

## CHAPTER EIGHT:

### CONCLUSIONS

In the conclusion to this thesis I present an overview of the main argument and its significance for the anthropological study of AIDS. I also explore what implications the findings have for the roll-out of AIDS treatment and how this can further understandings of responses to AIDS in the ‘treatment era’.

This thesis chronicles experiences of the AIDS epidemic in Bushbuckridge and addresses the underlying question: why the devastating impact of the epidemic has failed to provoke a more robust public response. I argue that despite the overwhelming evidence of the threat that AIDS poses to the health and lives of the local population and widespread awareness of the epidemic, the disease continues to be a shared secret and suffering is concealed. The ethnographic material presented in the thesis suggests that secrecy and concealment can be more fruitfully regarded as attempts by ordinary people to exert agency in the midst of an unmanageable and unimaginable epidemic.

Although anthropology is located at the margins of public health research on AIDS there is increasing recognition of the importance of ethnographic methods in documenting and analysing responses to the epidemic from the micro-perspective (Parker & Ehrhardt 2001). In particular, ethnographic research questions the relevance of concepts commonly employed within public health in different social and cultural contexts. In this regard this thesis has challenged the tendency to construct silence and concealment solely as barriers to health seeking behaviour and the adoption of healthy lifestyles. I argue that silence, concealment and secrecy are creative attempts to handle

dangerous knowledge (Chapter 4), and can be construed as performances of suffering (Chapter 7). Gossip and rumour form a local epidemiology of the epidemic that shapes individual and community responses (Chapter 4 and Chapter 5). By recasting AIDS illness and death as witchcraft, without directly contradicting the biomedical models of HIV infection and its spread, families could avenge AIDS deaths and protect individuals against misfortune (Chapter 6). In these ways the global AIDS epidemic is rendered local, reimagined in terms of local frames of reference and thereby made meaningful with regard to local histories, categories and ideas about illness.

In the following discussion I explore the possible implications of the provision of AIDS treatment in the light of the findings presented in the thesis. Before proceeding I need to declare the limitations of my conclusions and of the thesis overall. My research ended on the eve of the inception of the national treatment program; regrettably I was not able to explore first-hand the impact of this important event on local experiences of AIDS. Therefore the discussion below is an attempt to reflect upon my research findings in the light of changes in treatment guidelines and policy.

### **AIDS IN THE TREATMENT ERA**

In the era prior to the roll out of ART in public health treatment centres, South African AIDS policy was ‘a sorry tale of missed opportunities, inadequate analysis, bureaucratic failures, and political mismanagement’ (Nattrass 2004, 41). AIDS policy was based on the ‘metaphor of triage’, a rational policy in the context of low resources and high causalities such as in wartime, yet morally dubious in the context of the AIDS epidemic. The policy emphasized prevention and primary health care, but argued that

treatment was ‘unaffordable’ (Nattrass 2004). In terms of the discourse of triage, HIV positive patients were ‘heavy burdens’ on an already overextended health care system. They were less deserving of bed space and resources than ‘healthy’ patients who have a better chance for survival. For example, Le Marcis (2004) described the situation for HIV positive people seeking care in hospitals in and around Johannesburg:

Faced with a major shortage of hospital beds, the doctors often choose not to admit HIV-positive patients at an advanced stage of AIDS, because their chances of recovery are limited...

This scenario was mirrored in my experiences in trying to access care for the terminally ill at hospitals in Bushbuckridge and Johannesburg, as depicted in the accounts described in Chapter 1 and Chapter 7. As I experienced, the emphasis on prevention contributed in no small way to the attitudes of health workers toward patients who presented with HIV. Health care workers found it easy to blame the infected and deny them the care required. More broadly, failures to respond positively to prevention messages were blamed on ignorance, tradition and culture. Indeed, AIDS awareness and education directly opposed ‘tradition’ and created barriers to active community engagement (Chapter 2).

The direction of resources toward prevention strategies rather than treatment was in line with prevailing discourses in the international donor environment. For instance, some donors warned that treatment could be a contributing factor to the spread of HIV because it would increase the life span of HIV infected people and result in disinhibiting sexual behaviour because HIV would be seen to no longer pose a threat. As a result of these attitudes, many poor people in contexts where the epidemic was at its height, were

relegated to HIV prevention only (Hardon 2005, 603), despite prevention's dismal failures.

This double standard continued until the early 2000s when global policy regarding treatment for HIV positive people shifted toward increasing access to drugs, particularly for the poor. The costs of AIDS drugs were radically reduced and co-funding was provided by donors such as the US Presidents Emergency Fund for AIDS (PEPFAR). Underlying this switch in international health policy was increased recognition of the threat that the AIDS epidemic posed for global security and the potential spread of the epidemic to other parts of the world.

In September 2003, in response to pressure from cabinet members and AIDS activists, the South African government announced its intentions to introduce a publicly funded national HIV/AIDS treatment plan; twelve billion Rand was committed to roll-out anti-retroviral therapy in public health institutions<sup>1</sup>. In terms of this new policy, HIV positive people with a CD4 cell (lymphocytes) count of less than 200/mm<sup>3</sup> (a 'normal' count is 500 cells/mm<sup>3</sup>) would be placed on a free treatment program<sup>2</sup>. The aim of the HIV/AIDS and STI National Strategic Plan is to roll out treatment to 80% of those in need by 2011. Yet, progress has been slow, retarded by inadequate health systems and foot dragging (Nattrass 2005a). By 2006, 711 000 people were defined as in need of medication, while only 225 000 were actually accessing ARVs (Dorrington et al. 2006).

In Bushbuckridge, two hospitals initiated treatment and by 2005, 1750 people were on ARVs (Moshabela 2006). The majority of patients were female and had low CD4 counts were at a late stage (stage III or IV) of disease progression. This is expected given the feminisation of AIDS and the tendency for patients to delay seeking treatment

until terminally ill. Relatively good levels of retention to treatment have been achieved in Bushbuckridge. At the Rixile AIDS clinic in Tintswalo Hospital more than 80% of patients continued on a treatment program over a 24 month period (MacPherson et al. 2009).

What are the social implications of the roll out of ARVs? I frame this question, not simply with regard to the numbers of patients accessing and continuing treatment, and the resultant rates of morbidity and mortality, but in terms of its consequences for social suffering.

The literature on AIDS treatment draws attention to the phenomenal success of medical treatments even for those patients who are at an advanced stage of illness. This picture is informed by a predominantly biomedical model, promoted at the expense of locally, patient-defined responses and experience. In contrast, anthropological perspectives on treatment suggest a broader conceptualisation of the effect of medications. For example, Etkin argues:

...the paradigm of biomedicine defines treatment in almost exclusively biophysical terms, largely disregarding cultural and social factors. Thus (...) in order to conform to the biomedical paradigm, there must be a 'primary' effect to which all others are subordinated. (Etkin 1992, 100)

The cultural and social context of therapeutics can reveal how biomedically-designed drugs are reinterpreted through local paradigms. Medicine is used with the intent of transforming the body from illness to health. Yet, medicine also has social significance. Medicines assume a 'social life' in that they have social uses and consequences; they have the power to transform individual bodies from illness to health but they also change minds, understandings and modes of understanding (Whyte et al.

2002; Whyte et al. 2004). Following Appadurai in the 'Social Life of Things' (Appadurai 1986), 'things' such as medicine acquire meaning, when they become part of peoples' lives. Although the effect of medicines and their efficacy is presumed to be universal, their social effects are shaped according to cultural and social contexts.

The power of ARVs to transform the AIDS body is a dominant theme in medical discourse. Drugs can potentially change AIDS from a deadly disease into a chronic disability that can be managed using drugs. It is assumed that the drugs also transform the way people regard AIDS and those who are infected (Karim et al. 2003), for example creating a greater willingness to test for HIV (Kapp 2004). Successful treatment 'normalises' the disease and creates hope for those infected and affected. The treatment program offers:

a more optimistic script, one in which HIV-positive people are able to access life enhancing drugs that can return the patient to health and the possibility of reintegration into the social world (Robins 2006, 312).

And that which was previously an untreatable affliction resulting in social 'death before dying' is reconfigured as a rebirth. Robins (2004) suggests that effective treatment of AIDS results in individuals taking on a new 'responsibilised citizenship'.

The transformative effects of ARVs are evident in the personal testimonies of patients. The constitutional court judge and AIDS activist, Edwin Cameron (2005, 38-39), writes on his personal experience of starting ARVs:

There was only one word for it. It was glorious. The drugs were working. I could feel that I was getting healthy again. I knew that I would be well again. That, in turn, spurred my inner confidence. Physiological wellbeing had a pronounced psychic effect. If the drugs were working – and it was utterly clear they were – it meant that for the first time since my infection more than twelve years before, the

virus was no longer multiplying within me. It was no longer progressively taking over my body, taking over my life. It was being beaten back to some deeply secluded (although latently dangerous) viral reservoirs. But outside these recesses, the rest of my body was free of it. And my immune system was, for the first time in all these years, free of its burdens.

Health workers similarly report on incredible recoveries amongst patients who are at the brink of death, brought back to life after taking ARVs. They see the benefits not only for their patients but also for the morale of doctors and health workers. The senior registrar at the JF Jooste Hospital in Cape Town:

This really was the hospital where people used to come to die; it was like a hospice (...) but now 85% will leave alive. We now see patients coming in who are severely unwell and they get better. 40–50% of all admissions into the medical ward have AIDS. Before we couldn't deal with it; now we can start to try (Kapp 2004, 1710)

Similar sentiments are expressed not only by medical practitioners and affluent judges; the following excerpt from an interview with a traditional healer in KwaZulu-Natal draws attention to a spiritual and social reawakening of a patient taking ARVs:

Really ARVs reawaken people (*ngempela amaARVs ayabavusa abantu.*) I remember that I told you I had a person who was very sick in a way that cannot be described. I told you that I did not know what I could do. He now really has the hair of a person (*Manje usenezinwele zangempela zomuntu*). One can now endure looking at his face (literally, 'His face can now be looked at', '*Ebusweni useyabhekeka*'.) He is stout (*ukhuluphele*). When he walks on foot he is unable to walk slowly, he goes at a fast pace (literally, 'he stabs with doves', *ahlabe ngejubane*). He says it is as if he is dreaming of himself [as he used to be before the illness] because of the good life he is now living (Henderson 2005, 45)

The possibility of becoming well enough to work and contribute towards the household reaffirms the eroded social identities of those afflicted with AIDS. Castro and

Farmer (2005) present the case study of Samuel Morin, a HIV positive Haitian man whose physical recovery reinvigorated his social and domestic relations:

Of his recovery, Samuel said, ‘I was a walking skeleton before I began therapy. I was afraid to go out of my house and no one would buy things from my shop. But now I am fine again. My wife has returned to me and now my children are not ashamed to be seen with me. I can work again.’ (Castro & Farmer 2005, 56)

The healer from KwaZulu Natal and the Haitian man both draw attention to the possibility for re-socialisation: a renewed confidence to leave the seclusion of the homestead, and return to normalcy. Their experience is likened to religious conversion, of being ‘born again’ (Robins 2006).

A return to health and regaining ones identity as a sociable person was a pressing concern for those who experienced AIDS illness. In Chapter 7, we saw how Khayellhle and Solomon were stripped of their status as fathers, husbands, and sons, due in part to their inability to provide for and support their families. AIDS not only threatened their corporeal existence but also presented an existential challenge to their identities. Following biomedical treatment would have offered hope to a return to normalcy.

Yet, these optimistic scripts of treatment tend to obscure the persistence of inequalities that constrain the choices that people have in their everyday lives (cf. Hardon et al. 2006). In contexts such as Bushbuckridge, access to health services is mediated by resources: transport to hospital and the ability to navigate the bewildering maze of paperwork and tests. Treatment is also mediated by acquiescence to moral scripts of safe sex and an ideology of healthy lifestyles.

The eligibility criteria for treatment are based on biological stages of infection and psychological profiling. In terms of South African treatment policy<sup>3</sup>:



Those accepted for therapy must have a CD4 count of less than 200, no alcohol or substance abuse, and a stable domestic environment conducive to compliance with the treatment regimen (Kapp 2004)

Using these biological, social and psychometric criteria to exclude certain individuals from accessing AIDS medication reinforces social divisions and alienates those who do not meet the criteria. Personal experience of illness is irrelevant to biomedical constructs of disease. In this way treatment policy continues to transform suffering, from a ‘moral experience into a mere technical inexpediency’<sup>4</sup> (Kleinman & Kleinman 1997, 15). Reflecting on his ethnography of AIDS treatment amongst the poor in Brazil, Biehl writes:

...bureaucratic procedures, informational difficulties, sheer medical neglect and moral contempt, and unresolved disputes over diagnostic criteria all mediate how these people are turned into absent things. (Biehl 2004, 119)

He suggests that the medical and state bureaucracy surrounding AIDS treatment can be seen as ‘technologies of invisibility’.

AIDS treatment amongst the poor poses particular challenges. Kalofonos’ reports that treatment created hunger amongst HIV patients in Central Mozambique.

As people on treatment regained their health, they also regained their appetites, as in some cases they became healthy for the first time in months or even years, and the irony of recovering from AIDS in order to suffer from hunger was frequently commented upon. Thus, though people’s lives were extended, they were not improved, and were often more challenging than before (Kalofonos 2008, 199).

Kalafonos proceeds to argue that the manner in which treatment was introduced in Mozambique promoted social divisions.

By targeting a biological condition, political and economic concerns are sidelined, and local forms of solidarity are undermined as disease-related distinctions determine eligibility for scarce resources (Kalofonos 2010, 364).

As he notes, despite the dramatic and miraculous transformations of the bodies of the AIDS ill, treatment did not alleviate the condition of the poor. What we learn from this is that biomedical interventions cannot address the political, social and economic context in which infections and illnesses arise. Therefore, while it is indeed possible to roll out HAART in ‘resource poor settings’, to assess the success solely in terms of retention of patients in treatment programs does not address the underlying issues of exclusion and inequalities.

Securing access to medical and welfare support is also mediated through adopting new lifestyle changes, participating in support groups, and demonstrating treatment literacy. In his thesis on AIDS treatment at the same hospital used by my informants, Mfecane writes about the role of support groups in reconstructing masculinities. For example, ‘Any man who had multiple partners was chastised rather than being celebrated as “successful”’ (Mfecane 2010, 287). Access to drugs and support therefore came at a certain cost to dominant masculine identities and acceptance of a moralising discourse that blamed men with multiple partners for the spread of HIV.

AIDS treatment policy also creates paradoxical situations for patients wishing to access care due to the linking of disability grants to health status. Natrass (2005b) comments on the irony of the conditionality of disability grants in the context of high levels of unemployment in South Africa. She warns that by linking welfare grants to health status in this way threatens the prospects of long term adherence to ARVs by patients.

In situations of extreme poverty, material need and dependency on state welfare, AIDS medications acquire a new set of meanings. Defaulting from treatment may therefore be a means to continue to be eligible for state grants. Ill health can therefore become a commodity transacted with the welfare state. Patients may therefore have a vested interest in maintaining poor health<sup>5</sup>. The state grant in South Africa is a major source of income; old age pensions were R950 per month, child support grants were R170, and disability grants were R950. According to a survey conducted in a village in Bushbuckridge, increasing numbers of households were becoming dependent on such grants (cf. Niehaus 2006b). Grants such as those linked to AIDS are regarded as household resources and not solely for the purposes of alleviating individual suffering. Desperation to obtain disability grants may even lead to purposeful infection with HIV<sup>6</sup>:

In the Eastern Cape, there is a saying that you have ‘won the lotto’ if you test HIV-positive because it is seen as a ticket to the disability grant. If HAART is regarded (incorrectly) as a ‘cure’ for HIV, then it is possible that some people may desire to become HIV-positive under the mistaken notion that they will be able to get access to the disability grant and obtain HAART (Nattrass 2005b, 15).

These theories rationalise non-compliance or refusal to take medication in terms of material consequences. Others speculate that competing claims between biomedicine and ‘traditional’ healing can explain non-compliance. As the illness narratives presented in Chapter 7 illustrated, individuals draw on a wide variety of healing options (cf. Ashforth 2005b). People move between traditional healing and Western biomedicine freely to find solutions to their health problems (Nattrass 2005a, 9-10). In Bushbuckridge, AIDS was defined simultaneously as a traditional disease and as a modern affliction. Although ‘traditional healers’ and biomedical health practitioners draw attention to the

divide between traditional and biomedical, people draw on services, diagnoses, and pharmacopoeia that are regarded as both traditional and biomedical (cf. Saethre 2007, 103).

The belief in witchcraft is also sometimes seen to contribute toward the rejection of ARVs and the search for traditional healing in cases of AIDS illness. In Bushbuckridge, AIDS was clearly not witchcraft. Yet, the epidemic stimulated ‘spiritual insecurities’ (Ashforth 2005b) and uncertainties about the efficacy of biomedicine. I argue that witchcraft could be seen as a form of therapy to deal with the emotional anguish and desire for revenge. The witchcraft paradigm is invoked to provide answers to questions of individual misfortune. The provision of HAART in Bushbuckridge is unlikely to undo peoples’ beliefs in malevolent forces such as witches.

The introduction of ARVs in public health settings is a significant step in the fight against AIDS. It represents hope for an end to suffering. However, what medicine cannot solve are the material conditions of peoples’ lives as they struggle to access health care and fight their way through the bureaucratic structures that restrict their access to health. Even those who are successful in gaining access to lifesaving medication face new challenges of hunger, and face new paradoxes that link their access to welfare to health and to their acquiescence to biomedical authority. Given this scenario I am not optimistic that the answer lies solely in a biomedical intervention.

## END NOTES

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<sup>1</sup> Highly Active Anti-Retroviral Therapy (HAART) was introduced in the mid-1990s in the US and Europe. HAART leads to ‘significant reductions in HIV-related morbidity

and mortality’ and ‘is a highly cost-effective medical intervention’ (Chen et al. 2007). Despite the overwhelming scientific evidence, until 2004, the South African state continued to prioritise behavioural interventions to prevent infection. AIDS drugs were ‘too expensive’ to treat the large numbers of AIDS ill (Nattrass 2004).

- <sup>2</sup> Psycho-social considerations listed in the Department of Health Web Site are: Demonstrated reliability; No active alcohol or other substance abuse; No untreated active depression; Disclosure or joined a support group; Acceptance of HIV status; Insight into the consequences of HIV infection and the role of ART before commencing therapy; Able to attend the antiretroviral centre on a regular basis or have access to services that are able to maintain the treatment chain (National Department of Health 2004).
- <sup>3</sup> Recent changes to treatment guidelines changed the required CD4 count from 200 to 350.
- <sup>4</sup> The national roll out of the prevention of mother to child treatment program (PMTCT) is a good example of how the cost benefits of providing pregnant HIV positive women with the drug Nevirapin were weighed up against the future costs of healthy but orphaned children (Nattrass 2004).
- <sup>5</sup> A similar situation arose with state welfare grants for epilepsy sufferers who purposefully missed medication in order to qualify (Segar 1994). More recently the child support grant has attracted criticism that young women purposefully fall pregnant in order to have children and then benefit from the grant (MacGregor et al. 2003).
- <sup>6</sup> This is noted elsewhere: homeless drug users in California regard a HIV positive status as a way of accessing welfare (Crane et al. 2002).