

Title: 'Long Live Zackie, Long Live': AIDS Activism, Science and Citizenship after Apartheid

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*'Long Live Zackie, Long Live': AIDS Activism, Science and Citizenship after Apartheid**

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This article analyses the complex cultural politics of HIV/AIDS in South Africa. It focuses on how AIDS 'dissident' science impacted on policy discourses and how AIDS activists, together with scientists, the media and health professionals, responded. It also shows how the HIV/AIDS debate and struggles over access to treatment were framed by historically embedded cultural and political interpretations of AIDS that were a product of South Africa's apartheid and post-apartheid history. However, rather than adopting a cultural nationalist response to this historical legacy, activists from the Treatment Action Campaign (TAC) deployed a class-based politics that concentrated on access to anti-retroviral drugs rather than debates on the complexities of AIDS causation. This approach contrasts with AIDS activists' in the United States attempts to influence the production of scientific knowledge on AIDS directly, for example, research funding and protocols for trials. The article discusses how TAC and its partner organisation, Médecins Sans Frontières (MSF – Doctors without Borders), strategically positioned themselves in the struggle for access to AIDS drugs, and how new forms of health citizenship, gendered identities and political subjectivities emerged in the course of these struggles. For example, ideas of bodily autonomy associated with liberal individualist conceptions of citizenship collided with patriarchal cultural ideas and practices that prevent many women from accessing biomedical interventions (for example, contraception, HIV testing and treatment). The biomedical paradigm that underpinned TAC/ MSF campaigns also had to contend with local understandings of misfortune and illness. While TAC's strategies included networking with global civil society organisations such as MSF, Health Gap, and Oxfam, they also involved grassroots mobilisation and an engagement with local socio-cultural realities. This brand of health activism produced solidarities that straddled local, national and global spaces, resembling what Arjun Appadurai and others describe as 'globalisation from below'.

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It was not AIDS that was killing our loved ones, the dominant analysis went. It was witchcraft. Fingers were pointed at suspected neighbours.

(Thokozani Mtshali, *Sunday Times*, 28 April 2002)

The biggest challenge for doctors in rural KZN is getting HIV-positive women to ask for treatment: A bitter pill to swallow.

(*Mail & Guardian*, 23 August 2002)

This monograph discusses the vexed question of HIV/AIDS ... It also accepts that the HIV/AIDS thesis [is] informed by deeply entrenched and centuries-old white racist beliefs and concepts about Africans and black people ... In our own country, the unstated assumption about everything to do with HIV/AIDS is that, as a so-called 'pandemic', HIV/AIDS is exclusively a problem manifested among the African people...

(*Castro Hlongwane*, March 2002)

African children's faces have been paraded in the media in the name of giving a face to AIDS. I agree the disease must be given a face – but it should be human, not African ... Parading African children in the media adds to the stigma already suffered by those infected and affected by HIV/AIDS.

(Phumzili Simelela, *Mail and Guardian*, 6 December 2002)

Introduction: Science, Race and Cultures of Colonialism

AIDS statistics in South Africa have unleashed an extraordinary amount of political heat, controversy and contestation, with the government persistently questioning the reliability of such figures and projections. Matters came to a head in 2001 with the 'leak' to the press of a Medical Research Council (MRC) report which estimated that 'AIDS accounted for about 25% of all deaths in the year 2000 and has become the single biggest cause of death'.¹ The government's initial response to the MRC report was to challenge its findings by claiming that 'violent death', not AIDS, was the single biggest cause of death. This triggered a major controversy that raged in the media, culminating in the government's concerted efforts to 'delay' the release of the MRC report, while applying considerable pressure on the MRC Board chair to institute a 'forensic enquiry' to uncover the source of the press 'leak'.

The MRC President, Dr Malegapuru Makgoba, was also subjected to pressure to withdraw the report, with government spokespersons claiming that its findings were

1 See R. Dorrington, D. Bourne, D. Bradshaw, R. Laubscher and I. Timaeus, *The Impact of HIV/AIDS on Adult Mortality in South Africa* (Medical Research Council Technical Report, Burden of Disease Research Unit, MRC, 2001), p. 6. Estimates drawn from Department of Health surveys based on blood tests of pregnant women in antenatal clinics throughout the country indicated that by 2000 over 4.7 million South Africans were infected with HIV, and that this figure was likely to double by 2010 (Abt Associates/SA Department of Health, 2000, p. 7). Since 1990, the national Department of Health has conducted annual anonymous surveys of blood tests of pregnant women in antenatal clinics around the country. At the end of 2000 the seropositive rate for HIV amongst pregnant women was 24.5 per cent (Department of Health, 2001). The current estimates of HIV-positive South Africans stand at between 4.3 and 7 million. In October 2002, a study by the University of Natal's health economics and HIV/AIDS research division found that the pandemic would rob three million children of their parents in the next ten years (*Sunday Independent*, 6 October 2002).

‘alarmist’ and ‘inaccurate’. In response, he stated in 2002 in *MRC News* that the long-term effects of political interference threatened ‘the whole national system of innovation in general’, while posing ‘the greatest threat to the MRC and health research in particular’.² Makgoba also reminded his readers of the dangers of the ‘Sovietisation of science’ and drew attention to Stalin’s direct role in ensuring that Lysenko’s views dominated Soviet science in the early decades of the twentieth century. In what appeared to be a direct reference to the political interference of President Mbeki and the Minister of Health in scientific research in South Africa, Dr Makgoba noted,

Let us also remember what collusion between scientists and the State did for the Nazis, and apartheid South Africa. Finally, let us also remember what happened to science in post-colonial Africa – it has been decimated by uninformed and foolish political decisions and choices. African political leadership should be ashamed of itself in this regard.

By the end of 2003, the controversy concerning the MRC Report, dissident science and AIDS statistics seemed to be something of the past.³ President Mbeki was also no longer publicly supporting the AIDS dissidents, and his Cabinet had committed R12 billion to a national anti-retroviral therapy (ART) programme.

One of the possible interpretations of this response from government was that the findings were perceived to imply that the government was not managing the pandemic effectively, the situation was ‘out of control’, and this could have negative impacts in terms of much needed overseas investment. Other possible reasons for this change include discomfort with the findings amongst certain sectors of government and the ruling ANC party who believed that the report reinforced media and popular beliefs and prejudices that AIDS is a ‘black disease’ concentrated in the rural areas of the former black ‘homelands’ of KwaZulu-Natal and the Eastern Cape provinces. This racial and geographical ‘profiling’ of AIDS, it would appear, shaped both state and citizen responses. The questions of race and identity, I argue, lie at the heart of responses to the AIDS pandemic and to AIDS science. The racialised character of these responses was not, however, confined to President Mbeki’s inner circle. It has been far more widespread.

In December 2002, the Human Science Research Council (HSRC) released a study that questioned popular perceptions about the racial and geographical distribution of AIDS. A large-scale household survey was conducted to determine the HIV prevalence rates in different provinces, among races, sexes and geographical locations. In an article entitled ‘AIDS Survey Shatters Stereotypes’, the *Mail and Guardian* reported that ‘KwaZulu-Natal has shaken off the tag of having the highest HIV-

2 *MRC News*, 2002, p. 6.

3 The South African writer and journalist, Rian Malan, attempted to reopen the statistics debate by questioning the accuracy of official statistics on AIDS deaths. He claimed that these figures were grossly overestimated and that existing statistical models were fundamentally flawed. Malan’s ‘dissident’ position was vigorously challenged by TAC activists. See Malan *Cape Times*, 17 October 2003; *Rolling Stone*, 22 November 2001; *Nosweek*, December 2003; *The Spectator*, 13–20 December 2003; ‘Can we Trust Aids Statistics?’, *Sunday Times*, 19 October 2003. Responses to Malan included letters from Prof. Ed Rybicki, Department of Molecular and Cell Biology, University of Cape Town, ‘Aids Dissent Based on Fallacies’ and Nathan Geffen, TAC National Manager, ‘Rian Malan Spreads Confusion about AIDS Statistics’, both in *Sunday Times*, 2 November 2003.

prevalence rate [and] the Western Cape⁴ gets a wake-up call because its HIV prevalence rate of 10.7% is higher than the 8.6% revealed by [MRC] antenatal survey'. The article also noted 'a surprising finding is that the Eastern Cape has the lowest prevalence rate (6.6%)'. In contrast to studies that indicated that AIDS prevalence was highest among poor, rural, uneducated black people of the former homelands, the HSRC study found that highly mobile urban people in the informal settlements and townships, as well as the middle classes in the suburbs, were most certainly at risk.⁵

Notwithstanding this challenge to AIDS stereotypes and prejudices, the 'cold facts' of AIDS statistics are likely to continue to produce competing interpretations, including those that construct AIDS as a 'black disease'.⁶ It is therefore quite conceivable that African nationalists such as President Mbeki interpreted these statistics as evidence of a long colonial and apartheid legacy of scientific racism. In other words, they were read through the colour-coded lens of colonial histories of discrimination and dispossession. For Mbeki and his 'dissident' supporters, such findings were not the product of neutral, rational and universal scientific enquiry, but were understood as the products of historically constructed and politically driven processes embedded in specific histories of colonialism, apartheid and capitalism.

In South Africa, the dissident debate and the numerous cultural obstacles encountered when implementing AIDS prevention programmes have forced scientists, NGOs, AIDS activists and government to acknowledge and respond to 'local' and 'lay' interpretations of AIDS. These include the blaming of AIDS on witchcraft, as well as a variety of AIDS conspiracies: 'whites' who want to contain black population growth; 'white doctors' who inject patients with AIDS when they go for tests; the CIA and pharmaceutical companies who want to create markets for drugs in Africa; the use of Africans as guinea pigs for scientific experiments with AIDS drugs; beliefs that sex with virgins, including infants, can cure AIDS; and beliefs that anti-retrovirals are dangerously toxic. But perhaps the most daunting problem for AIDS activists and health professionals was the President's initial flirtation with AIDS 'dissident' theories and the implications this had in terms of attempts to establish AIDS treatment programmes. The President's position, along with a plethora of popularly held 'AIDS myths' and the stigma and shame associated with AIDS contributed towards defensive responses and AIDS denial amongst both the general population as well as within the President's inner circle of policymakers and politicians. What are the implications of all this for contemporary debates on science and citizenship in a globalising world?

The AIDS pandemic in South Africa raises a number of troubling dilemmas for attempts to democratise science. Given the relative weakness of African states and the extremely thin spread of scientific knowledge and institutions, what can citizen science,

4 This historically 'white' and 'coloured' province was assumed to be the least vulnerable to AIDS prior to the HSRC findings.

5 *Mail and Guardian*, 6 December 2002. The HSRC study estimated the overall HIV prevalence in the South African population at 11.4 per cent, or about 4.5 million people. Other estimates put the figure at between 5–7 million.

6 Although the HSRC 2002 AIDS prevalence report found that all races were at risk, Africans had the highest incidence rate with 18.4 per cent. Whites and coloureds were around 6 per cent and Indians 1.8 per cent. The 6 per cent rate for whites was up from 2 per cent in 2000, at a time when the white population was perceived to be eight years behind the prevalence in the African population (M. Colvin *et al.*, 2000, cited in T. Marcus, 'Kissing the Cobra: Sexuality and High Risk in a Generalised Epidemic – a Case Study', paper presented for the conference 'AIDS in Context', University of the Witwatersrand, Johannesburg, March 2001).

popular epidemiology, ethnoscience and indigenous knowledge do to deal with a lethal pandemic such as AIDS? Or would state legitimisation of these public knowledges not further undermine already weak scientific institutions and biomedical knowledge regimes? 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 programmes? What about situations where people's own knowledge and practices result in AIDS denial, violence and oppression – as when, for instance, the South African AIDS counsellor Gugu Dlamini revealed her HIV-positive status to rural villagers, who responded by killing her for bringing shame and disease to her community?

This article explores what notions such as the 'democratisation of science' could look like from the epicentre of the worst public health hazard in Africa's history. It focuses on the opportunities and constraints that exist for mediation and negotiation between various experts and publics given this state of emergency. The AIDS pandemic raises particularly difficult questions concerning the role of deliberative and inclusionary processes in scientific domains: who is to be invited into what fora? What do these deliberative processes mean in contexts where scientific authority is distrusted both by powerful individuals within the state, and by large sections of the public?

By focusing on the responses and strategies of government, AIDS activists and civil society organisations such as the Treatment Action Campaign (TAC, whose foundation in 1998 and broader goals are described more fully below), it is possible to begin to address some of these questions. A case study investigates TAC's strategies of engagement with scientists, the media, the legal system, NGOs and government, as well as its grassroots mobilisation, AIDS treatment literacy campaigns and AIDS awareness campaigns. It examines the opportunities and limits that framed TAC's interactions within these different spaces.

The AIDS debate in South Africa is not merely academic. For example, certain lay knowledges and alternative, fringe, scientific perspectives (AIDS dissident science) have translated into support for AIDS myths and conspiracy theories that have, according to AIDS activists and health professionals, had a devastating impact on public health interventions, directly contributing to the loss of tens of thousands of lives. Some AIDS activists blamed dissidents and AIDS denialists within government for failing to provide ARV (anti-retroviral) treatment, and thereby contributing towards 600 AIDS deaths each day. Dr Costa Gazi of the Pan Africanist Congress (PAC) went as far as claiming that this shortcoming constituted a crime against humanity and complicity in genocide. The self-identified HIV-positive Justice Edwin Cameron, of the Supreme Court of Appeal, ultimately saw the triumph of apartheid thinking in the deniers:

We have a crisis of AIDS in our country. On the one hand that crisis is one of illness and suffering and dying – dying on a larger scale and in conspicuously different patterns from before; on a scale globally that dwarfs any disease or epidemic the world has known for more than six centuries. On the other hand that crisis is one of leadership and management ... The most fundamental crisis in the AIDS epidemic is our nation's struggle to identify and confront and act on

the truth about AIDS. The denial of AIDS represents the ultimate relic of apartheid's racially imposed consciousness, and the deniers achieve the ultimate victory of the apartheid mindset.⁷

While the dissident debate raged on, TAC activists, health professionals and the trade unions took to the streets and the courts in the struggle for AIDS treatment based on citizens' constitutionally-enshrined rights to health care. Zapiro,⁸ the best known of South Africa's political cartoonists, graphically captured this by depicting the President as playing the dissident fiddle while Rome was burning. In the face of relentless criticism of the President's pro-dissident stance, his spokespersons and supporters argued against the guild-like exclusivism of the scientific community and insisted upon the democratic right of the President to participate in debates on AIDS science. AIDS activists and health professionals made the counter-argument that the President's role in the debate was undermining public health institutions and the scientific authority and autonomy of experts, scientists and health professionals. While this case of high-level political interference in the scientific arena may appear extreme and exceptional, it nonetheless draws attention to more general questions relating to science, politics and citizenship in the 21st century.

Lethal Solidarities: Dissident Science and the Cultural Politics of AIDS

AIDS is a global disease that has devastated communities struggling under the burdens of poverty, inequality, economic crisis and war.⁹ AIDS is also 'an epidemic of signification'¹⁰ and responses to it have been unrelentingly moralising and stigmatising. In Africa, this 'geography of blame'¹¹ has contributed towards racist representations of African sexualities as diseased, dangerous, promiscuous and uncontrollable. This in turn has triggered defensive reactions that draw on dissident AIDS science, conspiracy theories and AIDS denial among African politicians, officials, intellectuals and journalists.

Representational politics have plagued AIDS debates and interventions in South Africa. These issues have had a profound impact upon the ways in which 'civil society' and 'the state' responded to the pandemic. Virtually every aspect of the pandemic – from AIDS statistics, to theories about the causal link between HIV and AIDS, to studies on AIDS drug therapy – led to contestation between government on the one side, and AIDS activists, scientists, health professionals and the media on the other. Given perceptions that AIDS fuels racist representations of Africans, it was perhaps not surprising that responses from President Mbeki took such a defensive turn.

The AIDS dissident debate in South Africa can be narrated from a variety of angles. It can be told as a story of how a small but powerful policy network was built

7 This quote is from Judge Edwin Cameron's speech delivered at the launch of photographer Gideon Mendel's book, *A Broken Landscape*, at the South African National Gallery, Cape Town, Saturday 13 April 2002.

8 Zapiro's real name is Jonathan Shapiro.

9 B. G. Shoepf, 'International AIDS Research in Anthropology: Taking a Critical Perspective on the Crisis', *Annual Review of Anthropology*, 30 (2001), p. 336.

10 P. Treichler, *How to have Theory in an Epidemic: Cultural Chronicles and AIDS* (Durham, NC, 1999).

11 P. Farmer, *AIDS and Accusation: Haiti and the Geography of Blame* (Berkeley and Los Angeles, University of California Press, 1992), p. 28.

around President Mbeki, and how this ‘inner circle’ was able to shape the direction of AIDS policy in South Africa. It is also the story of the Treatment Action Campaign and a highly organised and globally connected ‘community’ of scientists, health professionals, and civil society organisations who contested this dissident line. By November 2002, after three years of mass mobilisation, court cases, civil disobedience campaigns and demonstrations calling for AIDS treatment, the dissidents were on the retreat and ARV treatment was in sight. In August 2003 the Cabinet announced that it had decided to go ahead with a national ARV programme. But how and why did South Africa follow this tortuous path?

It was only in the late 1980s that AIDS in South Africa began to be acknowledged as a serious public health problem. Prior to this it was widely perceived to be a North American ‘gay disease’, with San Francisco and New York at its epicentre. It took almost a decade for the seriousness of the AIDS pandemic to filter into the consciousness of South African citizens, the media and policymakers. By the time of the World AIDS Conference in Durban in July 2000, most South Africans were aware that the country was in the midst of an epidemic of catastrophic proportions.

This Conference also exposed the international AIDS community to the deep rift between mainstream AIDS scientists and government supporters of the AIDS dissidents. Versions of the dissident view were articulated by President Mbeki and senior ANC figures such as the late Parks Mankahlana and Peter Mokaba.¹² In a press statement reported in the *Mail and Guardian* newspaper on 19 April 2002, a few months before his death, allegedly from AIDS, Mokaba, the then-ANC chief electoral officer, presented the AIDS dissident position in the following terms:

The story that HIV causes AIDS is being promoted through lies, pseudo-science, violence, terrorism and deception ... We are urged to abandon science and adopt the religion of superstition that HIV exists and that it causes AIDS. We refuse to be agents for using our people as guinea pigs and have a responsibility to defeat the intended genocide and dehumanisation of the African family and society...¹³

This line of argument, which was elaborated in detail by South African and international dissidents, was mercilessly challenged and lampooned by cartoonists and journalists. Its critics also included academics, opposition parties, AIDS activists and health professionals. Yet despite considerable challenge to the dissident view, even within the ruling party, it nonetheless came to represent the official government position on AIDS. This culminated in President Mbeki’s establishment of the President’s Select Advisory Panel of AIDS experts comprising an equal weighting of ‘establishment scientists’ and AIDS dissidents.

In March 2002 a controversial AIDS dissident document was posted on the ANC website. Its full title was *Castro Hlongwane, Caravans, Cats, Geese, Foot & Mouth and*

12 It is unclear how far these views were shared within the top echelons of the ANC government. There are nonetheless indications that there was considerable disagreement with Mbeki’s stance, even within his Cabinet. The strongest internal criticism came from the ANC’s Tripartite Alliance partners, the South African Communist Party (SACP) and the Congress of South African Trade Unions (COSATU).

13 Cited in J. Gitay, ‘Rhetoric, Politics, Science, Medicine: The South African HIV/AIDS Controversy’ (unpublished paper, Centre for African Studies, University of Cape Town, 18 September 2002), p. 2.

*Statistics: HIV/AIDS and the Struggle for the Humanisation of the African.*¹⁴ The document was subjected to intense criticism and ridicule from AIDS activists and the media, who portrayed it as an endorsement of President Mbeki's eccentric views. It quoted numerous scientific studies and journalistic forays questioning 'mainstream' AIDS science.¹⁵ Throughout, the author(s) referred to the 'omnipotent apparatus' that sought to bring about the dehumanisation of the African family and humiliate 'our people' (i.e. Africans). Citing numerous newspaper articles and scientific findings, the *Castro Hlongwane* document blamed AIDS drugs and pharmaceutical companies for 'the medicalisation of poverty' and for systematically destroying the immune systems of Africans. The posting also claimed that 'for the omnipotent apparatus [which includes the media, the medical establishment and drug companies] the most important thing is the marketing of the anti-retroviral drugs'. It concluded with the following statement:

No longer will the Africans accept as the unalterable truth that they are a dependent people that emanates from and inhabits a continent shrouded in a terrible darkness of destructive superstition, driven and sustained by ignorance, hunger and underdevelopment, and that is victim to a self-inflicted "disease" called HIV/AIDS. *For centuries we have carried the burden of the crimes and falsities of 'scientific' Eurocentricism, its dogmas imposed upon our being as brands of a definitive, 'universal' truth. Against this, we have, in struggle, made the statement to which we will remain loyal – that we are human and African!* (italics in original).

Although officially the ANC attempted to distance itself from the document in response to fierce general criticism, it became evident that the document's focus on the legacies of colonialism, 'underdevelopment', poverty, the Eurocentricism of science and racist representations of Africans as a 'diseased Other' appealed to a small group of African nationalists within the ANC leadership. *Castro Hlongwane* reads as an African nationalist defence of the AIDS dissident position in the face of what its authors claimed was a racist representation of AIDS as a 'black disease' associated with sexual promiscuity and the inability of Africans to control their sexual appetites. More generally, racist narratives about the sexually promiscuous, pathological and

14 The *Castro Hlongwane* document was allegedly posted on the ANC website by Peter Mokaba and is a lengthy exposition of the dissident position. The anonymous author, for example, 'rejects as baseless and self-serving the assertion that millions of our people are HIV positive ... It therefore rejects the suggestion that the challenge of AIDS in our country can be solved by resort to anti-retroviral drugs ... It rejects the assertion that, among the nations, we have the highest incidence of HIV infection and AIDS deaths, caused by sexual immorality of our people'. The author goes on to claim in Chapter VI, 'We do not know how many of our people have died [because scientists and doctors] at Chris Hani Baragwanath Hospital, conducted experiments on our people or "treated" them [with anti-retrovirals], relying on dangerously tendentious results of clinical [trials] sponsored by the pharmaceutical companies'.

15 The document also included numerous literary, journalistic and academic citations ranging from Adam Hochschild's *King Leopold's Ghost* (1998), Herbert Marcuse's *Eros & Civilisation* (1970) Paul Farmer's *AIDS and Accusation* (1993) and Angela Davis's *Women, Race and Class*, as well as a smattering of quotes from a diverse group of writers such as Henry Louis Gates, Jr., W. B. Yeats, Mark Twain, Jeffrey Sachs, John le Carre, Sun Tzu and many others.

uncontrolled black African fuelled Mokaba and Mbeki's African nationalist response. This may help explain support for their dissident ideas.¹⁶

Historically, Third World nationalist intellectuals have been very active in challenging what they have perceived as 'western ethnocentrism', especially when it comes to matters of culture, women and the family, sexuality, religion, and so on. Partha Chatterjee (1993)¹⁷ has shown how anti-colonial nationalists in India produced their own domain of sovereignty within colonial society before beginning their political battle with the imperial power. This involved staking out an autonomous spiritual sphere represented by religion, caste, women and the family and peasants. Not surprisingly, African nationalists, like their Indian counterparts, generated their own gendered nationalisms that accepted the 'western' culture of the state, while simultaneously carving out sovereignty in the domain of 'African culture', and African women and the family. However, AIDS threatens the integrity of this domain of sovereignty by appearing morally to condemn African male sexualities, as well as declaring the failure of 'the African family' to live up to the 'western' nuclear family ideal. It is resistance to this perceived moral and cultural onslaught that animates the African nationalist response to AIDS. Just as the 'dissident' view attributed AIDS to African poverty and disease reproduced through western racism, colonial conquest, capitalism and underdevelopment, it also challenged attempts to attribute the African AIDS pandemic to 'dysfunctional' sexualities and family structures.

While dissident support may have been limited to a relatively small circle of intellectuals, journalists and politicians, this position resonated with, and possibly gave credibility to, 'popular' forms of AIDS denial and alternative and 'traditional' explanations for AIDS and illness (see below). This popular contestation of establishment AIDS science is hardly surprising given that millions of South Africans are not exposed to 'mainstream' AIDS science. As a result, HIV/AIDS has been assimilated into a variety of 'popular' epistemologies and local ways of making sense of disease and misfortune, for example, 'witchcraft' and Christianity.¹⁸

Following two years of confused mixed messages, in 2002 President Mbeki appeared to distance himself from the dissidents, claiming that public perception of the government's support for the dissidents reflected a 'failure of communication on our side'.¹⁹ But was this simply 'a failure of communication'?

16 TAC has adopted a very different approach to these representational questions. Instead of resorting to a defensive, and potentially lethal, response of AIDS denial, TAC AIDS activists have sought to destigmatise and depathologise African sexualities. For instance, in Jack Lewis's much acclaimed documentary on TAC, entitled *Aluta Continua*, the key male and female characters, both of whom are black HIV-positive AIDS activists, consciously seek to affirm black African sexualities. They state that there is nothing to be ashamed about in having multiple partners, and it is quite normal and acceptable as long as safe sex is practised. This acceptance of different sexual cultures is very different to the ideologically driven character of Mokaba's nationalist rhetoric. What is also clear is that some senior government politicians, in an attempt to discredit TAC, claim that its leadership, in particular Zackie Achmat, has a 'hidden agenda', which is to introduce 'liberal' ideas about sexuality that are in line with those held by the international gay and lesbian movement.

17 P. Chatterjee, *The Nation and Its Fragments: Colonial and Postcolonial Histories* (Princeton, New Jersey, Princeton University Press, 1993).

18 I am grateful to Renee Fox (personal communication) for insightful e-mail discussions on the relationship between 'dissident' views and 'popular' religious and spiritual beliefs about illness and disease derived from her work with *Medicins Sans Frontières* in Khayelitsha, Cape Town, and other parts of the world.

19 *Cape Times*, 25 April 2002.

Gitay concludes that politicians, who ‘lack scientific tools’, should not be allowed to base their health policies on rhetoric, but should instead follow the consensus of the health sciences: the experts’ translation of the scientific data.²⁰ In support, he quotes approvingly from Sulcas and Gordin, who argue that ‘*HIV/AIDS is not a freedom of speech issue*. It is about scientifically verifiable facts. There are findings that, after testing, an overwhelming number of scientists consider accurate’²¹ (emphasis added).

While AIDS activists and the media described the positions of Mbeki and Mokaba as irrational, politically-motivated, and incompatible with western science, it would appear that the dissidents were insisting on their democratic right to criticise the science establishment. They did this by drawing attention to their alternative science. ANC spokespersons attempted to justify this high-level government intervention by referring to it as an expression of freedom of thought: a matter of rights. They described Mbeki as a latter-day Galileo burned at the stake by the media for refusing to conform to scientific orthodoxy. Calls for Mbeki to withdraw from the debate were described as attempts by the ‘scientific guild’ to shut down and stifle debate on questionable scientific findings. Mbeki’s spokespersons also described his interventions as an attempt to ‘open up’ what was perceived to be a narrowly technical, biomedical framing of the AIDS pandemic that ignored conditions of poverty and underdevelopment. Whereas much of this critique of the biomedical paradigm would have sat comfortably with most left-leaning South African AIDS and public health activists, the questioning of the link between the HI virus and AIDS was what went beyond the pale. It was this strand of the dissident critique that was perceived to be discontinuous with western science. The question remains: why did President Mbeki’s deployment of race and nationalist rhetoric in his challenge to mainstream AIDS science fail to win widespread public support?

AIDS and the Limits of ‘Race Talk’

Given the history of South Africa, it is perhaps not surprising that race and cultural identity came to assume such a central place in public discourses on AIDS. By the time AIDS began to take such a visible toll on South Africa, the country had barely surfaced from apartheid, a political system characterised by extreme forms of social and economic inequalities and ideological domination that systematically denigrated and dehumanised black people. As a result of this history, as well as colonial legacies of deep distrust of western science and modernisation policies,²² President Mbeki was able to make the claim that AIDS was being interpreted through a profoundly racialised (and racist) lens: African sexualities are ‘dysfunctional’, and Africans are to blame for their morally irresponsible and destructive sexual behaviour. The president no doubt felt compelled to challenge these racist readings of black bodies and sexualities, as did many other African nationalists. It would seem that AIDS has become a Rorschach, an ideological screen upon which a range of fears and fantasies have been projected.

20 Gitay, ‘Rhetoric, Politics, Science, Medicine’, p. 25.

21 A. Sulcas, J. Gordin, *Sunday Independent*, 23 April 2000.

22 Africa has a long colonial legacy of contestation over ‘scientific’ versus ‘local’ knowledge about environmental degradation relating to pastoralism, forest management, and soil and water conservation. Africans’ distrust of ‘western science’ and ‘development’ often resulted in fierce resistance to colonial cattle culling policies that were justified on the basis of foot and mouth disease or overstocking. In many cases such grievances concerning colonial development and conservation interventions contributed towards swelling the ranks of the liberation movements and advanced the cause of anti-colonial struggles.

Mbeki's response suggests that he believes that there is a widespread view that it is the socially irresponsible, excessive and immoral sexual practices of Africans that is the root cause of the spread of the AIDS pandemic: the victim is to blame.

Although HIV/AIDS exists amongst white, middle-class heterosexual communities throughout the world, the stigma of its early associations with homosexuals, bisexuals, blacks, sex workers and drug users has continued to stick. This troubling genealogy of the disease continues to shape the AIDS debate in South Africa. It explains the intense sense of shame associated with AIDS as well as the attraction of dissident AIDS science and nationalist views, especially amongst young, educated black South Africans. A TAC activist spoke of significant support for Mbeki's dissident views amongst intellectuals and educated township youth, while in the rural areas she encountered widespread denial and myths. By December 2002, it appeared that while TAC may have won 'the Nevirapine battle',²³ and in the process mobilised thousands of black mothers seeking to ensure the survival of their babies, it had not yet won the war against misinformation, fear, denial, silence and shame.

For those HIV-positive, unemployed and working-class black mothers who joined TAC, cultural nationalist arguments did not resonate with their all-too-real experiences of contracting the virus from HIV-positive men and losing children to AIDS, a tragedy that they believed could be averted through mother-to-child-transmission (MTCT) prevention programmes. For example, V, a young black female TAC volunteer, tells the story of how, following the trauma of rape by an uncle who later committed suicide, she was diagnosed with AIDS, hospitalised and told that she 'must wait for my day of death'. V eventually joined TAC and received anti-retroviral therapy treatment (ART). For V, TAC literally saved her life - 'now I can stay alive for a long time. I have my whole life' – and the organisation became the family that she lost when she was diagnosed HIV-positive:

I started the medicine [ART] and I am happy now because my immune system is picking up. So I tell the youngsters they must wake up and fight HIV ... TAC has helped me a lot. Before I was scared to go on TV or newspaper, but now I am not, because they give me a lot of support ... Mandla and Zackie are like my brother and my father... They are not the big guys – they are coming down to us...

V's account of her confrontation with AIDS and the spectre of death suggest why the abstract and ideological language of the cultural nationalist response to AIDS and AIDS science did not resonate for her. It also draws attention to the experiential dimensions of belonging that TAC is able to provide for HIV-positive people who, once they reveal their HIV status, are often exposed to stigma and rejection from their families and communities. Such trauma highlights the limits of ideological mobilisation in terms of shaping people's understanding of their identities and their place in the world; their citizenship. Nationalism or 'imagined communities' cannot easily be conjured up in the absence of experientially based understandings and social realities. How then was TAC able to catalyse and mobilise community belonging and civic action in a time of AIDS?

The Treatment Action Campaign (TAC)

23 Nevirapine is the anti-retroviral drug that is given to pregnant mothers as part of a national programme of prevention of mother-to-child-transmission (PMTCT).

TAC was established on 10 December 1998, International Human Rights Day, when a group of about fifteen people protested on the steps of St George's Cathedral in Cape Town to demand medical treatment for people living with the virus that causes AIDS. By the end of the day, the protestors had collected over a thousand signatures calling on the government to develop a treatment plan for all people living with HIV.²⁴

TAC's membership has grown dramatically over the past few years. The rank-and-file comprises mainly young urban Africans with secondary schooling. However, the organisation has also managed to attract health professionals and university students. The international face of the organisation is Zackie Achmat, a forty-something Muslim former anti-apartheid and gay activist. He is also a law graduate and an openly HIV-positive person. Until very recently Achmat had made it known publicly that he refused to take ART until it was available in the public health sector. Other TAC leaders include African men and women who joined TAC as volunteers and moved into leadership positions over time. The majority of the volunteers are young African women, many of them HIV-positive.

When TAC was founded, it was generally assumed that anti-AIDS drugs were beyond the reach of developing countries, condemning 90 per cent of the world's HIV-positive population to a painful and inevitable death. While TAC's main objective has been to lobby and pressurise the South African government to provide AIDS treatment, it has been forced to address a much wider range of issues. These included tackling the global pharmaceutical industry in the media, the courts and the streets; fighting discrimination against HIV-positive people in schools, hospitals and at the workplace; challenging AIDS dissident science; and taking the government to court for refusing to provide MTCT programmes in public health facilities. Rather than responding to AIDS from a cultural nationalist perspective, TAC mobilised within working-class black communities and the trade union movement, and used a variety of methods to pressurise the global pharmaceutical industry and the South African government to provide cheap anti-retroviral (ARV) drugs. I argue that this class-based mobilisation created the political space for the articulation of radical forms of 'health citizenship' linked to a genuinely progressive project of democratising science in post-apartheid South Africa.

Soon after its establishment, TAC, together with the South African government, became embroiled in a lengthy legal battle with international pharmaceutical companies over AIDS drug patents and the importation of cheap generics to treat millions of HIV-positive poor people in developing countries. As a result of highly successful global and national media campaigns, TAC managed to convince international public opinion, and the Pharmaceutical Manufacturers' Association (PMA), that it was moral and just for drug companies to bring down their prices and allow developing countries to manufacture generics. In the face of international public opinion in favour of TAC, PMA withdrew their case – no doubt influenced by the costs of adverse publicity that corporate greed was responsible for millions of deaths in Africa.

Despite TAC's highly successful global networking, much of TAC's energy was devoted to more local matters: mobilising poor and working-class communities, using the courts to compel the Ministry of Health to provide ARVs at public facilities, and campaigning to protect the autonomy of scientific institutions from government interference. Although grassroots mobilisation was primarily in black African working-

24 For a detailed account of the early history of TAC and its campaign for MTCT prevention programme, see *Treatment Action: An Overview, 1998–2001*, p. 2 in www.tac.org.za.

class areas, TAC's organisational structure and support networks crossed race, class, ethnic, occupational and educational lines.

TAC volunteers were involved in AIDS awareness and treatment literacy campaigns. In addition, TAC disseminated reports, scientific studies, website documents²⁵ and media briefs refuting government claims that ARV treatment was dangerously toxic, ineffective, too costly, and could not be implemented due to infrastructure and logistical problems such as inadequate management structures, shortages of trained staff and so on. The organisation also came out in strong support of doctors, hospital superintendents, medical researchers and the MRC who, by virtue of their report findings or provision of ARV treatment, found themselves on the wrong side of government, and subject to high-level political interference and intimidation.

AIDS Activism and 'Globalisation from Below'

TAC's mode of activism could be described as 'grassroots globalisation' or 'globalisation from below'.²⁶ Following the precedent of the divestment campaigns of the anti-apartheid struggle, TAC activism straddled local, national and global spaces in the course of struggles for access to cheaper AIDS drugs. This was done through the courts, the Internet, the media and by networking with South African and international civil society organisations. Widely publicised acts of 'civil disobedience' also provided TAC with visibility within a globally connected post-apartheid public sphere. By concentrating on access to ARV treatments for working-class and poor people, TAC was participating in a class-based politics that departed significantly from the cultural nationalist/identity politics promoted by the new ruling élite of Mbeki and Mokaba. It was not coincidental that COSATU, having lost thousands of workers to the pandemic, readily joined the TAC campaign.

The 'Christopher Moraka Defiance Campaign' was perhaps a defining moment in TAC's pro-poor political mobilisation around AIDS. It began in July 2000, after HIV-positive TAC volunteer Christopher Moraka died, suffering from severe thrush. TAC's spokespersons claimed that the drug fluconazole could have eased his pain and prolonged his life, but it was not available on the public health system because it was too expensive. In October 2000, in response to Moraka's death, TAC's Zackie Achmat visited Thailand where he bought 5,000 capsules of a cheap generic fluconazole. When TAC announced Achmat's mission in a press conference the international public outcry against the pharmaceutical giant Pfizer intensified as it became clear how inflated were the prices of name-brand medications; no charges were brought against Achmat, and the drugs were successfully prescribed to South African patients. By March 2001, Pfizer made its drugs available free of charge to state clinics.

This David and Goliath narrative of TAC's successful challenge to the global pharmaceutical giants captured the imagination of the international community and catapulted TAC into the global arena. Preparation for the court case also consolidated TAC's ties with international NGOs such as Oxfam, *Medicins Sans Frontières*, the

25 See H. Wasserman, 'New Media in a New Democracy: An Exploration of the Potential of the Internet for Civil Society Groups in South Africa', in Katherine Sarikakis and Daya Thussu (eds), *Ideologies of the Internet* (London, Hampton Press, 2003). Wasserman has a chapter on TAC and the Internet's potential for civil society groups in South Africa.

26 See A. Appadurai, 'Grassroots Globalization and the Research Imagination', in J. Vincent (ed), *The Anthropology of Politics: A Reader in Ethnography, Theory and Critique* (Malden, MA, Blackwell Press, 2002); and A. Appadurai, 'Deep Democracy: Urban Governmentality and the Horizon of Politics', *Public Culture*, 14, 1 (2002), pp. 21-47.

European Coalition of Positive People, Health Gap, and Ralph Nader's Consumer Technology Project in the United States. It seemed as if this was indeed a glimpse into what a progressive global civil society could look like.

TAC activists nevertheless stressed that grassroots mobilisation was the key to their success. This was done through AIDS awareness and treatment literacy campaigns in schools, factories, community centres, churches, *shebeens* (informal/illegal drinking places), and through door-to-door visits in the African townships. By far the majority of TAC volunteers were poor and unemployed African women, many of them HIV-positive mothers desperate to gain access life-saving drugs for themselves and their children.

TAC was also able to rely on support from middle class business professionals, health professionals, scientists, the media, and ordinary South African citizens, and used rights-based provisions in the South African Constitution to secure poor people access to AIDS treatment. These legal challenges created the space for the articulation of a radical democratic discourse on health citizenship. TAC's grassroots mobilisation and its legal challenges blurred the boundaries between the street and the courtroom. The Constitutional Court judges could not but be influenced by growing public support for TAC. The campaign achieved extraordinary media visibility and shaped public opinion through sophisticated networking and media imaging. They were able to give passion and political and ethical content to the 'cold letter' of the Constitution and the 'cold facts' of AIDS statistics.

Flexible Politics for Flexible Times

In December 2001, TAC's legal representatives argued in the High Court of South Africa that the state had a constitutionally-bound obligation to promote access to health care, and that this could be extended to AIDS drug treatment.²⁷ While the thrust of the TAC case focused on socio-economic rights, and specifically citizens' rights to health care, their lawyers raised broader issues relating to questions of scientific authority and expertise. The court was obliged to address the ongoing contestation over the scientific 'truth' on AIDS that raged between TAC, the trade unions, and health professionals on the one side, and government and the ANC on the other. By the end of 2003 it looked as if TAC and its allies had won this battle for ARV treatment.

Despite efforts to avoid being perceived as anti-government, TAC's criticism of President Mbeki's support for AIDS dissidents created dilemmas and difficulties. TAC activists were publicly accused by government spokespersons of being 'unpatriotic', 'anti-African' and salespersons of the international pharmaceutical industry. This locally situated cultural politics of race and national identity was addressed through a variety of strategies, including workshops, treatment literacy programmes and public meetings. TAC developed ways of combating what it perceived to be smear campaigns and attacks on its political credibility orchestrated by government spokespersons. It also managed the difficult feat of straddling the grey zones between cooperation with and opposition to government policies. Indeed, TAC's legal and political strategies reveal a clear understanding of the politics of contingency in contrast to an inflexible antagonistic politics of binaries: 'us' and 'them'.

TAC avoided being slotted into 'the conservative white camp' through the creative re-appropriation of locally embedded political symbols, songs and styles of the

30 The South African Constitution is unique in providing for water and housing (along with health care and a clean environment) as basic rights in the Bill of Rights.

anti-apartheid struggle. For example, the Christopher Moraka Defiance Campaign resonated with the historic anti-*dompas* (pass law) defiance campaigns of the apartheid era. By mobilising township residents, especially working-class and unemployed black women, TAC challenged attempts by certain government officials to whitewash it as 'anti-black'. By bringing the trade union movement on board, TAC also challenged accusations that it was a front for 'white liberals', the drug companies, and other 'unpatriotic forces'. By positioning themselves as supporters of the ANC, SACP and COSATU Tripartite Alliance, TAC activists have managed to create a new space for critical engagement with the ANC government. They have also introduced new concepts of health citizenship that have raised questions about the nature of democracy in South Africa.

TAC's strategic engagement with politics of race and class emerged from the organisational memory of AIDS activists who participated in the United Democratic Front (UDF) in the 1980s. This has expressed itself through songs at marches, demonstrations and funerals, and the regular press releases and conferences, website information dissemination, television documentaries, and national and international networking. This political style is a sophisticated refashioning of 1980s modes of political activism, drawing on the courts, the media, and local and transnational advocacy networks, along with grassroots mobilisation and skilful negotiations with business and the state.

Perhaps the most important reason for the successes of TAC's grassroots mobilisation has been its capacity to provide poor and unemployed HIV-positive black South Africans with a biomedical and a psychological lifeline, often in contexts where they experience hostility and rejection from their communities, friends and families. The story of V draws attention to how experiences of sexual violence and AIDS can trump cultural nationalist ideologies and race solidarities. The politics of class, and the access to life-saving drugs to poor people, seems to offer an alternative to an élite-driven politics of race and cultural identity.

Health Activism in Local Spaces

In December 2003, TAC activist Lorna Mlofana, aged 21, was gang-raped at a Khayelitsha (Cape Town) shebeen toilet, and beaten to death when she told her attackers that she was HIV-positive. For a period after Mlofana's brutal murder many TAC activists in Khayelitsha were afraid to wear the TAC HIV Positive T-shirts. The Campaign's response to this traumatic event was to hold a protest outside the Khayelitsha Magistrate's Court, and to launch educational 'blitzes' on trains and at clinics. Activists also made door-to-door visits to households in Town Two, the area in which Mlofana was killed, to educate people about AIDS. This shocking HIV/AIDS-related murder took place despite the fact that MSF and TAC had managed to establish exceptionally successful AIDS prevention and treatment programmes in Khayelitsha.

A number of studies have drawn attention to AIDS myths, conspiracies, stigma and denial in many parts of South Africa, showing how particularly pervasive they are in rural areas and poor communities that have had little exposure to AIDS activism, treatment literacy campaigns and grassroots mobilisation. It is also widely documented, for example, that in many parts of the country, women are not able to make independent decisions about contraception, or whether to take the HIV test and seek ARV treatment if they are HIV-positive. This was certainly the case in Mpumalanga Province where I recently encountered extremely low uptake rates in PMTCT programmes operating in

rural clinics. These socio-cultural obstacles clearly have serious implications in terms of access to ARV treatment programmes.

It is perhaps no coincidence that TAC and MSF activity has, until recently, tended to be concentrated in the urban centres of the Western Cape, KZN and Gauteng, i.e. areas that have the highest rates of uptake for PMTCT programmes.²⁸ This observation raises the following questions: are NGOs and community-based organisations such as MSF and TAC creating the socio-cultural conditions for the uptake of biomedical interventions such as PMTCT and ARV treatment? In what ways are these organisations able to ‘export’ these new ideas about health citizenship to rural areas where ‘traditional’ practices may clash with notions of female bodily autonomy? In South Africa, are we witnessing the emergence of a globally connected ‘politics of the body’ (reproductive health, immunisation, HIV/AIDS, etc) that draws on liberal individualist conceptions of the autonomous citizen as well as biomedical knowledge and practices?

Although TAC can be described as a rights-based social movement that uses the courts and constitutional rights to health care, it is also a grassroots social movement that goes beyond liberal individualism and ‘rights talk’. At the recent TAC national conference in Durban, I witnessed a particularly powerful session in which members gave impromptu testimony. Each highly charged testimony was followed by outbursts of song, dance and struggle chants: ‘Long live, Zackie, long live. Long live, TAC, long live!’ The following excerpts suggest that through grassroots mobilisation and treatment literacy campaigns TAC is able to articulate new forms of health/biological citizenship and political subjectivities that resonate amongst young, educated black youth in South African townships. Many of the testimonies demonstrated a sophisticated understanding of rights talk as well as intimate biomedical knowledge relating to AIDS treatment. They also expressed a sense of collective solidarity and belonging:

I’m a person living with HIV. I received counselling before and after I tested. The counsellors at the hospital where I work as an admin clerk gave me nothing. I just found out I was HIV-positive and that was that. Three times I tried to commit suicide. Now I’m more positive than HIV-positive, thanks to TAC.

(Thirty-something black man)

When I go to my doctor I tell him exactly what medicines I need. He asks me if I’ve trained in medicine at the university. No, I say to him. It was TAC that taught me...

(Thirty-something black woman)

Thank you to MSF. My CD4 count was 28 now it is 543. Thank you to TAC.

(Twenty-something black man)

I’m Phumzile from Cape Town in the Western Cape. I was diagnosed in 2001 three days after my birthday. I was very sick. When you get sick you just ignore it. You say, ‘Oh, its just the flu’. You’re in the denial stage. You say your neighbour is a witch ... We thought this disease belonged to other people elsewhere in Africa. From my point of view HIV is real, it’s there. I never

28 TAC and MSF have recently established treatment programmes in rural Lusikisiki (former Transkei) in the Eastern Cape Province.

thought I would be here today. I couldn't stand, I was sick. My CD4 count was 110 and my viral load was 710,000. Then I started ARVs with MSF in Khayelitsha. Now I'm strong...

(Twenty-something black man)

These testimonies suggest that participants at the TAC conference in Durban have overcome stigma, fear, denial, 'witchcraft' beliefs and other barriers to HIV/AIDS testing, disclosure and treatment. This contrasts strikingly with the numerous obstacles to treatment access I encountered in 2003 during a visit to rural parts of Mpumalanga.²⁹ While Nevirapine was available at many of the clinics, a dizzying array of socio-cultural obstacles, as well as political, logistical and capacity problems, seemed to stymie the implementation of PMTCT programmes at every turn. This visit raised several questions: were the socio-cultural obstacles in places like Mpumalanga largely due to the absence of the forms of AIDS activism and health citizenship and subjectivities promoted by TAC and MSF? Could TAC and MSF overcome these obstacles to biomedical interventions through their grassroots mobilisation and treatment literacy campaigns?

Renee Fox³⁰ recounted to me her experiences in Khayelitsha during a discussion with a group of research fieldworkers from the area, who were preparing to conduct interviews on local attitudes to HIV/AIDS. Fox asked the fieldworkers whether it would be possible to avoid 'resistance' to questions relating to 'witchcraft' by framing the questions differently, for example, by asking whether the respondents thought that angry and envious thoughts and feelings, the breaking of certain taboos, or seeking the intervention of a magico-religious specialist to do harm to another, could cause AIDS. She was surprised by the responses:

At first the group met what I said with total silence. But then they began to respond. One person said jokingly, 'There are those who believe that God will punish them [with AIDS] if they don't go to church on Sunday.' Another person suggested that others believed 'the ancestors' might punish you in this way if you broke taboos. Then, someone else exclaimed, 'How is it possible that in this beautiful, free land of ours' such an epidemic of AIDS could come to pass? This was a sheer outcry of a question of meaning. What followed rapidly were suggestions that some people believe that 'foreigners' can cause AIDS – 'foreigners' being defined as other black Africans immigrating to South Africa from surrounding countries, as well as whites; that condoms could cause AIDS (rather than prevent it); and that ARV treatment and modern Western medicine more generally could do harm. At the end of this discussion with this field team, I wasn't sure any longer whether they were simply describing beliefs of others, or whether they themselves subscribed to the same beliefs...³¹

29 I also encountered numerous serious managerial and logistical problems in the Mpumalanga public health system, including lack of political will from the MEC for Health to implement PMTCT, as well as a range of other institutional capacity problems, lack of leadership, resource and staff shortages, and so on.

30 Renee Fox, Professor of Sociology, personal communication (January 2004).

31 *Ibid.*

Tobias Hecht, an anthropologist working in Mandela Park, Hout Bay, encountered similar views and was told by Xhosa-speaking residents that ‘God sent AIDS to punish us for our sins’, and that becoming HIV-positive through witchcraft was the most lethal mode of transmission.³² Both Fox and Hecht are uncertain whether their informants shared these beliefs, or whether they were simply reporting on other members of the communities in which they lived. It is quite possible that people living in places such as Khayelitsha and Mandela Park, like most people, are able to believe in both universalist biomedical truth and ‘spiritual’/‘cultural’ interpretations of illness; the healing powers of ‘western’ biomedicine, Christianity and the spiritual forces of the occult are not necessarily viewed as incompatible. These examples of double or triple consciousness question public health arguments that it is necessary for patients to abandon ‘traditional’ beliefs in order fully to embrace biomedical truth.

My initial impression from my visit to Mpumalanga was that, to improve access to AIDS treatment, rural villagers should be exposed to a strong dose of TAC and MSF health activism and grassroots mobilisation of the sort that emerged in the urban centres of Cape Town, Johannesburg and Durban. However, while there can be little doubt that TAC and MSF have contributed enormously towards creating the conditions conducive to the ‘uptake’ of biomedical HIV/AIDS interventions such as ARV treatment, this does not mean that rank-and-file TAC members have been unambiguously ‘converted’ to biomedicine. While many of the participants in the ARV trials at Khayelitsha appear to have accepted the biomedical truths and rights-based approaches to health citizenship promoted by their MSF doctors, this does not necessarily exclude beliefs in the occult or other faith-based and spiritual forms of healing. ‘Conversion’ to ‘mainstream’ AIDS science may be partial and precarious: for instance, a TAC activist recounted how even some of their seasoned volunteers had been seduced by President Mbeki’s dissident views. Religious, spiritual and ‘traditional’ explanations and modes of healing are significant contenders in the struggle to fight and make sense of HIV/AIDS. Again, Tobias Hecht and I visited the MSF clinic in Khayelitsha to find out what had happened to an HIV-positive TAC member who, we were told, had thrown her ARVs away after joining the local branch of the Brazilian Universal Church of the Kingdom of God (UCKG). An MSF nurse told us that TAC activists had successfully persuaded the woman to return to ARV treatment. We later visited a UCKG pastor who tried to convince us that numerous HIV-positive congregation members had become HIV-negative through prayer: ‘If Jesus could heal leprosy, then why not AIDS?’, he asked.

Despite the partial character of TAC and MSF’s ‘conversion’ process, it is nonetheless clear that they have contributed enormously towards combating AIDS fear and stigma, and promoting easier access to PMTCT and ARV treatment programmes. These forms of health activism also appear to have succeeded in overcoming many of the socio-cultural obstacles to HIV testing and treatment referred to above. They have also contributed towards creating new forms of belonging, citizenship, scientific knowledge and subjectivity that resemble those emerging from the people’s health movements in Europe as well as developing countries such as Brazil. Instead of being rejected by family, friends and ‘community’, many HIV-positive TAC members are now able to belong to local and global activist communities that recognise and celebrate their humanity and vitality; they are no longer the ‘walking dead’ to be pitied or

32 Tobias Hecht, personal communication (March 2004).

avoided. They are ‘more positive than HIV-positive, thanks to TAC’.³³ Politicising the right to health care has empowered citizens.

However, there is a downside to this seeming wholesale endorsement of the power of biomedicine. In an interview with Eric Goemaere,³⁴ an MSF doctor in Khayelitsha, it became clear that MSF and TAC are acutely aware of the Janus-like character of ARVs and other biomedical technologies. Goemaere pointed out that whereas anti-retroviral therapy can undoubtedly prolong lives, it can also become a conduit for the ‘medicalisation of poverty’ and the creation of dependencies on medical experts and drugs. Although MSF consciously seeks to counter disempowering and normalising biomedical discourses by stressing citizen rights to health care and medical and scientific knowledge, such messages are seldom heard in the public health clinics. Instead, clinic nurses and doctors tend to reproduce hierarchical and paternalistic expert–patient relations. Language, class, race, ‘ethnic’ and education divides and socio-cultural barriers also collude to reproduce the passivity and disempowerment of working-class users of public health facilities.

The hierarchical and authoritarian cultures of many public health facilities can create obstacles in terms of access to AIDS programmes, particularly in areas untouched by social mobilisation and health activism. These problems are exacerbated in contexts where patriarchal ideas and practices prevent women from accessing health facilities, for instance, for HIV-testing and participation in PMTCT programmes. The testimonies of young women at the 2003 TAC conference (cited above) allude to TAC and MSF’s effective challenges to both ‘patriarchal’ and ‘biomedical’ ways of controlling female bodies and minds, i.e. the capacity of women to exercise agency in relation to male family members and medical experts.

While the dissident debate now appears to be ‘mere history’, stigma, fear, denial and patriarchal attitudes are likely to continue to be serious obstacles to AIDS prevention and treatment programmes. For example, ‘Thembeke’, a young HIV-positive, AIDS Counsellor in Mandela Park, Hout Bay, told me how she was struggling to access residents in this informal settlement. She mentioned that while her visits were appreciated when her HIV-positive ‘clients’ were seriously ill and desperately needed home-based care, they were furious with her when she visited them in shebeens and other public places, where, in the eyes of residents, her mere presence associated those she visited with AIDS.³⁵ They would ‘disappear’ when they were relatively healthy and reappear when they became critically ill. TAC, MSF, public health professionals and other civil society organisations clearly have their work cut out for them in places such as Mandela Park.

33 Renee Fox, personal communication, reminded me that saying ‘I am stronger now thanks to MSF and TAC’ does not necessarily refer exclusively to physical health. It could also be a statement about the role of ARVs in producing a spiritual strength in the battle against the occult and ‘evil’ forces of envy and jealousy. This spiritual empowerment, however, does not mesh with TAC and MSF’s stridently secular and scientific cosmology. As a result, public testimonies of the sort that were made at the TAC Durban Conference emphasised secular rationalist discourses on empowerment through access to scientific and medical knowledge.

34 Interview with Eric Goemaere, Khayelitsha, 20 May 2004.

35 ‘Thembeke’ spoke of having tried, unsuccessfully, to use the AIDS counselling methods she learnt at Khayelitsha, where she receives ARV therapy at the MSF clinic. She reported that Mandela Park’s HIV-positive residents remained in a state of AIDS denial, and that the two AIDS support groups in the area were clandestine as their members did not want to be exposed to the stigma so pervasive in the community.

Health professionals, church groups, and organisations such as MSF and TAC are emerging as catalysts for attempts to democratise science and public health, often in contexts of chronic poverty, everyday violence, AIDS denial, and beliefs in witchcraft and other alternatives to AIDS science. It remains to be seen in what ways, if at all, these organisations and HIV/AIDS interventions are able to challenge such socio-cultural obstacles. Nor is it clear to what degree they could unwittingly be promoting the dependencies and ‘medicalisation of poverty’ about which Goemaere expressed concern. It also remains to be seen how AIDS activists and public health professionals will address ‘alternative’ (non-biomedical) interpretations of disease and illness. Will a national ARV treatment programme extend normalising biomedical discourses and reduce citizens to docile consumers of medical technologies and scientific expertise? Or will citizens be able to engage with biomedicine in empowering ways?

A Provisional Conclusion

South Africa’s devastating HIV/AIDS statistics, President Mbeki’s controversial support for the ‘dissidents’, and TAC’s widely publicised court victories over both the South African government and the multinational pharmaceutical giants, thrust the South African AIDS pandemic onto the global stage. Mbeki’s ‘African nationalist’ response to the AIDS pandemic illustrates the workings of a cultural politics of identity that diverted attention from working-class and poor people’s struggles for access to life-saving AIDS treatment that are accessible to the middle classes. The responses of African nationalists and dissidents within government and the ruling party clashed with the class-based mobilisation of AIDS activists and trade unionists who insisted that ARVs be made freely available in public health facilities as part of citizens’ constitutional rights to health care. The case study of these starkly contrasting responses to AIDS draws attention to the potential pitfalls as well as the emancipatory possibilities that exist for democratising science in a time of AIDS.

TAC’s mode of activism captivated the imagination of AIDS activists, journalists and millions of supporters throughout the world: here was the archetypal David and Goliath epic. In their quest for AIDS drugs, a small group of committed activists were able to build a globally connected social movement – a form of practised citizenship – that successfully ‘persuaded’ pharmaceutical giants and the South African government to put measures in place for the provision of AIDS treatment.

The AIDS pandemic, and the ways in which responses to it have unfolded in South Africa, raises important concerns about the social responsibilities of, and relationships between, the state, business and ‘civil society’. It has also drawn attention to the role of scientific expertise and trust in expert systems, as well as issues of political and scientific authority and moral legitimacy, and the ways in which publics relate to these. In addition to the profound confusion and uncertainty experienced by South African publics as a result of President Mbeki’s questioning of conventional AIDS science, it has become apparent that people’s interpretations of the AIDS pandemic are far more complex and differentiated than either the government or TAC originally anticipated. Journalists and researchers have uncovered a proliferation of AIDS myths and cultural interpretations of HIV/AIDS, including patriarchal conceptions of sexuality, which threaten to undermine treatment and prevention programmes. AIDS science and scientific authority were certainly undermined by the politicised nature of the dissident debate, but not all blame can be pinned onto the President.

TAC drew on a rights-based approach as well as grassroots mobilisation in working-class black communities. Its dramatic courtroom victories, along with its innovative forms of mobilisation, were part of a largely working-class struggle to gain access to life-saving drugs. It was also a campaign to assert the right of citizens to scientific knowledge, treatment information and the latest research findings: a post-apartheid expression of health citizenship.

TAC's mode of social mobilisation operated at a number of levels: global, national and local. At the global level, it challenged the intellectual property regime and drug pricing protocols and regulations imposed by the pharmaceutical industry; at the national level, it posed a fundamental challenge to the South African government's AIDS treatment policies; and at the local level, it mobilised working-class black communities, creating the conditions for the articulation of forms of health/biological citizenship as well as new gendered identities and subjectivities that challenged 'traditional' and patriarchal ideas and practices. While TAC's mobilisation practices and treatment access campaigns operated at all three levels simultaneously, its activities have been, until recently, largely confined to urban areas, where it has drawn in young, black secondary school leavers and students. It remains to be seen to what degree MSF and TAC will be able to extend their social mobilisation and treatment access campaigns to other contexts, for instance the countryside of the former homelands, where patriarchal cultures and the politics of shame and denial continue to frustrate efforts to make the public health system more accessible to HIV-positive people, especially women.³⁶ Is it possible to replicate and 'scale up' TAC and MSF's dramatic successes in urban centres such as Khayelitsha as part of the national ARV programme? What lessons from the Khayelitsha programme can be 'exported' to other ARV rollout sites?

It also remains to be seen what role TAC/MSF will play in mediating these universalist biomedical understandings of 'disease' and 'illness' in South African communities where there are competing explanations for misfortune and ill-health. In what ways will MSF and TAC continue to be a catalyst for the spread of new notions of health citizenship and the democratisation of science in post-apartheid South Africa?

Finally, will the South African government and public health officials responsible for running an extremely over-burdened public health system agree, once and for all, to bury the 'dissident hatchet' and work together with TAC, MSF and other civil society organisations? While it is clear that many provincial and local government health managers and public health practitioners look favourably upon such partnerships, it is unclear whether the political fallout from the dissident debate will continue to stymie national government responses to the epidemic.

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36 See S. Robins, 'Reclaiming Bodies, Extending Citizenship: Health Activism in a Time of AIDS' (unpublished paper, Association of Anthropology in Southern Africa conference, University of Cape Town, 24–27 August 2003).