy' said that she was afraid Xolisa would die if she took HAART, as evinced in the following extract:

> "It was between 2000 and 2001 … I have heard stories that you have problems with your liver, some are dying and others are blind. So I was scared … They [the doctors at the clinic] wanted me to bring the person who was going to watch me. Then I took Thobeka. Even she was scared and said, 'Xolisa I won't let you die'. Just imagine if I came to you and asked for help and you tell me that you don't want me to die. So I went to another one in a support group and she said, 'No we can't go and sign for your death'." (Interview with Xolisa, 2007).

Unable to find a friend willing to assist Xolisa in moving onto the HAART program, she eventually resorted to finding a stranger at the hospital to sign the relevant forms:

> "That showed that there is no care in hospital when you take ARVs, because I just found someone outside the hospital to sign. … And there are people who were supposed to visit me at home, to see whether I was taking my ARVs but no one came to my place. Even now I stopped taking ARVs no one has come to see me. There is no one. It shows that there is no care."

Xolisa's experience of the lack of care through the clinic's HAART program resonated with her earlier diagnosis and treatment of breast cancer in Kwa-Zulu Natal. Xolisa was diagnosed HIV-positive in 1997 when she went into hospital because she had a breast lymphoma:

> "I didn't know what was happening in my breast. You know they I would go for appointments and there were lots of doctors on top of me they were discussing about me, but no one told me what was wrong with me." (Interview with Xolisa, 2007).

Xolisa's father visited her, and convinced her to move down to Cape Town for treatment. In Cape Town they discovered that Xolisa had been put on chemotherapy without her knowledge or consent. Her experience of the treatment and care of her breast cancer improved in Cape Town; in 2001 she was recommended to enter MSF's HAART program because the chemotherapy had undermined her body's immune system and reduced her CD4 count to below 200. However, her distrust in health care practitioners following her cancer, and her uncertainty borne through her friends' distrust of HAART, was reinforced by the poor follow-up Xolisa received once she entered the HAART program. In particular, Xolisa struggled with lipodystrophy – the redistribution of her body fat made her feel 'uncomfortable in her skin':

> "There is no chance to talk to the doctor … I think they check your CD4 count and see that you don't need to see a doctor and you are

> called by a nurse … What made me laugh every time I was there they would say, no you look nice and every time your CD4 count is going up, although I knew that I was not taking ARVs in the right way…
>
> I asked the doctor if he can change me to another treatment because the one I was using was not working for me: I was shapeless. He [the doctor] asked, 'Why do you worry about your shape and a big stomach? Are you not happy that your CD4 count is going up and your viral load is going down?' And I told him, 'I am still young. I was not born like this but my shape has changed now and my shape is going to show people that I am using dome drugs.'" (Interview with Xolisa, 2006).

Xolisa had started taking HAART every alternate day in an attempt to balance the treatment of HIV with the redistribution of her body fat. Noticing that her health remained constant, and feeling frustrated that she had not been able to discuss her concerns with her doctor, she stopped taking ARVs. At this time Xolisa became more closely involved with NAPWA, and in the course of her training to become a community development worker, she attended a talk by the Rath Foundation

> "When I was in Joburg for NAPWA workshop they invited Dr Rath. Then during the break I went to speak to the person who was doing the presentation and asked for Dr Rath's telephone number. When I arrived in Cape Town I phoned them, and they referred me to Site B and I went there.
> EM: What did Dr Rath say about taking ARVs?
> Xolisa: What I know is that the ARVs are toxic and they are killing people and AZT causes TB. Sometimes I agree because I did not even get the right information when I was asking my doctor in MSF so I would say Rath was right about what he said." (Interview with Xolisa, 2006).

Xolisa recalls a sense of relief at stopping HAART and moving onto Rath's treatment, saying, "I am back to my normal weight, back to my normal skin… I feel that I am Xolisa."

Beyond her support of Rath's vitamin treatment, Xolisa advocates for the recognition and use of traditional healers and nutrition for healing HIV. The following extract suggest in addition to her opinion that HAART is lethal, Xolisa notes that belief in any treatment, including HAART, is a critical factor in its success:

> Xolisa: “I have friends who are dying. When the ARVs came [to South Africa] the doctor who was our leader in the support group forced one of my friends to take ARVs while she was on TB treatment. And she did not want to take ARVs and the doctor told her she was going die if she did not take them. I am telling you she took ARVs and the TB treatment [for] two weeks and then she got sick and was admitted at Groote Schuur hospital … They said there is nothing they can do about her… She was just there waiting for the day she died.
> EM: Why do you think she died?
> Xolisa: She took things she did not believe in. The other friend was … so beautiful. She started on ARVs and she developed red spots all over her body. And she was told that she had a blood cancer. Two months [later] she died. So that’s why I am saying it can kill.
> EM: What can kill?
> Xolisa: ARVs can kill people. (Interview with Xolisa, 2006).

The notion that an individual needs to believe in, and be ready for, HAART is reiterated by Xolisa’s colleague. Nocawa states below that although her CD4 count is below 200, a biomedical indicator that an HIV-positive person should start HAART, she has decided to consider all other alternative HIV treatments until they are exhausted, and there is no other option other than moving onto HAART:

> “I see them [ARVs] as the last option because one must be aware that when you decide to take ARVs you must know that you will take them for life. And you must take them at specific times and also they have side effects. For me I checked my CD4 count last June. It was 150, less than 200 and I told myself that I am not going to take ARVs. I must first change my lifestyle. I must take good food and practice positive living. Now my CD4 count is 191[9].
> …
> I am not ready to take ARVs because I am a busy woman. You see now I am studying, I am working and I am looking after my child, so if I am taking ARVs I will forget them. ARVs must be taken at specific times and you must stick to those times… [W]ith Rath vitamins you don’t have to stick to specific times.” (Interview with Nocawa, 2006).

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[9] In this statement Nocawa refers to the improvement in her health as judged by the increase in her CD4 count – an indicator of the strength of an individual’s immune system. However, a CD4 count of 191 is dangerously low; the WHO recommends that PLWH move onto HAART when they have a CD4 count of below 200.

Nocawa and Xolisa's narratives highlight Dr Rath's discourse of privileging 'benign' vitamins over 'toxic' HAART; their decision to use Rath's vitamins in place of HAART connects with a wide range of factors, including: Xolisa's negative experience of the health care system and HAART's side-effects; Xolisa's belief that ARVs can kill, especially when taken by an individual who is 'not ready'; similarly, Nocawa refers to the importance of being 'ready' to take HAART and her reluctance to commit to the regimen because she was 'a busy woman'. Sibongile, like Xolisa and Nocawa, was also affected by Rath's claims that HAART was toxic, as seen in the earlier quote on the 'turf-wars' between TAC and Rath's posters in Khayelitsha. Further on in the narrative interview Sibongile started to speak about some of the deep concerns she has had about HAART, including: the rigid adherence regime; the possibility that 'Manto is right' and that nutrition or Rath's multivitamins were better than antiretrovirals; and her concern that HAART was damaging her liver. Additionally, Sibongile states that moving onto HAART is complicated, and because it requires disclosure to a household member, some people prefer the easy access, anonymity and confidentiality that are offered by alternative therapists like Rath:

> Sibongile: [Some people are] scared to go onto ARVs because ARVs have lots of complications: one needs to have disclosed; you need treatment buddy. And other people are not ready to disclose, they just want to take the treatment. So multi-vitamins that Rath gives you just take the medicine. You don't have to disclose.
> EM: How do *you* feel about taking ARVs?
> Sibongile: Sometimes I feel when it's time for my medication, I feel so tired... I wish I was taking multi-vitamins,
> EM: Really? Can you tell me why?
> Sibongile: I am thinking now, maybe Manto is right. We must just take the natural herbs, you know… I am scared. I must be tested for liver damage. Nevarapine and AZT can affect the liver. Sometimes I get scared and think maybe my liver is going to be affected by ARVs. Must I just stop and take the multi-vitamins? I don't know... (Interview with Sibongile, 2006).

Although Sibongile questioned the efficacy of HAART she was subsequently reassured by her doctor, following a test to assess possible liver damage, that her treatment regimen was successful and that she should continue with it in favour of alternative treatments, like Rath's multivitamins.

The narratives above suggest that in addition to the affect of political discourses around HIV-treatment, the respondents' decisions around HIV treatment were affected by their personal psycho-social and physical experiences including

HIV-related stigma, the presence or absence of personal faith in treatment, lack of care from public health staff, AIDS-related deaths of friends, and experience or fear of HAART's side-effects compared to the 'natural' or 'traditional' alternatives like nutrition and traditional medicine. Notably, they interpreted their own experiences of ARVs, and the experiences of others, in ways which resonated with AIDS denialist claims about ARVs causing, rather than preventing, death. This suggests a much more active interpretation and experientially-based understanding of what is good for one's health than that implied by an approach highlighting the 'confusing' messages of the President and Health Minister.

Beyond the 'black and white' of equivocation and activism: nuanced factors affecting uptake and adherence to HAART

In South Africa, representational politics have plagued public health interventions, affecting the way civil society and the state have responded to every aspect of the epidemic – from the causal link between HIV and AIDS, to AIDS drug therapy (Schoepf, 2001; Robins, 2005). This discussion centres on the factors presented in the findings, both political and biopsycho-social, that have affected the respondents' perception of HIV treatment, and their uptake of HAART through the public health system. It argues that the focus on the supply-side factors impeding the HAART roll-out, like political engagement with pseudoscience and poor health care infrastructure, need to be considered alongside the demand-side factors presented in the findings that affect uptake this public health intervention by PLWH. This argument is developed, firstly, in relation to existing empirical analysis of South Africa's political and civil society response to HIV treatment policy and implementation. This paper argues that political equivocation and national activism have highlighted supply-side constraints to HIV policy implementation, and that in turn, they have both obscured and exacerbated some of the demand-side factors that influence uptake and adherence. The demand-side factors affecting health-seeking behaviour, as presented in the findings, are explored in the second part of the discussion. This paper suggests that one of the casualties in the battle between national activism and political equivocation on AIDS science has been the politicisation of HIV treatment, in which key social actors, like politicians like Tshabalala-Msimang and activists foreground the relative risks and benefits of HAART respectively. As the findings suggest, personal responses to HIV treatment move beyond the black and white of political equivocation and national activism to a grey area in which the respondents negotiate and battle with the duality of risk (stigma or side-effects) and benefit (improved health) associated with accessing and adhering to HAART.

Two predominant stories have been foregrounded in discussions of South Africa's approach to HIV and treatment. One: the story of how a small powerful network, critical of AIDS science, was built around Thabo Mbeki and how this inner circle, which includes Tshabalala-Msimang, was able to shape policy (Robins, 2005; Gevisser, 2007; Nattrass, 2007). The second story that can be read from South Africa's approach to HIV is the story of South Africa's highly organised and globally connected 'community' of scientists, health professionals and HIV-positive activists, most visibly represented by TAC (Robins, 2005). When considered together, these stories point to a discursive and political struggle around science and pseudo-science, and the impact this struggle has had on policy development and implementation. In particular, some of the documented ramifications of this struggle include: delayed development of urgent tuberculosis (TB), HIV and AIDS treatment policy (Nattrass, 2004); sluggish policy implementation, particularly with regard to the antiretroviral roll-out (Geffen, 2000; Achmat, Mtathi & Heywood, 2001; Hassan et al., 2005); and proliferation of pseudo-scientific and AIDS-denialist quacks (Geffen, 2005; Nattrass, 2007).

As stated in the introduction, the struggle around appropriate HIV/AIDS policy development has, to a large extent, been resolved through the development of South Africa's ambitious 2007 - 2011 NSP. The implementation of this policy, however, continues to lag behind its targets. For example, the NSP has set targets for 2007 to provide HAART to an additional 120 000 adults and 17 000 children, to test 70% of all pregnant women, and to offer PMTCT packages to 60% of HIV-positive pregnant women (NSP, 2007; www.tac.org.za). However, these targets are threatened by: failure to reach PLWH in rural areas; slow ARV accreditation for clinics; inaccurate statistics on uptake of PMTCT, and number of people of first and second line HAART; failure to provide dual MTCT treatment throughout South Africa; failure to address drug resistant TB through better ventilation and diagnostics in clinics; and limited independence and capacity of the South African National AIDS Council, which oversees the implementation of the NSP (cf. Harling et al, 2007; Maskew et al, 2007; Rosen et al, 2007; Sripipatana et al, 2007; Wilson and Blower, 2007). These factors present a combination of political and infrastructural constraints on the implementation of the NSP.

In addition to political endorsement of AIDS science and infrastructural capacity in the health system, another important component of successful health care policy implementation is the intervention's ability to secure uptake and enhance adherence among its target population. In the case of the HAART roll-out, high levels of adherence are necessary for the intervention to succeed. As stated above, one of the theoretical and public health approaches to ensuring the success of health care interventions has been to advocate for 'responsibilised health citizens'; good epidemiological outcomes in industrially advanced countries follow a health systems model in which citizens are encouraged to bear the greater obligation for their health outcomes (Baldwin, 2005; Robins, 2005 and 2006; de Waal, 2006). The role of the state is reduced, and the health care industry is run on the principle of 'democratic public health' in which self-control, voluntary compliance and individual responsibility is critical for good health care outcomes (Baldwin, 2005; de Waal, 2006). Activists in South Africa are calling for a slightly different approach: a well-resourced and managed public health sector in which citizens are empowered as 'client-citizens' through knowledge (Robins, 2006)[10]. Robin's claims "[t]hey are calling for an effective health system together with new forms of community participation and citizenship." Given South Africa's high level of unemployment and poverty, the majority of South Africans rely on the state's public health care system rather than private health care providers, to cater to their health care needs. In this context, the state's responsibility for creating an enabling health care system for its citizens is unambiguous.

As stated earlier, political and infrastructural factors have undermined the state's commitment and ability to create an enabling health care system that caters to the needs of all PLWH. This is particularly evident in the context of the HAART roll-out, and the political contestation over pseudo-scientific and scientific approaches to HIV treatment (Geffen, 2000; Achmat, Mtathi and Heywood, 2001; Hassan, 2005; Nattrass, 2007). The findings suggest that not only has political equivocation over HIV treatment limited the state's ability to provide adequate health care, but that it has also affected the respondents' decisions to take up and adhere to public health interventions, like the HAART roll-out, even when they are made available.

Theories of lay expertification (Epstein, 1996) and citizen science (Irwin, 1995) are increasingly used to describe citizen responses to poorly managed and unpredictable health hazards (cf. Robins, 2006). Conditions like these result in citizen scepticism and a distrust of mainstream science and expertise. Anthony Giddens (1990) and Ulrich Beck (1992) refer to this as 'conditions of reflexive modernity' and 'world risk society'; their thesis considered the impact of

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[10] This is accomplished, for example, through TAC's treatment literacy program and its Equal Treatment magazine. These projects aim to generate and transfer knowledge among PLWH on HIV treatment regimens, possible side-effects and management of illness and health care in general (Ashforth and Nattrass, 2005; www.tac.org.za).

advanced capitalism and globalisation on citizens' increased access to information and their distrust in scientists and scientific findings promulgated by governments and business:

> "Globalisation is changing the nature of science and technology, as it is being shaped by their developments: altering the intensity of innovation of new technologies and the resulting constitutions and flows of knowledge and expertise, and the character and scope of risks and uncertainties." (Leach et al, 2005: 3)

These risks and uncertainties were managed, according to Epstein (1996) and Irwin (1995), through civil society mobilisation that drew on a range of sources to collect information beyond that which was supplied by the state or business. In turn this led to increased lay expertification in fields ranging from nuclear energy, genetically modified crops and AIDS biomedicine (Robins 2006 & 2005; Leach et al, 2005; Petryna, 2002). The intention of lay expertification was to reduce reliance on state-based evidence given the capitalist state was intrinsically biased and did not necessarily act in the best interests of its citizens. In turn, increased knowledge, through lay expertification, was aimed at mitigating the risks of state-based interventions. Ironically, in South Africa government officials, like Mbeki and Tshabalala-Msimang, have not unequivocally advocated science. Instead, they have argued that their equivocation emanates from concern for the well-being of HIV-positive South African citizens have suggested, conversely, that activist endorsement of biomedicine is a result of 'selling-out' to pharmaceutical companies for financial profit (Nattrass, 2007). To this end, Mbeki and Tshabalala-Msimang have pursued and endorsed HIV pseudoscience, indicating distrust in the efficacy of HAART, and a concern that they are a toxic and dangerous biomedicine. They have framed their distrust in the efficacy of antiretrovirals as a concern for the health of 'people on the ground'; conversely, civil society organisations that challenge their discourse of 'choice' are spuriously accused of having financial rather than humanitarian motivations for endorsing AIDS biomedicine (cf. Nattrass, 2007; Youde, 2005; Heywood, 2004; Makgoba, 2000).

In writing on citizen responses to Giddens's (1990) 'world risk society', Ravetz (2005) calls for a reappraisal of risk theory to accommodate a more subtle response to uncertainty, that is, the management of safety: "concerns with safety increasingly animate encounters between science and society, safety being a more vernacular, qualitative concept which embodies political, moral and relational concerns as well as technical ones." (Leach, Scoones and Wynne, 2005: 41). As illustrated above, political equivocation has compounded South Africa's poorly managed health crisis by reinforcing distrust in AIDS science and the scientific consensus in HAART's capacity to extend the lives of AIDS-sick individuals. High-level political actors, most notably Tshabalala-Msimang and Mbeki, have developed a discourse of choice that frames ‘risk’ in line with HAART’s side-effects, and characterised local knowledge and untested remedies as ‘safe’. This is evident in Xolisa and Nocawa’s discourse of ‘readiness’, in which nutrition and Dr Rath’s vitamins were cast as ‘safe’, whereas HAART was associated with dangerous side-effects; PLWH, they claimed, had to be ‘ready’ to take on HAART’s side-effects and the life-long commitment the regimen entailed. Xolisa and Nocawa’s approach to HIV treatment also highlighted the extent to which they and their organisation, NAPWA, had not only adopted Tshabalala-Msimang’s discourse of ‘choice’ but also the rationale underlying her equivocation. In post-apartheid South Africa, both Tshabalala-Msimang and Mbeki have advocated lay healing practices, like traditional healing, that had been marginalised under the apartheid and colonial governments (cf. Hoad, 2005; Mills, 2005), and eschew ‘western’ scientific expertise on the efficacy of HAART for treating AIDS-related illnesses. Nocawa, for example, referred to Tshabalala-Msimang’s discourse of choice as consultative and respectful of the people and practices ‘on the ground’; conversely, civil society organisations that promote HIV treatment based on science, were described as ‘up there’ and out of touch with the real needs and wishes of the ‘people on the ground’.

As the respondents’ narratives suggest, lay pseudoscientific practices and practitioners have entered in, and capitalised on, this space of uncertainty in South Africa. This is evident in Mzimazi’s narrative, in which he describes his attempts to get healthier by eating large quantities of garlic, or the fatal attempts by members of his support group to achieve health by using an untested mixture of fish oil and garlic instead of their continuing with their HAART regimen. These findings suggest that the boundary between science and pseudoscience has been muddied through political equivocation; instead of mitigating risk (the claimed intention behind the political equivocation on HAART), equivocation has exposed AIDS-sick individuals to greater health risks as a consequence of their distrust in HAART and their attempts to draw on lay remedies promoted by pseudo-scientific quacks and the Minister of Health.

Robins, too, considers some of the consequences of undermining the boundary between scientific and pseudoscientific approaches to AIDS, as he asks:

> “What does citizen science mean in contexts where contestation between the public’s and experts’ forms of knowledge and science threaten to undermine biomedical scientific authority and AIDS interventions that could potentially save lives? What about contexts where contestation over AIDS science becomes highly politicised because governments are distrustful of the autonomy of the scientific establishment, or where ‘indigenous knowledge’ and ‘local

> solutions' are reified as part of cultural nationalist ideologies and programs?" (Robins, 2006: 115)

The sociology of health and citizen science has pursued social constructionist agendas, in which they allow for equivocation around appropriate responses to health and illness (Lupton, 1994; Leach et al, 2005). The danger of this approach, as illustrated by the findings, lies in its failure to prioritise scientific consensus and scientific method of evaluating biomedical efficacy. This paper recognises that health and illness are not simply constructed as the absence or presence of disease, and responses to securing health and addressing disease need to accommodate and balance a range of biomedical and psycho-social factors in order to secure well-being (cf. Kleinman, 1998; Wreford, 2005; Mills, 2005). Similarly, the most recent post-structuralist wave within the health and social sciences recognises the importance of accommodating a range of epistemologies around health and illness, but acknowledges the value of prioritising certain approaches over others. For example, theorists of science and citizenship (like Leach et al, 2005) argue that scientific expertise should be allocated a privileged role in decision making, and that although members of the public (and in South Africa's case, the state) can bring contributory expertise their input needs to be continuous with international scientific consensus.

This approach is adopted, for example, by TAC's Treatment Literacy campaign and its Equal Treatment publication. By offering TAC's members and other people the tools to understand the science of HIV and its treatment, it aims to create 'empowered' citizens (Ashforth and Nattrass, 2005). TAC, too, acknowledges the role that lay practitioners, like traditional healers, play in facilitating psycho-social well-being, but they assert the importance of prioritising biomedicine (and HAART) over untested treatment. In addition to TAC's treatment literacy campaign, it also mobilises around the right for all to access health care, and HAART in particular (ibid). Robin's argues that the intersection of biomedical education and awareness of the political economy of health combine to create 'empowered citizens'; as 'responsibilised health citizens', they are equipped to take 'responsibility' for their health through 'positive living' and full adherence to HAART through the public health system (Robins, 2006).

The findings of this qualitative study, however, suggest that even with appropriate biomedical knowledge, the respondents are not always able to take up the 'positive' HIV-positive banner promoting healthy living and HAART. As Jasanoff argues, "[T]he focus on knowledge and epistemology obscures from view more fundamental questions of ontology, or of the 'mutual embedding of natural knowledge and social order." (2003: 392 in Leach et al, 2005: 18). The epistemology of science needs to be considered alongside its ontology; knowledge of AIDS science and the biomedical efficacy of HAART is not sufficient in securing uptake or adherence to the treatment. There is a dearth of recognition and research into "the cultural contingencies of scientific knowledge deployed in the framing, definition and attempted resolution of public policy issues" (Leach et al, 2005: 7). In line with this assertion, this paper suggests that researchers need to better understand how knowledge around AIDS science is interpreted, negotiated and lived. The following section of the discussion explores how knowledge of AIDS science, as contested through political equivocation or asserted by activism, is 'lived' by the respondents as they negotiate their path to health by managing hope, fear and experiences of the relative risks and benefits HIV treatment.

As illustrated in the findings, both political equivocation and biopsycho-social responses to HIV treatment have affected the respondent's decisions to access particular tested and untested HIV treatments. In contrast to Robin's assertion that treatment literacy combined with awareness of the political economy of HAART facilitate access and adherence to HAART, the findings suggest that deep fears of stigma and of HAART's side-effects persist alongside these forms of knowledge. This challenges the conception that "TAC's mobilization appears to have been so successful at reconfiguring the stigma, isolation, and suffering of AIDS into a positive and life-affirming HIV-positive identity and quasireligious commitment to "new life" and social activism." (Robins, 2006: 318). The more intimate personal struggles around HIV treatment can be obscured by larger public struggles that promote 'positive' HIV-positive identities. The emphasis on 'positive identity' may mask an acknowledgement of the real losses inherent in a diagnosis of HIV; the identity work involved in constructing an HIV positive self may overshadow other and equally important aspects of the person's identity connected to and beyond the disease itself (cf. Ashforth and Nattrass, 2005; Almelah, 2004; Soskolne, Stein and Gibson, 2003).

Sibongile, for example, has undergone extensive HIV literacy training, has mobilised for the national HAART roll-out through her activism in TAC, and has herself been taking HAART since 2001. Her narrative, however, suggests that her 'empowered' HIV-positive identity exists alongside some deep fears around HAART's side-effects, causing her to wonder if, perhaps, 'Manto is right' and HAART is toxic. Her account of the 'turf-wars' between the AIDS denialists (Dr Rath) and the treatment activists (TAC) in Khayelitsha suggests an underlying tension in the struggle for discursive supremacy between scientists and pseudo-scientists. Dr Rath's posters of women and children dying from ARVs were deeply disturbing for Sibongile, particularly given that both she and her son had taken the supposedly ‘poisonous’ ARVs. Her fears were not unfounded: Sibongile had been told by her doctor, before starting HAART, that ARVs had side-effects, and that she would need to work with the doctors to monitor and manage these effects. Despite her knowledge of HAART’s risks and benefits, Sibongile’s deep fears of HAART’s impact on her and her child’s long-term health were not allayed by TAC’s posters of healthy happy people taking ARVs. Rath’s posters did not prompt Sibongile’s concerns – they echoed them. Sibongile’s narrative calls attention to the discursive ‘grey’ space between the representation of HAART as beneficial and noxious by TAC and Dr Rath’s posters respectively. As Sibongile’s narrative highlights, HAART has both risks and benefits which require careful monitoring and management. Furthermore, the risks of side-effects and the benefits of restored health can, as in the case of Xolisa, exist alongside each other, thus challenging the bifurcated ‘turf-wars’’ representation of HAART as either ‘noxious’ or ‘beneficial’.

Xolisa, like Sibongile, had taken HAART for a couple of years. Unlike Sibongile, Xolisa and her friend’s fears of HAART’s side-effects were borne out; lipodystrophy affected the distribution of her body weight, and made Xolisa feel ‘uncomfortable in her skin’. In addition to her initial fear and then experience of side-effects, Xolisa had seen friends die of what she had perceived to be HAART-related complications; she also attributed their death and, in part, her decision to stop taking HAART, to a lack of faith in the medicine itself. Additionally, Xolisa’s decision to stop HAART was also influenced by her negative experiences of the health care professionals when she was treated for breast cancer, using chemotherapy, without her consent or knowledge. Xolisa’s perception of health care professionals as ‘uncaring’ was reiterated when they rejected her concerns about lipodystrophy as ‘silly’ and ‘vain’ in light of her restored physical health, and failed to follow up with her after she had stopped taking HAART. These factors coalesced, and when she saw that a ‘safer’ alternative was available, and that she could return to her ‘old shape’, she opted to move across onto Dr Rath’s untested, but supposedly ‘benign’, vitamin treatment. This narrative suggests that perhaps the fears associated with HAART, and the failure of the health practitioners to take these concerns seriously, can prompt PLWH to seek alternatives. Alternative treatments, like Rath’s vitamins, which are not regulated by the South African state through the Medicines Control Council[11], are particularly dangerous because they have not undergone double-blind clinical trials to assess their efficacy. These findings suggest that in order to mitigate harm caused by untested substances, researchers

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[11] This is particularly difficult in South Africa where even supposedly autonomous bodies, like the MCC, have limited power because are restricted by the state as a result of AIDS denialism (Nattrass, 2007).

need to be engaging more directly with some of the psycho-social factors that affect PLWH's decisions to access them.

In addition to fears and experiences of HAART's side effects, the respondents, including Xolisa, referred to the importance of having hope and faith in the ability of a particular treatment to heal. Mangwanya, for example, discussed how she had faith in the traditional medicines she was receiving from the traditional healer living next door. The traditional healer offered anonymity which was an important factor in preventing HIV-related stigma. Faith and stigma were not the only factors, however, that affected Mangwanya's decision to use traditional medicine. She had also witnessed her HIV-positive sister's loss of weight and her death, and attributed them to the ARVs she had been taking. Mzimazi, too, refers to the importance of having hope in HAART. Members of his support group, he said, had died after taking HAART because they had not believed in them. Similarly, Xolisa refers to two friends who had died because they had started HAART before they were 'ready', and because they had no hope in HAART's ability to restore their health.

These respondents' recollection of their friends' deaths as a result of their lack of hope points to a larger quandary that challenges some researchers' assertion that over time the positive effect of HAART will encourage more people to get tested for HIV, and also to access HAART when necessary (Nattrass, 2004; Nguyen, 2005; Robins, 2006). For example, Robin's draws on Turner's (1969) method of ritual analysis to contextualise the identity transformation among PLWH who testify, at TAC meetings, to the 'Lazarus effect' of HAART (2006). He argues processes of personal transformation from 'bare life' (before HAART) to 'new life' (on HAART) are pronounced by collective action through a social movement, like TAC[12]. As illustrated by Xolisa and Sibongile, both former treatment activists, the combination of HAART and treatment activism does not have a linear, and solely positive, impact on their lives; Robin's analysis falls short of recognising the fluidity of individual and social identity, as well dynamic physical impact of HAART. Like Robins (2006), Nguyen suggests that "[i]ncreasing drug availability will have a multiplier effect, as the voices of people with HIV are no longer extinguished by illness but grow louder as their bodies respond to the treatments." (2005: 142). The respondent's recollection of HAART's effect on their or their peers' health challenges these statements; the availability and efficacy of HAART may well have a positive impact on PLWH's perception of the treatment, but this is not

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[12] Robins (2006) maps the 'citizen-activist's' linear physical and social transformation onto three stages: separation (illness, isolation and stigma); liminality ('in between' health and illness while waiting for HAART to work); reintegration (restoration of physical and social health, and incorporation into the social movement).

reflected in the respondent's association of HAART with their friends' deaths. It must, however, be noted that the respondents' recollections of the deaths of the friends due to HAART focus on their friends' lack of faith rather than on the toxicity of the treatment. Fears regarding HAART's side-effects are reflected elsewhere in the narratives and in relation to the more direct and personal experiences of these side effects, as discussed above.

The two overarching factors that have affected the respondent's health seeking behavior, namely political equivocation and biopsycho-social responses to illness and treatment, point to an intersection of epistemology (what they know and are told of HIV treatment) with ontology (how they perceive and experience the affect of HIV treatment). Similarly, Treichler refers to a continuum between popular and biomedical discourses, and to our susceptibility to what we are told about science:

> "Science is not the true material base generating our merely symbolic superstructure… Our social constructions of AIDS are based not upon objective, scientifically determined 'reality' but upon what we are told about this reality… There is a continuum, then, not a dichotomy, between popular and biomedical discourses." (Treichler, 1987: 35).

A useful approach to understanding how discourses around HAART are generated and interpreted can be seen in Whyte et al.'s taxonomy of treatment (2002). They argue that medicines should not only be considered as the material 'things' of therapy, but as substances with vigorous commodity careers and histories:

> "their dissemination to every part of the globe has far-reaching implications for local medicinal systems. They have become part of the *material medica* of every local society – an eminent example of globalisation. At the same time they are the most personal of material objects..." (2005: 3).

Medicines, they argue, embody and objectify meaning, and are commodities of economic significance and resources with political value (Whyte et al, 2002). They are also tokens of hope for people in distress, as reinforced by the findings of this research. Conversely, difficulty comes in when leaders do not sanction certain types of medicines, or when medicines are shown to have mixed positive and negative effects on the client, as discussed above. This is evident in Winstone Zulu's story; when his hero, Thabo Mbeki, was seen to question the efficacy of HAART, Winstone followed suit and stopped his regimen. Winstone and the respondents' narratives illustrate Whyte et al's (2002) assertion that medicines' transformative power is not necessarily implicit – in order for medicines to work, they need to be ‘believed in’. In addition to their projected or implicit power to transform (positively and negatively), so too can perceptions of their transformative power be affected by attributions made by social actors.

In South Africa, the attribution of various medicines’ powers has been mediated by a range of social actors, not least politicians, PLWH, activist groups and researchers. Given the different attributions accorded to tested and untested medicines, South Africans are, as Mzimanzi states, ‘swimming in confusion’. Medical pluralism around HIV treatment is not only symbolic of political equivocation, but it is connected to biopsycho-social factors, including fear, hope, stigma and physical side-effects, that are pinned onto HIV treatments. It follows, therefore, that in order for HAART to succeed as a public health intervention, it not only requires unequivocal political endorsement of science, it also requires further engagement around the biopsycho-social factors that limit uptake and adherence to HAART in the public health system.

Conclusion

The success of South Africa’s hard-won antiretroviral (ARV) roll-out is determined by both supply and demand-side factors. Political equivocation and national activism around AIDS science and the provision of ARVs have emphasised ideological, fiscal and infrastructural supply side-factors that constrain the provision of ARVs through the public health system. Conversely, the ‘responsibilised health citizen’ model focuses on demand-side factors, in which greater responsibility for health care outcomes is transferred to the health citizen. There are limits to this approach in countries like South Africa, and therefore activists have called for a combination in which the state ensures effective and efficient health care provision, and the client is empowered with knowledge that can equip them to take on the responsibility for adhering to treatment. Knowledge and provision of HAART, however, are not sufficient for ensuring uptake and adherence among its target population. This study indicates two mutually-reinforcing demand-side factors that have influenced the respondents’ decisions around HIV treatment: political equivocation along with physical and psycho-social responses to illness and healing.

This preliminary and qualitative study gives shape to some of the nuanced personal and political struggles that exist in the ‘grey’ area between the poles of political equivocation and activism on AIDS science and treatment in South Africa. Like Winstone Zulu, even when the respondents were able to access HAART, some of them were deterred by key political actors who questioned the international scientific consensus that HAART is biomedically efficacious.

Additionally, this study illustrates that belief in the transformative power of HIV treatment like HAART, or of untested HIV treatments like traditional medicine, is also mediated by personal ‘beliefs’ in the medicine, and the extent to which they have ‘hope’ in its capacity to bring health. Additionally, the study highlights some of the personal struggles entailed in adhering to HAART, particularly in relation to side-effects like lipodystrophy, or HIV-related stigma. Like Winstone Zulu, some of the respondents had been treatment advocates, but their intimate struggle with HAART’s side-effects, combined with the confusion generated by AIDS dissidents, compelled them to question or stop HAART in favour of untested remedies, which were conceived as ‘safe’ alternatives with less rigid criteria around access and adherence. This study, therefore, highlights the danger of focussing too narrowly on the politicised and dichotomised struggle between proponents of the discourse of ‘choice’ versus proponents of the scientific governance of HIV treatment and illustrates the kinds of social and intimately private experiences that also play a role in the decisions HIV-positive South Africans make around accessing HAART through the public health care sector.

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