AIDS, Science and Governance: The battle Over Antiretroviral Therapy in Post-Apartheid South Africa.

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#### Abstract

South Africa's approach to AIDS has been shaped by persistent antipathy on the part of President Mbeki and his Health Minister towards antiretroviral therapy. This was initially framed by Mbeki's questioning of the science of AIDS and by their direct resistance to implementing programs using antiretrovirals. Having lost that battle, the Health Minister has continued a war of attrition by portraying antiretrovirals as 'poison' and by supporting and protecting purveyors of scientifically untested alternatives to antiretrovirals. In so doing, she has continued the process of challenging and eroding the authority of science and scientific regulation in the health sector. Two key scientific bodies, the Medicines Control Council (MCC) and the Medical Research Council (MRC) fall under the ambit of the Department of Health. Although notionally independent, both have experienced political interference as a consequence of their conventional scientific approach on AIDS. But whereas the MRC has (so far) been able to resist, the MCC appears no longer able to respond to complaints if these are lodged against alternative therapists supported by the Health Minister. By supporting and facilitating the running of unofficial, unscientific 'trials' of products punted as alternatives to antiretrovirals, the Health Minister has sharply curtailed the ambit of the scientific regulation of medicines.

#### Introduction

South Africa's strategy for combating AIDS has been shaped by a long-standing antipathy on the part of President Thabo Mbeki and his Health Minister towards antiretroviral therapy. In the early years of his Presidency (1999-2000), this was framed by Mbeki's questioning of the science of AIDS and his support for AIDS denialists/dissidents who believe that HIV is a harmless passenger virus and that AIDS symptoms are caused by malnutrition and antiretroviral therapy. This openly AIDS dissident phase proved so controversial that Mbeki withdrew from the public debate in October 2000. Since then, his Health Minister, Dr Manto Tshabalala-Msimang has fought a rear-guard action by resisting the introduction of antiretrovirals for mother-to-child transmission prevention (MTCTP) – until she was forced to do by a Constitutional Court ruling – and by resisting the introduction of highly active antiretroviral therapy for AIDS-sick people until

a cabinet revolt in late 2003 forced her to back down on this too. Undaunted, she has continued to undermine the 'rollout' of antiretroviral treatment in the public sector, *inter alia* by supporting unproven substances, and by couching this within a dissident discourse that highlights the side-effects of antiretrovirals – even portraying them as 'poison'.

In both periods, Mbeki and Tshabalala-Msimang have demonstrated a disregard for the orthodox scientific cannon on AIDS by a) portraying it as but one of several viewpoints and; b) undermining the credibility of those who accept the science of antiretroviral treatment by accusing them of being salesmen for the large pharmaceutical companies. In the process, they have undermined the authority of established science and have eroded the independence and effectiveness of the institutions governing medical research and the scientific regulation of medicines.

This paper traces the history of this opposition to antiretroviral therapy and the implications it has had for the role of scientific governance in the health sector. Particular attention is paid to the conflicts which have arisen between Mbeki and his Health Minister on the one hand, and two quasi-independent scientific bodies: The Medicines Control Council (MCC), South Africa's key regulatory authority for the scientific testing and registration of medicines; and the Medical Research Council (MRC), South Africa's parastatal medical and epidemiological research institute. Both these bodies are located institutionally within the Department of Health, but are designed to operate without political interference. However, as a direct result of their challenging Mbeki on AIDS-related issues, the independence of these institutions has been threatened, and in the case of the MCC their authority and effectiveness has been sharply curtailed.

# Deputy President Mbeki's Conflict with the Medicines Control Council over Virodene

The first major confrontation between Mbeki and scientific governance occurred in 1997 when he was Deputy President. This so-called 'Virodene saga' began in January 1997 when 'Ziggie' and Olga Visser (scientists at the University of Pretoria) informed the Health Minister (then Nkosazana Dlamini-Zuma) about an unofficial trial they were conducting on AIDS patients using a freezing solution (dimethylformamide) which they called 'Virodene'. They told the Health Minister that their results were promising but that 'the AIDS Establishment' was blocking their research because it threatened the profits of large pharmaceutical companies (Myburgh 2005). The Health Minister responded by side-stepping the usual procedures governing medical research and inviting the Vissers (and some of their patients) to a cabinet meeting.

Writing in the ANC magazine, *Mayibuye*, Mbeki described what a 'privilege' it was 'to hear the moving testimonies of AIDS sufferers who had been treated with Virodene, with seemingly very encouraging results' (Mbeki, 1998). Cabinet Secretary Jakes Gerwel told a journalist that "It was like a church confessional. The patients said they were dying, they got this treatment, and then they were saved! The thing I will always remember is the pride in South African scientists". After giving the Vissers a standing ovation, the Cabinet took a decision to help them win

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<sup>&</sup>lt;sup>1</sup> Quoted in *The New Yorker*, May 2003, Samantha Power "The Aids Rebel". Available on http://www.pbs.org/pov2003/stateofdenial/special\_rebel.html

approval for a scientific drug trial and to 'support the Virodene research up to the completion of the MCC process' (Mbeki, 1998).

The MCC operates through a network of committees drawing on independent scientists, usually based in universities, to manage the registration of medicines and ongoing assurance of the quality of medicines on the market and control over their distribution and use. As part of its work, the MCC evaluates clinical trial protocols and assess the evidence from such trials. After evaluating the Virodene trial protocol (which described the underlying science and the design and management of the trial) the MCC refused the Vissers permission to continue. Subsequent applications were also turned down, earning Peter Folb, a professor of pharmacology at the University of Cape Town and Chair of the MCC, the wrath of Mbeki and the Health Minister. Mbeki accused the MCC of denying AIDS patients the 'possibility of mercy treatment' (Mbeki, 1998) and the Health Minister attempted to pressurize Folb politically by saying 'You're ANC. Why won't you back me on this?"<sup>2</sup>.

Conflict escalated between the Health Minister and the MCC over Virodene and a range of other issues relating to her emerging plans to restructure the MCC (including removing all those with industry links). The Health Minister excluded the MCC from the process she had initiated to restructure South Africa's drug legislation (Gray *et al*, 2002: 53) and set up a 'review team' to evaluate the MCC. This team, which was 'widely seen as working on behalf of the minister of health for political ends' (Sidley, 1998a: 1037), recommended that the MCC should 'cease to exist' and that an entirely new structure be created (Dukes *et al*, 1998: 2-3). Echoing Mbeki's and the Health Minister's growing suspicion that scientists were too easily bought by pharmaceutical interests, the review team pointed to the absence of 'adequate rules...to avoid the risks posed by conflict of interest, particularly where commercial interests do not run parallel with those of the community at large' (ibid).

The MCC, finding itself marginalised and under fire, had to feed its concerns about the draft legislation (the South African Medicines and Medical Devices Regulatory Authority Bill) through the public hearings that were held in September 1997. The MCC was concerned about the proposed new regulatory authority (to replace the MCC) and the proposed fast-tracking mechanism under the control of the executive which, the MCC argued, could compromise 'scientific rigour' (*ibid*: 39). The bill, which *inter alia* made provision for alternative mechanisms for approving traditional/complementary medicines, was passed in 1998 but repealed in 2002 without ever succeeding in creating such mechanisms.

Nevertheless, acting on the recommendations of the review team, the Health Minister suspended the Registrar of Medicines and his deputy – an action that was subsequently overturned by an arbitration hearing of the Commission for Conciliation, Mediation and Arbitration (Gray *et al*, 2002: 40).<sup>4</sup> Folb complained that the review team had made inappropriate recommendations that were outside the laws governing the MCC (Folb, 1998). The Health Minister eventually got rid of this thorn in her side when Folb's term expired in April 1998. She appointed Dr Helen Rees,

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<sup>&</sup>lt;sup>2</sup> Quoted in Van der Vliet (2004: 56).

The executive summary of this report is available on http://legacy.hst.org.za/info/medicine/execsum.html)

Interestingly, as of March 2006, Chrystal Bruckner (deputy) had still not got her job back, despite a subsequent ruling in her favour by the Labour Court (personal communication with Andy Gray).

who at the time was regarded as more sympathetic to the Health Minister's concerns than Folb had been (Sidley, 1998b: 1696).

Ironically, the MCC continued to deny the Vissers permission to conduct Virodene trials. It also acted quickly to shut down the so-called 'Genesis Research Centre' offering experimental 'oxytherapy' (i.e. injecting ozone into people's blood vessels) to AIDS patients – despite the fact that the Health Minister was reportedly about to visit the clinic on the recommendation of Winnie Madikizela Mandela (Sidley, 1998b: 1969). When the Vissers had exhausted all avenues with the MCC, they finally opted to test Virodene (with the support of the ANC<sup>5</sup>) on Tanzanian soldiers. Virodene has not been registered in any country but is being marketed surreptitiously in southern Africa and over the internet. In September 2005, the parliamentary opposition Democratic Alliance complained about this re-emergence of Virodene and referred the matter to the MCC, but no action has yet been taken.

The attempt by Mbeki and his Health Minister to 'fast-track' a supposed miracle AIDS drug has distinct echoes with a similar saga in Kenya. After initial trials (later revealed to be faulty), Kenyan scientists announced in 1990 that they had discovered that alpha interferon was a cure for AIDS. President Moi formed a company to promote the product, which he named 'Kemron', branding those who expressed doubts as unpatriotic (Hyden and Lanegran, 1993). Kemron was subsequently promoted among African-Americans in the United States as a potential cure that was being ignored because it posed competition for antiretrovirals (Noel, 1998; Wakefield, 2000). Despite a number of studies showing that alpha interferon was ineffective against AIDS, the Federal Drug Administration (FDA) in the United States was eventually prevailed upon to allow a clinical trial of Kemron, but this was subsequently terminated by the National Institutes of Health.<sup>8</sup>

## The Link between Virodene and AIDS Denialism

According to Myburgh (2005), it was the Vissers who, in March 1999, alerted Mbeki to a debate between Anthony Brink (an AIDS denialist with no training in medical science) and Dr. Des Martin (president of the Southern African HIV/Aids Clinicians Society) in the pages of *The Citizen*. In his article 'AZT: A medicine from hell', Brink defended the Health Minister's decision not to make AZT available for MTCTP, comparing her to the FDA's Francis Kelsey who saved the USA from thalidomide by delaying the drug's approval. He asserted that AZT was so toxic that prescribing it 'was akin to napalm-bombing a school to kill some roof-rats'. Prof Martin responded by pointing out that antiretroviral therapy in the USA had resulted in a 40% decline in AIDS mortality between 1995 and 1997, and that AZT has been shown to cut mother

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<sup>&</sup>lt;sup>5</sup> According to Myburgh (2005) the ANC Treasurer transferred funds to the Vissers at several points between 1998 and 2000 to assist with legal fees, foreign-based clinical trials and the costs of patent registration.

According to the company that promotes Virodene, the Tanzanian trials showed that Virodene could have a positive impact on the immune system. However, no evidence is available on the impact of the drug on viral load. See http://www.virodene.com/downloads/Virodene Executive Brouchure.pdf.

Cape Argus, 7/9/05. Di Caelers 'Virodene drive to be reported to watchdog'.

<sup>&</sup>lt;sup>8</sup> Washington Post, 24/7/97, Amy Goldstein, "After Unpromising Start, NIH halts study of disputed Aids drug, Kemron".

Anthony Brink published his article on 17/3/99 and Martin responded on 31/3/99.

to child transmission by 67%. He agreed that the toxicity of AZT was a 'very real issue' requiring constant monitoring and vigilance on the part of clinicians. However, its benefits for MTCTP rendered the drug in his view, 'a medicine from heaven'.

In some respects, this 'debate' rehearsed the often emotional clash of perspectives over AZT in the United States during the early 1990s. Given the contestable (and contested) results of the early AZT trials, the issue of how to balance up unclear long-term therapeutic benefits with the side-effects of taking the drug, was source of great anxiety and contestation in the AIDS activist community (see Epstein, 1996). However, by 1999, the anti-AZT position had been relegated to fringe websites <sup>10</sup> by the therapeutic success of triple therapy (i.e. using AZT or another nucleoside analogue in combination with a protease inhibitor and a non-nucleoside reverse transcriptase inhibitor), and by AZT's proven success in MTCTP. The overwhelming consensus in both activist and scientific communities was that the benefits of AZT outweighed the risks.

A small group of AIDS dissidents, have, however, in the face of substantive criticism and evidence to the contrary, been arguing for nearly two decades that AZT is a cause of, rather than a treatment for, AIDS. These dissidents have no credibility in the scientific community. As far back as 1995, an investigation by *Science* concluded that none of the claims made by the leading dissident, Peter Duesberg (a professor of molecular and cell biology at the University of California), stood up to scrutiny (Cohen, 1995). In 1998, the journal *Genetica* published an article by Duesberg and Rasnick (1998) summarizing the key dissident claims – followed immediately by a point by point refutation (Galea and Chermann, 1998). According to Bialy, Duesberg's biographer and fellow dissident on Mbeki's Presidential Panel, the Duesberg and Rasnick article had a major impression on Mbeki (2004: 182). This suggests that either Mbeki was not aware of the rebuttal, or if he was, that he rejected it along with the many substantial arguments available at the time that HIV causes AIDS (e.g. NIAID, 1995) as being part of the existing corrupt scientific establishment.

One of the hallmarks of AIDS dissidents is that they believe the entire cannon of established science on AIDS is faulty and hence that *none* of its conclusions about the relationship between HIV and AIDS, or about the efficacy of antiretroviral drugs, can be trusted. In short, losing respect for the established scientific community is a necessary condition for becoming an AIDS dissident. As Papadopulos-Eleopulos (a dissident biophysicist at the Royal Perth hospital) puts it, conventional AIDS science is "all just rubbish, rubbish" (quoted in Brink, 2000: 104). Unsurprising, conventional scientists are offended by this attitude as it implies that 'tens of thousands of health care professionals and research scientists are either too stupid to realize that HIV is not the cause of AIDS, or too venal to do anything about it for fear of losing income from the government or drug companies' (Moore, 1996: 293).

## Challenging Orthodox Science: Mbeki's Openly Dissident Phase

By the time that Mbeki became President in June 1999, it would appear that he had already immersed himself in the dissident AIDS literature and was in close contact with Brink, Rasnick and Duesberg (Brink, 2000; Bialy, 2004). Mbeki launched his first broadside when he addressed

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For an archive of AIDS dissident beliefs and arguments, see www.virusmyth.com

the National Council of Provinces (a body bringing together national and provincial government ministers) in October 1999. He reported that AZT was toxic and formally asked the Health Minister to find out 'where the truth lies' 11 (a process which culminated in the setting up of the Presidential AIDS Advisory Panel the following year, comprising both dissident and conventional scientists). Mbeki also urged council members "to access the huge volume of literature on this matter available on the internet". 12

The notion that government ministers should educate themselves about the science of AIDS through internet research was a less-than-subtle shot across the bows of the scientific community. It implied a belief that "the truth might be on the internet, free of 'Western' or US self-interested censorship" (Sheckels, 2004: 72) rather than in the pages of peer-reviewed academic journals (see also Price, 2005: 165). As such, it demonstrated a clear disregard for the authority and credibility of established scientific expertise.

In his opening address to the first meeting of the Presidential AIDS Advisory Panel in May 2000, <sup>13</sup> Mbeki describes his process of self-education in disarming detail:

"I faced this difficult problem of reading all these complicated things that you scientists write about, in this language I don't understand. So I ploughed through lots and lots of documentation, with dictionaries all around me in case there were words that seemed difficult to understand. I would phone the Minister of Health and say, 'Minister, what does this word mean?' And she would explain. I am somewhat embarrassed to say that I discovered that there had been a controversy around these matters for quite some time. I honestly didn't know. I was a bit comforted later when I checked with a number of our Ministers and found that they were as ignorant as I, so I wasn't quite alone."

This is strongly reminiscent of the way that AIDS activists in the USA came to grips with the science of their disease through self-education (Epstein, 1996: 229-30). But unlike these AIDS activists, Mbeki was head of state. Why did he not instead seek the advice of South Africa's internationally recognised medical scientists – including for example, Professor Malegapuru Makgoba, an immunologist and head of the MRC? The MRC, an autonomous research institution which 'accounts to the people of South Africa through the Department of Health' has a large body of research scientists any number of which would have been up to the task. However, by this stage, it appears that Mbeki had already developed a strong distrust of the scientific establishment, and was poised to argue with orthodox scientists rather than seek their advice.

In January 2000, Dr Michael Cherry (a zoologist from the University of Stellenbosch and, inter alia, correspondent for *Nature*) published a newspaper article 15 quoting Makgoba as saying that he had 'read nothing in the scientific or medical literature that indicates that AZT should not be provided to people'. Mbeki promptly sent both Cherry and Makgoba a paper by Papadopulos-

<sup>&</sup>lt;sup>11</sup> Shortly thereafter, the Health Minister suggested that AZT could weaken the immune system and could lead to disabling mutations in babies (Van der Vliet, 2004: 58).

This speech is available on http://www.anc.org.za/ancdocs/history/mbeki/1999/tm1028.html.

This speech is available on http://www.anc.org.za/ancdocs/history/mbeki/2000/tm0506.html.

<sup>14</sup> See http://www.mrc.ac.za/history/seti.htm.

M. Cherry. "SA needs policy on preventing mother to child transmission of HIV", in Business Day, 31 January, 2000.

Eleopulos  $et\ al$  (1999) arguing that because the prevailing scientific understanding of the way that AZT worked was (in her view) inadequate, whereas its toxic effects were demonstrable, the drug should not be prescribed.

Makgoba responded to Mbeki, providing detailed counter-arguments (Cohen, 2000: 590). He subsequently complained about Mbeki's enthusiastic embrace of Virodene without any scientific evidence and his apparent support for dissident 'pseudo-science' on AIDS – concluding that 'this undermining of scientists and the scientific method was especially dangerous in a developing country still in the process of establishing a strong scientific research base' (Makgoba, 2000: 1171). Makgoba's approach was thus to reassert the authority and integrity of the scientific community, and to tell Mbeki to 'leave science to the scientists'. When, in April 2000, Mbeki wrote to world leaders (including Clinton, Blair and Annan) defending his support for the dissident scientists, Makgoba took the gloves off entirely by describing the action as 'emotional and irrational' and predicting that Mbeki "will regret this in his later years... (because he) ...displays things he does not understand' (quoted in Cohen, 2000: 150-1).

Cherry's approach was less confrontational. After consulting with several specialists, he replied by arguing that Papadopulos-Eleopulos *et al* had presented no original research, had based their case against AZT on a very selective (and dated) set of references (thereby ignoring the best available science on the effectiveness of AZT), and had failed to weigh the costs of the drug (toxicity) against the benefits of MTCTP. Mbeki forwarded these comments to Papadopulos-Eleopulos, who wrote a response (which Mbeki passed on to Cherry), to which Cherry responded once more, as did she.

This correspondence, the latter part of which is publicly available, <sup>17</sup> is a typical example of the way in which dissident scientists counter the conventional science on AIDS. In her response to every reference that Cherry made to the scientific literature, Papadopulos-Eleopulos asserted that none of it amounted to sufficient 'proof', in her view, of the efficacy of AZT. When he pointed out that AZT in combination with other antiretroviral drugs has been shown to reduce the viral load in patients, she responded, not by disputing the evidence, but by arguing that in terms of her understanding of virology, AZT could not possibly be effective. When Cherry observed that studies had shown that antiretroviral therapy had resulted in a large drop in mortality and morbidity, she responded by complaining about its side effects.

On the issue of MTCTP, Cherry argued that her reading of the literature was selective and that any toxic side effects had to be balanced against the benefits of reduced transmission of HIV. He pointed out that the authors of one of the articles she referred to in support of her 'AZT is toxic' argument had themselves concluded that the side effects should not be regarded as a reason not to use AZT for MTCTP. She responded by saying that those authors had no choice but to add this qualification to their work in order to get it published. Unable to deal with what he saw as her 'intellectual dishonesty' 18, Cherry ended the correspondence.

Correspondence with Mike Cherry.

http://www.tig.org.za/pdf-files/attached.pdf,

Personal communication with Michael Cherry.

It is hard to know what anyone who is not a medical scientist could make of the exchange. The issues are clouded by complex medical terminology, by what appears to be interminable quibbling over what can or cannot be learned from existing studies, and by apparent rival understandings of virology, immunology and pharmacology. Ultimately, the issue of who to believe boils down to credibility and scientific authority. As Epstein puts it, "Since no one can 'know' all or even a fraction of the corpus of scientific knowledge through direct experience, science is made possible through the allocation of trust" (1996: 15). Trust, in turn, rests on the reputation of experts, which in turn derives from their being able to publish in peer reviewed journals. In this regard, most reasonable non-specialists will opt to trust mainstream science on the assumption that the scientific cannon rests on the best available information and that when existing theory is shown to be incorrect by new evidence, theories change. While it is of course true that scientific advance is often shaped by commercial interests, that people with an intellectual or material stake in an existing paradigm may resist the implications of new evidence as long as possible (Kuhn, 1962), and that the construction of scientific fact is a contested social process (Epstein, 1996), revolutions in scientific thinking are ultimately achieved through persuasion. Unfortunately, what characterises all exchanges between dissident and conventional scientists on AIDS is an impenetrable persuasive barrier resulting from an extraordinary tenacity on the part of the dissidents to resist counter evidence (see also Maddox, 1993) and by their pervasive mistrust of the integrity and credibility of orthodox scientists.

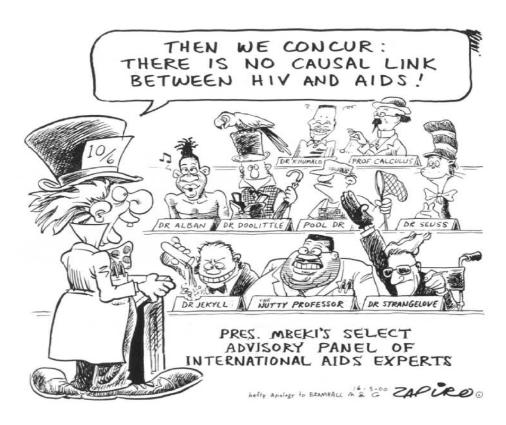


Figure 1: Cartoon in the Mail and Guardian, 16/3/00

How, then, Mbeki believed that rational debate was possible between the dissidents and conventional scientist is something of a puzzle. What did he think he was going to achieve by bringing dissident and conventional scientists together in his 'Presidential AIDS Advisory Panel' to debate the science of AIDS? He certainly had bold ambitions as evidenced by the line-up he proposed for the panel. He invited all the major dissidents as well as the co-discoverers of the HIV virus, Robert Gallo and Luc Montagnier (but only Montagnier was able to attend) and a few senior international and South African scientists (including Makgoba). This panel met in May 2000 and again in July that year, finally reporting in March 2001. The results were predictable: ignoring the evidence presented by conventional scientists showing that HIV-infected babies succumbed rapidly to AIDS and that antiretroviral treatment reduced HIV transmission substantially (PAAPR, 2001: 22, 33), the dissidents argued "AIDS would disappear instantaneously if all HIV testing was outlawed and the use of antiretroviral drugs was terminated" (*ibid*: 15). The result was total non agreement between the dissident and orthodox scientists.

Whether Mbeki was simply naïve in assuming that any other outcome was possible, or whether he was simply using the panel as a means of boosting the authority of the dissidents and as a delaying tactic in the battle over antiretroviral therapy, will never be known. What we do know, is that the panel served as a means for Mbeki and the Health Minister to portray AIDS science and policy formation as deeply contested, and contestable. This, in turn, provided them with the space to resist the introduction of AZT and other antiretrovirals on the grounds that 'more research was needed' into their toxicity and effectiveness. For example, in a news conference in February 2000, the Health Minister revealed that she had turned down two reports from the MCC concluding that the benefits of AZT outweighed the risks on the grounds that more information was needed about toxicity. This suggests that the Health Minister believed that she knew better than the MCC about weighing up the risks and benefits of AZT – an extraordinary assumption of authority on her part over that of the scientists represented on the MCC.

We also know that Mbeki and his spokesmen were quick to heap contempt on conventional scientists by accusing them of being stooges for pharmaceutical companies. In the run-up to the International AIDS Conference held in early July in Durban, Prof Jerry Coovadia (the chair of the conference) pleaded with Mbeki to keep clear of scientific debates. The Health Minister and two cabinet colleagues responded by describing him as one of the 'frontline troops for the pharmaceutical industry'. For Mbeki and his henchmen (and women), the established scientific cannon was merely a viewpoint (and probably a corrupt one at that) rather than a respected elite body of knowledge subject to constant and critical examination. In a letter he wrote to Tony Leon, the leader of the parliamentary opposition, this view is spelled out very clearly:

"The idea that as the executive, we should take decisions we can defend simply because views have been expressed by scientist-economists, scientist-agriculturalists, scientist-environmentalists, scientists-pedagogues, scientist-soldiers, scientist-health workers, scientists-communicators is absurd in the extreme. It is sad that you feel compelled to sink to such absurdity, simply to promote the sale of AZT". <sup>20</sup>

<sup>&</sup>lt;sup>19</sup> Sunday Independent, 25/6/00

Quoted in the Mail and Guardian, 6/10/00.

In response to Mbeki's questioning of the science of AIDS, 5,000 scientists put their names to what became known as 'the Durban Declaration' (subsequently published in *Nature*) spelling out the established scientific cannon.<sup>21</sup> The Health Minister's responded by calling it an 'elitist document' written by 'a certain exclusive group of people'.<sup>22</sup> Coovadia replied dryly that 'science is elitist' – but it is unlikely that the Health Minister appreciated his point. Mbeki's spokesman, Parks Mankahlana, was more forthright, warning that if the Declaration was given to the president "it would find its comfortable place among the dustbins of the office'.<sup>23</sup>



Figure 2: Cartoon from the Mail and Guardian, 17/7/00

Shortly thereafter, Parks went on sick leave and died (almost certainly) of AIDS in October. Mankahlana's death is tragic for many reasons. He was a senior member of the ANC's Youth League, served as Presidential spokesman under Mandela and Mbeki, and was widely liked and respected by the media for his intelligence and humour. The loss of a 36 year old man with such potential is always tragic. But, the fact that he probably died of AIDS makes it particularly poignant. As the *Sunday Times* put it: "His battle with his illness became mixed up with the battle

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Nature, 406, 6/7/00.

Independent Online, 3/7/00.

<sup>&</sup>lt;sup>23</sup> Van der Vliet, (2004: 60)

Parks' family never confirmed that he died of AIDS. It was, however, later revealed in a dissident document that he had been taking antiretrovirals shortly before he died. http://132.230.108.107/people/sitas/seminar-Freiburg-2002/Castro-Hlongwane.pdf.

he was fighting on Mbeki's behalf. And he lost both". It is precisely because Mbeki's undermining of the science of HIV treatment costs lives, that his position is so controversial.



Figure 3: Cartoon, Sunday Times 16/7/00

Despite their efforts, Mbeki and his Health Minister were unable to win what Gramsci would call the 'war of position'<sup>26</sup> they were fighting over AIDS science, and by implication, over the authority of the scientific community to shape AIDS policy. The dissidents were portrayed by the mainstream media as cranks (Figure 1) and Mbeki was portrayed as severely out of step with scientific opinion (Figures 2 and 3) and as stupidly pig-headed in his insistence that all avenues should be explored, even when they flew in the face of a substantial body of scientific evidence (Figure 4). To make matters more difficult, Mbeki and his Health Minister ran into increasing opposition within their own ranks. In September 2000, the ANC's alliance partners, the Congress of South African Trade Unions (Cosatu) and the South African Communist Party (SACP), called on the government to end its scientific speculation on the cause of AIDS and concentrate on providing affordable treatment.<sup>27</sup> Even closer to home, the ANC Health Portfolio Committee in Parliament sent a confidential memorandum to the Health Minister urging her and Mbeki to make

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<sup>&</sup>lt;sup>25</sup> Sunday Times, 29/10/00.

<sup>&</sup>lt;sup>26</sup> A 'war of position' is fought by governments when they attempt to manufacture consent through political hegemony (see Showstack Sassoon, 1982).

Mail and Guardian, 8/9/00 and Independent online (9/9/00). The September Cosatu conference passed a unanimous resolution to this effect (available on (www.cosatu.org.za/congress/cong2000/)

a public statement stating that HIV causes AIDS. She demanded that the document be withdrawn, but the Committee refused.<sup>28</sup> Last ditch attempts by Mbeki to swing internal support behind him by telling the ANC caucus that the CIA (working with the large drug companies) was part of the conspiracy to promote the view that HIV causes AIDS<sup>29</sup> could not unite his own party behind him. In mid-October he announced his withdrawal from the public debate on AIDS science because it was causing confusion and widening divisions between the ANC, Cosatu and the SACP.<sup>30</sup>

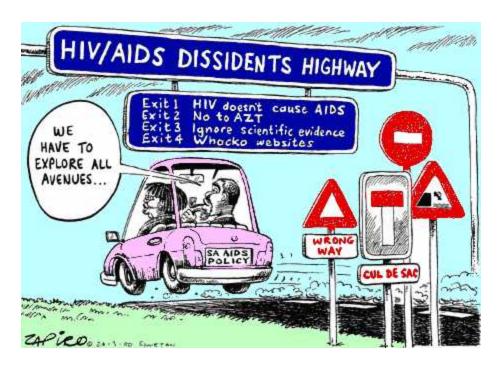


Figure 4. Cartoon in the Sowetan, 20/3/00

Despite this 'public withdrawal', Mbeki continued to espouse denialist views (albeit in a lower key way) – such as his comment on TV in April 2002 that he would not take an HIV test because it would be 'confirming a particular paradigm.'<sup>31</sup> He was also linked (via an electronic signature) to a notorious ANC dissident document probably written by Peter Mokaba claiming, *inter alia*, that antiretrovirals were poisonous.<sup>32</sup> However, his interventions appear to have been more than merely ideological. As discussed below, he also attempted to wield political pressure against the MRC. This was the first direct challenge to the independence of the scientific research and regulatory bodies (i.e. the MCC and the MRC) falling within the ambit of the Department of Health.

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Independent Online, 13/9/00.

Mail and Guardian 6/10/00.

<sup>&</sup>lt;sup>30</sup> Sunday Times, 15/10/00

Reported in Van der Vliet, 2004: 63.

The document is available on http://132.230.108.107/people/sitas/seminar-Freiburg-2002/Castro-Hlongwane.pdf.

## Mbeki's Ongoing Conflict with the MRC

In September 2001, Mbeki crossed swords once again with the head of the MRC, Makgoba. Mbeki suggested, on the basis of 1995 figures he found on the internet, that only 2.2% of recorded deaths are listed as AIDS deaths, and therefore the government's social and health priorities should be revisited.<sup>33</sup> At this time, it was common knowledge in academic circles that an MRC cause-of-death study had come to diametrically opposite conclusions, but was being embargoed by government. The following month, this study was leaked to the media. It showed that death rates had increased substantially in the population especially for young people and that this was consistent with the results of demographic modelling of the impact of AIDS (Dorrington et al, 2001). The Department of Health responded by putting out a joint statement with Statistics South Africa (South Africa's official statistics body) saying that the "MRC research is not absolutely definitive and its mortality rates are estimates rather than exact calculations because they rest on various assumptions". 34 This resulted in a tense exchange between Statistics South Africa and the MRC researchers who argued that Statistics South Africa had misunderstood and misrepresented their findings.



Figure 5. Cartoon in the Sunday Times, 24/10/01

Van der Vliet, 2004: 66.

"Release of MRC Report on Aids-related Mortality in Adults", Issued by Statistics SA and the Department of Health, 16/10/01. Available on http://www.doh.gov.za/search/index.html

Individual members of the MRC were placed under political pressure to disassociate themselves from the report and Makgoba was put under pressure to withdraw it, which he refused to do, saying it was an excellent document.<sup>35</sup> A journalist, Charlene Smith, reported that the government had threatened three times to withdraw MRC funding unless it toed the line on HIV/AIDS. Makgoba declined to deny that he had told Smith this (Malan, 2003). A second journalist, obtained a copy of a letter written by the Health Minister to the MRC in which she demanded that the 'anti-dissident' who had leaked the MRC report be found and dealt with (*ibid*).

Why was the cause-of-death study such a political hot potato? The answer has to do with the importance of death statistics for AIDS denialists who claim that so-called 'AIDS deaths' are simply deaths from other diseases that have been relabelled as AIDS deaths. If it can be shown that AIDS deaths by age and gender have been rising in line with what we would expect given HIV prevalence data over time – which is precisely what the MRC report did – then this amounts to a knock-out blow to AIDS denialism. <sup>36</sup>

This battle was a watershed in the relationship between government and the MRC. Interviewed shortly before his tenure came to an end at the MRC in August 2002,<sup>37</sup> Makgoba observed that the cause-of-death study was "a ground-breaking report in a country where denials rule the day". He then went on to talk about the dangers that the MRC faced from political interference:

"My greatest love and passion for scientific research is its creative spirit, its detached reflective perspective, its power to assault ignorance, and its autonomy. Equally I have the greatest dislike or allergy for political interference and manipulation in scientific research and the running of scientific institutions. Unfortunately the MRC faces these challenges of political interferences. There is great pressure for it to toe the party line and become the trusted scientific voice that justifies unscientific findings or pseudo-scientific ideas. There is an unwise and pernicious view that sees such institutions as extensions of the political machinery of the day. .... The politicisation of scientific research, trying to do research according to political ideology and along party political lines, and trying to manage, recruit and appoint staff along these lines have never worked successfully anywhere where excellent science is being done. This approach has been a death knell to science."

Makgoba was able to resist the pressure placed by government on the MRC largely because he was a strong personality and because the government lacked credibility when trying to counter the report (as the media interpreted the saga as yet another attempt on the part of Mbeki not to face up to the AIDS epidemic, see Figure 5). However, the episode is noteworthy for the fact that substantial political pressure was brought to bear on a scientific research institute that was supposedly independent.

<sup>&</sup>lt;sup>35</sup> In an interview given shortly before his departure from the MRC, Makgoba said that it was the best technical report he had seen in 23 years as a scientist and the best report ever produced by the MRC. <a href="http://www.mrc.ac.za/mrcnews/aug2002/makgoba.htm">http://www.mrc.ac.za/mrcnews/aug2002/makgoba.htm</a>.

This is why South African AIDS denialists continue to dispute the AIDS deaths statistics – see e.g. Malan, R. (2003) and the critique by Nathan Geffen in the TAC newsletter 20 January 2004, available on http://www.tac.org.za/newsletter/2004/ns20 01 2004.htm.

See http://www.mrc.ac.za/mrcnews/aug2002/makgoba.htm.

## Resisting the introduction and undermining the rollout, of Antiretroviral Treatment

Mbeki's public withdrawal from the debate on AIDS appeared to open up a new dawn for AIDS policy. Within two weeks of his announcement, the HIV/AIDS and STDs Directorate of the Department of Health released its recommendations for the prevention and treatment of 'Opportunistic and HIV related Diseases in Adults' which accepted that "HIV causes immune system damage through the effects of ongoing viral replication and this ultimately leads to AIDS". However, this did not represent as much of a policy shift as might appear. Government's support for the South African Vaccine Initiative and its promotion of safe sex (including the distribution of hundreds of thousands of condoms free to clinics) has long rested on the conventional understanding of the link between HIV and AIDS. None of this changed under the Mbeki presidency – indeed, at the very time he was corresponding with the dissidents and setting up his Presidential panel in early 2000, the Department of Health released the government's 'Strategic Plan' to promote AIDS awareness, safe sex and to cope with AIDS-related opportunistic infections. As Ayanda Ntsaluba, the Director General of the national Department of Health commented, "a conscious decision" had been taken to prioritize such programs "whatever debates are going on".<sup>38</sup>

But while an AIDS dissident can accept safe sex policies as being at worst an irrelevance, the same cannot be said about the use of antiretrovirals because these are seen as inherently dangerous. Antiretroviral therapy is precisely the issue over which one would expect an AIDS dissident to dig in his or her heels. Such obduracy was evident in the Minister of Health's resistance to implementing a national rollout of MTCTP. Unable to prevent the Western Cape Provincial Department of Health from defying national policy and implementing its own pilot programs, she fought a legal challenge from the Treatment Action Campaign (TAC) all the way to the Constitutional Court. When she lost her final appeal against the ruling that she should implement a national MTCTP program, she complained bitterly about being forced to 'give my people poison' (quoted in Van der Vliet, 2004: 75).

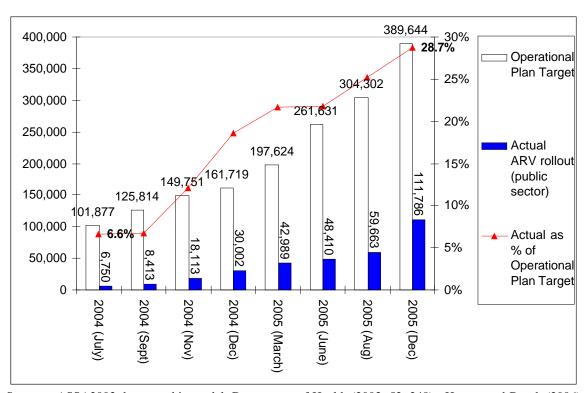
The Health Minister also put up a strong resistance against the introduction of antiretroviral treatment for people living with AIDS, but was ultimately defeated politically on this issue. In July 2002, Mandela visited TAC leader Zackie Achmat, who had vowed not to take antiretrovirals himself until they were available in the public sector. Mandela left the meeting calling him a 'role model' and reporting that he had a case to take up with President Mbeki.<sup>39</sup> To add to the political woes of Mbeki and his Health Minister, TAC launched a civil disobedience campaign in March 2003, which resulted in mass marches and arrests all over the country, and which saw the Health Minister heckled at every public occasion. In April, Deputy President Jacob Zuma appealed for an end to the campaign in order to give the government more time to respond to the demand for a treatment rollout. TAC agreed, but when no action had been forthcoming by the time their national congress was held in August, they threatened to re-launch the campaign. Five days later, on 8 August 2003, the cabinet made its ground-breaking

<sup>&</sup>lt;sup>38</sup> Quoted in The New York Times, 31/4/02, "An AIDS skeptic in South Africa feeds simmering doubts' by Rachel Swarms

http://www.aegis.org/news/sapa/2002/SA020712.html.

announcement committing the government to rolling out antiretroviral treatment in the public health sector.

According to the *Mail and Guardian* (15-20 August) this 'cabinet revolt' was carefully planned, with cabinet meetings being stalled until sufficient support had been mobilised. The ANC's head of elections (Manne Dipico) and the party's chief strategist (Joel Netshitenzhe) were apparently key players. Concern about the impact of Mbeki's AIDS policies and TAC's civil disobedience campaign on the ANC's electoral prospects were clearly important (with elections to be held around April 2004). External pressure to comply with the international effort spear-headed by UNAIDS and the World Health Organisation to improve access to antiretroviral treatment probably also played a role (Willan, 2004: 114-6) as it made the South African government's resistance to antiretroviral therapy look ever more out of step with global opinion and action in other developing countries.



Sources: ASSA2003 demographic model; Department of Health (2003: 52, 248); Hassan and Bosch (2006).

Figure 6: Planned and Actual Growth in the Provision of Antiretroviral Treatment

Butler (2005: 15-18) argues that this reassertion of cabinet authority over presidential authority was one of the positive impacts of AIDS on governance in South Africa. That this cabinet revolt was a blow to the Health Minister is clear. She was reportedly despondent and distanced herself from the decision, saying "I am not the one making the decisions; the Cabinet decides

collectively". <sup>40</sup> However, as she (with Mbeki's protection) remained firmly in the driving seat, her power to shape the rollout (or lack of it) remained substantial. Cabinet authority over policy is easily shipwrecked on the rocks of ministerial intransigence over implementation – especially when the minister concerned is acting under the protection of the President. In addition to her conspicuous failure to energize the antiretroviral rollout from the centre, the Health Minister has undermined the HAART rollout by interfering with the ability of provinces to raise money from the Global Fund (Naimak, 2006), by dragging her heels over drug procurement, <sup>41</sup> and by failing to address adequately the human resources crisis in the health sector.

One month after the Cabinet decision on antiretroviral treatment, the government released its 'Operational Plan' to have 54,004 people on treatment by March 2004 (DOH, 2003: 248). <sup>42</sup> The Health Minister procrastinated, the result being a slow start and poor performance in relation to the planned targets (see Figure 6). It was only from late 2004 and into 2005 that the rollout gathered pace – a performance driven in no small measure by outside funding from the Global Fund and PEPFAR (Nattrass, 2006). As can be seen in Figure 6, by the end of 2005, the numbers of people on treatment in the public sector was still less than 30% of the original planned total.

Rather than actively supporting the rollout, the Health Minister constantly points to the side effects of antiretrovirals whilst highlighting the benefits of nutrition (notably garlic, lemon and olive oil), saying that patients must exercise 'choice' in their treatment strategies. This has resulted in AIDS patients being reluctant to take antiretrovirals because they feared they were 'poisonous' and on additional burdens being placed on treatment counsellors to dispel myths about the drugs. The March 2006 meeting of the Joint Civil Society Monitoring Forum (a forum for those involved in the public and private sector antiretroviral treatment rollout) highlighted the need to address the 'confusing treatment messages that are affecting service delivery' and called on the government to 'issue unambiguous and scientific messages about treatment options for people living with HIV/AIDS' (JCSMF, 2006: 2). Unfortunately, the Health Minister continues to create the space for alternative remedies to compete with antiretrovirals even though their clinical effects are at best unproven.

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Mail and Guardian, 15-20 August, 2003.

It was only as a result of TAC's threatening legal action, that the Health Minister in March 2004 allowed provinces to use 'interim' drug procurement procedures to procure antiretroviral drugs. Although initially promised in early 2004, the final national government tender was awarded only in March 2005. As over half of the tender was for patented drugs (Hassan, 2005: 13), TAC demanded that the Health Minister use her powers under the Patents Act to issue compulsory licences to enable local production of generic versions, or the importation of generic versions. As yet, she has failed to act on the matter.

Although ostensibly the product of the Department of Health, this plan was drawn up by outside experts.

K. Cullinan. "Health Minister promotes nutritional alternatives to ARV rollout", health-e news, 30/5/05.

<sup>44</sup> K. Cullinan. "Another bizarre year for Aids policy", 5/12/05, Health-e news.. on http://www.health-e.org.za/news/article.php?uid=20031345

<sup>&</sup>lt;sup>45</sup> See K. Cullinan and L. Reid. "Patients fear antiretroviral drugs", Health-e news, 10/8/05 on http://www.health-e.org.za/news/article.php?uid=20031287

## Support for Alternative (scientifically untested) Remedies

In September 2003, Mbeki infamously said, 'Personally, I don't know anyone who has died of AIDS. I really honestly don't.'46 By this time, his spokesman, Parks Mankahlana, and his close ally Peter Mokaba, had almost certainly died of AIDS. Mokaba told a journalist shortly before his death that he had refused to take antiretrovirals because his illness was not AIDS and because he was receiving strong support for his stand from friends and well wishers, including 'Comrade Thabo (Mbeki)'. The journalist continues:

"Mokaba remembers a telephone call from Mbeki, in which the president said: 'No, you can't die. Give me a last chance. Let us see what we can do.' He recollects that ... Mbeki marshalled a 'formidable medical team' to examine him. Reflecting on that visit, Mokaba says: 'In three days, they helped me to life.' He acknowledges his debt to Mbeki: "He is the person who refused to let me die. I am grateful....,47

Just a few days later, Mokaba died. Although there is no firm evidence that Mokaba died of AIDS (his doctor blamed a lung infection), he clearly died of something which left him weak and unable to work for four years. The fact that both he, and Mbeki, understood that he was dying certainly suggests that, at some level, they knew that his illness was a lot more serious than a lung infection. Given Mokaba's rejection of the science of AIDS and his strong antipathy to antiretrovirals, this placed his choice of treatment strategy in uncharted waters. Little is known about Mokaba's treatment strategies other than that he was treated at one stage by a self-styled 'traditional healer' and medical technologist called Siphiwe Hadebe who gave him an unregistered anti-AIDS medicine called 'umbimbi' (which in itself is a further indication that Mokaba knew he had AIDS) made out of indigenous herbs and salt.<sup>48</sup>

Since 2001, when he claimed to have cured five people of AIDS, Hadebe had been amassing a substantial fortune treating people with HIV. The end came in 2003 when one of these five patients (the sister of a popular TV talk-show host) revealed to *The Star* that Hadebe's treatment had not cured her HIV but had instead left her feeling ill and drained. The Star then discovered that three of the remaining four patients had since died and that the remaining patient had returned to Botswana and could not be located.<sup>49</sup> A complaint was subsequently lodged with the MCC about Hadebe's activities and his many business premises were raided by the police. Included in the haul were injectable anaesthetics, antibiotics, multivitamins, cigarettes dipped in brown liquid, bottles of umbimbi, and two receipt books with 400 entries dated from February to November 2002 each for about R1,000 each.<sup>50</sup> The Assets Forfeiture Unit subsequently seized property worth millions of Rands and found files on over 600 patients.<sup>51</sup>

http:www.health-e.org.za/news/article.php?uid=20031154

The journalist was Patrick Lawrence. http://hsf.org.za/focus26/focus26interviewaids.html

See SABCnews.com. "Five Houses seized from alleged traditional healer" 20/11/03. Available on http://www.sabcnews.com/south\_africa/crime1justice/0,2172,69417,00.html

See "I am still HIV-positive, says TV star's sister", by Thuli Nhlapo, The Star, 21/7/03. Available on

http://www.thestar.co.za/index.php?fArticleId=191845.

See 'Bogus Aids Cure Exposed' by Jo-Anne Smetherham, The Star, July 17. Available on http://new.hst.org.za/news/index.php/20030726/

SABC News. "Five houses seized from alleged alleged traditional healer' 20/11/03. Available on http://www.sabcnews.com/south\_africa/crime1justice/0,2172,69417,00.html

Why would Peter Mokaba choose to reject the orthodox science in favour of antiretroviral therapy and go instead to an apparent charlatan like Hadebe? We will probably never know the answer to this. One of the tragic consequences for those who reject orthodox science in favour of the AIDS denialists is that it leaves them without any tools for choosing an alternative therapy. If the scientific establishment cannot be trusted, then who do you trust? You can obey the dissident call not to take antiretroviral therapy and eat well – but when you start to sicken and die, what then? At this point, people living with AIDS are particularly vulnerable to 'alternative' therapists peddling their (scientifically untested) wares. Dissident discourse on the horrors of antiretroviral therapy are thus very helpful for those marketing 'traditional', or 'natural' or 'alternative' – i.e. anything-but-antiretroviral-therapy nostrums. It should thus come as no surprise that AIDS dissidents like Rasnick, Brink and Mhlongo have ended up working for the Rath Foundation which peddles expensive multivitamins as an alternative to antiretroviral treatment (more details below).

We don't know if Mbeki had anything to do with Mokaba seeking help from Hadebe, or whether he sent him any other alternative therapists when he mobilised the 'medical team' which Mokaba tragically believed had saved his life. But we do know that the Health Minister, in 2003, sent an alternative therapist to Fana Khaba (a popular DJ for Johannesburg's youth radio station, Yfm) when he lay sick and dying of AIDS.<sup>52</sup> Having initially started taking antiretrovirals, Khaba discarded them after a week in favour of alternative remedies. These included taking *muti* from sangomas and courses of 'Amazing Grace' pills (manufactured by a white woman from Brakpan using 'supermarket ingredients') that cost R100 a course. When these did not work, Tshabalala-Msimang sent Tine van der Maas to the Khaba household.

Van der Maas is a retired Dutch nurse who sells a nostrum called 'Africa's Solution' as an AIDS remedy and recommends that people fight HIV through diet rather than through antiretroviral therapy. 'Africa's Solution' comes in liquid form and the label on the bottle (in the ANC colours of gold green and black) says that it contains *inter alia* African potato extract, olive green leaf extract, vitamins and grapefruit seed extract. The bottle also advises patients to take two crushed cloves of garlic a day and to eat one cup of Pronutro (a South African cereal). Even though Khaba's CD4 count was two at the time (i.e. his immune system was very seriously compromised), Van der Maas claimed that she could treat him, saying 'He doesn't want ARVs. I say to him it is not necessary' (quoted in McGregor, 2005: 17).

### Fana Khaba's family were delighted:

"Mrs Khaba was effusive in her praise of Tine. 'Manto phoned me and told me she would send Tine. Since Tine has been here, it has been a great relief. She is so devoted in her work. I am a nurse, so I know how devoted she is. I spoke to Manto and I thanked her. I said God had sent her. He [Fana] is getting there. He must just give it a chance" (quoted in McGregor, 2005: 18).

This discussion is drawn from McGregor (2005) and from 'Hungry for life, the hip deejay clutched at futile straws' by Liz McGregor in the Sunday Times, 7/3/04. Available on http://www.suntimes.co.za/2004/03/07/insight/in01.asp.

<sup>&</sup>lt;sup>53</sup> See McGregor, 2005: 17-23.

Yet none of this helped. Khaba was simply too desperately ill to be treated by nutritional interventions alone. McGregor describes how Van der Maas gave him a drink made of liquidized beetroot, olive oil, ginger, carrots, tomatoes, spinach, lemon juice olive oil, pawpaw, watermelon, banana, yoghurt and Pronutro – which Khaba promptly vomited up (2005: 21). He died three months later, his body wasted and in agony, aged thirty-five.<sup>54</sup> If the Health Minister, instead of actively supporting an alternative remedy of unproven benefit, had instead encouraged Khaba to take his antiretrovirals, the outcome would almost certainly have been very different.

There is evidence that the Health Minister referred other people to Van der Maas – such as Nozipho Bhengu, who reported in May 2005 that she had been introduced to Van der Maas by the Health Minister, and had been on Van der Maas's lemon and garlic diet for three years now and was the 'scientific proof' that it worked. Even though she is still technically considered to have full blown AIDS because her CD4 cell count is only 134, Bhengu was satisfied with her health. 55

The Health Minister appears to have promoted Van der Maas's activities a lot more substantially than merely referring her to potential patients. She also arranged for Van der Maas to address a meeting of all the provincial health ministers, after which she was invited to conduct 'trials' with AIDS patients at various government hospitals and clinics.<sup>56</sup> The Health Minister visited Van der Maas's 'research sites' in Natal more than once, and has appeared on Van der Maas's promotional videos (which were, in turn, funded by the Rath Foundation).

It is unclear what was involved in Van der Maas's 'trials'. There is no indication that she applied for or obtained permission from the MCC to run them. She claims to have treated over 40,000 people, but has no records of these patients because a burglar allegedly urinated on them in 2002.<sup>57</sup> She is nevertheless confident that her patients are well, because 'If you don't hear from your patients, they are usually doing well. If it's not going well, they'll phone'. 58 The Health Minister has also allocated an advisor (Dr Cyril Khanyile) working in the Department of Health to assist and advise Van der Maas.<sup>59</sup> When asked if they would be prepared to take part in a scientific study of the diet, Khanyile said: "We don't want to be tied up with scientists in the laboratory. But we would be prepared for the diet to be given to patients in an academic hospital where the benefits can be monitored by an independent neutral person". <sup>60</sup>

This speaks volumes about the attitude of Department of Health officials towards scientists and scientific regulation: scientists are not neutral, and their testing procedures are inappropriate for non-orthodox remedies. This has distinct echoes with the unsuccessful attempts in 1997 by the previous Health Minister to free traditional/complementary/alternative remedies from scientific regulation. Despite her various proposals to this effect, the Medicines and Related Substances

"Aids patient backs Manto", HIV/Aids News 121 (6/5/05)

K. Cullinan. "Health Minister promotes nutritional alternatives to ARV rollout", health-e news, 30/5/05.

59 K. Cullinan. "Health Minister promotes nutritional alternatives to ARV rollout", health-e news, 30/5/05.

<sup>&</sup>lt;sup>54</sup> For a depressing account of the many illnesses and afflictions that Khaba suffered in his final months, see McGregor, 2005: 236-47.

E. Brits "Burglar 'peed' on Aids records", HIV/AIDS News 124, June 2005.

<sup>&</sup>quot;Burglar 'peed' on Aids records", HIV/AIDS News 124, June 2005.

<sup>60</sup> K. Cullinan. "Health Minister promotes nutritional alternatives to ARV rollout", health-e news, 30/5/05.

Control Act of 1965, as amended in 1997 and 2002, endorsed the role of the MCC as scientific regulator of all medicines and related substances. According to the Act, a medicine:

"means any substance or mixture of substances used or purporting to be suitable for use or manufactured or sold for use in –

- a) the diagnosis, treatment, mitigation, modification or prevention of disease, abnormal physical or mental state or the symptoms thereof in man; or
- b) restoring, correcting or modifying any somatic or psychic or organic function in man, and includes any veterinary medicine". <sup>61</sup>

This clearly includes all orthodox, complementary or traditional medicines – and the MCC stresses this on the home page of its website. Rather than following the letter and spirit of the Act, the Health Minister appears to be supporting the kinds of alternative non-scientific procedures which her predecessor had tried and failed to introduce into the legislation.

More worrying even than her involvement with Van der Maas is the Health Minister's support for the activities of Matthias Rath, a wealthy German entrepreneur. The multinational 'Rath Health Foundation' sells multivitamins which cost more than antiretrovirals<sup>63</sup>, claiming that these micronutrients treat, or cure, a range of illnesses including cancer, asthma and AIDS.<sup>64</sup> As part of its marketing strategy, the Rath Foundation engages in scare-mongering over antiretrovirals, saying that they are "severely toxic" and "attack the immune system of patients already suffering from immune deficiency." Such misleading and aggressive advertising is a hallmark of Rath Foundation advertising world wide, and he has had a number of warnings and rulings against him by regulatory authorities in several countries (Geffen, 2006). His marketing is also in contravention of South Africa's Medicines and Related Substances Control Act which prohibits 'false or misleading advertising concerning any medicine'.

When informed of Rath's activities, Peter Piot (the head of UNAIDS) commented that anyone who claims vitamins are a cure for AIDS is a charlatan: "It is really unfortunate there will always be people who try to make money out of the misery and suffering of others'. 66 Piot is, of course, correct to point out that charlatans will be with us always. Ashforth has pointed out that, in the era of AIDS, business for healers of all descriptions is 'booming' (2005: 54). He argues that the AIDS epidemic has sparked off heightened concerns about witchcraft which, in turn, means good business for those claiming to be able to counter it. In this context of desperation and fear, those who claim to have provided a 'cure' for AIDS stand to do well – as was the case with Hadebe as well as the purveyors of 'oxytherapy' until they were shut down by the MCC. Even cabinet ministers, it would appear, have not been immune to this search for a cure. For example, in July 2001, the *Sunday Times* reported that the Minister of Public Works, Stella Sigcau had cooked up an anti-AIDS remedy based on ground, sun-dried peach leaves and other 'secret' ingredients, saying that her work was in its early stages, but that she would be applying for a patent. 67

 $<sup>^{61}</sup>_{\rm --}$  This act is available on the MCC website: http://www.mccza.com.

http://www.mccza.com.

Rath's Vitacor Plus is sold for \$29.95 (about R180) for a month's supply at <a href="http://www.drrathhealthalliance.com/products/vitacorplus.html">http://www.drrathhealthalliance.com/products/vitacorplus.html</a>. As of May 2005, a year's supply of first line antiretroviral treatment cost \$182, i.e. \$15.2 a month (Berger, 2005: 2-3).

http://www4.dr-rath-foundation.org/THE\_FOUNDATION/press\_release20050615.htm.

Rath Health Foundation Africa, 2005, Silondoloze You Can!, p. 2.

<sup>&</sup>lt;sup>66</sup> [HIV/AIDS News 123 (May 27, 2005), www.learnscapes.co.za]

<sup>&</sup>lt;sup>67</sup> Sunday Times, 22/7/01, discussed in Ashforth, 2005: 54-5.

What makes the Rath Foundation much more worrying than minor charlatans is that, in a way strongly reminiscent of the Virodene saga, the Rath Foundation seems to have had the implicit if not explicit support of the Health Minister for an unofficial trial or experiment. Such a trial was conducted outside of South Africa's regulatory structures in Khayelitsha in 2004/5 under the leadership of Sam Mhlongo (apparently a close friend of Mbeki's<sup>68</sup> and the only dissident African scientist that Mbeki could find to appoint to his Presidential AIDS Panel). This trial, involving the administering of high doses of vitamins to people with HIV, failed to get approval Mhlongo's home institution, the University of Limpopo's Medunsa campus, which identified 34 problems with the protocol, and was never presented to the MCC.<sup>69</sup> Undaunted. Mhlongo went ahead with the trial which had no control group and breached numerous ethical norms.<sup>70</sup> The results were subsequently published in newspaper advertisements posted in May 2005, claiming that his micronutrients reversed the course of AIDS (Geffen, 2006). Rasnick and Mhlongo were then invited to present their findings to the National Health Council (a body comprising all the provincial ministers of health).<sup>71</sup>

In April 2005, the Health Minister addressed an 'imbizo' (community consultation) in Khayelitsha, where she was asked by several members of the community to condemn the Foundation's activities, but she refused to do so. Instead, she told journalists that rather than undermining the government's position on AIDS, the Rath Foundation was in fact supporting it by providing vitamins and micronutrients.<sup>72</sup> In an answer to a question in Parliament on 15 June 2005, the Minister admitted to having had a meeting alone with Rath on 16 April 2005, and said that they "discussed his concern for people infected with HIV and suffering from the impact of AIDS". She said: "I will only distance myself from Dr Rath if it can be demonstrated that the vitamin supplements that he is prescribing are poisonous for people infected with HIV". 73

It is extraordinary that the Health Minister was prepared to adopt such a supportive line despite the fact that complaints had been lodged with the Department of Health and the MCC. However, the MCC appears to have been rendered ineffective in this respect.

### A De-clawed MCC

Whereas in 2003, the MCC was quick to act against complaints about Hadebe's umbimbi AIDS scam, the opposite has been the case with regard to the Rath Foundation. Despite a series of complaints by TAC and the opposition Democratic Alliance, no action has yet been taken against him. The TAC first alerted the MCC in February 2005 about Rath's selling of unregistered medicines and his conducting illegal trials in Khayelitsha. Medecins Sans Frontieres, which

<sup>&</sup>lt;sup>68</sup> The close connection between Mbeki and Mhlongo was reported by K. Cullinan, "The curious tale of the Minister and the vitamin seller", health-e news, 25/4/05. http://www.health-e.org.za/news/article.php?uid=20031215.

K Cullinan and A. Thom. "Official nod for voodoo trials?", Mail and Guardian online 19/1/06. London, L., 2005, Affidavit in TAC and SAMA v. Rath and Others, Cape High Court. Available at http://www.tac.org.za/Documents/RathCases/LeslieLondonOnEthics.doc.

<sup>71</sup> K Cullinan and A. Thom. "Official nod for voodoo trials?", Mail and Guardian online 19/1/06. K. Cullinan. "The curious tale of the Minister and the Vitamin Seller", health-e news, 25/4/05.

<sup>&</sup>lt;sup>73</sup> TAC electronic newsletter 29/11/05 and K Cullinan and A. Thom. "Official nod for voodoo trials?", Mail and Guardian online 19/1/06.

operates a pilot antiretroviral treatment project in Khayelitsha, filed a separate complaint with the MCC. As no action had been taken by April, TAC met with Department of Health law enforcement agencies about Rath. TAC subsequently submitted a detailed affidavit about Rath to the Department of Health Law Enforcement Unit.<sup>74</sup>

In June, the Democratic Alliance voiced its concern about the situation by criticising the MCC for not acting in response to reports that Van der Maas and Rath were conducting unapproved clinical trials on HIV positive people.<sup>75</sup> Nothing came of this either. Finally, after it became clear that the Minister of Health was protecting, if not actively supporting Rath, TAC and the South African Medical Association filed court papers on 29 November 2005 against the Minister of Health, Matthias Rath and several associates including Brink, Rasnick and Mhlongo.<sup>76</sup>

It is unclear, precisely, what has been happening in the MCC as there is no annual reporting, minutes are secret and decision-making processes are very opaque.<sup>77</sup> There are some indications that the MCC started an investigation, but that this stalled in late 2005 when the original investigator, Lionel Snyman, was removed from the case.<sup>78</sup> Furthermore, the Health Minister and her new Director General have sought to downplay the need for such an investigation at all. The Director General (Mseleku) said:

"There have been allegations that Dr Rath was actually using medicine that was not registered in South Africa. And the law enforcement agency says, in accordance with what was pronounced by the Department of Health before about the complementarity of Dr Rath's vitamins, there hasn't been anything that was done wrong with regard to that". 79

This suggests, once again, that officials in the Department of Health do not appear to believe that the rules of scientific testing which govern the activities of the MCC somehow do not apply to the trials run by Van der Maas and Rath because these are 'complementary' medicines. When questioned about her close relationship with Rath, the Health Minister told reporters:

"We cannot transplant models designed for scientific validation of allopathic medicine and apply it to other remedies. There is need for creativity to come up with relevant and pragmatic models to prove safety, quality and efficiency of complementary, alternative and African traditional medicines'. 80

The problem with this attempt to recast Rath's vitamins as 'complementary' medicines, is that it ignores the fact that he touts them as cures, prescribes them in dangerously high doses, and rather than portraying them as complementary to antiretrovirals, campaigns actively against antiretrovirals. It also ignores the fact that in accordance with the existing legislation, the MCC is supposed to investigate all medicines, whether complementary or otherwise. In responding to the TAC's legal action, the Director General of Health commented that since the MCC had not

<sup>&</sup>lt;sup>74</sup> TAC electronic newsletter 29/11/05.

HIV/AIDS News 124 (June 6, 2005), www.learnscapes.co.za

See http://www.tac.org.za/Documents/HealthMinisterCase.html.

Andy Gray, the lead author of the most substantial study to date on drug policy making in post apartheid South Africa (Gray et al, 2002) describes the situation as a 'researcher's nightmare' (personal communication, 19/3/06).

K Cullinan and A. Thom. "Official nod for voodoo trials?", Mail and Guardian online 19/1/06. K Cullinan and A. Thom. "Official nod for voodoo trials?", Mail and Guardian online 19/1/06.

<sup>&</sup>lt;sup>80</sup> K Cullinan and A. Thom. "Official nod for voodoo trials?", Mail and Guardian online 19/1/06.

yet resolved whether any of Rath's products were medicines subject to registration, there was nothing objectionable in their distribution bearing in mind that the Department also viewed them as foodstuffs.81

The Health Minister appears to have finally succeeded in de-clawing the MCC – at least in the sense of presiding over a situation where it appears that the MCC is either unwilling or incapable of responding to complaints against the illegal trials undertaken on AIDS patients, by Van der Maas and Rath. Whereas during the Virodene saga, Mbeki and the Health Minister respected the authority of the MCC to rule that the Vissers were not allowed to conduct trials, in the case of Rath and Van der Maas, the Health Minister has simply side-stepped the MCC. In the case of Van der Maas, she gave her access to AIDS patients in hospitals to run trials – none of which appear to have been presented to the MCC for permission. In the case of Rath, she appears to believe that his trials are appropriate, and that she is only obliged to act against him if it can be shown that his vitamins are harmful. In other words, under her stewardship, the burden of proof has shifted from the purveyor of the remedy to those who raise doubts about the remedy. That this undermines the scientific governance of medicine goes without saying.

Although the legislation clearly places all alleged remedies and cures under the ambit of medicines, the Minister of Health appears to be acting according to an alternative set of rules for 'traditional' or 'alternative' remedies – even to the point of supporting their distribution through the public health system without their ever having been tested scientifically. The most recent example of this is the distribution through AIDS clinics in KwaZulu-Natal of a herbal product called 'ubhejane'. The Health Minister and KwaZulu-Natal MEC (Peggy Nkonyeni) apparently also told a home-based care project, run by Deputy President Phumzile Mlambo-Ngcuka's mother, to administer ubheiane to HIV-positive patients.<sup>82</sup> According to a government advisor (a retired sociologist), ubhejane research at the University of KwaZulu-Natal has shown that the product has anti-bacterial properties that may help people suffering from opportunistic infections (Vilakazi, 2005: 7). The university subsequently put out a statement denying such claims.<sup>83</sup>

This, of course, has added to the confusion amongst AIDS patients as to whether they should be taking such products instead of, or in addition to, antiretrovirals.<sup>84</sup> When the opposition Democratic Alliance complained about the manufacture of 'fake cures' such as ubhejane by 'backyard chemists', the Department of Health retorted that the Democratic Alliance was simply perpetuating racist stereotypes, and went on to re-iterate its support for traditional medicines and micronutrients.<sup>85</sup> The Democratic Alliance responded by investigating the matter further and laying charges of fraud and of contravening the Medicines and Related Substances Control Act against Zebalon Gwala (who is neither a doctor nor a traditional healer) for producing and selling

SAPA Statement on Government Court Papers, by Wendell Roelf, 8 March 2006.

<sup>&</sup>lt;sup>82</sup> A City Press report reported on News24.com. 13/2/06. 'Health Ministry backs AIDS muti'. Available on http://www.news24.com/News24/South\_Africa/Aids\_Focus/0,,,2-7-..

University of KwaZulu-Natal statement on claims that its studies promote traditional medicine "Ubhejane", released 17 March 2006.

Personal communication with TAC, 8/3/06.

Department of Health, 13/2/06, 'DA undermines Indigenous Knowledge'. Available on http://www/doh.gov/za/docs/pr/2006/pr0213.html

ubhejane as an AIDS cure.<sup>86</sup> Gwala sells ubhejane for R342 a month,<sup>87</sup> i.e. three times the cost of first-line triple antiretroviral therapy. According to the Democratic Alliance, the long queues outside his establishment suggest that he is making a great deal of money out of it.<sup>88</sup> The Health Minister responded by calling the Democratic Alliance's action a 'publicity stunt' and reasserting the role for traditional and alternative medicines.<sup>89</sup>

### Conclusion

The most pernicious legacy of President Mbeki's dissident stance on AIDS has been the erosion of the authority of science and of scientific regulation of medicine in South Africa. Scientists, including the MCC, have been persistently portrayed as, at worst, biased spokespeople for the pharmaceutical industry, and at best, as promoting scientific protocols that are inappropriate for traditional or alternative medicines. Despite the fact that South Africa's existing legislation requires all medicines (defined very broadly) to be tested by the MCC, the Health Minister has undermined the MCC and increasingly side-stepped this requirement. In the case of Van der Maas and Rath's micro-nutrient and dietary based interventions, the Health Minister has justified her actions on the grounds that these are 'foodstuffs' not medicines. What the law courts will make of this argument remains to be seen.

In the meantime, however, the Health Minister is apparently formulating additional legislation to free alternative/traditional remedies from the requirement of scientific testing. According to a press release (18 March 2006), the Health Minister notes that "in finalising the regulation of these [complementary, alternative, African traditional] medicines, we are avoiding the pitfall of putting such products in the same regulatory environment as pharmaceutical drugs whose testing is very different". <sup>90</sup>

Not only does this pose serious problems for effective and safe governance within the health sector, but it threatens the health and lives of the many AIDS patients who are ill-equipped to judge the relative efficacy of antiretroviral and alternative therapies. Once science is discarded as the best yard-stick of efficacy, patients are at the mercy of charlatans selling unproven substances. Responsible governments should not place them in this position – especially in this age of AIDS when so many people's lives are at stake.

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Statement from the Democratic Alliance: 'AIDS Cure Ubhejane – DA lays fraud charges against manufacturer', issued on 8 March 2006. Available on http://www.da.org.za/DA/Site/Eng/News/print-article.sap?ID=6275
'Ministry slams DA Aids charges', news24.com, 9/3/06.

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