

# THE GHOST OF AIDS DENIALISM: MANGUZI HOSPITAL AND DUAL LOYALTY

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*This boy is Ignorance. This girl is Want.  
Beware them both, and all of their degree, but most of all beware this boy,  
for on his brow I see that written which is Doom,  
unless the writing be erased ...<sup>1</sup>*

On 19 November 2003, the South African Cabinet approved the 'Operational Plan for Comprehensive Treatment and Care for HIV and AIDS'. After years of international protest, court action and unnecessary deaths, the South African government committed itself to a plan 'that provide[d] for Anti-retroviral Treatment in the public health sector'.<sup>2</sup> Many activists believed that this event heralded the end of AIDS denialism and what Nattrass terms 'the associated rejection of scientific authority in the regulation of medicine, ... Thabo Mbeki's initial questioning of AIDS science and ... his Health Minister's characterization of ARVs as 'toxic' and her support for alternative, scientifically untested therapies'.<sup>3,2</sup> Recently, the Department of Health claimed that 478 000 people with HIV/AIDS (PWAs) were accessing ARVs by end of April 2008 and triumphantly noted that South Africa was the country with most people initiated on ARVs in the world.<sup>4</sup>

To initiate almost half a million people onto ARVs in a few years is no small feat, and much of the success of South Africa's ARV programme can be attributed to committed and principled private and public sector health care professionals. These statistics could also be viewed as evidence of government-level refutation of AIDS denialism and its associated phobia about ARVs. Yet recent events at Manguzi Hospital have prompted people to recall the years 2000 - 2003, when AIDS denialism - and the concomitant ethical difficulties that principled health care workers faced in adequately treating and preventing HIV - was at its peak.

In this article, we will first explore Manguzi Hospital, outline the prevention of mother-to-child transmission (PMTCT) programme controversy, and suggest that divergent views existed concerning senses of urgency in the face of the suffering caused by HIV/AIDS. Unpacking the case of Dr Colin Pfaff, we then look at some of the goals of medicine and argue that the actions of Pfaff and his colleagues were morally praiseworthy. Then we will identify the way in which the spectre of AIDS denialism re-appears in the case of Manguzi Hospital. Finally, we show how health care professionals are once again caught up in the phenomenon of dual loyalty.

## MANGUZI CASE STUDY

Manguzi Hospital is situated in the Umkhayakude Health Ward, a deep rural area that is 'under ruling of Inkosi M.I. Tembe and the Municipality of Umhlabuyalingana'.<sup>5</sup> The HIV prevalence rate in the hospital's antenatal clinic was between 24% and 28% in 2007. By October 2007 the hospital was laudably treating over 2 600 adults and children with ARVs.<sup>6</sup>

In July 2006, the World Health Organization (WHO) released its new guidelines on PMTCT, which recommended the use of dual therapy where indicated.<sup>7</sup> Despite advocacy efforts to urge the National Department of Health to revise its PMTCT guidelines in line with WHO recommendations, the 2002 guidelines remained in force. In the public sector, scores of pregnant women with HIV/AIDS therefore received the less efficacious monotherapy.

Pfaff, Chief Medical Officer of Manguzi Hospital, as well as other concerned doctors in the province, investigated national and international PMTCT programmes, noting that in KwaZulu-Natal 23% of women with HIV/AIDS on the existing single-therapy PMTCT programme transmitted HIV to their infants. This was in contrast to, for example, a less than 5% transmission rate in the Western Cape province where dual therapy had been in use since 2004.<sup>8</sup> Gravely concerned, in May 2007 Pfaff and his colleagues wrote to the KwaZulu-Natal Department of Health requesting permission to start rolling out dual

therapy in the Manguzi PMTCT programme: 'We cannot sit in silence any longer.'<sup>8</sup>

When the Department failed to keep its promises concerning dual therapy implementation, Pfaff and his colleagues took the initiative and raised funds from an international donor in order to purchase dual therapy. In August 2007, Pfaff began to implement the 2006 WHO dual-therapy programme at Manguzi Hospital.

Six months later, on 25 January 2008, the National Department of Health (NDoH) released its new PMTCT guidelines. These guidelines followed the WHO recommendations for the use of dual therapy for HIV-positive pregnant women. Here it should be noted that, as in all bureaucratic processes, a lag-time does exist from policy to implementation, so to censure the NDoH for delay might be considered unfair. Sibani Mngadi, a spokesperson for South Africa's Health Department, acknowledged that the government took the time needed to review the data and consult various players after the WHO recommendation. 'There were a number of issues to be debated,' Mngani commented.<sup>9</sup> Agreed – policy implementation requires logistical sorting, and some delays are inevitable. However, we suggest that the magnitude of the problem should have been sufficient to warrant a much greater assignment of urgency.

So far, we have outlined the PMTCT problem and have suggested that the NDoH did not respond with the necessary urgency. However, we admit that some hindrances in bureaucratic processes are plausible allowing for some delay in implementation. We have noted that Pfaff, backed by colleagues, stressed the

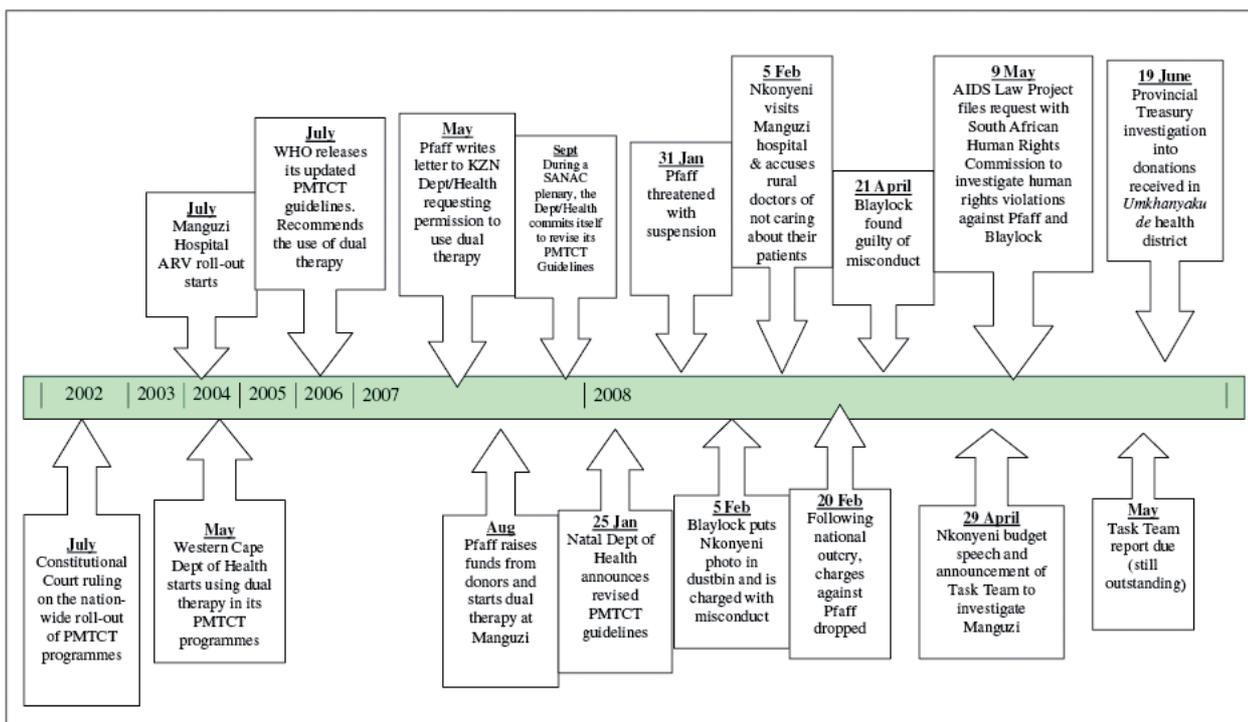
immediacy of need to the provincial authorities. Failing to receive what was considered a reasonable response, the initiative was taken to secure dual therapy for pregnant women with HIV/AIDS in Manguzi Hospital at no cost to the government. What is obvious here is that we have two entities with apparently polar opposite approaches to a 'sense of urgency'.\*

### SENSES OF URGENCY

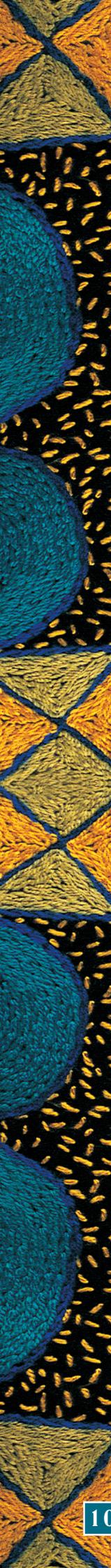
It is well acknowledged that the practice of medicine revolves around the doctor-patient relationship. Professional values such as honesty, integrity, and compassion, a respect for persons, dedication to a patient's welfare, and commitment to continuing scientific learning are some facets that are integral for doctors to hold as custodians of this bond. The truism that disease destroys the wholeness and integrity of the body while pain and suffering can destroy the wholeness of the person is a fact of medical practice. With this in mind, it is a doctor's moral responsibility to use her medical competence, knowledge, and technical skills in tandem with her patient's wishes to create overall a greater amount of benefit over harm. The cure of disease (when it is possible to cure), prevention of untimely or premature death, and the relief of suffering are some examples of long-time held medical goals.<sup>10</sup>

'Suffering occurs when an impending destruction of a person is perceived; it continues until the threat

\*For example, concerning AIDS orphans, in 2001 there were an estimated 660 000 AIDS orphans in South Africa. By 2010, the AIDS orphan population is expected to reach nearly 2 million.<sup>9</sup> Moreover, these figures should be viewed in the context of poverty and the lack of available social services to communities in which the orphans are homed. The HIV infection rate for pregnant women in KwaZulu-Natal is 4:10.<sup>8</sup>



Important events relating to PMTCT programmes and Manguzi Hospital.



of disintegration has passed or until the integrity of the person can be restored in some other manner', writes Cassell.<sup>11</sup> It is an unfortunate fact that the *idea* of suffering and its relief and its *personification* are viewed differently on the part of some policy-makers and health care professionals on the ground. Policy-makers are usually removed from the experience of suffering. Moreover, they may recognise that a problem exists (for example, there are many pregnant women with HIV/AIDS in KwaZulu-Natal) but their myopic lens may fail to see, acknowledge or support those involved in the moral practice of medicine. For example, health care professionals have a *prima facie* duty to relieve the suffering of their patients. By a *prima facie* duty, we mean all things considered duty. For example, a *prima facie* duty to do X gives me a valid moral reason to do X, and in the absence of countervailing moral considerations, implies that I must do X.<sup>12</sup> If we accept that health care professionals have a *prima facie* duty to relieve suffering, to ignore this is to be less than one can and should be; it is more than an action which 'should be good to do', it is morally obligatory.

There is also a decided difference in reading about suffering and experiencing it, seeing, smelling, hearing and living it – a phenomenon often lost to bureaucrats removed from the scene. Nearly 80% of the children in the paediatric ward at Manguzi Hospital are HIV positive and suffer from wasting and a host of infections, pneumonias and chronic lung diseases.<sup>13</sup> Children experiencing these disease processes are uncomfortable, distressed, helpless and often in pain. Such suffering is not unique to Manguzi – it is repeated throughout South African hospitals daily.

For health care professionals it is a wrong to see an individual patient suffer. When compounded in visualising a dual burden of suffering – for example, mother and infant or child in the face of established preventable measures – the situation on the ground for health care professionals such as Pfaff becomes morally untenable. It is morally untenable because it could be otherwise. If we make a request to ameliorate or end suffering, it necessarily includes an appeal to whatever causal sequences will prevent it from happening. This is the crux of the problem such health care professionals faced: suffering ought not to occur when there are measures available to prevent its occurrence. In acting to procure antiretrovirals to prevent or reduce suffering, Pfaff and his colleagues acted in accordance with the requirements of morality.

Governmental health care systems (which of course are composed of individuals) should have moral ideals. Such ideals may not be wholly attainable and their total non-achievement should not be unnecessarily condemned. However, moral ideals are different from moral requirements. Government health care systems can be

held accountable for doing what is morally required and certainly are obligated to avoid what is morally prohibited. With the burden of HIV/AIDS so heavy, one could rightfully ask why a similar sense of urgency did not thrust the NDoH into immediate action.

On the part of Pfaff and other health care professionals, we can say then that they were doing their moral duty. They investigated the situation and informed others of their actions through the proper channels of communication. Rebuffed, they sourced an alternative provider and through that beneficent action were able to provide their patients with greater hope of relief from suffering.

Concerning the KwaZulu-Natal Department of Health, their response becomes morally murky. We have noted that they were deficient in their lack of a sense of urgency; oddly this was followed by what can only be called display of 'muscle-flexing'. During the same month as the revised PMTCT guidelines were announced, Pfaff was threatened with suspension. Disciplinary action was taken against him in January 2008 because, as it was stated, he had 'allegedly acted beyond his authority in accepting a donation and implemented a Prevention of Mother-To-Child Transmission (PMTCT) dual therapy to pregnant mothers and newborn babies without prior permission of his superiors.'<sup>14†</sup>

In this statement repudiation by the government of the moral grounding of medicine is clear. One may also wonder what particular end the government had in mind in the threatening of suspension of a dedicated doctor. It may well be, as Schneider puts it, that 'Ultimately, policy contestation around AIDS in South Africa can be understood as a series of attempts by the state to legitimately define who has the right to speak about AIDS, to determine the response to AIDS, and even to define the problem itself.'<sup>15</sup> Pfaff and his colleagues informed the officials of their intentions, and we have argued that their intentions were morally praiseworthy. That they were not viewed by provincial authorities as such, does not speak well of any attempts to move towards a participative democracy. Indeed, it belies the government's advertisement of March 2003, 'Let's build a people's contract to fight HIV/AIDS ... Our energies should be spent fighting AIDS, not one another' (*Cape Times*, 20 March 2003, as quoted by Van der Vliet<sup>16</sup>). But there is more.

## THE GHOSTS RETURN

To reiterate the whole history of factors and factions involved in delays of HIV treatment roll-out is beyond the scope of this article. Suffice to say that from its

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<sup>†</sup>After an international outcry by health care workers and human rights activists, these charges were dropped later in the month.

onset, a denial of the epidemic seems to be linked to a denial of the behaviour that fosters it. Moreover, HIV fostering behaviour must be viewed in concord with South Africa's political history. Following apartheid and its brutal discriminatory practices, the onset of HIV/AIDS in South Africa as a racially differentiated, sexually transmitted epidemic came in tandem with the political upheaval needed to advance a rightful democratic process. It is not surprising that early on factors such as under-funded HIV budgets, fragmented NGOs, exorbitant therapy costs, and the unrealised scope of the epidemic led to poor service delivery.

Meshed within such complex processes emerged the well-known dissident views, all variants on the theme that HIV did not cause AIDS. The admixture of appeals to African-only solutions, to customary practices, conspiracy theories and racism, impeded the public's acceptance of the need for safer sex and HIV testing.<sup>16</sup> AIDS denialism, spearheaded by President Thabo Mbeki and his Minister of Health, Manto Tshabalala-Msimang, was espoused by lower levels of government and created a variety of obstacles to principled health professionals acting in the best interests of their patients and in line with best practice and international standards.

With time and the increasing availability and affordability of antiretroviral therapy to prevent transmission and treat HIV/AIDS from 1998 onwards, the resistance of some sectors of government to facilitating its access became commonplace. Disagreements followed between health professionals and Department of Health officials over the efficacy and necessity of prescribing ARVs for (i) preventing the transmission of HIV to rape survivors;<sup>17,18</sup> (ii) preventing transmission from pregnant mothers to their infants;<sup>19</sup> and (iii) treating people with HIV/AIDS.<sup>3,20</sup>

Although such rhetoric appears to have abated somewhat during more recent years it still exists, as does the confrontation between the moral duties of health care professionals and their obedience to the state.

In 2001, in the Western Cape's Khayelitsha township, triple therapy came into use and AZT was used 'off-label' for prophylactic treatment against HIV transmission to rape survivors. While 'off-label' use of AZT for rape survivors was covertly practised in many hospitals, it did not have national approval. The issue reached the public domain in 2001 - 2002 in the province of Mpumalanga, where an NGO called GRIP (the Greater Nelspruit Rape Intervention Project) set up their rape crisis centre at the Rob Ferreira Hospital in Nelspruit. Through generous donations from the public, they were able to supply antiretrovirals to rape survivors. Because they realised government officials did not approve of this,<sup>†</sup> the drugs

were hidden in the bellies of stuffed teddy bears that lined the corners of the crisis centre - their presence known only to the staff and the doctors assisting them.

This situation became known to the then MEC of Health of Mpumalanga, Sibongile Manana, who was deeply suspicious of ARVs. For example, when interviewed in 2002 on the Constitutional Court ruling on PMTCT, Manana responded, 'we will implement [Nevirapine] because we are forced to implement ... I must give my people a drug that is not approved by the FDA.<sup>5</sup> I must poison my people' (L Garret, *Newsday New York*, 8 July 2002, as quoted by Van der Vliet<sup>16</sup>). As for GRIP, the accusation was that they were acting in contravention of the provisions of the Medicines and Related Substance Control Act (for 'off-label' use) and placing the health and lives of 'our poor black people' under serious threat. In addition, she suggested that GRIP was hypocritical in claiming to have 'poor black people's interests at heart' and that GRIP was politicising HIV/AIDS and 'trying to overthrow the government'.<sup>22,23†</sup> The consequence of this was the closure of GRIP and suspension of Rob Ferreira Hospital's well-respected hospital superintendent Dr Thys von Mollendorf, who supported and facilitated GRIP's access to the hospital.<sup>\*\*</sup>

Similar to the rhetoric waged at GRIP and von Mollendorf, comments attributed to the MEC of Health, KwaZulu-Natal, during a visit to Manguzi Hospital on 5 February 2008 clearly display a return of the ghosts of denialism and a blatant confrontational stance towards medical professionals:

AZT is toxic and must be controlled. Dual therapy [for prevention of mother-to-child transmission for HIV] has not been agreed upon. We have a problem with doctors who work in rural areas. They do not care about people. It is all about profit not about caring for people. I have heard that ARVs have bad side-effects, especially for children.<sup>24</sup>

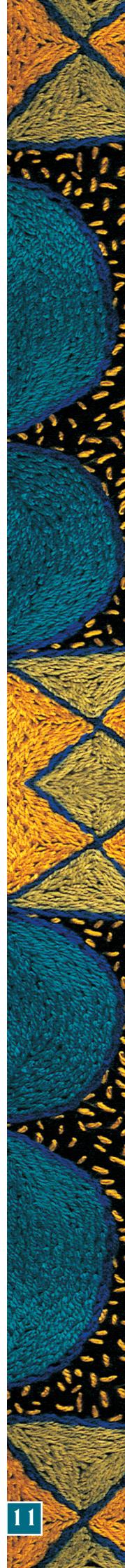
That claim that ARVs are toxic is not new. All drugs have side-effects. It is part of a medical professional's duty to have the scientific knowledge to understand a patient's physiological response to antiretrovirals and ameliorate, when necessary and as best they can, those effects which are adverse. The knowledge that HIV/AIDS is ultimately fatal if not treated is not new either. The point is to avoid further transmission of the virus and, if it is present, to delay the onset of AIDS - in other words, to avoid suffering. Concerning the allegation that doctors who

<sup>†</sup>Government policy at the time only allowed for ARVs to be prescribed for needle-stick injuries of health care workers to prevent HIV transmission from a possibly infected patient to a health care worker. Prescribing ARVs following sexual assault was not included in this policy.

<sup>5</sup>The manufacturer of nevirapine, Boehringer Ingelheim, suspended their application to the USA's FDA following reports that some aspects of their Ugandan trials were found not to have met certain record-keeping regulations. The validity of the study, however, was never in doubt.<sup>21</sup>

<sup>†</sup>For additional information, see the AIDS Law Project complaint to the Public Protector on the conduct of Ms Sibongile Manana, the MEC of Health of Mpumalanga, dated 14 September 2001 - [www.alp.org.za](http://www.alp.org.za).

<sup>\*\*</sup>GRIP re-opened shortly after this without the ARVs on site. For more information read Von Mollendorf's book *Dare to Care* (forthcoming).



work in rural areas care only about profit and not people, one is hard put to find any truth or relevance. Was the MEC referring to international conspiracy myths, for example that HIV was developed by imperialist countries in secret laboratories to ensure that South Africa would not become a world power,<sup>25</sup> or that antiretrovirals remain an international pharmaceutical plot, in which rural doctors are somehow involved? It is difficult to find any conceivable connection. One only needs to visit rural hospitals and see under what conditions doctors are obliged to live and work to prove this allegation false.

Scrooge learned from the visitations of his ghosts, but some government officials may '... walk the earth eternally after death, invisible among his fellow men, burdened with chains, seeing the misery and suffering he could have alleviated in his life but now is powerless to intervene.'<sup>1</sup> And who could plead more eloquently for the alleviation of HIV suffering than the health care professionals who have seen people live and die?

This tension between the ethical duties of health care professionals and their loyalty towards their employer, the state, is best expressed in the concept of Dual Loyalty.

## DUAL LOYALTY

The International Dual Loyalty Working Group defines Dual Loyalty as 'simultaneous obligations, express or implied, to a patient and to a third party, often the state.'<sup>26</sup> Throughout the evolution of health care ethics, absolute commitment and loyalty to one's patient have been stressed. The Hippocratic Oath requires that a doctor be committed to the following maxim: 'That I will exercise the art of medicine solely for the cure of my patients ...', while the following extracts from the World Medical Association's International Code of Medical Ethics are particular applicable to patient commitment:

A physician shall be dedicated to providing competent medical service in full professional and moral independence, with compassion and respect for human dignity. A physician shall act in the patient's best interest when providing medical care. A physician shall owe his/her patients complete loyalty and all the scientific resources available to him/her.<sup>27</sup>

The International Dual Loyalty Working Group has identified six areas within the medical profession where Dual Loyalty dilemmas could arise:

(A) Using medical skills or expertise on behalf of the state to inflict pain or physical or psychological harm on an individual that is not a legitimate part of medical treatment

(B) Subordinating independent medical judgment, in therapeutic or evaluative settings, to support medical conclusions favourable to the state

(C) Limiting or denying medical treatment or information related to treatment to an individual to effectuate policy of the state in a manner that violates the patient's human rights

(D) Disclosing confidential patient information to state authorities or powerful non-state actor

(E) Performing evaluations for legal or administrative purposes in a manner that implicate human rights

(F) Remaining silent in the face of human rights abuses committed against individuals and groups in the care of health professionals.<sup>28</sup>

Sadly, South Africa has had a very poor history of health professionals choosing patient loyalty over loyalty to the state. Under apartheid, a number of health professions conducted themselves in ways that fall under the six categories delineated above. The unethical conduct of health professionals were described in great detail during the Truth and Reconciliation Commission (TRC) hearings and documented in book format afterwards.<sup>28</sup> The final TRC report found that:

the health sector, through apathy, acceptance of the status quo and acts of omission, allowed the creation of an environment in which the health of millions of South Africans was neglected, even at times actively compromised, and in which violations of moral and ethical codes of practice were frequent, facilitating violations of human rights [as quoted by de Gruchy and Rubenstein<sup>29</sup>].

With the advent of democracy, the emphasis on a culture of human rights and progressive health legislation such as the National Health Act created a clear expectation that Dual Loyalty dilemmas that forced health care professionals to choose between patient care and obeying an oppressive state, were something of the past. The goals of medicine are clear, as are the moral duties of doctors and other health care professionals. To go against the state when it is morally necessary is not easy matter, but it is a right and just action.

## CONCLUSION

In this article, we have shown that the actions of Drs Pfaff and Von Mollendorf, their colleagues, and many other unnamed health care professionals in the face of AIDS denialism is morally praiseworthy. We have also suggested that there is a decided difference in perceptions of urgency between principled health care professionals and those who are removed from the daily cauldron of misery caused by HIV/AIDS. We have shown

that the early propagation of AIDS denialism is still with us, and we have outlined the nature of 'dual loyalty' in relation to this.

In conclusion, we suggest that medicine is a complex practice in its own right, and is best left up to those who are skilled in its practice. It is grounded as a moral enterprise in the very gift of a patient's trust and the health care professional's return of that trust – to do all that he or she is able to do for the patient's benefit, and not for that of the state or any other third party.

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