

From both sides of the bed:

**A history of doctor and patient AIDS activism in South
Africa, 1982-1994**

by

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Declaration

I, Mandisa Mbali, hereby declare that this thesis is my own original work, has not been submitted for any degree or examination at any other university, and that the sources I have used have been fully acknowledged by complete references.

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(5th February 2004)

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Abstract

This thesis explores the history of AIDS activism ‘from both sides of the bed’, by doctors and gay patients, in the 1980s and early 1990s. Such AIDS activism was formed in opposition to dominant racist and homophobic framings of the epidemic and the AIDS-related discrimination that these representations caused. Moreover, links between both groups of AIDS activists have their origins in this period. This history has emerged through oral interviews conducted with AIDS activists and an analysis of archival material held at the South African History Archive and the Centre for Health Policy at the University of the Witwatersrand. Evidence reveals that AIDS activism was politically overshadowed in the 1980s by the overwhelming need to respond to apartheid. Although the Gay Association of South Africa (GASA) resisted AIDS-related homophobia, it was politically conservative, which later led to its demise, and then the creation of new, more militant anti-apartheid gay AIDS activism. By contrast, the anti-apartheid doctor organisations such as the National Medical and Dental Association (NAMDA) and the National Progressive Primary Health Care Network (PPHC) were militantly anti-apartheid, but did not seriously address AIDS in the 1980s. In the early 1990s, in the new transitional context, AIDS activists framed the epidemic in terms of human rights to combat AIDS-related discrimination in AIDS policy. Simultaneously, doctor activists in NAMDA and PPHC mobilised around AIDS in the early 1990s, but both organisations disbanded after 1994. Meanwhile, gay AIDS activists remained prominent in AIDS activism, as some who were living with HIV adopted the strategy of openness about their HIV status. On the other hand, AIDS-related stigma remained widespread in the transition era with important implications for post-apartheid AIDS activism and policy-making. Ultimately, this history has significantly shaped post-apartheid, rights-based AIDS activism and its recent disputes with the government over AIDS policy.

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This thesis in loving memory of Tshepo.

I have spent the last five years trying to both interpret the world through my academic endeavours and change it through my work as an AIDS activist. This thesis, which has so successfully merged the two would not have been possible without the assistance of many individuals from the academic and activist spheres.

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This project would have also been impossible without the help of all the people who agreed to be interviewed and discuss my research with me: Jerry Coovadia, Salim Abdool Karim, Janet Giddy, Umesh Laloo, Promise Mthembu, Zackie Achmat, Lucky Barnabus, Lynn Dalrymple and Michael Worsnip.

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GLOSSARY

ACT UP AIDS Coalition to Unleash Power

AIDS Acquired Immune Deficiency Syndrome

AIDS Denialism a term used by AIDS activists in the post-apartheid era to describe to denial that HIV cause of AIDS, the extent of the epidemic and the efficacy of combination anti-retroviral therapy.

ANC African National Congress

Anti-retrovirals (also referred to as anti-HIV drugs) are drugs that suppress HIV in the body allowing the immune system to recover and thereby prevent opportunistic infections.

CHISA Committee for Health in South Africa

CODESA Convention for a Democratic South Africa, often also referred to as “the negotiations”.

COSATU Congress of South African Trade Unions

FDA The United States’ Federal Drug Administration

GASA Gay Association of South Africa

GASA 6010 Gay Association of South Africa, Western Cape Region Branch

GLOW Gay and Lesbian Organisation of the Witwatersrand

HIV Human Immuno-deficiency Virus, the viral cause of AIDS.

ILGA International Gay and Lesbian Association

Karposi’s Sarcoma an opportunistic infection associated with HIV infection

MASA Medical Association of South Africa

MCC The South African Medicines Control Council

‘**Moffie**’ a colloquial and derogatory South African term for gay men.

NACOSA National AIDS Convention of South Africa

NAMDA National Medical and Dental Association

NUM National Union of Mine Workers

OLGA Organisation of Lesbian and Gay Activists

PPHC National Progressive Primary Health Care Network

SACP South African Communist Party

SAHA South African History Archive, University of the Witwatersrand

SAMA South African Medical Association

SAMDC South African Medical and Dental Council

SAMJ South African Medical Journal

SHRG Scottish Homosexual Rights Group

TAC Treatment Action Campaign

UDF United Democratic Front

A Note on Sources

The bulk of the archival evidence cited in this thesis was taken from the archives held at the South African History Archive (SAHA) and the Centre for Health Policy's (CHP) Resource Room at the University of the Witwatersrand. I gathered this material during a research trip to Johannesburg in July 2003.

I wish to explain that my seemingly haphazard manner of citing the sources relates to the fact that collecting archival material on gay histories and 'struggle' histories of AIDS has led me to turn to incompletely catalogued and unconventional sources to obtain archival material. I have aimed for accuracy in listing box and file names, where possible in my footnotes, according to the cataloguing of the documents during my trip.

The National Medical and Dental Association and the National Progressive Primary Health Care Network's archives had only been recently deposited at SAHA and partially catalogued at the time of my visit. Moreover, only partial information was available in these archives due to the fact that both organisations were opposed to apartheid and may not have minuted their more politically sensitive deliberations in the 1980s. This in turn necessitated conducting interviews with key activists from both organisations to gain a fuller picture of their activities.

I discussed my thesis project with several AIDS activists in the course of my work as an AIDS researcher and my voluntary work with the TAC at the University of KwaZulu-Natal. In particular, I gained some key insights from discussions with Umesh Laloo, Zackie Achmat and Lynn Dalrymple which I noted and decided to include in my thesis.

All the archival material on gay activism came from the Gay and Lesbian Archive (GALA) held at the South African History Archive at the University of the Witwatersrand. The Gay Association of South Africa archive was more thoroughly archived than the material on doctor activism, however it contained unconventional material such as scrap-books compiled by gay activists like Leon Eksteen, which contained many of the articles referred to in Chapter One. The Simon Nkoli and Edwin Cameron collections contained many pieces of personal correspondence, which have also been cited. As with techniques commonly used in feminist histories, I found myself turning to scrap-books, personal letters and notes to gain insights into gay AIDS activism.

At the Centre for Health Policy, I found many of the policy documents and publications on AIDS such as the Medical Research Council's *AIDS Bulletin*, "The AIDS Consortium Project Bulletin" and early TAC documents. As this is a Resource Room and not an archive, these documents were not archived in the classic sense, however, they are 'old documents' which revealed key insights into the history I have documented.

I n t r o d u c t i o n

One of the important outcomes of the truth seeking process is the record of the fact that there were health professionals who resisted coercion; those who fought to maintain the primacy of ethics and human rights despite threats to life or personal security and blocks to professional advancement

Pierre Sané. Amnesty International, 1999.¹

A campaign on “Openness” is in reality a call for activism and the assertion of identity. People with HIV/AIDS are on our own (whether in or out of the closet)-while we should seek love, compassion and care-we should also demand treatment. But organising openly and in public spaces is crucial.

Zackie Achmat, National Coalition for Gay and Lesbian Equality, 1998.²

Introduction

On the August 4th 2003 Treatment Action Campaign (TAC) activists marched on the first South African AIDS Conference. The singing and toyi-toying demonstrators reached the court-yard next to the entrance to the conference’s venue, Durban’s International Convention Centre, which is usually blocked off to protestors. After a few minutes, Zackie Achmat, the well-known gay rights and AIDS activist and national chairperson of the TAC took the microphone to much applause, and he denounced government denialism questioning the viral cause of AIDS and the extent and seriousness of the epidemic and outlined the rights-based case for HIV treatment access in the public health sector in South Africa.³ At the end of his impassioned speech he called upon the conference organisers, Professors Hussein ‘Jerry’ Coovadia,⁴ and Salim Abdool Karim prominent AIDS-

¹ Pierre Sané, Foreword, in Baldwin Ragaven, L, de Gruchy, J and London, L (eds.), *An ambulance of the wrong colour: Health Professionals, human rights and ethics in South Africa*, (Cape Town:University of Cape Town Press, 1999), vi.

² Centre for Health Policy Resource Room, University of Witwatersrand, Box 4148, Zackie Achmat, “Letter from Zackie Achmat dated 6 December 1998”, in “A Reading Package for Treatment Action Campaign Volunteers: HIV/AIDS: An Activist Guide to Treatment Rights and Literacy”, p.1.

³ I have documented the historical roots of such denialism and its TAC’s opposition to its devastating impact on AIDS policy-making extensively elsewhere. Mandisa Mbali, “HIV/AIDS policy-making in post-apartheid South Africa”, in Habib, A, Daniel, J and Southall, R (eds), *State of the Nation: South Africa 2003-2004*, (Cape Town: Human Sciences Research Council Press, 2003).

⁴ I will refer to Professors Coovadia in terms of his nickname ‘Jerry’, the name which is commonly used to refer to him by close colleagues. This is no sign of disrespect and is merely reflects how he is referred to by colleagues in the archives and in contemporary times.

researchers and former anti-apartheid doctors, to take the podium and declare whether or not they would use the conference to support TAC's campaign for wider HIV treatment access: both duly did as Achmat asked. This contemporary doctor and patient activist alliance has an apparent naturalness and ease, which betrays its origins in longer legacies of AIDS activism 'from both sides of the bed'.

Indeed, current struggles by doctors and gay rights activists (who had opposed apartheid), against government denialism for the realisation of human rights in AIDS policy is a product of longer histories of both groups' mobilisation against discriminatory apartheid AIDS policy. To be more precise, my central contention in this thesis is that contemporary rights-based South African AIDS activism is the product of at least two political movements in the 1980s and early 1990s, which began to develop nascent links to fight AIDS-related discrimination in the period. Patient-driven AIDS activism, which advocates for the protection of the rights of HIV infected patients, emerged from anti-apartheid gay rights activism. In turn, anti-apartheid gay rights activism emerged from splinter groups formed in opposition to the Gay Association of South Africa (GASA) and its accommodationist policy with the apartheid government. Early patient AIDS activism was driven by anti-apartheid, anti-GASA, gay rights splinter groups such as the Organisation for Gay and Lesbian Activists (OLGA) and Gay and Lesbian Organisation of Witwatersrand (GLOW). Similarly, AIDS activism by doctors emerged from anti-apartheid doctor-activism through the National Medical and Dental Association (NAMDA) and the National Progressive Primary Health Care Network (PPHC) in the 1980s and early 1990s⁵.

As the opening paragraph reveals, current AIDS activism has involved both former anti-apartheid doctors and gay rights activist patients. In terms of this, this thesis's focus will be on how doctor and patient activists struggled politically in the 1980s and early 1990s for a *human rights-based* framing of AIDS policy. This history of late apartheid and transition era doctor and patient AIDS activism contributed to very recent post-apartheid conflicts between government and civil society over HIV treatment policy in three ways. Firstly, the

⁵ I do not aim to completely rule-out the possibility of other movements, such as the unions having shaped modern-day AIDS activism a la TAC but I am making a case for the influence of both these movements.

history documented in this thesis shows just over a decade-long tradition of doctor and patient rights-based AIDS activism, which has built on earlier traditions of anti-apartheid activism. Secondly, it points towards the reasons why gay activists have played such a leading role in TAC: because of the shift towards militancy and an anti-apartheid stance in the late 1980s and relative success of militant anti-apartheid gay rights organising in forwarding its agenda in the liberation movement in the early 1990s. Thirdly, it shows that the relative quiescence on AIDS policy issues until the early 2000s by former anti-apartheid doctors is related to the disbanding of anti-apartheid doctor organisations around the time of the first democratic elections.

I will situate this history of rights-based AIDS activism within a rich and growing corpus of historical literature on this epidemic. Much South African historical literature has been written about socio-cultural changes in South African sexualities and their impact on the AIDS epidemic,⁶ the socio-historical roots of AIDS stigma⁷ and the apartheid government's AIDS policy.⁸ However, there has been almost no literature dealing with this dissertation's particular problem: how to historicise doctor and patient activist responses to

⁶ Much of this literature has focussed on changes in sexual socialisation and gender relations brought about by the impact of migrancy, urbanisation and missionary Christianity. See for instance: Peter Delius and Clive Glaser, "Sexual Socialisation in South Africa: A Historical Perspective", *African Studies*, 61, 1 (2002); Karen Jochelson, *The Colour of Disease: Syphilis and Racism in South Africa 1880-1950*. (London and New York: Palgrave, 2001); Mark Hunter, "'The Materiality of Everyday Sex': Thinking beyond prostitution", *African Studies*, 61, 1 (2002); Shula Marks, "An Epidemic Waiting to Happen? The Spread of HIV/AIDS in South Africa in Social and Historical Perspective", *African Studies*, 61, 1 (2002). Simone Horowitz, "Migrancy and HIV/AIDS In Historical Perspective", *South African Historical Journal*, 45 (2001) Deborah Posel has also discussed post-apartheid discourses about sex, but not how these have influenced the language, genres, tactics and strategies of AIDS activism. Deborah Posel, "'Getting the Nation Talking About Sex': Reflections on the Politics of Sexuality and 'Nation-building' in Post-Apartheid South Africa", (2003), Unpublished Paper presented at the University of the Witwatersrand's Institute for Social and Economic Research, "On the subject of sex" seminar series on 25th February 2003. Available at <www.weserweb.ac.za>.

⁷ Suzanne Leclerc Madlala has written on how Zulu cultural notions of pollution have been used to stigmatise women for the spread of AIDS. See: Suzanne Leclerc Madlala, "Demonizing Women in the Era of AIDS: An Analysis of the Gendered Construction of HIV/AIDS in KwaZulu-Natal", (Unpublished Anthropology PhD Thesis, University of Natal, Durban, 1999).

⁸ Loius Grundlingh has documented homophobia and racism in AIDS policy-making, however, he includes nothing on the gay rights or doctor activist response to this. See Louis Grundlingh, "Government Responses to HIV/AIDS in South Africa as Reported in the Media", *South African Historical Journal*, 41 (2001). My earlier work has also critiqued the apartheid government's AIDS policy. See: Mandisa Mbali, "'A Long Illness': Towards a History of Government, NGO and Medical Discourses Around AIDS Policy-making", (Unpublished Bachelor of Arts Honours Thesis, University of Natal, Durban, 2001).

AIDS-related discrimination and contextualise AIDS activism within these socio-cultural and political changes in the period of investigation.

The existing literature on the socio-cultural and historical causes of stigma can also be drawn upon to illustrate a key limitation to AIDS activism both in the late 1980s and early 1990s. This limitation was that social attitudes had not caught up with policy moves towards anti-discrimination because AIDS was stigmatised as a problem of the racial and sexual “Other”.⁹ Community AIDS activists encountered widespread reverse “Othering”, in African communities in the early 1990s which framed AIDS as a white disease blamed on Africans by white racists. This reverse “Othering” differed from the “Othering” of white racist framings of the epidemic as a ‘black plague’, because it blamed AIDS on the white “Other”. In the post-apartheid era, the persistence of popular attitudes that involve reverse Othering, and its implicit denial of the seriousness of the epidemic, is a plausible socio-historical explanation of why there hasn’t been even greater resistance to post-apartheid government AIDS denialism.

A medical history “from both sides of the bed”¹⁰

Just as I will try to demonstrate the relevance of this thesis for understanding contemporary events, I will locate this thesis’s focus on doctor and patient AIDS activism in terms of broader theoretical framings of medical history. Some medical historiographies have emphasised the importance of issues of representation in the exercise of medical power. On the other hand, other medical historiographies have emphasized agency and resistance to oppressive aspects of medical power.

Firstly, in reaction to Whiggish histories of medicine as a doctor-driven phenomenon, characterised by an ever increasing spiral of rationality through great medical discoveries,¹¹

⁹ I am using Edward Said’s notion of “Othering”, in that it describes how colonial era Western culture depicted colonised peoples in negative terms as possessing all traits deemed to be negative in Western culture. Edward Said, *Orientalism*, (New York: Vintage, 1979). I discussed the use of notions of “Othering” in analysing the history of AIDS policy-making in my BA Honours thesis. Mbali, *A Long Illness*’.

¹⁰ This term is taken from Judith Walzer Leavitt’s review of medical history literature. Judith Walzer Leavitt, “Review Article: Medicine in Context: A Review Essay of the History of Medicine”, *American Historical Review*, 98, 2 (1993), p.1473.

Foucault's medical historiography arose which highlighted oppressive and alienating effects of medical discourse in the exercise of modern power.¹² Secondly, in response to both Foucauldian and doctor-driven historiographies, social histories of medicine, exemplified by the work of medical historians such as Roy Porter, have tried to show *patient* experiences and understandings of medicine, health and illness and healing.¹³ In terms of this, a key debate in recent medical history has been whether medical history should, in a Foucauldian sense, focus on oppressive aspects of Western biomedicine (a history largely focussed on doctors and the medical profession) or, in a Porterian sense, on patients and the broader socio-economic and cultural contexts in which they existed, which in turn shaped their understandings of health and illness.

In this vein, Foucauldian medical historians have drawn on the notion of bio-power to argue that medicine has operated as an instrument of oppression in the modern power/knowledge regime.¹⁴ Moreover, according to such a Foucauldian medical historiography, medical doctors have oppressed patients through alienating them from healing practises and objectifying their bodies: differently put, according to such a viewpoint modern Western bio-medical power has been written onto patients' 'docile and useful' bodies.¹⁵ Therefore, bodies are not 'natural', eternal and unchanging and representations of them have changed over time in medical thought.¹⁶ An example of this kind of medical historiography is the work of Foucauldian Alexander Butchart, who has argued that in colonial Africa 'the African Body' and 'the African mind' were constructed by the perceptions of colonial health professionals in Africa.¹⁷

By contrast, Megan Vaughan another medical historian of Africa, has acknowledged a theoretical debt to Foucault in showing modern power as partially exercised through discourse. However, she has argued that colonial African societies differed in important

¹¹ Walzer Leavitt, "Review Article", p.1471.

¹² Michel Foucault, *The Birth of the Clinic: An Archaeology of Medical Perception*, Transl. A. M. Sheridan. Ed. R. D. Laing, (London: Tavistock, 1973).

¹³ Roy Porter, "The Patient's View: Doing Medical History from Below", *Theory and Society*, 14 (1985).

¹⁴ Foucault, *The Birth of the Clinic*. Michel Foucault, *Discipline and Punish: The Birth of the Prison*, Transl. A. Sheridan, (Tavistock: Penguin, 1977).

¹⁵ Foucault, *Discipline and Punish*, p.136.

¹⁶ Foucault, *The Birth of the Clinic*.

¹⁷ Alexander Butchart, *The Anatomy of Power: European Constructions of the African Body*, (London and New York: Zed Books, 1998), p..31.

ways from the Western post-Enlightenment societies studied by Foucault. In such societies, as Foucault has shown, there were liberal shifts in Western thought from naked repressive power, where punishment was exercised on the body, to disciplinary power's concern for human welfare and notions of the autonomy and rights of individual subjects.¹⁸ Instead, for Vaughan, colonial states in Africa relied on naked repressive power intellectually under-girded by racism. For Vaughan and Karen Jochelson, the iron fist of sovereign power was never replaced by the velvet glove of disciplinary power in colonial Africa.¹⁹ Furthermore, both Jochelson and Vaughan have positioned themselves as 'social constructionists' in that they see the natural and the social as interrelated and biomedicine as socially constructed.²⁰ For instance, Jochelson's medical history of sexually transmitted disease epidemics in South Africa views the epidemics as having been socially constructed in the sense of colonial and apartheid public health discourses around syphilis having reflected the social anxieties of whites.²¹

Agency, Resistance and Rights-talk

Powerful critiques of Foucault's seamless notions of modern power have been made have been made by thinkers such as Nancy Fraser and Jürgen Habermas. Both thinkers have argued that his schema of modern power provides scant allowance for historical agency for individuals to exercise normative, human rights-based resistance to oppressive power.²² Human rights, founded as they are on notions of equality, freedom and human dignity, are a powerful way to frame normative political claims, which focus on about how the world *ought* to be. Indeed, as Habermas has argued, ideas within modernity itself, such as human

¹⁸ Foucault, *Discipline and Punish*.

¹⁹ Megan Vaughan, *Curing Their Ills: Colonial Power and African Illness*, (Cambridge and Oxford: Polity Press, 1991), pp.8-10.

²⁰ Vaughan. *Curing Their Ills*, 4-6; Karen Jochelson, "The Colour of Disease: Syphilis and Racism in South Africa 1880-1950, (London and New York: Palgrave, 2001).

²¹ Jochelson, *The Colour of Disease*, pp.6-7.

²² Jürgen Habermas, *The Philosophic Discourse of Modernity*. (Cambridge: Polity Press, 1987), pp.282-283. Jürgen Habermas, *Between Facts and Norms*. Transl. W Rehg, (Cambridge: MIT Press, 1996), pp.370-372. Nancy Fraser, *Unruly Practices: Power, Discourse and Gender in Contemporary Social Theory*, (Cambridge: University of Minnesota Press, 1989), pp.38-39.

rights-based discourse, can be used to criticise oppressive aspects of Western humanist traditions.²³

To focus briefly also on why the thesis focuses specifically on struggles for *human rights-based* framings of AIDS policy, I am not specifically dealing with medical ethics at a micro-level, that is, the actual ethics of individual doctor-patient relationships on AIDS. My interest in AIDS policy, as expressed in this thesis, stems from an interest in how activists and their organisations politically talk about the AIDS epidemic in a normative sense, as a public health issue: how they talked about moving from the way that AIDS policy *was* to discussing how it *ought* to be. I would contend that a focus on human rights (as opposed to merely ethics) in AIDS policy is appropriate due to its socio-political level of analysis. As Jonathan Mann has argued, public health (which incorporates health policy analysis) is interested in disease at the level of society, not the individual (which is the concern of medicine, where ethics is the appropriate way to analyse normative issues). In terms of this, human rights, which are a more political way of talking about normative ideals (and which largely focus on how governments, societies and institutions relate to the individual) are the appropriate way to normatively frame analyses of disease from a socio-political perspective.²⁴

Human rights exist on paper, but they require governments, the judiciary, civil society and the media to be interpreted and to be given political force. As Marie Benedict Dembour has argued, human rights do not exist objectively and outside time, but the invocation of human rights language can be seen as a useful political-rhetorical strategy in certain historical contexts (such as the democratising South Africa of the early 1990s) for certain groups (such as people living with HIV) to articulate normative claims.²⁵ The power of human rights-based language is that it is essentialised when used as a political strategy to

²³ Habermas, *Between Facts and Norms*, pp.370-374.

²⁴ Jonathan Mann, "Medicine and Public Health, Ethics and Human Rights", in Gruskin, S., Grodan, M. A. and Annas, G (eds), *Health and Human Rights- A Reader* (New York: Routledge, 1999), pp.443-444.

²⁵ Marie Benedict Dembour, "Human rights talk and anthropological ambivalence: the particular contexts of universal claims", in Harris, O. (ed.), *Inside and Outside the Law: Anthropological Studies of Authority and Ambiguity*. (London: Routledge, 1996), p.32-35. This is more thoroughly discussed in another paper I wrote: Mandisa Mbali, "Researcher/Activist Engagements with AIDS Policy-making After the Death of Objectivity", (2002), Available at <www.nu.ac.za/ccs>

give political claims an incontestable legitimacy and to make them seem unchallengeable,²⁶ when in reality they are interpreted and negotiated differently in different socio-political contexts over time. As shall be shown in Chapter Three, AIDS activists operating in the early 1990s, in a society that was negotiating a new Constitution, found a powerful political strategy in making normative claims in terms of rights-based discourse.

In terms of these Habermasian/Fraserian critiques of Foucault, and as I argued in my Bachelor of Arts Honours thesis, there is strong historical evidence of resistance to discriminatory framings of AIDS policy as a 'gay plague' and a 'black plague' in the 1980s and early 1990s. Anti-apartheid leftist and feminist academics and activists resisted stigmatising framings of the epidemic by representing AIDS as a symptom of the socio-economic effects of apartheid. More precisely, they used rights-based discourse to resist racist, sexist and homophobic framings of the epidemic and the real discrimination that resulted from such framings.²⁷ Due to time and space constraints and the limited oral and archival material available to me when I wrote my Honours thesis this was an underdeveloped theme and one that is developed in this Masters project.

As Chapters One and Three of this thesis show, rights-based discourse, due to its universal claims was a malleable tool for the fashioning of early links between anti-apartheid gay patient activists and anti-apartheid doctors: it was a language that could be used by gay activists to resist *both* homophobia in the liberation movement *and* racism within the gay movement. For instance, in the case of anti-apartheid gay rights activists, the universality of rights-based discourse provided a common discursive ground for co-operation. This was the case as anti-apartheid gay activists were not merely fighting for sexual freedom, they were fighting for political freedoms for all, they were not merely fighting AIDS-related homophobia they were fighting for freedom from all AIDS-related discrimination for all people living with HIV.

²⁶ Dembour, "Human rights talk", p.35.

²⁷ Mandisa Mbali. 'A Long Illness'

Active and Un-Docile Doctor and Patient Political Bodies

Relationships between doctors and patients have formed a central part of African and South African medical histories which have focussed on representations of African patients in Western biomedical discourse, actual healing interactions, and through public health and health policy and planning.²⁸ The history of HIV-positive patient resistance by gay men to dehumanising uses of medicine from the earliest days of the epidemic in South Africa, as charted in Chapter One, undermines the Foucauldian notion of such patients as a mere fabrication of the medical gaze, or mere actors reading from a script of the modern medical system.²⁹ Anti-apartheid doctor activists exercised their agency to resist AIDS-related stigma and discrimination as Chapters Two and Three, which focus on anti-apartheid doctor AIDS activism, clearly demonstrate.

In highlighting histories of doctor and patient activism for a rights-based framing of AIDS policy, this thesis will use archival and oral evidence to undermine some easy binaries suggested by a slavish interpretation of Foucault's medical historiography evinced, for example, in Butchart's African medical history. Chapter Four, which focuses gay rights activism and social attitudes towards AIDS in the early 1990s, shows that the binary doctor/patient, active/passive, is undermined by the fact that HIV positive gay rights activists, supported by anti-apartheid gay rights organisations, took public and highly politicised stances against AIDS related discrimination from the early 1990s.

Secondly, the doctor/patient, oppressor/oppressed binary suggested by such interpretations also disintegrates under historical investigation: Chapters Two and Three, which focus on anti-apartheid doctor AIDS activism, show that whilst some doctors collaborated in or advocated discriminatory state policies against people living with AIDS and reinforced stigmatising representations of AIDS, other doctors opposed to apartheid and apartheid in medicine, most notably those who belonged to National Medical and Dental Association (NAMDA) and the National Progressive Primary Health Care Network (PPHC), resisted stigmatising and discriminatory approaches to AIDS policy.

²⁸ See for instance, Vaughan, *Curing Their Ills*. Jochelson, *The Colour of Disease*. Nancy Rose Hunt, *A Colonial Lexicon: Of Birth Ritual, Medicalization and Mobility in the Congo*, (Durham and London: Duke University Press, 1999).

²⁹ Porter, "The Patient's View", p.182. Foucault, *The Birth of the Clinic*, pp.8-15.

Thirdly, as Chapters Three and Four both argue, both groups of activists formed nascent links in the period against AIDS- related discrimination through organisations such as the AIDS Consortium and at forums such as NACOSA and attained a limited measure of success getting rights-based anti-discriminatory provisions into post-apartheid AIDS policy, at least on paper. However, whilst the AIDS activism by gay rights activists became more vocal in the mid-1990s, doctor activism was muted due to the disbanding of anti-apartheid doctor organisations with the ANC's rise to power. Finally, (after my project's primary period of investigation), with the revival of progressive doctor organisation and the discovery of powerful new combination drug treatment, links between doctor and patient anti-apartheid activists strengthened. Both went on to form important components of a powerful civil society alliance named the Treatment Action Campaign (TAC), formed in 1998, which used rights based arguments to push for greater access to powerful new combination anti-HIV drug therapy just over two decades into South Africa's epidemic.

AIDS as “an epidemic of signification”: Representation of AIDS and Its Impact on AIDS Activism

However, I shall argue that it is important to avoid ‘throwing the baby out with the bathwater’ by completely rejecting Foucauldian medical histories’ understandings of the importance of issues of representation to histories of medicine and public health. As Paula Triechler has argued in the case of the history of AIDS in the United States of America, AIDS in South Africa can be viewed as having caused ‘an epidemic of signification’.³⁰ In common with social constructionists such as Vaughan and Jochelson, Triechler has argued that AIDS is socially constructed through language. However, AIDS for Triechler cannot be merely reduced to discourse as it has a natural and a social reality illustrated by the fact it sickens and kills real people.³¹

³⁰ Paula Triechler, *How to Have a Theory in an Epidemic: Cultural Chronicles of AIDS*, (Durham and London: Duke University Press, 1999), p.19.

³¹ Trechler, *How to Have a Theory in an Epidemic* , pp.11-19, p.328.

Moreover, as this thesis' history of doctor and patient AIDS activism shows, activists' understandings of AIDS were shaped by and in reaction to discriminatory and stigmatising government and media representations of AIDS first as a 'gay plague' and later as a 'black plague' and ideas that the 'inherent pathologies' of both groups spread AIDS. As Chapters One and Three show, such representations had material effects for South African people living with HIV/AIDS or perceived as belonging to crudely defined 'high risk groups': they were fired from their jobs, deported, turned away from medical facilities, and in the case of gay men (infected or uninfected) barred from donating blood.

As Chapter Three shows, although several people spoke in the third person of "those people" who lived with AIDS in the early 1990s, a mere handful of AIDS activists spoke openly of being HIV positive, or in terms of "my status" or "my personal risk" in the first person and in a political sense to fight against AIDS related discrimination. Many of the earliest struggles around AIDS-related discrimination in the early 1990s focussed on the right to confidentiality, which may have been widely interpreted as an absolute obligation to secrecy, as I argue in Chapter Four. Seen from the contemporary context where thousands of TAC activists have donned "HIV Positive" t-shirts at demonstrations to realise the right to access to treatment. For AIDS activists living with HIV in the late 1980s and early 1990s a key choice existed: whether to be open about their status and risk attracting further discrimination, or whether to remain silent and for AIDS to stay an invisible and, therefore, a misunderstood epidemic disease. Despite the existence of rare early examples of openness about HIV, as I show in the Postscript, it took the rise of a movement opposed to unequal access to powerful new combination anti-retroviral drug therapy, in the late 1990s, for stigma to begin to seriously erode as late as two decades into the epidemic.

A Social History of Doctor and Patient AIDS Activism Understood in the Political Context of the Late Apartheid and Transition Eras

However, this history of rights-based doctor and patient AIDS activism in South Africa would be incomplete without seeing the emergence of the frightening and new epidemic and the activism that arose in response to it, in the context of the dehumanising apartheid

system which denied black people, women and gay people their rights. In the 1980s, the early images of emaciated white gay men dying of AIDS and a later panic about AIDS as “the black death” caught the media’s attention. In this context, the epidemic and the discrimination it caused featured on the gay organisation’s agendas from the early 1980s and anti-apartheid doctor and health worker organisations’ agendas from the late 1980s. However, there was the bigger issue on both groups’ agendas of how to deal with the apartheid system itself and the socio-economic and political injustices it caused

In terms of this, as Chapter One shows, the emergence of publicly, self-identified and explicitly anti-racist and anti-apartheid gay rights organisations, who were prepared to engage in more militant tactics was a pre-requisite for the emergence of more outspoken patient AIDS activism and for political success in getting the liberation movement to reject AIDS-related discrimination (at least on paper) and make the outlawing of sexual orientation-related discrimination a key plank of the country’s post-apartheid Constitution.

Similarly, as Chapter Two demonstrates, the social history of doctor AIDS activism needs to be rooted in the political and socio-economic context of the late apartheid era. NAMDA was an anti-apartheid United Democratic Front (UDF) affiliated organisation for doctors and dentists formed in 1982, in response to human rights violations committed by doctors working for the state. The PPHC was in turn formed as an offshoot of NAMDA, which was focussed on working towards promoting Primary Health Care. As Laurel Baldwin-Ragaven, Jeanelle de Gruchy and Leslie London have shown, South Africa’s post-apartheid Truth and Reconciliation Commissions’ (TRC) Health Sector Hearings 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, and even at times actively compromised, and in which violations of moral and ethical codes of practice were frequent, facilitating violations of human rights.³²

³² Laurel Baldwin-Ragaven, Jeanelle de Gruchy and Leslie London, *An Ambulance of the Wrong Colour: Health Professionals, Human Rights and Ethics in South Africa*. (Cape Town: University of Cape Town Press, 1999), p.6.

Human rights violations perpetrated by doctors documented at the TRC's Health Sector hearings included several cases of violations of doctor-patient confidentiality, through enabling police to sit in on consultations, which should have been confidential, with patients who were political prisoners or protestors and allowing police access to confidential patient records.³³ While organisations representing most doctors, such as MASA and SAMDC, paid lip-service to ethical professional behaviour, as enshrined in the Hippocratic Oath and other international codes of ethics, their interpretation of medical ethics was narrow and did not incorporate human rights issues: for instance, in practice, for many district surgeons, the 'criminal' status of political prisoners or the 'national security threat' they posed meant that they were seen as having fewer rights as patients.³⁴

In this context, as Chapter Two demonstrates, in the 1980s the over-arching struggle of anti-apartheid doctor organisations such as NAMDA was for the elimination of apartheid in general, and in medicine in particular, and highlighting human rights violations in medicine and the public health effects of the socio-economic and political injustices of apartheid. However, exiled anti-apartheid doctors and small NAMDA and PPHC AIDS interest groups pushed for the liberation movement to form a political response to the epidemic and formed nascent links with anti-apartheid gay rights activists and organisations in this regard.

Doctor and patient AIDS activism in the political context of the transition of the 1990s

The turn of the decade in 1990 brought a sea-change in South African politics, which as I will outline in Chapter Three would impact on rights-based AIDS activism. AIDS was placed firmly on the agenda of the 1990 Maputo Conference on Health in Southern Africa, which was held to develop a blueprint for post-apartheid health policy. Non-discrimination was included as a key principle in the Maputo Conference's statement on AIDS. Similarly, the National AIDS Convention of South Africa (NACOSA) held in

³³ Baldwin-Ragaven *et al*, *An Ambulance of the Wrong Colour*, pp.54-69.

³⁴ *Ibid.*, pp.67-68.

1992 mirrored the broader CODESA negotiations and at NACOSA non-discrimination was advanced as a principle in AIDS policy.

However, social attitudes were slow to catch up with the progressive non-discriminatory rights-based AIDS policy papers which were negotiated in the period, with serious implications for post-apartheid AIDS policy-making. The ANC was limited in the extent to which it could be seen by its constituency, most of whom weren't convinced of the serious threat the epidemic posed, to be committing resources and political energy to fighting AIDS when there were major outstanding issues to be resolved to ensure a democratic South Africa throughout the transition period. Moreover, the denial of the extent of the problem and seeing it as a white plot to discredit black people were themes that would be taken up in government denialism.

Furthermore, when the ANC came to power post-1994, it was still 'learning how to govern' and scrambled to find 'quick-fixes' to the epidemic immediate post-1994 period. In the transition era, anti-apartheid doctor organisations such as NAMDA voluntarily disbanded due to the fact that they saw no ongoing need for a critical organisational voice for doctors concerned with social justice: the government they had fought for was in power, which they saw as obviating the need for organised critical opposition from doctors on health policy. When some former anti-apartheid doctors fell out with the ANC government over AIDS denialism, it was a bitter disagreement between former comrades.

This medical history of the struggle for human rights in AIDS policy 'from both sides of the bed' is relevant to contemporary struggles several other ways. The South African Medical Association (SAMA) which was formed in the spirit of reconciliation through a merging of NAMDA and MASA in the post-apartheid era has carried forward the legacy of doctors as advocates for their patients' rights by joining with the TAC in the early 2000s in its struggles for access to HIV treatment. And the TAC itself carries forward the legacy of anti-apartheid gay activism around AIDS: it was formed partially in response to the death of Simon Nkoli and it is led by Zackie Achmat and supported by

Judge Edwin Cameron, both of whom have histories as outspoken gay anti-apartheid and AIDS activists.

A large part of the tragedy of AIDS is that globally it is a disease that targets a society's most productive young citizens in their socio-economic, cultural and political prime. An additional, and particularly South African, aspect of this global calamity is that the tragedy of AIDS has followed the tragedy of apartheid. Today, like the 1980s, South Africa is still burying its young en masse, not as a result of murder by the apartheid security forces, but from AIDS. In the midst of this fundamental crisis, this thesis aims to document a history of AIDS activism, which accounts for the agency and possibilities for resistance by patients and doctors to human rights abuses. The contemporary human rights-based struggle for access to treatment, for realisation of the right to life itself for people living with HIV, has built on earlier struggles and alliances and demonstrates that neither do patients have to be passive victims nor doctors active collaborators in the undermining of human dignity.

PATIENT ACTIVISM: AIDS, REPRESENTATION AND THE POLITICS OF
GAY ACTIVISM ADDRESSING THE “GAY PLAGUE” IN THE 1980S

Two South African Airways stewards have died after apparently becoming the first South African victims of a rare disease which is believed to affect mainly homosexuals and drug addicts”.

“‘Homosexual’ disease kills SAA Staff” *Argus* 4th January 1983¹

Introduction: The ‘Homosexual’ Disease

South Africa today has an AIDS epidemic where it is estimated that over five million of its citizens are HIV positive.² The AIDS policy-making process in recent years has been characterised by conflict between AIDS activists aligned with the Treatment Action Campaign (TAC) and the government over government denialism and access to HIV treatment.³ Contemporary AIDS activists aligned to the TAC have in turn framed their struggle for HIV treatment access in terms of the human rights of people living with HIV/AIDS: that access to such life-saving combination antiretroviral drug treatment for all HIV positive people is a human right. In the midst of this devastating AIDS crisis and the policy-making conflicts surrounding it, it may be worth remembering a time when there was only a handful of white gay men dying of AIDS and when a public panic was created by the arrival of a new and poorly understood disease, which was then commonly phrased as the “homosexual plague”.

AIDS emerged in South Africa in 1982, one year after the American Centres for Disease Control announced the emergence of the new disease amongst young gay

¹ South African History Archive (SAHA), Gay Association of South Africa (GASA), Gay Association of South Africa, Gay Association of South Africa /Gay Association of South Africa 6010 (GASA/GASA 6010) Box, Media Scrap Books, “Scrap Book Kept by Leon Eksteen who died in August 1986. He was the 5th Capetonian to die of AIDS”, Leon Eksteen.

² A figure extrapolated from the 2003 Department of Health’s annual anti-natal clinic survey.

³ I have documented and traced the possible reasons for this disagreement extensively elsewhere. Mandisa Mbali, “HIV/AIDS policy-making in post-apartheid South Africa”, in Habib, A, Daniel, J and Southall, R (eds), *State of the Nation: South Africa 2003-2004*, (Cape Town: Human Sciences Research Council Press, 2003).

men in New York and San Francisco in its Weekly Morbidity and Mortality Report.⁴ In South Africa, as in the United States, shocking headlines announced that the ‘homosexual’ disease or the ‘gay plague’ had arrived in South Africa.⁵ Illustrative of the fundamental crisis that the AIDS epidemic represented for gay men in South Africa in the period, by the mid-1980s it was estimated that ten to fifteen percent of gay men in Johannesburg were infected.⁶

Theories of Patient Activism, Representation and Identity

Contrary to medical histories which focus exclusively on the role of doctors and medical authorities,⁷ I am arguing that the history of gay activism around AIDS in the 1980s can be framed as in a Porterian sense, as a history of a disease from a patient perspective:

For it takes two to make a medical encounter—the sick person as well as the doctor...Indeed it often takes more than two, because medical events have frequently been complex social rituals involving family and community as well as sufferers and physicians.⁸

In terms of this, early gay AIDS activism can be framed as “patient activism” on the basis of the fact that a significant and growing number of gay men were identified as HIV

infected or as having AIDS during the period. Moreover, even uninfected gay men who participated in gay organisations were fairly likely to have known other gay men

⁴ For excellent accounts of the homophobic panic generated by the emergence of AIDS in the US see Paula Trierchler, *How to Have a Theory in an Epidemic: Cultural Chronicles of AIDS*, (Durham and London: Duke University Press, 1999), pp.19-26.

⁵ SAHA, GASA, GASA/GASA 6010 Box, Media Scrap Books, “Scrap Book Kept by Leon Eksteen”, Leon Eksteen. “‘Gay’ plague: More victims?” *Sunday Times*, January 9 1983, p..3

⁶ Ruben Sher, “HIV infection in South Africa 1982-1989- A review”, *South African Medical Journal*, 76, (1989), pp.314-318.

⁷ I would argue that Jochelson’s medical history of venereal disease focuses too much on doctors and medical authority perspectives, this is probably due to the methodological fact that colonial medical records are easier to come by than oral/written patient orientated histories of colonial medicine especially in its earliest periods. Karen Jochelson, *The Colour of Disease: Syphilis and Racism in South Africa 1880-1950*. (London and New York: Palgrave, 2001). Similarly, Ragaven Baldwin et al do not focus on the patient perspective sufficiently. Laurel Baldwin-Ragaven, Jeanelle de Gruchy and Leslie London, *An Ambulance of the Wrong Colour: Health Professionals, Human Rights and Ethics in South Africa*. (Cape Town: University of Cape Town Press, 1999). Buchart takes it a step further by seeing African patients as a mere product of the colonial medical gaze. Alexander Buchart, *The Anatomy of Power: European Constructions of the African Body*, (London and New York: Zed Books, 1998).

⁸ Roy Porter, “The Patient’s View: Doing Medical History from Below”, *Theory and Society*, 14 (1985), p.175.

infected with HIV, not least through social support networks established for members of gay organisations who were HIV positive. Also they were concerned about the issue of AIDS and because of the media-induced homophobic panic inspired by the epidemic in its first years. Representations of the epidemic as a 'gay plague', which depicted it as a phenomenon that resulted from an 'innate pathology' in gay sexuality and the material discrimination that resulted from these representations catalysed such patient activism by gay AIDS activists.

As I argued in the Introduction to this thesis, just as there were doctors who resisted coercion, unfair discrimination and dehumanising treatment in medicine and public health discourse, not all early AIDS patients, most of whom were gay in the early 1980s, were (Foucauldian) 'docile and useful bodies'. Gay activists in the 1980s exercised their agency and autonomy to resist crude representations of AIDS as a 'gay plague' and practical discrimination that this caused.

Gay identities were multiple as different interpretations and articulations of gay identity and gay political organisation led to a splintering of gay organisations in the 1980s with important implications for gay AIDS activism in the period. In terms of this, the main gay organisation in the early 1980s, the Gay Association of South Africa (GASA), which had mainly a white male membership adopted an 'apolitical' and non-militant stance and set of tactics against legalised and institutionalised homophobia. As shall be demonstrated, its apolitical stance was not without controversy, as critics within the organisation accused it of not condemning apartheid and tolerating racism within its ranks such as segregation of gay social events it organised. Tensions over how the organisation dealt with racism and treated black members came to a head when Simon Nkoli, one of its first African members, was detained on treason charges linked to his anti-apartheid activism in 1984. Many splinter organisations, such as the Organisation for Gay and Lesbian Activists (OLGA) were then formed by gay and lesbian activists opposed to GASA's 'apolitical' stance on apartheid. This in turn was a historical and political pre-requisite for gay activists and organisations forming tentative links with anti-apartheid doctors on AIDS, which as will be shown in Chapter Four, grew stronger in the 1990s as a result of the free political climate created transition to democracy.

In her excellent study of the history of the representation of AIDS in the media, medical discourse and by AIDS activist groups in the United States, Paula Trenchler has argued that AIDS was ‘an epidemic of signification’:

Whatever else it may be AIDS is a story, multiple stories, and read to a surprising extent from a text that does not exist: the body of the male homosexual...AIDS is a nexus where multiple meanings, stories and discourses intersect and overlap, reinforce and subvert each other. Yet clearly this male homosexual text has figured centrally in what I call here an *epidemic of signification*.⁹

Whilst Trenchler argues that AIDS is socially constructed through language, it is also worth noting that she does not deny its reality as a “real disease syndrome, damaging and killing real human beings”, that it cannot be merely reduced to discourse.¹⁰

Just as there have been multiple stories and representations of the AIDS epidemic, there are multiple sexual and gendered identities which can be used in an activist sense for rights-based politics. Monique Deveaux has argued that the ‘categories’ of ‘woman’ and ‘lesbian’ and ‘gay’ can offer both personal affirmation and can be politically effective especially if used to make rights-based claims.¹¹ This reading runs counter to Foucauldian feminist readings of, sex and sexuality as performative acts determined by the disciplinary power/knowledge regime, as suggested by Judith Butler.¹² I would argue, like Deveaux, that gay activists whose work I chart in this chapter creatively perceived of and inhabited their identities both socially and politically, which led to important splits within the movement.¹³

Certainly, there is evidence of representation of the epidemic as a ‘gay plague’ in the South African media in the early 1980s and that this sparked some resistance by gay activists. Gay activists at GASA, some of whom were dying of AIDS at the time, were reading and compiling media scrap-books which have been preserved at the Gay and Lesbian Archive at the South African History Archive at the University of the

⁹ Trenchler, *How to have a Theory in an Epidemic*, p.19.

¹⁰ *Ibid.*, p.11.

¹¹ Monique Deveaux, “Feminism and Empowerment: A critical reading of Foucault”, *Feminist Studies*, 20, 2 (1994), p.241.

¹² Judith Butler, “Excerpt from the Introduction to *Bodies that Matter*”, in Lancaster, R.N. and di Leonardo, M. (eds), *The Gender/Sexuality Reader: Culture, History, Political Economy*, (New York and London: Routledge, 1993), pp.531-532.

¹³ Deveaux, “Feminism”, pp.241-242.

Witwatersrand. Some gay activists were also responding, albeit in a relatively muted and non-militant sense, to the dominant discriminatory representation of AIDS as stemming from some innate pathological characteristic of ‘homosexuals’. For instance, some of the headlines gathered in these scrap-books depicted ‘AIDS carriers’ as sexual predators who lied about their infection and wilfully infected others¹⁴ and as menaces to public health who were unfit to even serve food on airlines. A *Sunday Times* article decrying the arrival of the ‘gay’ plague announced in horrified tones that “Seven months before he became the first South African to die of the newly discovered disease- Ralph Kretzen, a self-confessed homosexual- still handled food on overseas flights”.¹⁵



(This *Sunday Times* article from Leon Eksteen's scrap book announced that 'the gay plague had arrived')

Another, more sympathetic, early story showed the ‘living skeleton’ early AIDS ‘victim’ Hennie van der Wath, who was the first South African to publicly admit to having AIDS, lying helplessly in a hospital beds surrounded by flowers.¹⁶ However, Van der Wath’s confession not in the politicised, rights-based sense in which later

¹⁴ SAHA, GASA, GASA/GASA 6010 Box, Media Scrap Books, “Scrap Book Kept by Leon Eksteen”, Leon Eksteen, Chris Erasmus. “‘Concealment’ by AIDS victims” Unknown newspaper, undated.

¹⁵ “Gay plague: More victims?”.

¹⁶ As Chapter Three shows activists such as Shaun Mellors disclosed not only to get sympathy for their stigmatisation and suffering but to get support for protection of their rights. SAHA, GASA, GASA/GASA 6010 Box, Media Scrap Books, “Scrap Book Kept by Leon Eksteen”, Leon Eksteen, Charmain Naidoo. “...Victim’s Family”. Unknown newspaper, undated. .

gay activists would disclose their illness, it was solely aimed at generating sympathy. The photograph accompanying the article used similar visual imagery to generate sympathy as was used in early sympathetic articles in the United States. As Triechler has shown, early AIDS stories in the United States used 'cute' fluffy toys or live animals to separate the 'innocent' from the 'guilty'.¹⁷ In a story in which the innocence or guilt of the "AIDS victim" was discussed alongside the views of his family on the 'morality' of his partner 'deserting' him in his time of need, this type of interpretation may be relevant as it is clear that the portrayal of the patient with flowers was coded to reflect his 'innocence' and 'helplessness'.



(Triechler has written on the use of animals to generate sympathy for people with HIV in 1980s America)
Ralph



(INSERT Photo: This compares well with the use of flowers in this 1980s South African media photo of 'Aids Victim'

Kretzen)

In South Africa, as elsewhere, in the early 1980s, gay men faced the brunt of early AIDS-related institutionalised discrimination, and its impact on gay activism has been seldom documented and discussed in accounts of South Africa's history, in general, or its history of AIDS, in particular.¹⁸ For instance, posters went up in Natal urging

¹⁷ Triechler, *How to have a Theory in an Epidemic*, p.14.

¹⁸ With a few notable exceptions where the issue is very briefly discussed, as a part of broader discussions: Grundlingh, Gevisser's and Philips have all separately discussed the stereotyping of AIDS as a gay plague. I hope to build on these accounts by showing the real suffering and material discrimination this caused and how the effects of such representation catalysed activism. Howard Philips, "AIDS in the Context of South Africa's Epidemic History", *South African History Journal*, 45 (2001). Mark Gevisser, "Another fight for freedom", In Cameron, E and Gevisser, M (eds) *Defiant Desire: gay and lesbian lives in South Africa*, (Johannesburg: Raven Press, 1994). Loius Grundlingh, "Government responses to HIV/AIDS in South Africa as Reported in the Media", *South African Historical Journal*, 41, (2001).

“gays” and “moffies”¹⁹ or people who had had sex with “gays” and “moffies” not to give blood to prevent transmission of AIDS.²⁰ This discrimination was informed by the dominant public health constructions in the *South African Medical Journal* and by the Durban Medical Officer of Health’s Annual Reports, of gay men, black prostitutes and foreigners as abnormal “disease carriers”, as pathological types, not individuals with complex life histories who operating in complex socio-cultural contexts, as I demonstrated in my Honours thesis.²¹



(This is a photograph of the ‘moffie’ poster referred to in footnote 20)

It has been widely discussed how AIDS was frequently represented internationally, in the early phases of the epidemic, as ‘just desserts’ for the ‘sin’ of ‘homosexuality’, in line with the conservative view of homosexuality as ‘evil’.²² In South Africa, the discrimination against people living with AIDS in the early years even included some private hospitals refusing to admit AIDS patients.²³ My accounts of many of these early and panic-filled articles are taken from Leon Eksteen’s scrap book, who

¹⁹ A derogatory and prejudiced term for South African term for gay men. For more on the historical origins and genealogy of the term see Shaun de Waal, “Etymological note: On ‘moffie’”, In: Cameron, E and Gevisser, M. (eds) *Defiant Desire: gay and lesbian lives in South Africa* (Johannesburg: Raven Press, 1994), p.x.

²⁰ A discriminatory practice that continues today. SAHA, GASA, GASA/GASA 6010 Box, Media Scrap Books, “Scrap Book Kept by Leon Eksteen”, Leon Eksteen. Shaun Harris “Row brew over ‘moffie’ posters”, Unknown newspaper. SAHA, GASA, GASA/GASA 6010 Box, Media Scrap Books, Vol. 8.5, “Gays angry over blood transfusion poster” *The Citizen* 29 January 1986, p. 15.

²¹ Mandisa Mbali, *‘A long illness’: Towards a History of Government, NGO and Medical Discourses around AIDS Policy-making*, (Unpublished Bachelor of Arts Honours Thesis, University of Natal, Durban, 2001), pp.2-16. It is also important to remember that at that time, *SAMJ* was the mouthpiece of the Medical Association of South Africa, which had an accommodationist relationship to the apartheid government and refused to publish pieces documenting doctors’ collusion in human rights-violations. Baldwin Ragaven, Laurel, de Gruchy, Jeanelle and London, Leslie, *An Ambulance of the Wrong Colour: Health Professionals, human rights and ethics in South Africa*, (Cape Town: University of Cape Town Press, 1999), pp.158-159.

²² In these early years, even mainstream medical science toyed with the idea that there was something innate in ‘the gay lifestyle’, which made gays vulnerable to AIDS. Not, as Watney has argued at the time, a lack of access to accurate AIDS prevention information in the period. Paula Triechler, *How to have a Theory in an Epidemic*, p.21-23. Simon Watney, *Policing Desire: Pornography, AIDS and the Media* (Minneapolis: University of Minnesota Press, 1987).

²³ SAHA, GASA, GASA/GASA 6010 Box, Media Scrap Books, Vol. 8.5, Cas St Leger, “AIDS patients turned away”, *Sunday Times Metro*, July 6 1986.

according to its front cover was the fifth Capetonian to die of AIDS in 1986. Reading through all the media articles in the scrap book, I gained a sense of the stigma and panic that people living with AIDS in South Africa in earlier phases of the epidemic must have felt, which coupled with dying from an ill-understood new disease, must have exacted a great emotional toll on these individuals. The lethal nature of the disease, is shown in the scrap book itself, which ends at a certain point at which Leon Eksteen must have become too weak to continue its compilation. This in turn demonstrates that the epidemic was not just one that existed at the level of discourse, but also one with painful physical and emotional effects for those infected and their families, friends and partners. But this then leads one to question who would take up the case of these early AIDS patients and push for them not to be turned away from nursing homes and fired from their jobs?

The Gay Association of South Africa: ‘Apolitical’ and Nonmilitant

As histories of the epidemic in the West have shown, there was similar AIDS-related discrimination and relative apathy on the part of governments to the problem in Europe and North America in the early 1980s.²⁴ However, in the United States, AIDS-related discrimination, especially the refusal to spend sufficiently on developing HIV treatment, catalysed much more radical action. In particular, the radical group AIDS Coalition to Unleash Power (ACT UP) was formed in the late 1980s and it targeted the US government, pharmaceutical companies and AIDS researchers, for failing to develop effective HIV treatment in the first decade of the epidemic.²⁵ ACT UP loudly heckled to interrupt speeches, staged ‘lie-ins’ where they would ‘play dead’ and developed powerful political slogans such as “Silence=Death”. ACT UP activists even asked more moderate AIDS pressure groups: “WHAT ARE YOU DOING TO SAVE MY FUCKING LIFE!”²⁶

²⁴ Watney, *Policing Desire*. Alan M Brandt, *No Magic Bullet: A Social History of Venereal Disease in the United States Since 1880* (New York and Oxford: Oxford University Press, 1987).

²⁵ Ronald Bayer and Gerald M Oppenheimer, *AIDS Doctors: Voices from the Epidemic* (Oxford and New York: Oxford University Press, 2000), pp.138-140.

²⁶ Centre for Health Policy (CHP), University of Witwatersrand, Resource Room, “‘What Are You Doing to Save My Fucking Life’, Larry Kramer, *TAC: HIV & AIDS Treatment Action Campaign: A Reading Package for Treatment Action Campaign Volunteers: HIV/AIDS: An Activists’ Guide to Treatment Rights and Literacy: Building a movement to secure the rights and dignity and access to treatment for people with HIV and AIDS*”.

There was no such placard waving on the part GASA in the early 1980s, which actively eschewed militancy, in a context where gay and lesbian sexual activity was criminalized and political repression against state opponents perfectly legal. In this context, the relatively quiescent response by GASA to AIDS related discrimination targeted at gay people can be explained by the nature of gay political organisation at the time, which was dominated by conservative white members. GASA was the main nationwide gay and lesbian organisation in the early to mid-1980s and believed in a different ‘apolitical’ model of organisation, which mainly focussed on providing social support.²⁷ As has been documented by historians of South African gay organisations, it aimed to provide its members with total confidentiality and actively eschewed ‘militancy’ and demonstrations.²⁸ As Mark Gevisser has argued

For GASA’s architects being apolitical meant two things: firstly remaining non-aligned in broader South African politics, and secondly, following a moderate, non-confrontational and accomodationist strategy.²⁹

The reasons for GASA’s conservatism can be explained by its history and its membership. GASA was formed in 1982 by the merging of three gay organisations in Johannesburg and it became a nation-wide organisation soon after its founding. Its membership, which numbered over a thousand by 1983 was mostly middle class white gay men and its focus was on developing social support for gay men.³⁰ GASA had affiliated sports clubs, religious associations, provided counselling and health services and held ‘gay days’ and jamborees.

GASA did try to inform its membership about the threat of AIDS. It published basic information about AIDS and its transmission in its newsletter *Link/Skakel*. However, the depiction of the level of the threat posed by AIDS was not universally high across different branches in different regions of the country. As Gevisser has argued, whilst in Johannesburg GASA played down the threat posed by the epidemic in the early 1980s, GASA 6010 in Cape Town was, by contrast, a “shrill voice in the dark”

²⁷ I am not arguing that such social support wasn’t vital for lesbians and gays in a heterosexist and heteronormative South Africa, simply that it wasn’t accompanied by militant political resistance to homophobia and heterosexism. This social support through identifying and feeling a sense of belonging to a particular oppressed group is a vital pre-requisite to gay political organisation.

²⁸ Gevisser, “A different fight for freedom”, pp.50-51.

²⁹ Gevisser, *Ibid.*, p.51.

³⁰ Geviser, *Ibid.*, p.48.

providing a range of AIDS prevention and care services;³¹ and as I have found, and as shall be demonstrated below, it used its newsletter to decry homophobic AIDS-related discrimination.

In Durban, GASA also hosted seminars on AIDS for its members, such as the one held in aid of the Durban Gay Advice Bureau under the auspices of the GASA Natal Branch at the University of Natal's Psychology Seminar room in March 1985. The talk was entitled "AIDS Fact and Fiction" by a Dr D Sifris of the GASA AIDS Action Group in Johannesburg, which was billed as "A presentation on the disease, its effects in the community and the counselling of Persons with AIDS and the Worried Well".³²

The GASA Natal Coast Branch's Chairman's report presented at the GASA Natal Branch's Regional AGM in April of the same year reveals clearly that GASA felt that AIDS would mean a "massive homophobic backlash which we are going to have to deal with on many levels". He went on to say that

Individually some of us will be brought close to the reality of long term suffering and death, and collectively we will all be faced with caring for and dealing with people who are lonely and perhaps deserted by those closest to them. This is the kind of true gay spirit which I see developing out of the AIDS crisis.³³

Fundamentally, however, with its accomodationist and nonmilitant strategy, GASA's answer to this crisis was not to wave banners and toyi-toyi. It was to sit down with the National Department of Health and Population Development's National AIDS Advisory Group. Whereas, the anti-apartheid doctors of NAMDA down the road at the University of Natal's Medical School baulked at the idea of 'collaboration' with the 'apartheid regime', for GASA recognition by the minister of health of GASA as the 'official mouthpiece of the gay community' with which the National AIDS

³¹ Gevisser, *Ibid.*, p.59.

³²The seminar program was a general seminar program covering issues such as the legal position of gay men, transsexuality, STDs and "the process of establishing a gay identity". SAHA, GASA, Gay Groups Minutes Etc Box, File A: National Gay Groups Minutes- Northern Cape, Eastern Cape, Natal Coast (Durban) and Port Elizabeth 1984-1985, "Seminar Programme: To be held in aid of the Durban Gay Advice Bureau under the auspices of the Gay Association of South Africa (Natal Coast Branch) on 30/31 March 1985 at The Psychology Seminar Room, University of Natal, King George's Avenue, Durban".

³³ SAHA, GASA, Gay Groups Minutes Etc Box, File A: National Gay Groups Minutes- Northern Cape, Eastern Cape, Natal Coast (Durban) and Port Elizabeth 1984-1985, "GASA Natal Coast: Chairman's Report 1984/85: Report of the Second AGM held on Friday 19th April 1985 at GASA Natal Coast Office, 51 Williams Road, Congella, Durban", p.11.

Advisory Group was to liase was seen as ‘a positive development’.³⁴ However, consultation did not translate into representation, and as Chapter Three shows, GASA was actively excluded from the government’s AIDS Advisory Group, which provided expert guidance on its AIDS policy, despite representing the majority of people living with HIV/AIDS in the 1980s.³⁵

GASA perceived of its accomodationist strategy as having achieved some small regional gains in reshaping the representation of AIDS in a less discriminatory way. For instance, the Durban branch was concerned with dealing with “misinformed” and “hysterical” press coverage of AIDS, and had apparently succeeded in forcing Durban newspapers to consult them on AIDS stories.³⁶ However, action on AIDS-related homophobic discrimination only extended so far, as gay people in Durban were told by the GASA Natal Coast chairman to “respect the call by the medical profession not to donate blood under any circumstances until otherwise informed.”³⁷ This position was not, however, uniform within GASA, for instance the GASA 6010 (Western Cape Region) newsletter argued against such discrimination in its 1984 newsletter. It argued such restrictions were “blatant discrimination” and that they did not represent “scientific objectivity” but “straightforward hetero. hysteria which is being exploited by the media”.³⁸ This shows that responses to the epidemic by GASA branches were not uniform nation-wide and differed by region, which in turn demonstrates the historical agency of gay activists in either opposing or acquiescing to AIDS-related discrimination.

Racism and Conservatism in GASA

³⁴ Ibid., p.11.

³⁵ South African History Archive, University of the Witwatersrand, NAMDA, NPPHCN Funding/Finances Box, NPPHCN Discussion Papers File, “AIDS In South Africa: Experiences and Responses. August 1990. A paper prepared for the ANC presentation to Congressman McDermitt”. See also Chapter Three of this thesis.

³⁶ It is unclear what, if any, impact this had and requires further research.

³⁷ “GASA Natal Coast Chairman’s report”, p.11.

³⁸ Note here that the Western Cape GASA branch seems to have had a stronger anti-apartheid tendency than the Durban branch, tensions which would put an end to the national organisation as we shall see. SAHA, GASA, Gay Groups Minutes Box, File A, “A Village Voice: Purple Blood”. *GASA 6010: Newsletter/Nuusbrief*, 23 (1983).

“Of course, gay men can also be very racist and conservative!”³⁹

Yet there was the overshadowing issue of apartheid in the period, which related to issues of institutionalised racism and legal segregation, all of which were highlighted by GASA’s manner of dealing with the incarceration of one of its members: Simon Nkoli. Indeed, in the years when GASA was trying to respond to AIDS, the political divide in GASA between militant anti-apartheid and accommodationist non-militant apolitical activists would become so great that GASA ceased to exist as a national movement. This splintering process incapacitated gay rights activists from formulating any unified strategy to respond to homophobic AIDS-related discrimination and the obvious shortcomings of late apartheid AIDS policy.⁴⁰ The cracks in the movement appeared early on and related very closely to the controversy surrounding responses to the imprisonment of one of its members, Simon Nkoli, in 1986 for anti-apartheid activity. Significantly, Nkoli’s death from AIDS over a decade later would be a catalyst for the formation of the Treatment Action Campaign, as a former anti-apartheid gay rights activist, Zackie Achmat, would promise to carry forward Nkoli’s struggle for openness and the protection of the rights of people living with HIV, especially their right to treatment access.

Simon Tseko Nkoli joined GASA in 1983. Nkoli was from Sebokeng and he was deeply involved in anti-apartheid activism. He was the Transvaal Regional Secretary of the Congress of South African Students (COSAS). He also worked for the Detainees Parents’ Support Committee (DESCOM) and he coordinated the Education Support Project at the South African Institute of Race Relations.⁴¹ Illustrative of the fact that the vast majority of GASA’s membership were white middle class men, he was one of the few black activists in GASA, and as such he faced racist discrimination within the organisation.⁴² Like many gay men, he faced difficulties being accepted by his family once he revealed his sexuality and his family tried to

³⁹ So said Zackie Achmat to me when we discussed the history of racism in the South African gay movement in Durban, 4th October 2003.

⁴⁰ These shortcomings will not be discussed here, as I have already discussed them at length in my BA Honours short thesis. Mbali, “*A Long Illness*”.

⁴¹ SAHA, Nkoli Collection, Letters to Roy Box, “Letter to Roy”, 9th April 1986. SAHA, Nkoli Collection, File E: Delmas Treason Trial, Maureen Isaacson, “Proud to be bashing the gay-bashers”, *Saturday Star*, October 21 1995.

⁴² As has been demonstrated by Gevisser, “A different fight for freedom”, 52.

‘cure’ his sexuality through visits to different *sangomas* (traditional healers) and even a Western psychologist.⁴³ Eventually his parents managed to accept his sexuality.

Although he found some companionship in GASA (where he met his long-term partner Roy),⁴⁴ in general there was little racial tolerance for black members. There is strong archival evidence that racism existed in the organisation and that issues around racism within the organisation caused divisions comparatively early on in its history. In 1984, the more progressive Western Cape Branch (GASA 6010) denounced racism within GASA in 1984 its newsletter “The 6010th position”, in an article entitled “No Room for Racism”. It made its case by outlining incidents such as a “whites only” outing in Pretoria and the exclusion of seven black members of GASA from a religious meeting in Johannesburg where they were told the meeting was “a private affair”. Significantly, it showed the cracks that were emerging around the time of Nkoli’s detention. The article argued that gay rights were inseparable from human rights in general: as it stated

How dare anyone make a claim for human rights or against oppression when they themselves are guilty of oppression. To talk of human rights is to talk of fundamental rights irrespective of sex, sexual preference, race, colour or belief.

GASA has no room for bigotry

Human Rights are rights for ALL⁴⁵

The importance of this type of location of gay rights within wider discourses of universal human rights must not be understated: as shall be shown, this location of gay rights within wider human rights discourses of the anti-apartheid movement enabled collaboration with anti-apartheid doctors on AIDS in the early 1990s and the enshrinement of non-discrimination on the grounds of sexual orientation into the country’s post-apartheid Constitution.

However, in the mid-1980s such racist discrimination within GASA drove Nkoli, shortly before his detention, to form an affiliated but “separate” GASA-linked group for black gays called the Saturday Group. The Saturday Group folded soon after its formation due to the fact that Nkoli was arrested during an anti-apartheid stay-away

⁴³ Simon Nkoli, “Wardrobes: Coming out as a black gay activist in South Africa”, in Cameron, E. and Gevisser, M. (eds), *Defiant Desire: gay and lesbian lives in South Africa*, (Johannesburg: Raven Press, 1994), pp.250-253.

⁴⁴ SAHA, Simon Nkoli, “Letter to Roy”, 12th October 1985.

⁴⁵ SAHA, GASA, Gay Groups Minutes Etc Box, File A, “No Room for Racism”, *The 6010th Position*, 1 (1984).

on September 23rd 1984, at a funeral. He was held for two years and later brought to trial in 1986 on trumped up high treason charges, along with twenty-one other high profile United Democratic Front (UDF) activists including Mosoiua “Terror” Lekota and Popo Molefe.⁴⁶

GASA’s participation in the International Lesbian and Gay Association (ILGA) had been tenuous for some time due to the fact that anti-apartheid gay rights activists at the Scottish Homosexual Rights Group (SHRG) had taken issue with GASA’s ‘apolitical’ stance and refusal to condemn apartheid in 1983, a year before Nkoli’s arrest. Nkoli’s arrest catalysed a wave of international support from gay rights anti-apartheid activists. For instance, in 1985 the prominent British gay rights activist Peter Thatchell, in a letter to the Editors of *Capital Gay* (a British gay paper), urged gay rights activists to send Christmas cards to Nkoli in jail through his mother.⁴⁷

Activists from the SHRG successfully got GASA suspended from ILGA, in the light of its refusal to support Nkoli: this suspension was catalysed by GASA leader Kevan Botha’s announcement at the 1986 ILGA convention that GASA could not support Nkoli since he was charged with a common law charge and GASA could not sanction ‘criminal activity’.⁴⁸

On the other hand, an instance of the new anti-apartheid gay rights activism was the work of activist Edwin Cameron in the 1980s. As Chapter Three shows, he would go on to be an important activist and human rights lawyer (and later a judge) in defending the rights of people living with HIV/AIDS. In the 1980s, he was very active in advocating for law reform to ensure non-discrimination on the grounds of sexual orientation and defending anti-apartheid gay rights activists, such as Ivan Toms (whose case is discussed below), when they were imprisoned for anti-apartheid activity.

⁴⁶ Nkoli “Wardrobes”, p.253. Jeremy Seekings, *The UDF- A History of the United Democratic Front in South in South Africa, 1983-1991*, (Cape Town: David Philip, 1998). Also, on the violent context of youth anti-apartheid activism in the 1980s see: Monique Marks, *Young Warriors: Youth Politics, Identity and Violence in South Africa* (Johannesburg: University of Witwatersrand Press, 2000).

⁴⁷ SAHA, GASA, Media Scrap Books Box, GASA Media Watch, 3,6, February ’86-July ’86. Peter Thatchell, “A very brave gay comrade”, *Capital Gay*, Friday 22nd November 1985.

⁴⁸ Gevisser, “A different fight for freedom”, p.56.

In 1985 a National Law Reform Fund was formed against government proposals in the mid-1980s to add further homophobic amendments to the Immorality Act. As Gevisser has documented, these proposals would subsequently be dropped due to the government's increasing focus in the period on repressing the rising tide of anti-apartheid activism.⁴⁹ In a 1986 keynote speech Cameron argued that white gay people in South Africa were "living a dream" and merely looking after their own interests while ignoring both the discrimination and oppression that they faced as gay people and the overwhelming racist oppression that black South Africans faced.⁵⁰

GASA's refusal to support Nkoli during his detention, which revealed its 'apolitical' and 'accommodationist' nature simultaneously precipitated both the collapse of GASA as a national organisation and the formation of several explicitly militant anti-apartheid gay rights political organisations which were not only focussed on fighting homophobia, but were also directly opposed to both GASA and apartheid such as the Pink Triangle (which was mainly 'Coloured'), the Pink Democrats, The Rand Gay Organisation and the Gay and Lesbian Organisation of the Witwatersrand (GLOW) and Lesbians and Gays Against Oppression (LAGO) which was fifteen months later renamed Organisation of Gay and Lesbian Activists (OLGA).⁵¹ OLGA was the first gay organisation to merge anti-apartheid activism and gay rights activism and was formed by white anti-apartheid activists who had held leadership positions within GASA 6010, whose strong anti-apartheid and anti-racist tendencies have been shown above.⁵² As shall be shown OLGA and GLOW developed links with NAMDA and the Progressive Primary Health Care Network (PPHC) over AIDS from the late 1980s.

It was a messy break-up in which GASA Rand asked GLOW to prove the liberation movement was indeed against homophobia. Nor did Nkoli and his gay comrades find the liberation movement free of homophobia: Nkoli's fellow detainees at first asked not to be tried with him because of his sexuality.

⁴⁹ *Ibid.*, p.60.

⁵⁰ *Ibid.*, p.60.

⁵¹ Gordon Isaacs and Brian McKendrick, *Male Homosexuality in South Africa: Identity Formation, Culture and Crisis* (Cape Town: Oxford University Press, 1992), p.94. Gevisser, "A different fight for freedom", p.57.

⁵² Gevisser, "A different fight for freedom", pp.57-8.

Indeed, homophobia in the liberation movement remained strong in the early 1990s. In the 1991 “Stompie Sepele” trial, Winnie Mandela, in her defence against charges of abducting four youths from Methodist minister Paul Verryn’s *Manse* (vicarage) in Soweto and assaulting them, accused Paul Verryn of sexually abusing the young men: Verryn was later proven innocent of these charges at Winnie Mandela’s co-accused Jerry Richardson’s trial. Winnie Mandela used allegations of Verryn’s sexual abuse in her defense and argued that ‘homosexuality’ was ‘unAfrican’ a refrain which was repeated in the early 1990s by other African National Congress (ANC) figures.⁵³

However, gay rights activists like Nkoli believed in fighting against homophobia in the liberation movement from within and that his involvement in the liberation movement could win credibility for the gay rights within the liberation movement: he thought that gay activists had to “stand up and fight” for their rights in the liberation movement even if it meant courting “unpopularity” with other anti-apartheid comrades.⁵⁴ It has already been documented how gay ‘ anti-apartheid comrades’ in OLGA and GLOW, such as Nkoli, fought against this homophobia and to get the outlawing of discrimination on the grounds of sexual orientation included in the ANC’s Bill of Rights, which formed the blueprint for the country’s democratic post apartheid Constitution.⁵⁵ It can be surmised that this bigger struggle within the anti-apartheid movement as a whole by gay comrades for gay rights to be on the movement’s agenda would have further complicated efforts to work with NAMDA on AIDS, as discussed further in Chapter Three.

The fact that the relationship between the two movements was complex and often fraught is demonstrated by homophobia experienced by Ivan Toms, who was an active member of the UDF-affiliated End Conscription Campaign, which was formed to urge white South African men who were conscripted into the South African

⁵³ Rachel Holmes, “White rapists make coloureds (and homosexuals): The Winnie Mandela trial and the politics of race and sexuality”, In Cameron, E. and Gevisser, M. (eds.), *Defiant Desire: gay and lesbian lives in South Africa* (Johannesburg: Raven Press, 1994), pp.285-289.

⁵⁴ Nkoli, “Wardrobes”, p.256.

⁵⁵ Gevisser, “A different fight for freedom”, pp.70-71.

Defence Force to become conscientious objectors.⁵⁶ Illustrating the complexities of anti-apartheid gay rights activism in the period, Toms's experiences in the late 1980s reveal homophobia and a hostility to issues of gay rights both on the part of the government and, more generally, many anti-apartheid organisations. Toms was a doctor who had served at a government clinic in Cross-Roads Cape Town, who saw the effects of the violence inflicted by the security forces on the health and well-being of his patients, and refused to serve in the military. Toms also happened to be gay, although not publicly and politically so. In 1987, when he was jailed for his conscientious objection, his gay sexual orientation was used by the security forces to discredit him: homophobic graffiti and posters were placed in Cape Town claiming he was HIV positive and a 'fairy'. Edwin Cameron defended Toms at his trial where his gay sexual orientation was raised. Illustrating the complexity of the relationship between the gay rights movement and the anti-apartheid movement, whilst gay activists in OLGA argued for him to be open about his sexuality, some in the End Conscription Campaign felt that if he were to 'come out of the closet' it would 'detract' from the organisation's main aims to oppose conscription through forming broad coalitions with like-minded individuals and organisations.⁵⁷

Concluding Remarks

A new and militantly anti-apartheid gay rights activism had clearly come to the fore in the mid-1980s: a small, but vocal and growing body of gay rights activists saw that gay rights had to be brought into the broader struggle for freedom, as GASA 6010 activists in Cape Town had argued two years earlier.

The seismic shifts in South African gay politics in these years discussed in this Chapter had very important implications for the future of AIDS activism by early HIV/AIDS patients (most of whom were gay in the 1980s) and their support networks. The explicit anti-apartheid orientation of new gay organisations such as

⁵⁶ Ivan Toms, "Ivan Toms is a fairy? The South African Defence Force, the End Conscription Campaign and me", In Cameron, E. and Gevisser, M. (eds.), *Defiant desire: gay and lesbian lives in South Africa*. (Johannesburg: Raven Press, 1994), p.258.

⁵⁷ Toms, "Ivan Toms is a fairy?", p.259. Toms went on to serve eighteen months in jail. At the time of writing he was the Medical Officer of Health in Cape Town. Interview with Dr Janet Giddy, 15th September 2003, McCord's Hospital, Durban.

OLGA and GLOW would enable political links with anti-apartheid doctor activists in organisations such as NAMDA and PPHC: they could relate as comrades in with a largely shared lexicon calling for an end to apartheid and a society which respected universal human rights for all its citizens. Whereas GASA had been opposed to ‘placard waving’ and ‘toyi-toying’, OLGA and GLOW were prepared to engage in legal action, hold gay pride marches and openly appeal to and identify with anti-apartheid organisations.

This thesis’s aims to construct a medical history of AIDS activism “from both sides of the bed”. In terms of this, just as gay rights activism was largely focussed on how to respond to apartheid, so anti-apartheid doctor activism was fundamentally geared towards

fighting apartheid in medicine and public health, as the next Chapter will demonstrate. It would only be in the 1990s that serious links between both groups on AIDS began to be formed. This Chapter has shown important shifts in gay rights activism that enabled such links between doctor and patient activists.

While, in the 1980s, GASA merely demanded consultation and accommodation with the apartheid government on AIDS policy, in the 1990s OLGA and GLOW activists in the AIDS Consortium formed alliances with anti-apartheid organisations (including health activist organisations such as the PPHC) and used tactics such as litigation, and demanding representation on bodies such as NACOSA (which doctor activists had played a key role in forming), to shape the agenda in AIDS policy-making. As Chapter Three will show, in the transition era of the political negotiations, politicised anti-apartheid gay activists such as Cameron would play a key role in founding the AIDS Consortium which fought against unfair discrimination in AIDS policy and activists from anti-apartheid gay rights organisations would be the first patients to be open about their HIV status.

In the following decade, gay activists increasingly refused to be ‘docile and useful bodies’ and creatively used their different identities as gay men, as anti-apartheid and gay rights activists and even, sometimes, as HIV positive people to resist oppression and demand their rights. As shall be outlined in Chapter Four, in the 1990s these subsequent gains were largely on paper and social attitudes of most South Africans

were slow to catch up. However, after 1994 the principles enshrined in post-apartheid AIDS policy documents and the Constitution would enable them to achieve real remedies through legal and political means by the strategy of highlighting the contradictions between principles of non-discrimination in law and policy and discrimination in practice.

DOCTOR ACTIVISM: ANTI-APARTHEID DOCTOR ACTIVISM AND AIDS IN THE
1980S

Anti-apartheid doctors see their first AIDS patients

This Chapter will focus on the response of anti-apartheid doctors affiliated with the National Medical and Dental Association (NAMDA) to AIDS. NAMDA was an anti-apartheid organisation for doctors and dentists, which was formed to fight against apartheid and for patient's human rights to be respected in medicine and public health in South Africa. The fact that the organisation represented anti-apartheid doctor activists and focussed on issues of human rights is significant in relation to this thesis's concern to outline the history of rights-based activism "from both sides of the bed".

Coincidentally, NAMDA and the Gay Association of South Africa were both formed in 1982, the same year that the AIDS epidemic emerged in South Africa. Here the similarity between both organisation ends, for while GASA was 'apolitical' and nonmilitant, NAMDA was militantly, politically opposed to apartheid. At the same time as the gay rights movement was splintering, and a new, more militant anti-apartheid gay rights groups were being formed, anti-apartheid doctors, who were concerned about human rights issues in medicine and public health, began seeing their first patients with AIDS. Professor Salim Abdool Karim, who is today the Deputy Vice Chancellor of the University of KwaZulu-Natal and heads up one of the biggest AIDS research units in the country, was a medical student and the Assistant General Secretary of NAMDA in 1987. In that year he remembers hearing about a white gay man who medical students at the University of Natal's Medical School were talking about who had AIDS and symptoms of Karposi's Sarcoma¹: they were interested in his case as they suspected that the patient's condition would be included in an upcoming exam.² He never saw the patient, but remembers being intellectually interested in his condition as Karposi's Sarcoma was an extremely rare cancer, especially in young men, before the advent of AIDS.

¹ A skin cancer which is an opportunistic infection caused by the reduced immunity brought on by HIV infection.

² Interview with Professor Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

Dr Janet Giddy, who is today one of the leading AIDS clinicians at McCord's hospital in Durban, had been involved in the End Conscription Campaign and had links to NAMDA doctors at the University of Natal's Medical School in the 1980s. She remembers her experiences with an early AIDS patient because she heard nurses wheeling the patient, who was an African man through the corridors of the hospital where she was working in rural Zululand screaming "This one is the AIDS patient!". The nurses seemed terrified of the patient's infection, Giddy remembers feeling sorry for the patient and also unhappy at the fact that his confidentiality was being so unfairly breached.³

Professor Umesh Laloo, a leading AIDS researcher at the Nelson Mandela Medical School at the University of Natal, was the regional Natal chairman of NAMDA in the mid-1980s. He remembers one of his early patients in the mid-1980s, who was an immigrant from a neighbouring country, dying of AIDS, shortly followed by the death of the patient's wife and then both his children. It struck him how AIDS had the destructive potential to kill whole families.⁴

As Chapter Three demonstrates, anti-apartheid doctors with links to NAMDA would only seriously begin to address AIDS in an activist sense, as an organisation in 1990. In the 1980s they were only seeing a few patients with AIDS and reading academic articles on the epidemic. Indeed, the issue did not really feature on the organisation's agenda for most of the decade and only started to feature as an issue occasionally discussed at meetings in the late 1980s.⁵ This was in part because the extent to which the epidemic would develop was unclear to NAMDA's membership until the late 1980s. Moreover, there were more immediate concerns which directly affected their anti-apartheid membership: most notably, the waves of arrest, torture and murder caused by the States of Emergency which were filling the hospitals serving Africans and even affected their own members.⁶ It is also important to remember that public hospitals were still segregated in the 1980s and that the political and socio-economic situation in the country, especially the grinding poverty caused amongst Africans, meant that ill-health at

³ Interview with Dr Janet Giddy, 15th September 2003, McCord's Hospital, Durban.

⁴ Discussion with Professor Umesh Laloo, 18th December 2003, Durban.

⁵ Interview with Professor Jerry Coovadia, 3rd September 2003, University of Natal's Nelson R Mandela Medical School.

⁶ As Baldwin Ragaven *et al* have shown NAMDA members were imprisoned, killed and tortured for their anti-apartheid activism: Laurel Baldwin-Ragaven, Jeanelle de Gruchy and Leslie London, *An ambulance of the wrong colour: Health professionals, human rights and ethics in South Africa* (Cape Town: University of Cape Town Press, 1999), pp.197-204.

the time was seen by such doctors to be a result of the apartheid system. This view of patterns of ill-health as caused by apartheid is one which held sway in the political economy school of South African medical history.⁷

Similarly, Sidney and Emily Kark, who had briefly worked at Natal University's Medical School, had promoted the notion of social medicine, that is community-based medicine embedded within an understanding of the socio-economic causes of health.⁸ The popularity of these kinds of readings of public health by anti-apartheid doctors is that malnutrition and preventable childhood illnesses common amongst African children were seen by paediatrician and NAMDA founder member, Professor Jerry Coovadia, as caused by the impoverishment and discrimination against black people caused by the system of apartheid.⁹ By the end of the 1980s AIDS would be given more priority as an issue, but for much of the decade anti-apartheid doctors were largely focussed on fighting human rights violations in medicine more generally. Chapter Four argues that in the 1990s the ANC could not be seen by its membership to focus on AIDS at the expense of focussing on the democratic transformation and "bread and butter issues". Similarly, most of NAMDA's membership perceived of the organisation's primary struggle as fighting for the end of apartheid in medicine, and, more generally, in South Africa. The devastating impact the AIDS epidemic would have was not yet apparent to most of NAMDA membership in the 1980s and it took a struggle by exiled anti-apartheid doctors with links to NAMDA to push AIDS higher on the organisation's agenda.

However, although NAMDA's central focus on human rights in medicine and public health in the 1980s may have been at the expense of focussing on AIDS as an issue, its focus on human rights paved the way for a more specific focus by doctors concerned with issues of social justice on human rights in AIDS policy in the transition and post-apartheid eras. More importantly, as argued in the Introduction, it demonstrated that not all doctors were mere tools in the oppressive aspects of apartheid medicine and public

⁷ The most famous example of the political economy approach to South African medical history is Randall Packard's work on how the mining industry and the migrant labour used to sustain it profoundly shaped the impact of the epidemic in twentieth century South Africa. Randall Packard, *White Plague, Black Labour: Tuberculosis and the Political Economy of South Africa* (London and Berkeley: University of California Press, 1989).

⁸ This approach was described to me in my interview with Mervyn Susser, who knew the Karks well. Interview with Mervyn Susser, 7th August 2003, McCord's Hospital Durban.

⁹ Interview with Professor Jerry Coovadia, 3rd September 2003, University of Natal, Nelson R Mandela Medical School.

health, but that some used their agency to resist violations of their patient's human rights and sometimes paid a heavy price for their resistance. This in turn undermines easy Foucaudian binaries of doctor/patient, oppressor/victim.

NAMDA's Formation: The Steve Biko Scandal

NAMDA was founded in 1982, the same year as the founding of the UDF, partially in response to the scandal around the role of doctors in the death in detention of Steve Biko an anti-apartheid leader of the Black Consciousness movement in the Eastern Cape. Anti-apartheid doctors viewed the Medical Association of South Africa (MASA) and the South African Medical and Dental Association (SAMDC) as having covered up the violation of medical ethics (the malpractice) by doctors who cared for Biko in colluding with Security Police in his maltreatment and torture.¹⁰ Moreover, NAMDA was concerned with human rights abuses in general in apartheid era medicine, such as torture and mistreatment of political protestors prisoners, segregation of medical facilities and provision of inferior facilities for black people and the socio-economic effects of apartheid, which the organisation saw as determining patterns of disease.¹¹

In a passionate address to the 1985 NAMDA conference, Coovadia argued that the NAMDA "grew from the womb of apartheid and in vigorous opposition to it".¹² Significantly, in terms of how NAMDA would understand the growing AIDS epidemic, the organisation viewed health issues in South Africa as inseparable from the apartheid system which denied people their rights, especially their right to access quality health services: as Coovadia went on to argue, in the case of NAMDA

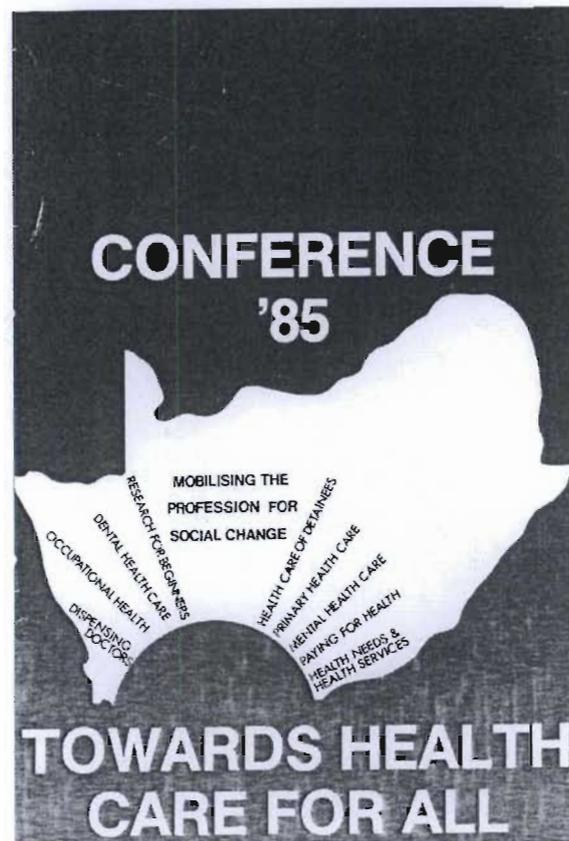
We have not been fooled by those who would have us view health in isolation from the other institutions of this racist society. We reject the argument which seeks to draw a curtain over the erosions into personal and public health by social injustice".¹³

¹⁰ South African History Archive (SAHA), University of Witwatersrand, National Medical and Dental Association (NAMDA), Manpower, Minutes of National Council Meetings, AGMs, Interns and Questionnaires/Publications Box, AGM Meeting Minutes 3.2.Vaal. File, "Keynote Address: The Struggle for Health and Democracy in South Africa. Address to the first AGM of NAMDA held in Durban on the 10th and 11th of December 1983", Dr E Jassat.

¹¹ Balwin-Ragaven *et al.*, *An Ambulance of the Wrong Colour*.

¹² SAHA, NAMDA, Conference Proceedings & Publications Box 85-90, *Proceedings of the NAMDA 1985 Conference: Towards Health Care for All*, "Overcoming Obstacles to Health in South Africa", Jerry Coovadia, p. 2.

¹³ Coovadia, *Ibid.*, p.2.



(The front cover of the proceedings of NAMDA's 1985 conference reveals that AIDS was far from the top of the organisation's agenda in the mid-1980s)

NAMDA's main focus was on human rights and health and the impact of apartheid on the provision of health services. Unlike GASA, it was deeply political and politicised from its inception and clearly had strong links with both the banned and exiled African National Congress (ANC) and the United Democratic Front (UDF). This is demonstrated by the fact that like the UDF, NAMDA it opposed State President PW Botha's constitutional reforms with their creation of a Tricameral parliament.¹⁴ Moreover, as shall be shown, NAMDA and its international support group, the Committee for Health in South Africa (CHISA), met with the ANC in exile, and NAMDA met the ANC's leader, Nelson Mandela, in jail in 1990.

Although NAMDA members were seeing AIDS patients, it did not feature early on its agenda. NAMDA had more immediate priorities. For instance, Janet Giddy remembers teaching Basic First Aid to anti-apartheid youths in townships around Durban so that they

¹⁴ SAHA, NAMDA, Manpower, Minutes of National Council Meetings, AGMs, Interns and Questionnaires/Publications Box, AGM Meeting Minutes 3.2.Vaal. File, Papers & Policy Decisions. Proceedings of the First AGM and Conference held at the University of Natal, Durban. December 1983. (Durban: NAMDA, 1983), "Implications of the Constitutional Proposals for the Health of the People of South Africa", L Platsky, p.1 For more on the origins of the UDF, see also, Jeremy Seekings, *The UDF-A History of the United Democratic Front in South Africa*, (Cape Town: David Philip, 1998).

could tend to protestors wounded by police.¹⁵ This was part of a nation-wide network of NAMDA doctors, referred to as the Emergency Services Group (ESG), who provided medical assistance to anti-apartheid activists who had been detained or injured during protests. At the University of Natal's Medical School (one of the few in the country which catered for black students) there was tear-gassing and assault of protesting students and staff and some anti-apartheid staff and students were detained for political activities. Academic and political freedom was never guaranteed during the States of Emergency, as illustrated by the fact that in 1987 the Dean of Medicine banned NAMDA activists from addressing staff and students; the same Dean also lamented the fact that an anti-apartheid academic boycott was in place, which effectively isolated the University of Natal like all other South African Universities at the time.¹⁶

Exiles Push for AIDS to be on NAMDA's Agenda

As I have already shown in my Honours thesis, AIDS researchers writing in the *South African Medical Journal* conceived of two crudely racialised and sexuality-determined AIDS epidemics: one affecting white gay men following what they referred to as "Western" lines, and another affecting "black heterosexuals" following the "African model".¹⁷ This crude apartheid view of AIDS as a racially and sexuality-specific epidemic was mirrored in the South African media where, as Gevisser has argued, the representation of AIDS as the "Gay Plague" changed in the mid-1980s to it being represented as "The Black Death".¹⁸ Similarly, it was rumoured in anti-apartheid medical circles that Koornhof, the Minister of Bantu Affairs, had said that "This is a black disease and the more it reduces the black population the better".¹⁹ As we shall see, this "Black Death" representation of AIDS would be resisted by anti-apartheid doctors just as the depiction of AIDS as a "Gay

¹⁵ Interview with Dr Janet Giddy, 15th September 2003, McCord's Hospital, Durban.

¹⁶ SAHA, NAMDA, NEC Minutes and Detainee Medical Reports Box 86-91, NEC Minutes File, "Letter to SAMJ Editor: Re: Prof Wasserman's Letter" dated 27th March 1988.

¹⁷ Schoub, B. D., Smith, A. N., Lyons, S. F., Johnson, S., Martin, D. J., McGilvray, G., Padayachee, G. N., Naidoo, S., Fischer, E. L. and Hurwitz, H. S., "Epidemiological considerations for the present status and future growth of the AIDS Epidemic in South Africa", *South African Medical Journal*, 74, (1985). For a discussion of the discursive effects of this crude categorisation see my short honours thesis: Mbali 'A long illness'. Moreover, it is worth noting that this crude early model discounted the fact of black homosexuals becoming infected, which clearly happened, as illustrated by Nkoli's death from AIDS in the late 1990s.

¹⁸ Referring to AIDS as "The Black Death" invoked the plague, which swept Europe in 1348 and decimated its population. In a racist sense it also implied that there was something essentially "black" about AIDS. Mark Gevisser, "A different fight for freedom", in Gevisser, M. and Cameron, E. (eds.), *Defiant Desire: Gay and lesbian lives in South Africa* (Johannesburg: Raven Press, 1994), p. 59.

¹⁹ Interview with Mervyn Susser, 7th August 2003, McCord's Hospital, Durban.

Plague” had been resisted (albeit in an accommodationist and rather muted manner) by GASA in the early 1980s.

In a more sophisticated and nuanced sense, Mervyn Susser and Zena Stein, two distinguished South African anti-apartheid public health experts in exile with strong links to NAMDA, observed the ‘heterosexual’ epidemics in countries such as Uganda (where it was referred to as the “Slim disease”) and began to worry that AIDS could follow a similar trajectory in South Africa. Shula Marks, a South African based in London, who published eloquent anti-apartheid accounts of health and the history of medicine and health in South Africa in those years, came to a similar conclusion.²⁰

A careful reading of the NAMDA archives, as well as oral accounts, reveals that Susser and Stein played a key role in catalysing the rise of AIDS activism in NAMDA. They had led long and eventful lives of struggle against apartheid health and for social medicine before they became interested in the issue of AIDS.²¹ Both were born into middle class Jewish families which moved in similar circles in Johannesburg. Susser attended primary and high school in Durban and went to University of the Witwatersrand in 1939. As with most young white South African men of his generation, his studies were then interrupted by the Second World War, where he served in the air-force. His experiences of war made him want to enter into a socially engaged discipline where he could make a difference to humanity, and so he chose to study medicine in 1945, where he met Stein for properly for the first time and where they married.

Both Stein and Susser were interested in the idea of socially engaged medicine and read about the work of Sidney and Emily Kark who had built a successful model of social medicine in Polela in rural Natal. In their second year of studying medicine, they sought out the Karks in Polela and were impressed by the Karks’s model, which saw health comprehensively as a part of the total social context of the community. Furthermore, the Gluckman Commission formed in 1943, in the dying days of the United Party government had given Stein and Susser hope that a National Health Service (similar to that later established in Great Britain) would be established. After the profound disappointment of the election of the Nationalist Party government to power in 1948, with its policy of

²⁰ Conversation with Shula Marks, 2nd August 2003, Durban.

²¹ This life history was obtained from Interview with Mervyn Susser, 7th August 2003, McCord’s Hospital, Durban.

apartheid, they remained in close contact with the Karks while completing their medical degrees. Stein and Susser were both members of the Communist Party and moved in similar circles as party leaders Ruth First and Joe Slovo. After graduation, Susser worked as a doctor from 1952-1955 at Alexandra Clinic in Johannesburg. In 1955, he was asked by the ANC to join its platform at a mass meeting. As a result of his political activities he was forced to resign from his medical post at Alexandra Clinic and he and Stein decided to go into exile, first in Britain and later in the United States.

By the 1980s, they were working at the Columbia School of Public Health in New York. They had participated in the Anti-Apartheid Movement in London from the mid-1950s to mid 1960s, but the period of oppression after Sharpeville had left them feeling “demoralised” and after their move to the US, at roughly the same time, they found there were limited opportunities for anti-apartheid activism in the US in the 1970s.²² The emergence of NAMDA in the early 1980s excited them as it merged their interests in the anti-apartheid movement and social medicine. Susser established the Committee for Health in South Africa (CHISA) in 1986, which was a foreign support organisation for NAMDA and also a US anti-apartheid health pressure group. CHISA provided what support it could to NAMDA and was regularly in contact with the ANC representative at the United Nations.

Meanwhile, in the early 1980s, Stein Co-Directed Columbia’s Centre for HIV/AIDS, established with a National Institutes of Health (NIH) grant at Columbia. Stein became especially interested in women and AIDS and how gender inequality shaped the epidemic, as she began to study HIV transmission and risk behaviours in prostitutes in New York. Crucially, however, she and Susser both realised from early on that the disease could be heterosexually transmitted, a point which was made apparent by hearing about the devastating impact of AIDS in other parts of sub-Saharan Africa.

At the 1985 International AIDS Conference, they heard from the chair of the South African Government’s AIDS Advisory Committee (which will be discussed further in Chapter Three) that of 300 000 miners tested for HIV, three percent were HIV positive. Many miners came from neighbouring states, which meant that the figure was higher than for the general South African population, where it was still under one percent, but a chilling fact

²² Interview with Mervyn Susser, 7th August 2003, McCord’s Hospital, Durban.

became clear to them as epidemiologists at the top of their field: AIDS was spreading from neighbouring states into South Africa and the country realistically faced a Ugandan scenario of a massive and growing heterosexual AIDS epidemic. In the meantime, Slim Abdool Karim and Quarraisha Abdool Karim were both awarded scholarships to study Public Health at Columbia University in New York through a scholarship brokered by Coovadia of NAMDA and Susser of CHISA.

As has been shown, AIDS had already morphed at the level of representation into the “Black Death” in the popular media and apartheid government circles by this time in South Africa. In 1987, the government launched a racist and culturally inappropriate “coffin campaign”. Salim Abdool Karim, then a Deputy Secretary General of NAMDA, remembers this campaign as depicting a coffin being lowered into a grave and the campaign as referring to AIDS as caused by the ‘African custom’ of men having the right to sleep with their late brothers’ widows, a practice which by then was almost non-existent in South Africa.²³ Furthermore, only a year earlier, in 1986, policy proposals had been seriously mooted by the government for enforced deportation of all foreign HIV positive miners, a move which was resisted by both the National Union of Mine Workers (NUM) and the Chamber of Mines.²⁴

Many Africans already mistrusted government family planning services²⁵ and the government and media largely depicted AIDS in a discriminatory way, which affected the policy proposals the government put forward. This demonstrated the need for a new mission for Stein and Susser, and at a later stage, for South African anti-apartheid activists who had studied public health under them, such as Salim and Quarraisha Abdool Karim: to convince the anti-apartheid movement of the serious threat posed by the AIDS epidemic to the black heterosexual population. This was necessary due to the illegitimacy of the apartheid government and its discriminatory and woefully inadequate response to the AIDS epidemic, which called for urgent activism by the movement around the problem.

²³ Interview with Professor Slim Karim, 15th September 2003, University of Natal, Durban.

²⁴ It is interesting to note that this was also being picked up by GASA in its media scrap books. SAHA, Gay Association of South Africa (GASA), Media Scrap Books Gay Association of South Africa /Gay Association of South Africa 6010 Box, GASA media file, 8, 5, “AIDS Reaction”. *The Star*, Tuesday August 1986. SAHA, GASA, SAHA, GASA, Media Scrap Books Box, GASA media file, 8, 5, “AIDS: Govt, chamber of mines on collision course”, *Sunday Times* August 31 1986, David Jackson and Lester Venter.

²⁵ Mbali, *A long illness*.

Such a campaign was necessary as NAMDA had many other priorities in the decade of the 1980s as a whole. The latter part of the decade was no exception, as is demonstrated by the fact that in Natal AIDS was not part of the organisation's day-to-day branch discussions.²⁶ The Durban NAMDA Branch was more preoccupied with important issues such as providing Detainee services and health services to communities and hosting public meetings.²⁷

Evidence shows that NAMDA activism around AIDS first emerged when it arranged to send a delegation to the 1989 Montreal AIDS Conference. Significantly, the anti-apartheid gay rights Gay and Lesbian Organisation of the Witwatersrand (GLOW) activist Peter Busse and a representative from Organisation for Lesbian and Gay Activists (OLGA) were invited to be part of the delegation put together by Max Price (of NAMDA Southern Transvaal branch) alongside delegates from the trade unions and NAMDA.²⁸ This is the only concrete archival evidence of cooperation between the two groupings in 1989, but it clearly demonstrates that cooperation between the two groupings was enabled, historically, by the emergence of a self-consciously anti-apartheid politicised model of gay rights activism, as I argued in Chapter One.

However, it clearly emerges from the archival and oral evidence available that foreign supporters of NAMDA played a key role early on in warning anti-apartheid doctors that they had to accord AIDS top priority status and fight against AIDS related discrimination. In the same year that the delegation was put together to attend the Montreal AIDS Conference, Mencer D Edwards of the US Minority AIDS Council (whose visit was probably facilitated by CHISA) gave a rousing address on the issue of AIDS at the 1989 National NAMDA Conference. He opened his speech with a protest song about the manner of Biko's death and argued that the Centres for Disease Control (CDC) in Atlanta had covered up the extent of infection amongst US blacks and that

²⁶ SAHA, NAMDA, NEC Minutes and Detainee Medical Reports Box 86-91, NEC Minutes File, "NAMDA Branch Activity Table: 1988".

²⁷ SAHA, NAMDA, Regional Reports and Correspondence '90 and Human Rights Commission Reports 87-91 Box, Regional Reports File, "Durban Regional Branch Report to AGM 5th December 1987". This was also confirmed to me in a conversation with Professor Umesh Laloo in Durban on 18th December 2003. Laloo was the Durban Branch Chair from 1987.

²⁸ SAHA, NAMDA, NEC Minutes and Detainee Medical Reports Box 86-91, NEC Minutes File, "Letter to NAMDA NEC from Max Price", dated 1st May 1989. SAHA, NAMDA, NEC Minutes File, NEC Minutes and Detainee Medical Reports Box 86-91, "Letter to Steven Smith of CIDA: Re: South African nominations for funding by CIDA to Montreal AIDS Conference". Busse of OLGA would go on to head up the National Association of People living with HIV/AIDS in the mid- 1990s. Interview with Promise Mthembu, 19th August 2003, Durban.

AIDS re-defined the civil rights agenda of the 21st century and that political leaders and activists needed to change their own personal conduct to prevent AIDS.²⁹

The AIDS Working Group of the National Progressive Primary Health Care Network (PPHC)

In the late 1980s, NAMDA also became increasingly interested in promoting the idea of Primary Health Care. In terms of this, the National Progressive Primary Health Care Network (PPHC) was formed in 1987 as an off-shoot of NAMDA by organisations who shared a common interest in Primary Health Care. The idea of Primary Health Care had emerged internationally in 1978 at the World Health Organisation's Alma Atta Conference, where the goals of "Health for All by the Year 2000", and a definition of health as "a state of complete physical, mental and social well-being", were affirmed.³⁰ Primary Health Care drew on notions of community-based health care: it placed a focus on community-based preventative health education as opposed to the most expensive curative medical solutions. It emphasised participation of 'communities' in their own health, along with issues of equity of access to health services and the effect of socio-economic and political factors on public health. It is easy to see why Primary Health Care was an attractive concept used to frame possible alternatives to apartheid medicine and public health: giving patients a voice instead of disempowering them, dealing with apartheid itself (which was seen as the root cause of disease) to tackle ill-health and ensuring more equitable access to health services.

Unlike NAMDA, PPHC did not only include doctors and dentists, it also included nurses, social workers, community health workers, members of non-governmental organisations dealing with health issues. Also, unlike NAMDA, which was a discreet organisation, PPHC was a network of health organisations that supported PHC. With

²⁹ SAHA, NAMDA, NEC Minutes Box, 1986-1991, HIV/AIDS Issue File, "Community Development and Personal Empowerment: Lessons from the Responses of African American People to the HIV Epidemic: Keynote Address by Mencer D Edwards, RN, MSN, MPH, executive director National Minority AIDS Council, Washington DC to the 6th Annual Conference of the National Medical and Dental Association of South Africa. Delivered May 12, 1989, Sandton Holiday Inn, Johannesburg, South Africa", Mencer D Edwards.

³⁰ David Werner, David Sanders, Jason Weston, Steve Babb and Bill Rodriguez. *Questioning the Solution: The Politics of Primary Health Care and Child Survival with an in-depth critique of Oral Rehydration Therapy*. (Palo Alto, California: Health Wrights, 1997), pp.18-21.

funding from the Kaiser Family Foundation the PPHC held its first national conference in 1987.³¹

In 1988 NAMDA Southern Transvaal Branch members formed a PPHC group to discuss issues of importance to NAMDA and “a doctor audience”: one of their first meetings April on "AIDS and public policy: A NAMDA response to the politics and prevention of AIDS".³² Minutes of a NAMDA National Executive Committee (NEC) meeting held in April 1989 reveal that three members of the NAMDA Southern Transvaal Branch formed a special interest group on the issue of AIDS, which was affiliated to the newly formed PPHC. The point-form minutes of that meeting reveal that they argued that AIDS "Needs to be put in the context of apartheid in health" they were also to give an interim policy on AIDS to be given to the NAMDA NEC within one week of the meeting.³³ The loose notes taken of the meeting also reveal a concern about "Government prejudices" and questions over what government's role should be in AIDS prevention and argued that "Government statistics are not exposed".³⁴

Concluding Remarks

In the 1980s anti-apartheid doctors affiliated to NAMDA and PPHC were largely preoccupied with ending apartheid in medicine and public health and society more generally. Indeed, their major focus was highlighting and resisting human rights abuses in apartheid era public health and medicine. While they were seeing AIDS patients and academically interested in the disease, they were not, on the whole, aware of the full extent of the tragedy that would be caused by the future growth and impact of the epidemic. Exiled anti-apartheid doctors were aware of this likelihood of the horrific expansion and effects of the epidemic and tried to increase awareness among anti-apartheid doctors. Similarly, small special AIDS interest groups affiliated to NAMDA

³¹SAHA, NAMDA, NPPHCN Discussion Papers/Job Descriptions/Adverts/Reports Box, NPPHCN File. "The Progressive Primary Health Care Network (PPHC) Report to the NAMDA STVL AGM, 23rd January 1988".

³² SAHA, NAMDA, NPPHCN Funding/Finances Box, NPPHCN Correspondence File, "Circular Letter: To all Namda members in the Southern Transvaal", dated 24th February 1988, Eric Buch.

³³SAHA, NAMDA, NEC Minutes 86-91 & Detainee Medical Reports Box, NEC Minutes File, "Minutes of Combined National Council and Conference Committee Meeting Held on 14 May 1989 at Sandton Holiday Inn-Johannesburg", p.1.

³⁴ *Ibid.*, p.1.

and PPHC began holding preliminary discussions on AIDS towards the end of the decade. However, as shall be demonstrated, the wider political changes that took place in the 1990s to enabled the correct political climate for doctor activists to begin to form a more rigorous political response to the epidemic.

As Chapter Three will show, in the 1990s, there was a political sea-change and the release of Mandela from jail and the negotiations leading to the transfer of power shook up AIDS policy-making processes and created a freer political environment. 1990 marked the year when AIDS would be placed firmly on the organisation's agenda and a year when CHISA hosted the Maputo Conference which placed anti-discrimination on the liberation movement's AIDS policy agenda. In the new decade there would also be more links between the anti-apartheid gay rights movement and NAMDA and PPHC, which were facilitated by the rise of anti-apartheid gay rights activism, as discussed in Chapter One.

As we shall see in Chapter Three, NAMDA would voluntarily disband before the 1994 elections, as with the ANC's rise to power, as many activists no longer saw the need for the organisation to exist because the "people's government" was in power post-1994, which included anti-apartheid doctors such as Nkosasana Zuma. In a sense then, NAMDA only began to show an interest in AIDS and lobbying around AIDS policy in the twilight days of its existence. Also, as Chapter Three will demonstrate, although there was success in pushing for the framing of AIDS policy in terms of rights *on paper*, social attitudes were slow to catch up, and the legacy of the early stigmatisations of AIDS as a gay disease or as a black plague meant that there were few patient activists vocal about their HIV status and discrimination until well into the epidemic.

Still, the historical record tells us that there were doctors in the 1980s who exercised their agency and refused to be mere cogs in the machine of apartheid power due to their concern for protecting the rights of their patients, and that these doctors began to become concerned about AIDS in the late 1980s. In the early 1990s, NAMDA and PPHC worked more closely with the ANC to the point where the organisations worked more closely on AIDS. Indeed, many anti-apartheid doctors saw the solution to improving AIDS policy as pushing for the ANC's rise to power, which would in turn obviate the need for a critical organisational doctor voice. However, relations between former

comrades cooled to freezing point over government promotion of AIDS denialism. As the Chapter Three will also discuss, they re-grouped around the South African Medical Association (SAMA) in the late 1990s, which was used to express their dissatisfaction with post-apartheid government AIDS policy. Furthermore, by the early 2000s they were also allied against the post-apartheid government's AIDS treatment policy with a patient activist organisation, the TAC, that was led by a black openly HIV positive gay rights activist.

Chapter 3

DOCTOR AIDS ACTIVISM AND THE LIBERATION MOVEMENT IN THE TRANSITION ERA

(1990-1994)

Introduction

In the era of the negotiations to end apartheid, AIDS activism by anti-apartheid doctors became more vocal and had more success in getting policy to be rights-based, at least on paper: for instance in the acceptance of the principle of the patient's right to confidential and voluntary testing. However, these successes in pushing for changes to policy on paper were heavily qualified because independent anti-apartheid doctor organizations such as the National Medical and Dental Association (NAMDA) and the Progressive Primary Health Care Network (PPHC) disbanded towards the end of the transition era from 1990-1994,¹ just as the AIDS epidemic began to seriously spread amongst the majority of the population and immediately prior to the period when the new ANC government would face major AIDS policy-making challenges. The collapse of NAMDA and PPHC limited critical input by organized progressive doctors in AIDS policy formulation and implementation until well into the post-apartheid era. This collapse was because many NAMDA members saw the organization as a front organization for the ANC and when it came to power no longer saw the need for a separate and independent doctor organization as "their government" was in power.

The vital relevance of this history to later debates is illustrated by the fact that whereas the ANC came to see AIDS as a serious problem requiring urgent input in the transition period, by the end of the decade in 1999, ANC government leaders would deny the viral causation and seriousness of the epidemic. Unfortunately, by the time this view

¹ I am drawing on Adrian Guelke's use of the term "Transition" to historically characterise the period between 1990 and 1994 in South Africa. Guelke uses the term to refer to South Africa's passage from white minority to black majority rule. Authors such as Allister Sparks and Guelke have written extensively on the significance of South Africa's negotiated transition to democracy. Allister Sparks, *Tomorrow is another country: The Inside Story of South Africa's Negotiated Revolution* (Sandton: Struik Books, 1994). Adrian Guelke, *South Africa in Transition: Misunderstood Miracle* (London and New York: I B Tauris, 1999).

came to predominate in government circles (with paralyzing effects for AIDS policy), progressive doctor organizations had disbanded and newly merged doctor organizations, such as the South African Medical Association (SAMA) took some time to formally respond and initially did so largely in a non-militant fashion.

The heavily qualified success of doctor AIDS activism to get the human rights of people living with HIV to be respected (at least in principle) in the transition era took place against the context of years of enormous political change. As has been demonstrated extensively in the literature on South Africa's political transition, the years from 1990-1994 were politically significant for the country as it was a period in which apartheid was brought to an end through the political negotiations between the African National Congress (ANC) representing those in favor of majority rule in South Africa and the Nationalist party government representing the white minority. By the end of the transition period a new democratic interim constitution had been adopted, which enabled an end to apartheid and white minority rule through the first democratic elections in April 1994. The return of the ANC from exile and their rise to power powerfully shaped the history of doctor AIDS activism, as it was perceived by many anti-apartheid organizations such as NAMDA as a cue to disband.

During this transition era, AIDS became, in a limited sense, increasingly recognized as a serious threat to the country's future well-being by the progressive health organizations with links to the ANC such as NAMDA and PPHC, then in the twilight of their existence. The rising level of concern about the threat posed by AIDS in the liberation movement was evident at the 1990 Maputo Conference, which produced a statement on AIDS strongly condemning AIDS-related discrimination. Moreover, it led to the creation of a new AIDS policy negotiating forum the National AIDS Convention of South Africa (NACOSA) in 1993, which mirrored the national constitutional negotiations known as the Convention for a Democratic South Africa (CODESA), in that it brought together a broad spectrum of stakeholders interested in the formulation of post-apartheid AIDS policy including government, anti-apartheid health organizations, and the ANC.

The anti-apartheid health organizations, such as NAMDA and PPHC, worked even more closely with the ANC than before, due to the return of exiles and the freer

political climate, a trend that may have precipitated their demise by suggesting they were obsolete. The ANC perceived of the late apartheid government suffering from a ‘crisis of legitimacy’ and was apt to represent AIDS as a ‘government responsibility’. On the other hand, in the spirit of the bigger CODESA negotiations, the ANC also began to represent AIDS as ‘beyond politics’ and an issue, which could not wait for the first democratic elections.

The National AIDS Plan that emerged from NACOSA in 1994 was widely recognized at the time as comprehensive and legitimate due to the consultative process through which it was formulated. The inclusion of civil society in the transition AIDS policy-making process can be contrasted with AIDS policy-making processes during the Presidency of Thabo Mbeki in the late 1990s and early 2000s, where critical civil society organizations such as TAC were actively excluded from the policy-making process. The shift was also related to the ANC in government’s shift in thinking on AIDS towards an espousal of AIDS denialism, which through its denial of the viral cause and efficacy of anti-HIV drugs, in effect denied HIV positive people the right to HIV treatment.²

The Maputo and Lusaka Conferences: Anti-apartheid Doctors get AIDS onto the Political Agenda of the Liberation Movement

The turn of the new decade in 1990 brought a number of significant historical events on the national political stage such as the un-banning of the ANC and the release of its leader Nelson Mandela from jail and the entering of the ANC and the apartheid government into political negotiations. 1990 was also a significant year for AIDS activism in South Africa, as it was a year when AIDS would be placed firmly on the liberation movement’s agenda by anti-apartheid doctors linked to NAMDA and PPHC and a year when CHISA co-hosted the Maputo Conference with the ANC, a conference where anti-discrimination was firmly established as a principle in AIDS policy.

² I have written elsewhere on the exact relationship between government AIDS denialism and HIV treatment access. Mandisa Mbali, “HIV/AIDS policy-making in post-apartheid South Africa”, in Daniel, J., Habib, A. and Southall, R., *State of the Nation: South Africa 2003-2004* (Cape Town: Human Sciences Research Council Press).

The significant broader political changes in South Africa in 1990, enabled NAMDA, the UDF affiliated anti-apartheid doctor organisation, and its offspring the PPHC to have closer links with the exiled ANC on all health issues, including AIDS. Illustrative of the political shifts which took place then and their influence on anti-apartheid health organising, it was a year in which a NAMDA delegation would meet with Nelson Mandela in jail to discuss general progress with “the struggle” in late January (before FW De Klerk’s announcement of his release on February 2nd) only for him to be released less than a fortnight later on February 11th.³

As Chapter Two has discussed, exiled anti-apartheid doctors such as Mervyn Susser and Zena Stein were gravely concerned that the AIDS epidemic would explode amongst the black ‘heterosexual’ population and pushed hard for the disease to be placed on the liberation movement’s agenda. This was necessary as many anti-apartheid health workers and the liberation movement in general were not fully alert to the urgent threat posed by AIDS. For instance, anti-apartheid paediatrician and founder member of NAMDA Jerry Coovadia had heard about the effect AIDS was having in the late 1980s amongst white gay men in Johannesburg and found the disease “academically interesting” but thought it was largely irrelevant as he “had enough work to do with poor black children”.⁴ For Coovadia for much of the 1980s AIDS had been dominated by white patients and white researchers, and was a localized problem for white people.⁵ Doctors like Coovadia suspected that it was yet another colonial-style example of whites unfairly blaming Africa for a problem initiated in the West: in the 1990s, many NAMDA members could not predict the sheer scale of the devastation it would cause.⁶

The Maputo Conference on Health in Southern Africa was held in April 1990, a mere two months after this seismic shift in South African political history. The conference was jointly organised by the ANC and the Committee for Health in Southern Africa

³ South African History Archive, University of Witwatersrand (SAHA), National Medical and Dental Association (NAMDA), Manpower, Minutes of National Council Meetings, AGMs, Interns and Questionnaires/Publications Box, AGM Meeting Minutes 3.2 Vaal File, “Minutes of Meeting of Southern Transvaal Branch Meeting Held at University of the Witwatersrand Medical School Held on 27th January 1990, pp.7-8.

⁴ Interview with Professor Jerry Coovadia, 3rd September 2003, Nelson R Mandela School of Medicine, University of Natal.

⁵ *Ibid.*

⁶ *Ibid.*

(CHISA).⁷ It was also significant in that it organizationally brought together for the first time exiled anti-apartheid health activists in CHISA and NAMDA activists who had been working in the country.⁸ In these exciting times of political change, the conference set out in a bold fashion to enable the liberation movement to formulate post-apartheid health policy in the region. The conference was broadly representative of South African anti-apartheid organisations both (internal and exiled) and regional and international anti-apartheid groupings: the internal South African delegation included NAMDA, PPHC, the United Democratic Front (UDF), Critical Health⁹ and the national union confederation Congress of South African Trade Unions (COSATU). The conference had fifty four thousand health-worker delegates from Southern Africa, to discuss post-apartheid health policy from the ANC in exile, Mozambique and the Frontier states. Maputo formulated specific health and welfare policy proposals for developing a non-racial, equitable, cost-effective, democratic national health and welfare system in transitional and post-apartheid Southern Africa.¹⁰

The issue of AIDS made it into the overall conference declaration, largely at the urging of American CHISA delegates such as Stein and Susser which featured a specific paragraph on the epidemic and which argued for: urgent action on the epidemic; that the state's response was flawed and that there was a need for an alternative progressive campaign under auspices of a progressive AIDS Task Force.¹¹ This was in all likelihood the direct outflow of a session at the Maputo Conference focused on AIDS, which included submissions by the National Union of Mineworkers (NUM), the ANC Department of Health and Zena Stein of CHISA. The ANC submission, which did not focus so much on issues of human rights and discrimination, centered more on the risks faced by its exiled comrades in neighboring states on the need for HIV prevention in South Africa and the “ANC community” in exile proposing standard HIV prevention methods, such as use of condoms and treatment of sexually transmitted diseases

⁷ See Chapter Two of this thesis, pp.42-44.

⁸ Interview with Mervyn Susser, 7th August 2003, McCord's Hospital, Durban.

⁹ Critical Health was an anti-apartheid health journal.

¹⁰ SAHA, NAMDA, NEC Minutes Box, HIV/AIDS File, “Maputo Declaration on Health in South Africa”, p.1.

¹¹ *Ibid.*, p.3. Interview with Jerry Coovadia, 3rd September 2003, Nelson R Mandela School of Medicine, University of Natal.

(STDs).¹²

The NUM's "Statement on AIDS" formed part of its general secretary Cyril Ramaphosa's letter written in January 1990, a year when 1% of black adults were infected, in response to the Chamber of Mines' proposed policy on AIDS.¹³ The NUM's statement to the conference, which drew on World Health Organization, International Labor Organization and the Panos Institute's¹⁴ work on AIDS and human rights was direct on the need for AIDS policy to be based on non-discrimination: it developed eight principles on AIDS policy on the mines, the first of which is worth quoting from:

1. No discrimination on the basis of HIV infection

An AIDS prevention program should be directed towards the protection of the human rights of HIV infected persons. The Chamber's document of 4 August 1989 refers to '...the need to treat those infected with HIV infection or AIDS with due compassion and with full regard for the rights of the individual'. We believe this principle should be implemented.¹⁵

The NUM declaration also declared that there should be safeguards against workplace discrimination against people living with HIV, that HIV testing should be entirely voluntary and non-coercive and that screening for epidemiological purposes "should guarantee absolute anonymity and confidentiality".¹⁶

In this vein, and obviously partially as a result of the NUM's stance on the issue, the resulting "Maputo Statement on HIV and AIDS In Southern Africa", which was recognized as representing a 'consensus statement' on the liberation movement's position on AIDS clearly included the principles of non-discrimination. However, for the purposes of this thesis's focus on doctor and patient activism, it is important to remember the role played by health workers in bringing about both the Maputo

¹² Centre for Health Policy (CHP) Resource Room, University of the Witwatersrand, ANC Health Department, Lusaka, Zambia, "Strategies for the Control of AIDS in the African National Congress", *Proceedings of the Maputo Conference on Health in Southern Africa*.

¹³ SAHA, NAMDA, Conference Proceedings and Publications 1985-1990 Box, Mervyn Susser, Keynote Address "Human Rights and Health", In *Health Priorities for the 1990s, 7th Annual National Conference, University of Natal Durban*, p.20.

¹⁴ The Panos Institute is an international NGO based in London who did early work on AIDS-related discrimination in developing countries.

¹⁵ CHP Resource Room, National Union of Mineworkers, Johannesburg, South Africa, "National Union of Mineworkers – Statement on AIDS", In *Proceedings of the Maputo Conference on Health in Southern Africa*, p.107.

¹⁶ *Ibid.*, pp.108-19.

conference itself, which was aimed at the health worker sector, and in forcing AIDS so strongly onto the conference's agenda.¹⁷

It argued that an HIV prevention campaign must be “non-stigmatizing and avoid stereotyping individuals or groups” and demanded that the South African state abolish “discriminatory, repressive and restrictive legislation such as that discriminating against gays, commercial sex workers, and foreign migrant workers”.¹⁸ The Maputo statement even went as far as to argue for “change in personal politics” by arguing that

Sexism, victim blaming and racial stereotyping decrease our ability to deal effectively with HIV infection at grassroots level. Discrimination against prostitutes, members of the gay community, injecting drug users, and other marginalized groups should be overcome. Programs to rectify these discriminatory forms of behavior should be initiated as part of the response to HIV disease.

The rights of people with HIV disease, as with any other health condition, must be firmly recognized.¹⁹

The Maputo Statement on AIDS established the principle of non-discrimination in AIDS policy in the liberation movement. Simultaneously, it laid the ground work for the establishment of the National AIDS Convention of South Africa (NACOSA) though mandating the establishment of an “AIDS Task Force” which included representatives of the “progressive movement” which would: set up the first NACOSA; distribute the Maputo Statement and get feedback on it and get support and involvement in forming a response to AIDS from progressive political and community-based leadership.²⁰ More importantly, as the long quote above shows, the statement also included a condemnation against homophobic AIDS-related discrimination, which, it is fair to suggest, may have stemmed from the nascent links on AIDS which had developed between anti-apartheid gay activists and health workers in the late 1980s and early 1990s over the issue of AIDS particularly in Cape Town (as will be shown in Chapter Four) and Johannesburg (as outlined in Chapter Two). It is also crucial to note that, as argued in Chapter Two, exiled anti-apartheid doctors such as Stein and Susser played a key role in pushing for the inclusion of AIDS in the liberation movement's health

¹⁷ This emerged from interviews with Mervyn Susser and Salim Abdool Karim who claimed that doctors drafted vast swathes of the statement. Interview with Mervyn Susser, 7th August 2003, McCord's Hospital, Durban; Interview with Salim Karim, 15th September 2003, University of Natal, Durban.

¹⁸ CHP Resource Room, “Maputo Statement on HIV and AIDS in Southern Africa”, pp.136-138.

¹⁹ “Maputo Statement on HIV”, p.138.

²⁰ “Maputo Statement on HIV”, p.140.

agenda through the overall The Maputo Conference Declaration.²¹

To focus specifically on the response of the ANC itself to AIDS, it began to seriously consider the threat posed by AIDS at an organizational level in 1990 as the ANC submission to the Maputo conference shows. Certainly, this was true in the case of its Health Desk, which was run by Cheryl Carolus, who had been on NAMDA's Emergency Services Group (ESG) providing emergency services to 'comrades' injured at protests in townships and who was widely tipped to become the Health Minister in the post-apartheid government.²²

Nkosasana Zuma, who did become the first post-apartheid Health Minister, was well-known in AIDS circles due to the fact that she had studied AIDS in the ANC camps in exile.²³ As Zuma documented, from an early stage, AIDS had affected ANC activists both in camps in exile and it also affected activists in prisons; however, this was not something which the organization wanted to publicise at the time, partly due to the fact that the government tried to discredit returning ANC exiles as "AIDS carriers" as shall be shown below.²⁴ The Western Cape PPHC AIDS Working Group also visited seven HIV infected political prisoners held in Pollsmoor Prison at the request of the ANC.²⁵ This shows that while the Maputo Conference didn't mark the beginning of the ANC's AIDS programs, it provided a catalyst for AIDS to be addressed more seriously as a political problem by the organization. Also, noting the influence of anti-apartheid doctors in exile the conference itself was organized by Mervyn Susser who chaired CHISA and its AIDS session by Zena Stein, which shows that as argued in Chapter Two, they played a key role in getting AIDS onto the ANC's agenda. The conference also cemented the PPHC's AIDS Working Group, which until that point had merely been small pockets of interested anti-apartheid doctors and health workers, but became more organized and prominent through the conference.

²¹ Interview with Jerry Coovadia, 3rd September 2003, Nelson R Mandela Medical School, University of Natal.

²² Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

²³ Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

²⁴ Interview with Mervyn Susser, 7th August 2003, McCord's Hospital, Durban.

²⁵ SAHA, NAMDA, NPPHCN Funding/Finances Box, NPPHCN Discussion Papers File, Western Cape Progressive Primary Health Care Network. "AIDS In the Western Cape: Assessment and Need. Presentation to US Congressional Delegation, 18 August 1990", p.7.

The ANC held an inter-sectoral workshop on AIDS for ANC membership in exile, which was also attended by representatives from democratic organizations in South Africa, including the PPHC AIDS Working Group.²⁶ The workshop's keynote address was given by Alfred Nzo, who was a senior member of the ANC who would become the post-apartheid Foreign Affairs Minister. Chris Hani, the popular and prominent head of the ANC-aligned South African Communist Party, also addressed the workshop. At the end of the workshop the ANC NEC issued a directive to all ANC formations to place AIDS high on its agenda and a program of action was formulated.

The Strengthening of Links Between the ANC, NAMDA and PPHC on AIDS: Relations with Government and Foreign Donors (1990-1993)

Politically, the transition enabled a new focus on AIDS activism in liberation movement circles. Activists operated in a rapidly shifting terrain, where both new opportunities and pitfalls were being created. The liberation movements were unbanned and skilled exiles such as Nkosasana Zuma and Manto Tshabalala.²⁷ The return of exiles also made it easier for the ANC to have day-to-day contact with progressive health-worker organisations such as PPHC and NAMDA. Cooperation between the ANC and NAMDA and PPHC became so close that anti-apartheid doctor activists often wore multiple hats: Tshabalala and Carolus both of the ANC worked for the PPHC and NAMDA activists such as Salim Abdool Karim in negotiations with the late apartheid government sometimes represented the ANC on AIDS and Coovadia on issues of childhood immunization.²⁸ The late apartheid government sought out such negotiations, in the context of the return of exiles and the unbanning of the ANC, as it

²⁶ SAHA, NAMDA, NPPHCN Funding/Finances Box, NPPHCN Correspondence File, S Ramburuth and N Knigge, N. "PPHC AIDS Working Group- Southern Transvaal: Circular Letter" Dated 4th October 1990.

²⁷ In the archives Manto Tshabalala Msimang, the Minister of Health in President Thabo Mbeki's cabinet at the time of writing is referred to as Manto Tshabalala.

²⁸ Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

recognised that it lacked political legitimacy in black communities to promote HIV prevention. Therefore, it met with NAMDA representatives to sound out the possibility of cooperating with the liberation movement on AIDS. Foreign donors, especially from the US, also sought out ways to fund the progressive health organisations' response to AIDS.

In the late 1980s, as has been shown in Chapter Two, small special interest groups on AIDS were formed in NAMDA, especially in the Transvaal, which crystallised in 1989 into an AIDS Working Group within PPHC, which was itself an off-shoot from NAMDA. PPHC and NAMDA helped the ANC prepare a brief on AIDS in South Africa for a congressional delegation to motivate for US foreign aid to South Africa to fight AIDS. While the relationships between these organisations were close on the issue of AIDS, as shown by the way that some activists represented both the ANC and anti-apartheid health organizations when negotiating with the government at different times, it was not entirely conflict free. For instance, there were significant differences at times about which of them should benefit from and control donor funding and also disagreements over how fast the AIDS Task Force should be set up.

A month after the Maputo Conference, on May 3rd 1990, a high-profile NAMDA delegation including Jerry Coovadia and Diliza Mji met with Bans Steyn the Deputy Director General of Department of Health and Population Development (DHPD) and Leon du Toit who was the government department's Chief Directorate of Health Care.²⁹ The government had not been invited to the Maputo conference and met with the NAMDA delegation to discuss the possibility of working together with anti-apartheid organisations on AIDS. What the ANC and NAMDA characterised as the government's 'crisis of legitimacy' on the issue of AIDS seems to have driven it to request the meeting with NAMDA to develop links with 'progressive NGOs'. The government saw the need to seek assistance from progressive organizations to launch a successful AIDS campaign and saw potential commonalities in areas such as counseling, health education, notification, screening and confidentiality and non-stigmatization. It also saw the need to expand AIDS awareness and campaigning out of medical circles.

²⁹ SAHA, NAMDA, NEC Minutes Box, 1988-1991, HIV/AIDS Issue File, "Report on Meeting Between NAMDA and the Office of the Director General of Health- 3 May 1990".

However, in 1990 negotiations between the ANC and the government were still at a tentative stage and could either lead to a peaceful transition or a violent civil war and much apartheid legislation remained on the books. In this context, where the ANC and Nationalist Party government were still bitter political foes, the government and NAMDA representatives had fundamentally different readings of the epidemic, which were revealed at the meeting. These different interpretations of the epidemic, combined with the broader political context illustrated the difficulties of collaboration and negotiations between the two and reveal the importance of representations and understandings of the epidemic in shaping activism around it.

NAMDA outlined how they saw AIDS in social and political context and mentioned the proposal formulated at the Maputo Conference to form an AIDS task force. They contrasted the proposed AIDS Task Force made up of representatives of progressive health organisations to what they saw as the state's National AIDS Advisory Group's inadequacies: that it was dominated by white males; that its members were selected for their technical expertise as opposed to social/political leadership, and the fact that the council was state aligned.³⁰ For NAMDA, the primary factor behind the failure of the state's AIDS program was the legacy of mistrust created by their racist and coercive family planning programs: they reported that "We stated that the largest single obstacle to any state campaign was mistrust and suspicion by the people, as had occurred in the Family Planning Campaigns".³¹

NAMDA agreed that the state did have a role to play in provision of resources that it viewed as belonging to the public and facilities for the care and counseling of AIDS patients. However, on the issue of apartheid and its socio-economic and political consequences as causing AIDS, the state representatives became defensive

The DHPD did not agree that political factors in South Africa exacerbate the spread of HIV. They were of the view that HIV is spread far more rapidly elsewhere in Africa where an apartheid regime does not exist. We maintained our opposition to this viewpoint, which downplayed the specific political, social and economic factors affecting the spread of HIV in SA.³²

³⁰*Ibid.*, p.1.

³¹*Ibid.*, p.1.

³²*Ibid.*, p.2.

The meeting was characterized by NAMDA in a reconciliatory tone as having been conducted in a “pleasant and constructive” spirit.³³ Anyway, for both sides, the meeting was merely exploratory and an agreement was made to keep lines of communication open on AIDS, especially on the proposed new AIDS Task force.

Even though different readings of AIDS complicated early meetings and communication between the government and anti-apartheid health organizations, such meetings laid the foundation for the NACOSA process discussed below. Moreover, such meetings need to be in turn seen in the context of the political negotiations, where compromises were being made on both sides. However, as with the broader negotiations such discussions were not without their conflicts. In the early 1990s, government’s refusal to admit that the negative socio-economic and political effects of apartheid were fundamentally related to the unfolding AIDS epidemic complicated these discussions and made it difficult to formulate joint positions on AIDS. In particular, the fact that the government had only recently initiated negotiations with the ANC and had seriously proposed discriminatory policy measures to combat the AIDS epidemic in the 1980s meant that any discussions between the two groups operated in an environment of mistrust. In turn, had the late apartheid government fully acknowledged that the socio-economic and political effects of apartheid were driving the epidemic, it would have further strengthened the ANC in steering AIDS policy-making and the broader negotiations.

On the other hand, for anti-apartheid health activists, fighting AIDS-related discrimination was complicated by the fact that there wasn’t a democratic constitution in place, amenable to protecting the rights of people living with HIV. Salim Abdool Karim, for instance, who had been a founder member of NAMDA, thought that the solution to producing well-formulated rights-based AIDS policy was to change the government and for the ANC to rise to power in the democratic elections.³⁴ This illustrates that the anti-apartheid organizations’ refused to see AIDS as an issue separate from abolishing apartheid and establishing democracy even if this complicated working with the government on the issue.

³³ *Ibid.*, p.2.

³⁴ Interview with Salim Karim, 15th September 2003, University of Natal, Durban.

In the same period, ANC members began to return from exile, which meant NAMDA, PPHC and the ANC began to work more closely on AIDS, especially on international fundraising: a development enabled by State President F W De Klerk's political reforms and the ensuing negotiations. In August 1990, an American congressman, Congressman McDermott visited South Africa following Mandela's visit to the US earlier in the year to explore possible AIDS projects which he could try to recommend for US government foreign aid. Illustrative of the increasingly close working relationship which the transition period enabled between both groups, PPHC assisted the ANC in preparing a submission to McDermott on the ANC's position on the epidemic and the its recommendation for the development of new and existing programs through potential US funding. It is worth dwelling for a while on the ANC paper presented to the congressman itself, as it was an extensive ANC/PPHC analysis of the history, meaning and relevance of the unfolding AIDS epidemic, understood in terms of the political and socio-economic context of the time.

The paper began with a summary of the ANC's view on progressive organisations' experiences of the history of the epidemic up to 1990 under the heading "Experiences of the AIDS Epidemic".³⁵ In bullet form they argued that in 1987 AIDS was represented as a gay disease and that there was "media sensationalism". The paper characterized 1988 as the year in which government and media widely depicted AIDS as a black disease and the government media campaign generated confusion and denial. In 1989 it saw the liberation movement as having first begun to see AIDS as its problem and to formulate responses especially amongst the unions, including policy analysis work conducted by COSATU unions (especially those representing mineworkers and metal workers). In that year the paper viewed anti-apartheid health workers, including doctors, as having mobilized for the first time.³⁶

³⁵ SAHA, NAMDA, Funding/Finances Box, NPPHCN Discussion Papers File, "AIDS in South Africa: Experiences and Responses. August 1990, A paper prepared for the ANC presentation to Congressman McDermott".

³⁶ Many anti-apartheid publications used the term "health workers" to include doctors and nurses and all working in the health sector. It is interesting how anti-apartheid doctors switched between emphasising their relatively privileged professional status and viewing themselves as 'workers' in the health sector.

This meant that by 1990 the paper's drafters saw the liberation movement as having begun to say that "AIDS is our problem: what do we do?": AIDS had arrived for the liberation movement in 1990. This was seen to be the case as the anti-apartheid health workers drafted the Maputo Statement on AIDS, which laid out the principles for national approach to AIDS. Health workers were characterized as being organized under PPHC whereas the ANC saw itself as engaging in practical activity in exile and at home. The churches and civic organizations had conducted some policy work and the unions had begun to implement small AIDS programs. However, early activism by anti-apartheid organisations did not reflect a broader shift in social attitudes towards viewing AIDS as a crisis, requiring urgent behaviour change and social mobilization. Indeed, for the drafters of the paper, the youth had no focus on AIDS and were seen to be in denial. This was the case because AIDS was seen as a white foreign disease. Furthermore, as shall be discussed more fully in Chapter Four, recent literature on historical changes in sexual socialization of African young people has shown, traditional forms of sexual education aimed at preventing sexually transmitted diseases had broke down decades before the 1990s, as a result of urbanization, and the influence of missionary Christianity around mid-century.³⁷

Unsurprisingly, as with UDF-affiliated NAMDA, the ANC saw AIDS as closely linked to apartheid itself and refused to see AIDS in isolation from the conditions which it saw as promoting its spread: for the ANC "The socio-political conditions in SA promote maximum spread of the epidemic. Youth are at greatest risk while being least educated on AIDS".³⁸ Whilst the ANC recognized the need to work fast, thoughtfully and creatively and plan on a large scale to develop AIDS work, the political conflicts of the time posed more immediate challenges : for instance, in Natal

The age group of people most susceptible to HIV are caught up in a war in which hundreds of people have died already this year. Thousands more have been directly or indirectly involved. The threat of AIDS seems distant and unreal in comparison to the reality of the conflict. The struggle for employment, housing, a living wage, schooling, social and political security are more important and tangible issues than the nebulous threat of an unknown and unseen disease.³⁹

The political impact of the fact that AIDS was not seen as a 'bread and butter issue' by

³⁷ Peter Delius and Clive Glaser, "Sexual Socialisation in South Africa: A Historical Perspective", *African Studies*, 61,1 (2002).

³⁸ "AIDS in South Africa", p.1.

³⁹ "AIDS in South Africa", p.2.

many ANC supporters will be discussed later in this chapter.

The ANC saw the government's response to AIDS as inadequate, disorganized and disinterested. Significantly, for this history of doctor and patient AIDS activism, it saw 'the gay community' as having been affected early by the epidemic and therefore having responded early to it and they acknowledged that the gay community faced unfair AIDS-related discrimination. In all likelihood this was linked to the fact that anti-apartheid gay activists, especially those linked to the Organisation of Gay and Lesbian Activists (OLGA) were successfully getting gay rights onto the ANC's agenda as shown by Gevisser and discussed in Chapter One.⁴⁰ Illustrative of gay activists' success in getting gay rights onto the ANC's agenda, the document argued that "South Africa is a homophobic society with legislation which makes homosexual sex illegal. It is therefore particularly difficult for gay people to campaign around AIDS".⁴¹ The ANC also noted that gay health workers established GASA 6010 in Cape Town and an HIV clinic in Johannesburg. It also lamented the fact that gay people were excluded from the AIDS Advisory Committee, which was dominated at the time by virologists, who were white, heterosexual and middle class which meant that the committee lacked racial and gender representivity and perspectives from patients and community organizations, which were seen as crucial to the movement.

Significantly, this showed that the ANC saw inclusion of patient perspectives as well as expert doctor perspectives as important in dealing with AIDS as a public health crisis. This in turn may be linked to the influence of Primary Health Care theories including community participation in health care and policy on health activists in the liberation movement as discussed in Chapter Two. Furthermore, as shall be demonstrated in Chapter Four, people living with HIV began to mobilize en masse as patients around their condition and to fight AIDS-related discrimination. This activist mobilization makes AIDS politically and socially unlike other epidemics in South Africa's history, even ones such as Spanish flu, which had similar morbidity and mortality rates amongst young people.⁴²

⁴⁰ Mark Gevisser, "A different fight for freedom", in Cameron, E. and Gevisser, M. (eds.) *Defiant Desire: Gay and Lesbian Lives in South Africa* (Johannesburg: Raven Press, 1994), pp.70-71.

⁴¹ "AIDS in South Africa", p.2.

⁴² Howard Philips, "AIDS in South Africa", *South African Historical Journal*, 45 (2001), p.22.

The ANC not only decried AIDS-related homophobic discrimination in its document to the congressman, it also denounced the government's racist and xenophobic AIDS policies. For instance, they pointed out that the government ignored recommendations of the AIDS Advisory Group on the issue of repatriation of HIV positive foreigners. As has been discussed in Chapter Two, the government also commissioned a coffin campaign: the ANC lamented the fact that

The image selected for the black population is a coffin being lowered into a grave. It has elicited fear and denial and generally been experienced as racist. The equivalent image for whites was graffiti written on a wall.⁴³

The campaign was also seen as shallow and insufficient to necessitate meaningful behavior change.

For the paper's drafters, who in all likelihood were PPHC and ANC doctors linked to the ANC Health Desk, such as Cheryl Carolus, Nkosasana Zuma and Liz Floyd (who was the national coordinator of PPHC), the political reforms and negotiations of 1990 presented new opportunities for activism, as the States of Emergencies of the 1990s had made progressive AIDS work very difficult. Progressive health organizations and the ANC had a sense that they could influence the government and build a new society.⁴⁴ Indeed the congressman's visit reveals that the ANC and PPHC worked very closely on AIDS, and that they both agreed on the need for AIDS policy to be non-discriminatory.

Although progressive health organizations and the ANC were working more closely together on AIDS, a trend which led to the former's demise with the latter's rise to power, there were some conflicts and divisions between the ANC and PPHC AIDS Working Group over how they ought to relate to each other and who ought to control foreign donor funding. The PPHC received half a million rand for its AIDS programs from USAid in 1990.⁴⁵ Congressman McDermitt's visit held out the promise of more funding, if the US Congress approved aid for AIDS programs in South Africa. On the other hand, a PPHC report written in August revealed that the ANC wanted to appoint a representative of its organization to be one of the co-ordinators of projects, which would be funded with American money, and there were also questions about the

⁴³ "AIDS In South Africa", p.3.

⁴⁴ *Ibid.*, p.6.

⁴⁵ SAHA, NAMDA, NPPHCN Discussion Papers, Job Descriptions, Adverts, Reports Box, NPPHCN Reports File, "Feedback from visit by US congressman", Dated 1 August 1990, p.1.

PPHC's fundraising policy and whether it was in line with the ANC's Harare Document.⁴⁶ The PPHC AIDS Working Group wished to retain some independence from the ANC: in a meeting in October they discussed their relationship to the ANC and agreed that the national AIDS Working Group should be independent of any particular political organization as they aimed to include people from across the political spectrum.⁴⁷ They wanted to avoid fragmentation, but at the same time relate to the ANC in the same way as they related to other affiliate member organizations. Michael Worsnip, the PPHC co-ordinator in Natal at the time remembers major disagreements within the organization over who ought to have controlled its AIDS program's funding and members such as Manto Tsabalala disputing whether AIDS ought to have been funded 'at the expense' of its other primary health care programs.⁴⁸ This may have been indicative of the splits over AIDS between former anti-apartheid doctor activist 'comrades' in the post-apartheid era.

NACOSA and the Era of Compromises: A break from the divisive past?

While a consultative national convention on AIDS had been proposed at the Maputo Conference two years earlier, in 1990, the immediate catalyst for holding NACOSA came from the late apartheid government's Department of Health and Population Development.

In 1990 the head of their AIDS Directorate, Amanda Holmshaw, had been determined to hold an international conference on AIDS in South Africa.⁴⁹ However, the anti-apartheid health organizations and the ANC had vetoed this idea due to the continuing existence of the international academic boycott against South Africa.⁵⁰ Instead a compromise was reached and a national conference called the National AIDS Convention of South Africa (NACOSA) was held on the issue in 1992. At the same time as the first public and political testimonies from HIV positive people were given at that conference as will be discussed in Chapter Four, important policy documents were

⁴⁶ SAHA, NAMDA, NPPHCN Discussion Papers, Job Descriptions, Adverts, Reports Box, NPPHCN Reports File, "Feedback from visit by US Congressman McDermitt (Democratic Party) to the A.N.C. August 1990", p.3.

⁴⁷ SAHA, NAMDA, NPPHCN Funding/Finances Box, NPPHCN Minutes File, "PPHC AIDS Working Group-Stvl. Johannesburg, 21 Sept 1990", p.9.

⁴⁸ Interview with Michael Worsnip, 3rd July 2003, Johannesburg.

⁴⁹ Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

⁵⁰ *Ibid.*

crafted behind the scenes. A resolution emerged from the first NACOSA Convention for the formation of a more lasting NACOSA structure to formulate post-apartheid AIDS policy. All these early documents leading to the formulation of the NACOSA structure were crafted by important anti-apartheid doctors and activists: as Salim Abdool Karim has said “ Nkosasana, Manto, Zweli [Mkhize] and Edwin [Cameron] came to our hotel room that first conference and we drafted the resolution to craft NACOSA”.⁵¹

For the ANC Health Desk’s Head, Cheryl Carolus, who was widely tipped to become the first post-apartheid Minister of Health, commenting on the process immediately prior to the April 1994 elections, in March of 1994, NACOSA represented a “window of opportunity” for multi-sectoral and representative participation in the shaping of AIDS policy in the transitional environment.⁵² Ralph Mgijima, the NACOSA chairperson who was a representative of the ANC on NACOSA, the ANC formed NACOSA as

We took a decision as the National Executive of the ANC that AIDS could not wait for the negotiations and the elections, which had not started at that time...people who were concerned had to get on with it irrespective of their political beliefs.⁵³

While he saw the government as ultimately responsible for AIDS, NACOSA provided the blueprint for an AIDS program for democratic and present governments. NACOSA was also seen by its founders in the ANC as providing insight into people, structures, policies and implementation of AIDS programs by all stakeholders including NGOs. Whilst the ANC saw NACOSA’s overall objective to "stop the spread of AIDS" through changing policies such as relevant legislation, and the introduction of AIDS education in schools.

By early 1994, the public face of NACOSA was of old enemies (the ANC and the government) co-operating on AIDS. In the NACOSA publication in which the interviews with Dr Ralph Mgijima (of the ANC) and government representative Dr

⁵¹ *Ibid.*

⁵² CHP Resource Room, “NACOSA: A Model for Our Times”, *NACOSA AIDS Talk*, p.1. Carolus was widely tipped in anti-apartheid health circles to become the first post-apartheid Minister of Health, Winnie Mandela was the person anti-apartheid doctors saw as the second most likely person and Zuma was the third most likely. Interview with Mervyn Susser, 7th August 2003, McCord’s Hospital, Durban. Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

⁵³ CHP Resource Room, Ralph Mgijima, *NACOSA AIDS Talk:South Africa United Against AIDS*, p.2.

Coen Slabbert were published there was a cartoon of both in a conciliatory pose jointly holding a sign saying “NACOSA Stop AIDS” and both saying “We agree!”.⁵⁴ This shows that government and ANC NACOSA participants saw themselves as being in negotiation and as having formulated a broad agreement on AIDS. Given the vast differences in interpretation of the meaning of the AIDS epidemic which characterized early meetings between UDF affiliated NAMDA and the Department of Health and Population Development, relations between both sides had come a long way on the issue of AIDS. However, this era of compromises between different role-players in AIDS policy-making would not last long in the post-apartheid era, where former doctor activist comrades would develop conflictual relations on AIDS due to the ANC in government’s adoption of AIDS denialism.

Writing in the immediate post-election period, AIDS policy commentator Mary Crewe argued that NACOSA had mirrored the CODESA negotiations which had led to South Africa’s democratic elections in that it represented a break from the “vindictive” and “divisive” political history of South Africa.⁵⁵ For Crewe, NACOSA was internationally unique as it was internally developed through consultative and inclusive process as opposed to imposed by the government or the World Health Organization’s Global Program on AIDS and the fact that the new government’s National Minister of Health was a part of the NACOSA strategy subcommittee which drafted the plan increased the chances of its successful implementation.⁵⁶

NACOSA’s National AIDS Plan was comprehensive in terms of its human rights and law reform strategy which recommended that policy follow such principles as: non-discrimination in the workplace; informed consent for HIV testing; a recognition of women’s gendered vulnerability to HIV infection; non-discrimination against children infected with HIV; and recommendations of prison reform to promote HIV prevention and legalization of same sex practices.⁵⁷ Human rights even featured in the Plan’s statement of principles which included non-discrimination and participation of people

⁵⁴ *NACOSA AIDS Talk*, p.2.

⁵⁵ CHP Resource Room, Mary Crewe, “Reflections on NACOSA”, Centre for Health Policy Resource Room, University of the Witwatersrand, *AIDS Bulletin*, 3,2, (1994), p.2.

⁵⁶ *Ibid.*

⁵⁷ CHP Resource Room, “Highlights of the law reform and human rights strategy”, *AIDS Bulletin*, 3, 2, (1994), p.9.

living with HIV in all prevention, care and intervention strategies.⁵⁸ The strong emphasis on non-discrimination and a protection of the rights of people living with HIV was clearly a result of the efforts of groups such as the AIDS Consortium as its emphasis on rights mirrored the Consortium's Charter. As Helen Schneider has commented the plan

...was drawn up during a time when the National Bill of Rights was being formulated and debates on human rights in South Africa were at their maximum...It went further than the WHO-inspired Medium Term AIDS Plan of the time to...accord people living with Aids a key role in policy development and implementation.⁵⁹

The Legacy of the AIDS Plan and Charter of Rights: The New Government and the Problems Implementing The Plan

Following the euphoria of the country's first democratic elections in 1994, there were several constraints to implementation of the NACOSA National AIDS Plan, despite the fact that the new government adopted it as the country's AIDS policy in the first few months of their administration. In particular, in the immediate post-apartheid era, NACOSA participants who found themselves in the new government, such as Quarraisha Abdool Karim, found themselves working for "A government trying to come to terms with what it meant to be in power...which looked for shortcuts and created policies they could not implement".⁶⁰ Indeed, in a bid to combat the AIDS epidemic the new government's Department of Health, headed by anti-apartheid health professionals, such as Nkosasana Zuma, looked for quick fixes to the epidemic, which precipitated crises such as the Sarafina II debacle and the scandal over Virodene.⁶¹

NAMDA disbanded in the early 1990s (archival evidence points to this in 1992) due to the fact that the ANC had returned from exile and was poised to take over the government: after all, for anti-apartheid doctors what was the need for the continued existence of an independent and critical organisational doctor voice, when anti-apartheid doctors were in government, pushing the struggle forward?⁶² NAMDA

⁵⁸ CHP Resource Room, NACOSA. *South Africa United Against AIDS: A National AIDS Plan for South Africa 1994-1995*, p.10.

⁵⁹ Helen Schneider, "The Politics Behind Aids: The case of South Africa", In Rosenbrock, R. (ed.) *Politics Behind Aids Policies: Case Studies from India, Russia and South Africa*, (Berlin: Public Health Policy Research Unit, Wissenschaftszentrum Berlin für Sozialforschung, 1998), p.10.

⁶⁰ Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

⁶¹ *Ibid.*

⁶² Discussion with Umesh Laloo, 19th December 2003, Durban

doctors such as Jerry Coovadia, Umesh Laloo and Salim Abdool Karim were card-carrying members of the ANC who had “put the ANC in power to do the right thing”.⁶³

As Baldwin Ragaven *et al* questioned, writing in 1999

With the sweeping changes towards democratization...Health activist organizations saw prominent members move into political parties, government or parastatal leadership positions, and becoming directly involved in policy formation and governance. As a result, the organizations of the late 1980s have either disbanded completely, ‘unified’ with more mainstream structures or merged to form new organizations...With moves towards mainstreaming, how can we be sure that human rights in health are guaranteed? What are the consequences of articulating a position at variance with that of the government? And what is the role of monitoring in the new South Africa?⁶⁴

It would take years for a critical doctor voice on AIDS to emerge in the South African Medical Association formed by the merger of MASA and elements of the then-defunct NAMDA. The PPHC’s AIDS program closed down soon after the 1994 elections, due to budgetary cuts. These were, in turn, linked to an unflattering report of their program produced by Salim Abdool Karim who was then at the Medical Research Council. The PPHC AIDS Project Manager in Kwa-Zulu-Natal saw the closure of PPHC as caused by an arbitrary budget cut imposed by the new government.⁶⁵ These two factors meant there was no organised critical doctor/health-worker voice on AIDS policy until well into the new dispensation.

But there were also technical issues which complicated post-apartheid AIDS policy-making. As policy analysts such as Schneider have shown there were also complexities in co-ordinating health policy between district, regional and national levels of government: responsibility for policy implementation lay with the provinces and they had an even commitment to fighting AIDS.⁶⁶ As shall be discussed in the Postscript, NACOSA also set high expectations of participation and consultation between government and civil society on AIDS policy, which would not be met leading to confrontation over a series of AIDS policy ‘scandals’.

Certainly, the massive shifts in the broader political context of the early 1990s impacted

⁶³ Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

⁶⁴ Laurel Baldwin Ragaven, Jeanelle de Gruchy and Leslie London, *An ambulance of the wrong colour: Health professionals, human rights and ethics in South Africa* (Cape Town: University of Cape Town Press, 1999), pp.205-206.

⁶⁵ Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

⁶⁶ Schneider, “Politics behind AIDS Policy”, 9. Joanne Stein and Helen Schneider, “Implementing AIDS policy in post-apartheid South Africa”, *Social Science and Medicine*, 52 (2001),p.724.

on AIDS activism. Activists become better linked and formed new alliances on new issues like AIDS: whereas, at the beginning of the decade NAMDA activists had to go abroad and contact the ANC through external solidarity organizations such as CHISA in the 1980s, they formed joint position papers on AIDS in the early 1990s; whereas the ANC was banned and its activists enemies of the state in the 1980s, it jointly negotiated a post-apartheid National AIDS Plan with government in the 1990s.

Gradually through these links, especially with CHISA activists who had been in exile, AIDS began to feature more prominently on the political agenda of the liberation movement in those years. Even if it was not at the very apex of the new government's agenda, its urgency as a political issue would only get louder in the post-apartheid years, where activists equipped with the new Constitution would continue to fight against AIDS-related discrimination.

AIDS-related discrimination was also perpetuated by the new ANC government, well into the new democracy: this was ironic given that the ANC saw AIDS as an emergency in the transition, yet a few years later its second post-apartheid leader denied its causation and seriousness, a denial in turn rooted largely in the legacy of racist framings of the epidemic and social and cultural reactions to them.⁶⁷ While the AIDS scandals would erode confidence and trust in the new government by doctor activists, the adoption of denialism spelled open intellectual and political warfare amongst former doctor-activist comrades. This battle was rendered especially bitter by the fact that most former NAMDA and PPHC members involved in AIDS work in the post-apartheid era were themselves "card-carrying members" of the ANC, who were steeped in the movement's political history, and whose political training and instincts as anti-apartheid doctors bristled at the notion of "turning on" the very government for which they had fought so hard.⁶⁸

Furthermore, as Chapter Four will show, the AIDS policy gains of the Transition era should not be over-estimated, for while the National AIDS Plan incorporated principles

⁶⁷ I discussed the historical roots of government denialism in my BA honours thesis. Mandisa Mbali, *'A Long Illness': Towards a History of Government, NGO and Medical Discourses Around AIDS Policy-making*, (Unpublished Bachelor of Arts Honours Thesis, University of Natal, 2001). I will discuss the social reaction to racist framings of the epidemic, which have also shaped government denialism in Chapter Four of this thesis.

⁶⁸ Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

of non-discrimination, social attitudes among both Africans and whites were slower to catch up. Indeed, widespread homophobia and white racism, and ‘knee jerk reactions’ amongst Africans to it, continued to feed into AIDS stigma and discrimination and formed the socio-cultural basis for government denialism.

However, doctor activists in alliance with patient activists would hold the new government to the promises of non-discrimination in the National AIDS Plan and the new constitution they had fought so hard for, even if this at times publicly pitted them against former comrades in government. Unequal access to powerful and effective new anti-HIV combination drug therapy that emerged in the mid-1990s, partially caused by government denialism, drove many doctor activists to oppose post-apartheid AIDS policy using the new democratic legal and political tools available to them to push for the rights of HIV positive people as citizens of the new democracy. Simultaneously, as the next Chapter and Postscript will illustrate, patients became increasingly politicized in new and more militant ways and formed stronger alliances with doctor AIDS activists. Therefore, this medical history ‘from both sides of the bed’ breaks down the clear binaries of doctor/active, patient/passive and doctor/oppressor, patient/oppressed suggested by Foucauldian medical histories⁶⁹ and shows that both groups of activists used their agency to resist AIDS-related discrimination.

⁶⁹ I have discussed how I frame my thesis theoretically in these terms in the Introduction to this thesis. See p.9.

Chapter 4

STIGMA, REPRESENTATION AND FIRST-PERSON PATIENT AIDS ACTIVISM IN THE ERA OF THE POLITICAL TRANSITION, 1990-1994

Introduction

As with many other previous epidemics, both internationally and in South Africa, outsiders and minorities have been blamed for the spread of AIDS.¹ The continuation of AIDS-related stigma and prejudice convinced many people that AIDS was the ‘Other’ racial or sexual groups problem and led to widespread, sustained social acceptance of unfair AIDS-related discrimination. Moreover, in such an environment, the first gay HIV positive patient activists to speak out against AIDS faced stigma, largely linked to their sexual orientation, and were far from universally accepted: whilst stigma did not prevent people from talking publicly about AIDS in the abstracted third person as something which affects ‘them’, it was largely ‘unspeakable’ for HIV positive people to speak about their HIV status in the first person in a public political context.

Moreover, there had been important shifts in the epidemiological profile of AIDS: whereas in the 1980s the majority of identified cases of HIV infection were amongst gay patients, in the 1990s black heterosexuals became the overwhelming majority of AIDS cases. This had important implications for AIDS activism in the early 1990s because whilst gay rights activists had from an early stage in the 1980s organised around AIDS (even if the earliest organisation was non-militant) and admitted its existence in their community, early community AIDS workers found that African young people largely saw AIDS as a white disease and a distraction from focussing on ‘bread and butter issues’.

In terms of this medical history of AIDS activism ‘from both sides of the bed’, it is important to note that in the early 1990s both anti-apartheid doctors and gay rights

¹ Howard Philips, “AIDS in the Context of South Africa’s Epidemic History: Preliminary Historical Thoughts”, *South African Historical Journal*, 45 (2001), pp.14-16.

activists exercised their agency to resist discriminatory and stigmatising framings of the epidemic using human rights-based discourse. Moreover, they developed stronger, albeit still nascent links on the issue of AIDS, which is significant, as it was a new alliance, which perhaps for the first time in South Africa's epidemic history relied on the political-rhetorical strategy of employing rights-based discourse. This in turn undermines binaries suggested by Foucauldian medical histories such as, doctor/patient, active/passive, and oppressor/oppressed.

The National AIDS Convention of South Africa (NACOSA) would be powerfully used by gay rights activists to lobby for post-apartheid AIDS policy to be rights-based and non-discriminatory towards both members of groups seen as vulnerable to HIV infection (such as gay people) and people living with HIV/AIDS. In particular, AIDS activists who had backgrounds in anti-apartheid gay rights activism who were linked to PPHC and the AIDS Consortium, such as Edwin Cameron and Peter Busse, played a key role in lobbying at NACOSA for the rights-based framing of AIDS policy. This demonstrates, as argued in Chapter One, that the emergency of militant, politicised, anti-apartheid gay rights activism was a pre-requisite for more vocal AIDS activism.

In terms of early patient activism, the Maputo Conference on Health in Southern Africa, and the NACOSA process it catalysed, also provided the first political forums for gay HIV positive AIDS activists such as Shaun Mellors and Peter Busse, to publicly declare their HIV status. They disclosed their HIV status publicly at such national forums to push for an anti-discriminatory framing of AIDS policy in line with the human rights-based approach outlined in the AIDS Consortium's *Charter of Rights for People Living with AIDS and HIV*. The full political potential of this strategy of disclosure to push for human rights-based AIDS policy would only become apparent when it was adopted en masse in the post-apartheid era. From a mere handful of white gay activists in the early 1990s, in the first years of the twenty first century, AIDS activists' protests would come to consist of a human sea of thousands of HIV positive and HIV negative activists wearing t-shirts proudly proclaiming "HIV POSITIVE". Yet the seeds of undocile and impatient patient activism of the late 1990s grew largely from anti-apartheid gay rights

activism in the late apartheid and transition eras.

In the early 1990s, the first handful of gay AIDS activists got the ANC to denounce AIDS-related homophobia, as shown in Chapter Three. This was a shift which was in line with the success of anti-apartheid gay rights activists getting non-discrimination into the ANC's Bill of Rights, discussed briefly in Chapter One, which influenced South Africa's post-apartheid democratic Constitution. Patient AIDS activism is a significant, under-documented and unique phenomenon in South Africa's epidemic history. As Philips has pointed out, patient AIDS activism was enabled by the fact that unlike many other infectious diseases AIDS has a long asymptomatic and relatively healthy period during which HIV positive people are able to organize and gather public sympathy around their condition.² However, to speak about HIV infection and risk of contracting the virus in the first person remained controversial in the early 1990s and there was by no means universal support amongst NACOSA participants for the first white gay activists who openly revealed their HIV status. This was at least partially due to widespread homophobia in the liberation movement, which has been noted above.

Although the leadership of the ANC spoke publicly about AIDS as a priority requiring attention, it was a political organization whose policies were to a certain extent shaped by the understandings of AIDS prevalent among its grassroots supporters. As the ANC Health Desk recognized, stigma about HIV infection was very strong in African communities in the early and mid-1990s. Furthermore, ANC leaders such as Cheryl Carolus (head of the ANC health desk) referred to the existence of a 'knee-jerk reaction' to AIDS amongst many Africans to the government and media's racist depiction of the epidemic as a black disease. In turn, the majority of Africans regarded AIDS as a 'white disease'. Moreover, this 'knee-jerk reaction' in turn provides some explanation for the social context in which the post-apartheid government was able to adopt AIDS denialism without receiving much higher degrees of criticism from its supporters. Furthermore, unlike issues of housing, access to basic services and jobs, many ANC grassroots supporters did not see AIDS as a 'bread and butter issue'.

² *Ibid.*, p.22.

Indeed, this had the political implication that, had the ANC diverted significant resources and attention away from these ‘bread and butter’ issues to focus on AIDS, it could have courted deep unpopularity with the bulk of its membership base, which constrained the ANC’s hand in responding to AIDS. AIDS was an ‘invisible epidemic’ in the period, which, due to stigma, was largely unspeakable publicly in the first person. The epidemic’s invisibility was assured by stigma and discrimination which had led to activist demands for the protection of the right to doctor-patient confidentiality. Doctors were professionally ethically obliged to maintain secrecy on the patient’s condition. However, this right may have been interpreted as the *necessity* for patients themselves to maintain secrecy, as opposed to the *right* of the patient to decide on whether to publicly disclose their HIV status.

Gay Rights Activists, Representation and Anti-Discrimination

While the overwhelming majority of AIDS cases were heterosexual by the early 1990s,³ almost no heterosexual people and a mere handful of gay men living with HIV were open about their status in a public and politicised sense: this means that gay men were the only vocal patient activist voice against discrimination in the period. The reasons why they remained virtually the only patient voice are suggested by several factors in the period. Firstly, the epidemic affected the gay community early and hard: according to one estimate ten to fifteen percent of gay men in Johannesburg were HIV positive in the mid-1980s, at a time when far less than one percent of the straight people were infected.⁴ As Chapter One has shown, AIDS was first represented as a ‘gay plague’ and homophobic AIDS related discrimination swiftly followed such representations. Also, as the same chapter discussed, there was a well-developed, militant gay anti-discrimination AIDS activist movement established in the United States by the late 1980s from which South African gay activists organizing against AIDS-related discrimination could draw upon for

³ Helen Schneider, Malcolm Steinburg and Carel Ijsselmuiden, “Understanding the possible: Policies for the prevention of HIV in South Africa” (Johannesburg: Centre for Health Policy, University of the Witwatersrand and Medical Research Council, 1993), p.3.

⁴*Ibid.*, p.3.

inspiration. While South African gay AIDS activism would not reach such a fever pitch until the late 1990s, freed from the shackles of the Gay Association of South Africa's (GASA) moderation and 'apoliticism', gay rights activism including AIDS activism became more militant and outspoken: differently put, some gay men living with HIV and the organizations which supported them refused for them to be merely 'docile and useful' bodies and creatively constructed and used their sexual identities for their AIDS activism.⁵ Indeed, they exercised their agency to push for equal rights and fair treatment in all contexts including the workplace, in the health sector, through litigation, use of the media and lobbying and relevant forums such as NACOSA.

Anti-discriminatory patient AIDS activism in the early 1990s also needs to be seen against the backdrop of significant events in broader gay politics in South Africa in the period, for instance, 1990 brought South Africa's first gay pride march in Johannesburg. The period was also an excellent one for shaping of networks and alliances between gay rights activists and anti-apartheid doctor activists. In this vein, whilst the ANC, the Progressive Primary Health Care Network (PPHC) and the National Medical and Dental Association (NAMDA) began to work more closely on the AIDS epidemic, gay rights activists also began to work more closely with PPHC on the issue of AIDS: for instance a member of the PPHC network in Cape Town was GASA 6010, which was an anti-apartheid organization which had splintered from GASA in the 1980s, and in the 1990s provided HIV-related health and social services to gay men.⁶ Indicative of the strengthening of these links between anti-apartheid health worker organisations and gay rights groups in general, in March of 1990, NAMDA Southern Transvaal region announced on the eve of the Gay and Lesbian Organisation of the Witwatersrand's (GLOW's) first Gay Pride March in Johannesburg that it "Wishes to extend our solidarity to GLOWA (sic) in your pursuit of our common struggle for human rights and national

⁵ As I argued in Chapter One, the rich tradition of gay political organisation undermines Foucauldian critiques of the political uses of sexual or gendered identities. Monique Deveaux, "Feminism and Empowerment: A critical reading of Foucault", *Feminist Studies*, 20, 2 (1994).

⁶ South African History Archive, University of the Witwatersrand, National Medical and Dental Association (NAMDA), National Progressive Primary Health Care Network (NPPHCN) Discussion Papers/Job Descriptions/Adverts/Reports Box, NPPHCN File, Western Cape NPPHCN, "AIDS in the Western Cape: Presentation to US Congressional Delegation", Dated 18th September 1990, pp.3-5.

liberation".⁷ NAMDA Southern Transvaal branch was leading NAMDA's response to AIDS from an organizational point of view at the time, so it is fairly significant for the history of links between the two movements over AIDS that this branch of the organization sent this faxed solidarity note to the GLOW on the eve of the first Gay Pride march in South Africa.

In a similar way, as has been shown, above the PPHC and the ANC, in their submission to US Congressman McDermott, had highlighted unfair representation of gay people as "AIDS carriers" in the 1980s. Even more significantly, the Maputo statement on AIDS had denounced unfair AIDS-related discrimination against gay people. However, despite the existence of documents expressing such lofty ideals the hard edge of AIDS-related homophobic discrimination remained a reality for gay South Africans.

Gay rights activist Edwin Cameron, who had fought against *both* regressive amendments to criminal law discriminating against gay people *and* against racism in gay organisations in the 1980s (as discussed in Chapter One), turned his brilliant legal and political mind to fight AIDS-related discrimination in the 1990s. By 1992, he was based at the University of Witwatersrand's Centre for Applied Legal Studies, which played a key role in founding The AIDS Consortium Project.⁸ Several anti-apartheid organisations who had played a key role in pushing for AIDS policy to be rights-based were involved in the AIDS Consortium including: Congress of South African Trade Unions (COSATU), the ANC Health Department, GLOW, PPHC AIDS Forum and the National Union of Mineworkers (NUM). The AIDS Consortium was key in lobbying for AIDS policy to protect the rights of people living with HIV as it was formed after meetings between several organisations were convened to discuss the drafting of a "Charter of Rights for People with AIDS and HIV"⁹. The organisation arose as a result of concerns expressed by participating organisations conducting AIDS work that they "...did not always have

⁷ SAHA, NAMDA, Branches and Reports Box, Branch Reports File 1988-1991, Pule Malumane, "Re: Johannesburg Lesbian and Gay Pride March 1990; 13/10/90", Letter Dated 2nd October 1990, p.1.

⁸ Centre for Health Policy (CHP) Resource Room, University of the Witwatersrand, "The AIDS Consortium Project: Bulletin: Issue 1, August 1992. Centre for Applied Legal Studies, University of the Witwatersrand", p.1.

⁹ *Ibid.*, p.1.

the time and resources to respond quickly and effectively to developments in AIDS policy and the media”.¹⁰

The formation of the Consortium was unprecedented, in terms of this history of doctor and patient AIDS activism, in that it brought together doctors and health workers, gay organisations representing the interests of patients and union and ANC representatives all with the aim of fighting against AIDS related discrimination and for the rights based framing of AIDS policy. Its formation also shows that clean binaries between doctor/patient, oppressor/oppressed, simply do not reflect the capacity of both groups, exercising their agency, to form alliances to resist the undermining of patients’ human rights.

The organisation aimed to facilitate contact and information sharing on AIDS between member organisations. However, most significantly, it aimed to be an effective lobbying and advocacy tool, by analysing and sharing information on AIDS policy from a rights-based perspective, it hoped to help affiliated AIDS organisations quickly present a united front on AIDS policy.

Instances of AIDS-related discrimination were not hard to find in the early-1990s. For example, the AIDS Consortium fought Boksburg town council’s attempt to shut down St Francis Home, a church-run home for terminally ill and indigent AIDS patients. According to an AIDS Consortium newsletter, the town council planned to shut down the home due to the fact that its neighbours saw it as leading to a devaluation of their property, alleged that the home’s residents were mentally unstable and most grievously of all (for the conservative white residents of Boksburg), the influx of ‘other racial groups’ caused by the Home could pose a ‘security risk’. The AIDS Consortium decided to send a press statement out about the issue, which presented an unequivocal stance against stigmatising and discriminatory responses:

The discrimination and stigmatisation of the St Francis Home cannot be justified on any rational basis. The claim that the health, safety, infection hazard or property valuation form foundation for the objections to the home is a thin smoke-screen for bigotry and

¹⁰*Ibid.*, p.1.

intolerance...The closure of the home would set a dangerous precedent in the face of the AIDS epidemic.¹¹

But the discrimination didn't end there: a month later the home had been ordered by the council to remove all nursing staff and personnel and revert to a private dwelling. The home appealed the order and took up the services of famous anti-apartheid lawyer George Bizos to act as their advocate in the appeal.¹²

This was by no means the extent of rights-based AIDS activism in the period. Edwin Cameron's major case involving AIDS-related discrimination in the early 1990s was acting as the plaintiff's advocate in legal action for breach of doctor-patient confidentiality, which was pursued by a man named Barry McGeary. There was an important principle at stake in this case: the right to doctor-patient confidentiality. The violation of this internationally-recognised principle was indicative of the broader systemic ethical bankruptcy of apartheid medicine because, as literature on apartheid medicine has shown, it was far from sacrosanct in all cases. For instance, during the apartheid era, political prisoners were granted scant right to privacy when consulting with physicians, in some cases information on their medical status could be used to determine methods of torture and purposeful maltreatment.¹³ As Ragaven Baldwin et al have argued:

Maintaining confidentiality has been a governing tenant of medical practice since the time of Hippocrates. The principle that any information which passes from the patient to the clinician is guarded in confidence at all times is enshrined in codes of professional ethics. Developing trust between the patient and the health professional requires respect for the autonomy and privacy of the patient in exchange for open communication...It is generally agreed that only in extraordinary circumstances can the patient's privacy be relaxed.¹⁴

¹¹ Boksburg Town Council was notoriously opposed to racial integration in this period and kept the petty apartheid of segregated benches etc. alive well into the 1980s. The residents of Boksburg even notoriously built a perimeter fence around the suburb to keep the black residents from the nearby informal settlement out of the town. See: Allister Sparks, *Tomorrow is Another Country: The Inside Story of South Africa's Negotiated Transition* (Johannesburg: Struik Books), pp.236-237.

¹² "The AIDS Consortium", p.2.

¹³ The right to doctor-patient confidentiality dates back to the Hippocratic Oath and is designed to ensure that the patient trusts the doctor and that the patient suffers no adverse consequences merely as a result of consulting with their doctor. Indeed, the violation of this right under apartheid was one of the most grievous violations of detainee-patients dignity by health professionals: Laurel Ragaven-Baldwin, Jeanelle de Gruchy & Leslie London, *An ambulance of the wrong colour: Health professionals, human rights and ethics in South Africa* (Cape Town, University of Cape Town Press, 1999), pp.54-69.

¹⁴ Ragaven-Balwin et al, *An ambulance of the wrong colour*, p.69.

McGeary was a patient infected with HIV, which was then heavily stigmatized and widely misunderstood disease, who lived in Brakpan. His right to confidentiality was violated by his doctor, who in 1991, without his consent told two other people of his HIV status.¹⁵ That same year, he decided to sue his doctor for violating his medical confidentiality as according to his lawyer Mervyn Joseph "...he felt control had been removed from his hands".¹⁶ Cameron handled McGeary's case as his advocate, which Cameron eventually won, although his client McGeary died of AIDS before the completion of the trial.

The case is significant as it highlighted issues of confidentiality, discrimination and stigma. Seen in the light of the subsequent tragic HIV prevalence figures and AIDS related mortality, which was earlier partially caused by the secrecy surrounding an individual's positive HIV status in the early 1990s, it also highlights a painful choice for AIDS activists living with HIV in the period: whether to make personal sacrifices by openly declare their status to tackle stigma and make themselves vulnerable to AIDS-related discrimination, or whether to reinforce the right to privacy and confidentiality in the face of stigma. The latter decision had the important implication of keeping the epidemic politically and socially invisible and, therefore, a marginal and poorly understood issue.

Issues of confidentiality, secrecy and 'truth-telling' around AIDS were also forced onto the agenda in the early 1990s as doctors began writing letters to Editors of newspapers arguing for AIDS to be made a notifiable disease: that is, an infectious disease where doctors would have to notify the authorities when patients were found to be HIV positive. For instance, as early as December 1990 an I B Copely of the Department of Neurosurgery at the Medical University of South Africa, wrote to the *Sunday Star* arguing for AIDS to be made notifiable because its infectious and contagious nature was

¹⁵SAHA, the Edwin Cameron Archive (Cameron), Box A, File B.1: Press Clippings-Local, "AIDS in the new constitution", *Springs Advertiser*, 27 May 1994.

¹⁶SAHA, Cameron, Box A, File B.1: Press Clippings-Local, Charmain Naidoo. "World watches as AIDS case drags on", *Sunday Times*, February 7 1993, p.4.

“...a danger to the health and lives of members of the community” and health workers could be infected through needle-stick injuries.¹⁷ Copeley dismissed activists’ arguments against the measure in the following way:

The argument that if everyone was tested it would lead to social and medical discrimination is the bogey put up by the philanthropists initially to protect gay people who were the first to contract the disease.¹⁸

In other words, he saw people opposed to notification as a group of idealistic and ‘out of touch’ liberals, inappropriately in the sway of gay activists and lacking an appreciation of the clinical realities of seeing HIV positive patients.

The letter did not remain uncontested, as someone replied a week later in the letter to the editor section under the *nom de plume* “Medical Ancillary” and argued against notification, as HIV infection unlike other infectious diseases such as cholera and tuberculosis could not be treated.¹⁹ The author of the letter argued that the ‘window period’ where HIV infection may be undetectable a few months into infection negated the benefits of breaching doctor-patient confidentiality through notification and that doctors were motivated by fears of their personal safety by arguing for notification. For the author, given the ‘window period’ and the untreatable nature of AIDS in the period, universal precautions applied to all patients to prevent occupational transmission ought to be implemented.²⁰ The letter contained used ironic and rhetorical emotional appeal asking

Having identified HIV positives how, apart from counselling them, are we going to put this information to good use in preventing the spread of infection? Will ‘HIV positive’ be stamped in their ID books?²¹

For the “Medical Ancillary”, Copeley was naïve in believing that public knowledge of a person’s HIV status wouldn’t lead to prejudice. Copeley’s opponent argued that if doctors who were well-informed about AIDS would be prepared to discriminate against

¹⁷SAHA, Cameron, Box A, File B.1: Press Clippings-Local, I B Copeley “Killer Aids should be a notifiable disease”, *Sunday Star*, 30 December 1990.

¹⁸*Ibid.*

¹⁹SAHA, Cameron, Box A, File B.1: Press Clippings-Local, ‘Medical Ancillary’, “Doctors’ puzzling prejudice against Aids”, *Sunday Star*, 6 January 1991.

²⁰*Ibid.*

²¹*Ibid.*

people living with HIV, how could they expect non-discrimination from others?²² The medical ancillary argued that doctors were the ones who ought to set the ethical example in being non-discriminatory to people with HIV. This demonstrates an important point that health-workers and doctors were not all in favour of AIDS-related discrimination, nor were they a monolithic block who were insensitive to the rights of patients.

Early AIDS activists, whose work was focused on protecting the rights of people living with HIV, thought that the discrimination surrounding AIDS meant that it had to be kept private and confidential, something certainly underscored by the McGeary case and debates over notification brewing at that time. However, this further fed into the secrecy around AIDS and contributed to what I will call the publicly “unspeakable” nature of their positive HIV status for the vast majority of people living with HIV in the period. But the fact that their status was for the vast majority “unspeakable” was a product of its time: discrimination against gay and lesbian people remained legal. In terms of race, in an analogous sense to the ‘Sanitation syndrome’ documented by Maynard Swanson in Cape Town over a century before, conservative racists were (incorrectly) arguing that racial integration which was taking place in the transition era through casual physical contact could ‘spread’ AIDS.²³ For instance, according to an article in *The Star* entitled “Aids-the end of denial”, an article in *The Patriot*, a Conservative Party newspaper, claimed on the authority of an “anonymous doctor” that AIDS could be spread by day-to-day contact such as the sharing of toys and sweets: for white conservatives arguing against the abolition of the apartheid Separate Amenities Act “we whites pay the bills and we have the right to survive in an Aids sea”.²⁴ Not all doctors took the same liberal approach to AIDS as anti-apartheid doctors with links to NAMDA and the PPHC and gay organisations. Indeed, some saw AIDS as an opportunity to defend conservatism and institutionalised-prejudice.

²²*Ibid.*

²³SAHA, Cameron, Box A, File B.1: Press Clippings-Local, “Aids-the end of denial”, *The Star*, Monday November 5 1990. In a similar vein, Maynard Swanson has shown how in turn of the twentieth century Cape Town, the spread infectious diseases was presented as due to the existence of multi-racial slums, which colonial officials used to argue for segregation on ‘public health’ grounds. See: Maynard Swanson, “The Sanitation Syndrome: Bubonic Plague and Urban Native Policy in the Cape Colony, 1900-1909”, *Journal of African History*, 18, 3 (1979).

²⁴ “Aids-the end of denial”.

Just as racism remained pervasive amongst white conservatives, sexual conservatism was still alive and well in the early 1990s as debates over gay HIV prevention sexual education material in Cape Town showed, and it is important to remember that these debates took place in a context where gay sex, or even its depiction or representation, was still criminalized. A certain A. D. Roberts who was an AIDS counsellor from Goodwood in Cape Town congratulated the Publications Control Board for banning an ‘explicit’ AIDS awareness video produced by an L. van Reenen who had written in previously to the paper to protest its banning. For Roberts, the video’s producer had attacked “the government, Publications Control Board and...the public for embracing Christian morals”. Roberts accused the Aids Support and Education Trust (ASET), who recommended the Board not to ban the video of being guilty of “something more sinister/a secret agenda” in that she argued that

AIDS education in Cape Town is conducted mainly by organizations who are sympathetic to the gay cause and embrace the Kinsey Curriculum. The ultimate goal is basically:

- a) To get heterosexuals to engage in homosexual experiences
- b) To progress towards ultimate-acceptance of the possibility of adult sexual relations with children...Persons being trained by these organizations are indoctrinated to teach that homosexuals should not be blamed for the spread of Aids²⁵

As this letter shows, producing relevant and explicit gay AIDS awareness materials was complicated by the fact that homophobia and a homophobic application of apartheid-era censorship laws were still very real in early 1990s South Africa. For many gay people it must have been hard enough to openly express their sexuality with homophobic bigoted beliefs (that gay people were paedophiles, a menace to the youth, guilty for their own HIV infection) being so widespread. To make matters worse, such discrimination was institutionalised and backed up by the country’s legal and governmental framework.

ASET replied to the letter by arguing that against Robert’s assertion that it aimed to somehow ‘convert’ heterosexual people to being gay or that it condoned or promoted paedophilia: it thought that “The provision of such education must be done factually, free

²⁵SAHA, Cameron, Box A.6: ASET, D. Roberts. “Young at Risk: Warning on teaching the wrong way on Aids”. *Weekend Argus*, 20-21 February 1993.

from moral overtones and judgmental attitudes”.²⁶ The organization also drafted a letter to the Mayor of Cape Town, who employed D. Roberts who was an AIDS counsellor at the Goodwood Fire and Rescue Services, and pointed out that in its legal counsel’s (Edwin Cameron’s) opinion, linking the organization to illegal and criminal paedophilia was defamatory.²⁷ The fact an AIDS counsellor had such stigmatising and discriminatory attitudes towards AIDS showed that AIDS activists such as Cameron faced an uphill battle to change such widespread prejudices attached to AIDS, even among people who ought to have been sympathetic to the plight of people living with HIV and vulnerable to HIV infection.

Cameron also offered free legal advice to ASET on whether the organization could legally distribute a series of erotic AIDS educational photos targeted at gay men and developed by British AIDS charity Terrance Higgins Trust.²⁸ The strategy of showing sexually explicit AIDS education material targeted at gay men was in line with calls dating back to the late 1980s by gay British AIDS activists such as Simon Watney for the development of such material.²⁹ Even more subversively, given the repressive context of legalised apartheid censorship of such material, and resistance to integration demonstrated above in white conservative circles, it even depicted men of different races together in erotic poses. Nevertheless, Cameron found in his detailed legal opinion that in the context of the development of Draft Bills of Rights by the ANC, the government, and KwaZulu, with a view to the development of the new Constitution, that the material would not be found “undesirable” under existing South African censorship provisions.³⁰ The fact that all three draft bills of rights prohibited discrimination on the grounds of sexuality held out the tantalizing promise of using the courts in the post-apartheid era to

²⁶ SAHA, Cameron, Box A.6: ASET, E D Beer “Letter to Editor”, 20 February 1993.

²⁷ As the cover page of the fax where the letters are sent reveals, counsel was Edwin Cameron. SAHA, Cameron, Box A.6: ASET, John V Pegge. “Letter to His Worship the Mayor. Re:Letter to the Weekend Argus of February 1993 by D Roberts, AIDS counsellor, Goodwood Fire and Rescue Services. Dated 24th February 1993”.

²⁸ SAHA, Cameron, Box A.6:ASET, John V Pegge. “Letter to Professor Edwin Cameron”. Dated 29th November 1992.

²⁹ Simon Watney, *Policing Desire: AIDS, Pornography and the Media* (Minneapolis:University of Minnesota Press, 1987).

³⁰ SAHA, Cameron, Box A.6: ASET, Edwin Cameron, “Opinion: Imported AIDS education materials for gay clients”, pp.11-15.

push for equal rights for people irrespective of their sexual orientation.

Meanwhile, grassroots AIDS prevention activism continued, as undertaken by anti-apartheid gay rights activists such as Simon Nkoli. After his release from jail, he formed the Township AIDS Project, which held the 1st Regional AIDS Conference for Lesbians and Gay Men in Soweto in October. Nkoli wrote an AIDS awareness pamphlet entitled “Loving Ourselves, Sharing Each Other & Caring for Our Lives: An AIDS Awareness Leaflet for Men who love others”, which contained far more practical AIDS advice than government material showing the “yellow hand” invoking the viewer to “Stop AIDS” or coffins being lowered into graves and graffiti on walls. Unlike the government’s irrelevant and vague admonitions to halt AIDS in unspecified ways, it included detailed safer sex advice for gay men relevant to a range of sexual practices, safer injecting drug use advice and advice for HIV positive people to try to stay healthy.³¹ Gay service organisations such as “Friends for Life” who aimed to care for people with HIV and AIDS visited AIDS-ill people at home and in hospital and provided food parcels.³²

As has been shown, even the most conservative racist and homophobic commentators felt comfortable talking about AIDS in the abstract third person (as ‘their’ problem), but talking about AIDS in relation to one’s own sex life or HIV status (as ‘my’ problem) was almost unheard of. As PPHC activist Michael Worsnip commented to me, in the early 1990s, almost no one was openly and publicly HIV positive, certainly he knew of no African ‘heterosexual’ young men or women who were openly living with the virus in the politicised contemporary sense.³³ In this context, when gay AIDS activists started to be open about their status and used their openness to argue politically against AIDS-related discrimination at the NACOSA conference they faced outpourings of both sympathy and controversy.

³¹ SAHA, The Simon Nkoli Archive (Nkoli), Box AM2623Q, HIV/AIDS File, Simon Nkoli. “Loving Ourselves, Sharing Each Other & Caring for Our Lives: An AIDS Education Leaflet for Men who love others”.

³² SAHA, Nkoli, Box AM2623Q, HIV/AIDS File, “Friends for Life-Caring for people with HIV and AIDS”.

³³ Interview with Michael Worsnip, 3rd July 2003, Johannesburg.

NACOSA: The Unspeakable in National Dialogue

In October 1992, the Conference of the National AIDS Convention of South Africa (NACOSA) met at NASREC under the theme “South Africa United Against AIDS”, which was clearly an outflow of the recommendation of the establishment of a National AIDS Task Force at the 1990 Maputo Conference. The conference was significant as it was the first national gathering on AIDS in South Africa, and it incorporated all the major anti-apartheid organisations and representatives from civil society, business and government. The AIDS Unit of the Department of Health and Population Development had begun organising for the conference earlier in the year by calling preparatory meetings with representatives of NGOs, political parties, trade unions and government. The keynote address was delivered by Nelson Mandela, whose speech was broadly inline with ANC AIDS policy at the time: that AIDS was a problem fuelled by the socio-economic conditions created by apartheid, that government lacked legitimacy on AIDS, and that there was a need for AIDS education.³⁴

The following session, entitled “What is AIDS? Two HIV positive people”, was addressed by Shaun Mellors. Mellors was a white HIV positive gay man who clearly had links to the AIDS Consortium and who was one of the HIV positive delegates who addressed the audience. He spoke first-hand about the painful effects of AIDS-related discrimination, including losing his job and medical aid benefits and urged the audience to sign the AIDS Charter which had been developed by the AIDS Consortium. His speech received a mixed response. Malcolm Steinburg of the Medical Research Council’s AIDS group found that his “moving” account “served to emphasize several complex human rights issues that arise with regard to the management of the HIV-infected person as well as their long term care as AIDS patients”. On the other hand, Professor Alan Flemming of the South African Institute of Medical Research found that while

The presentation was tearful and most in the audience found it moving: I was an obvious minority, as it was in my opinion an exercise in self-pity, and as the first speech from the floor diverted attention to the lesser problem (homosexual transmission) and away from the

³⁴SAHA, Cameron, Box A.11: NACOSA, Alan F Fleming. “Conference of the National AIDS Convention of South Africa (NACOSA): NASREC Conference Centre, Johannesburg 23-24 October 1992. Report”.

consequences of heterosexual and vertical transmission.³⁵

However, this reading of the speech is contingent on an understanding of the epidemic as only being important in terms of narrow concepts of risk groups and modes of transition, not as being important from a human rights perspective and as highlighting the real emotional and social-economic isolation caused by AIDS-related discrimination, in the sense that Steinburg suggested at the time. Moreover, just as anti-apartheid gay rights activists in the 1980s saw racial discrimination as equally as wrong as homophobia on the grounds of universal human rights, early openly HIV positive gay rights activists argued against discrimination less from the point of view of their sexual orientation and more from a universal human rights-based perspective: from the point of view that *all* HIV positive people should not be discriminated against on the basis of their HIV status

A second male 'heterosexual' HIV positive man spoke in Zulu to the crowd but refused to be recorded or filmed:³⁶ a factor which probably blunted the political impact of the talk. However, both of these early public first person statements on living with HIV, coupled with Barry McGeary's court action, were perhaps the first instances of a new and powerful constituency asserting itself: the HIV positive citizen who demanded his/her rights. In post-apartheid South Africa, this constituency would grow and become a powerful political voice against AIDS-related discrimination. As the first few brave openly HIV positive AIDS activists stepped forward, it showed that the right to confidentiality did not have to mean enforced secrecy, nor did people living with HIV have to give all power to the doctors treating them; they had the right to either hide or reveal their HIV status, showing their agency to form strategies and tactics to resist AIDS-related discrimination. Yet this early activism by people living with HIV was by no means the most militant internationally. As Chapter Two has shown, by the late 1980s, militant AIDS activism by people living with HIV for the development of HIV treatments had reached in United States had already reached fever pitch: with heckling of

³⁵ *Ibid.*, p.1.

³⁶ *Ibid.*, p.1. Lynn Dalrymple of the NGO Drama in AIDS Education (DramAidE) who attended that conference mentioned to me in a conversation in Durban on the 4th December 2003 that she remembers this man as having been a Zambian Zulu-speaking HIV positive man who almost a decade later denounced Mbeki's denialism as having made him stop taking his anti-retroviral combination therapy at a Treatment Action Campaign Congress in 2000.

scientists not seen to be doing enough, accusations of complicity in genocide against people living with HIV and unethical conduct of AZT drug trials and occupation of Federal Drug Administration (FDA) offices.³⁷

However, the AIDS Consortium was a network of the most militant organisations at the time pushing for rights-based AIDS policy in South Africa. Moreover, the AIDS Consortium was by no means entirely popular or universally accepted at the conference. As has been demonstrated in Chapter One, homophobia was widespread in the liberation movement as Winnie Mandela's use of a homophobic defence in the Stompei Sepeng trial and pronouncements by anti-apartheid figures about homosexuality as being 'unAfrican' (sic). While South Africa has non-discrimination on the grounds of sexuality enshrined in its post-apartheid Constitution, institutionalised, state-supported and legal homophobia has occurred in other Southern African countries (such as Zimbabwe and Namibia) in recent years, which has also been based on the fallacy that gay sexuality is 'unAfrican'. In reality, gay sexual practices and relationships are not merely a "colonial/white import" and such homophobia presents an essentialised and ahistorical notion of "African-ness", which as critics have argued relies on false notions of a "pure" and "uncontaminated" pre-colonial African culture.³⁸

In terms of my medical history 'from both sides of the bed', some anti-apartheid doctors may have been less directly prejudiced and more unfamiliar and uncomfortable with gay men or issues of sexual orientation, for instance, Jerry Coovadia admitted to me that

I grew up in a conservative Muslim home. My experience with gays was absolutely zero, so I was uncomfortable around them until I worked very closely with activists like Shaun Mellors, who was outstanding and my right-hand man at the 2000 Durban AIDS Conference...It was then that I came to really understand the importance of protecting the rights of people with different sexual orientations.³⁹

³⁷Ronald Bayer and Gerald M Oppenheimer, *AIDS Doctors: Voices from the Epidemic. An Oral History*. (Oxford: Oxford University Press, 2000), pp.138-140.

³⁸Gevisser has shown how gay Africanists have reversed the homophobic argument that gay sexuality is "unAfrican" by contending that homophobia itself, as opposed to gay sexuality, is the colonial missionary import, which some Africanists have assimilated and reconstructed as pre-colonial African purity. Gevisser, "A different fight for freedom", p.73.

³⁹ Interview with Jerry Coovadia, 3rd September 2003, University of Natal, Nelson R Mandela Medical School.

On the other hand, anti-apartheid doctors such as Salim Abdool Karim were comfortably working closely and writing AIDS policy documents with gay activists such as Edwin Cameron and in contact with gay activists living with HIV such as Peter Busse and Zackie Achmat.⁴⁰

The conference resolved to form a National AIDS Council of South Africa, representing all the groups and regions, a resolution which the AIDS Consortium's Cameron participated in drafting.⁴¹ Whereas the AIDS Consortium or the PPHC would have been natural candidates to represent AIDS NGOs, there was distrust towards the AIDS Consortium because it was

...perceived to be dominated by male homosexuals and to be concerned with issues more related to gay rights than to an AIDS campaign: several gay men expressed their disapproval of this confusing of two issues and their personal commitment to the campaign in response to the heterosexual epidemic.⁴²

Some gay men, such as Worsnip, who were promoting AIDS prevention in townships and rural areas didn't raise their sexual orientation on strategic grounds, so as to convince straight young black men and women that they were at risk of HIV infection as straight people.⁴³ On the other hand, perhaps some gay AIDS activists felt that the portrayal of AIDS as a gay issue may have fed into negative stereotypes that the disease only affected gay men and that there was something inherently diseased about gay sexuality. However, as Watney has argued, HIV infection was (and remains) a reality amongst gay people and gay AIDS educational needs should never be ignored.⁴⁴ In reality, South Africa was merely aligned to international trends where AIDS prevention material either ignored or demonized gay men, as the Aart Hendricks linked to the International Gay and Lesbian Association argued at the time, gay organizations internationally began to organize prevention activities for own communities (gay organizations did this in South Africa, as has been demonstrated above) because

⁴⁰ Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban. Salim and Quarraisha Abdool Karim met Zackie Achmat in 1994/5 and remember him being open about his HIV status.

⁴¹ Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

⁴² "Report", p.4.

⁴³ Interview with Michael Worsnip, 3rd July 2003, Johannesburg.

⁴⁴ Simon Watney, *Imagine Hope: AIDS and Gay Identity* (London and New York: Routledge, 2000).

Some governments only began education and information programmes once members of the heterosexual population were found to be infected. These programmes often neglected the needs of people in same-sex relationships or portrayed them as simply carriers of the virus.⁴⁵

Also, as has been shown above, human rights were inseparable from ordinary HIV prevention activities for gay men as censorship denied gay people access to accurate and relevant information on HIV prevention.

Despite the homophobic rumblings from some of its delegates, the first NACOSA Conference kick-started a process lasting just under eighteen months through which a broadly consultative National AIDS Plan would be debated. Despite Fleming's description of the existence of hostility towards a kind of 'white gay cabal', which some delegates saw as running the AIDS Consortium, and general hostility he picked up towards the PPHC, representatives from both groups were later elected to represent the NGO sector on the NACOSA steering committee.⁴⁶

Bread and Butter Issues, the White Invention and The Realities of Grass Roots AIDS Activism

In terms of this thesis's dual focus on "medical histories from below" and "from both sides of the bed" and the importance of different representations and readings of AIDS in shaping AIDS activism, it is important to analyze the actual views which community health workers encountered amongst 'ordinary people on the ground'. The AIDS epidemic largely affected gay men in the 1980s, but by the early 1990s that the epidemic would shift to largely affect heterosexual African young people, with predictions that infection rates amongst this demographic would reach over thirty percent.⁴⁷ As has been shown, an awareness and acceptance of personal and community risk and the emergence of more militant anti-apartheid gay rights activism were key to the formation of gay rights-based AIDS activism. However, in the amongst heterosexual African young

⁴⁵CHP Resource Room, Aart Hendricks. "On the frontline" *AIDS Action*, 17 (1992), p.6.

⁴⁶CHP Resource Room, "Update on NACOSA". *AIDS Bulletin*, 2, 1 (1993), p.1.

⁴⁷ Mervyn Susser felt as an epidemiologist that these infection rates were likely. Interview with Mervyn Susser, 7th August 2003, McCord's Hospital, Durban. See also: Solomon Benatar, "Medicine and Healthcare in South Africa-five years later", *New England Journal of Medicine*, 325 (1991), pp.30-36.

people there was limited acceptance of personal and community-wide risk and very limited mobilization on the issue, due to the characterization of the epidemic as a ‘white plot’ to discredit African sexuality which was in turn a ‘knee-jerk’ reaction to white racism around the epidemic.

AIDS activists doing grass-roots HIV prevention work in townships and rural areas, such as the PPHC’s Community AIDS Workers (CAWs) were confronted with a different reality for many African young people who were so vulnerable to becoming HIV positive AIDS was popularly referred to as either the ‘Afrikaner’ or the ‘American Invention to Discourage Sex’.⁴⁸ The racialisation of AIDS by the apartheid government in the 1980s and early 1990s led to an Othering of the epidemic, which in turn led to denial amongst many Africans.⁴⁹ For instance, aside from the proposal to deport foreign mine workers in the 1980s, and the Conservative Party’s fear of integration leading to whites being drowned in an “Aids sea” an anonymous pamphlet was circulated (probably by the apartheid government) claiming that all returning MK combatants were “AIDS carriers” and that befriending returning exiles carried the risk of becoming HIV positive.⁵⁰

Such a reverse Othering of the epidemic, as a white disease blamed on Africans to racially discredit them, may have provided the social basis for the development of post-apartheid government AIDS denialism in the late 1990s will be further discussed below. In terms of this it is interesting to note that in the early 1990s, in an interview with the ANC Health Desk’s director Cheryl Carolus interviewed in 1992, saw the greatest

⁴⁸ Interview with Michael Worsnip, 3rd July, 2003, Johannesburg. Interview with Promise Mthembu, 19th August 2003, Durban.

⁴⁹ Blaming epidemics on the racial other had a long and ignoble history both in South Africa and internationally. Here I am referring to a vast body of work, the history of representation of Africans as the sexually diseased Other, which I referenced in my BA Honors thesis to argue about Mbeki’s denialism as a response to the history of racist representations of the AIDS epidemic. For more on Othering in medicine and public health see: Sander Gillman, *Difference and Pathology: Stereotypes of Sexuality, Race and Madness* (Ithaca and London: Cornell University Press, 1985). Megan Vaughan. *Curing Their Ills: Colonial Power and African Illness* (Cambridge and Oxford: Polity Press, 1991). Karen Jochelson. *The Colour of Disease: Syphilis and Racism in South Africa* (London and New York: Palgrave, 2001).

⁵⁰ Anthony Zwi and Debbie Bachmayer. “HIV/AIDS in South Africa-Towards an appropriate public health response”. *Proceedings of the Maputo Conference on Health in Southern Africa*. Centre for Health Policy University of Witwatersrand, Resource Room, p. 69.

obstacles and limitations to the future government's response to AIDS as trying to correct the misconceptions that existed "For example, the belief among the white population that it is a 'black' problem and the kneejerk reaction that this sets off in the black population".⁵¹

Recent literature on historical changes in African sexuality has demonstrated that by the 1990s historical changes in the sexual socialisation of the youth have impacted on the vulnerability of African young people to HIV infection. For instance Peter Delius and Clive Glaser have argued that over the twentieth century the sexual socialisation of African youth transformed under the impact of Christianity, conquest, migrancy and urbanisation.⁵² Whereas, there was once a culture of intergenerational sexual openness and traditional sanctions on full penetrative intercourse, these changes caused a shift towards an intergenerational silence about sex and a peer based sexual culture, which encouraged sexual violence and the commodification of sex.⁵³

This meant that around the mid-twentieth century youths began to learn about sex from each other and the two most important mediums of sexual socialisation of the youth in townships became youth gangs (which encouraged rape and violence against women) and high schools. The 1976 Soweto Uprising led to the virtual collapse of the school system in many parts of the country. This in turn led to a merging of gang culture and school culture in *comrade* culture, which, in an African nationalist mode, expected girls to accede to the sexual demands of *comrades* to produce more soldiers for the struggle against apartheid.⁵⁴ The attraction of the explanation of AIDS as the "Afrikaner/American Invention to Discourage Sex" to many young *comrades* could in part be explained by the fact that it didn't demand behaviour change (such as use of condoms), which would have been seen as trying to reduce the production of more foot-soldiers for the struggle, or as an apartheid era government plot to control their sexuality.

⁵¹ CHP Resource Room, Michelle Galloway "Individual Focus: Addressing the Challenge of AIDS: Cheryl Carolus" *AIDS Bulletin*, 1, 1 (1992), p. 4.

⁵² Peter Delius and Clive Glaser, "Sexual Socialisation in South Africa: A Historical Perspective", *African Studies*, 61, 1, (2002), p.27.

⁵³ *Ibid.*, p.48-50.

⁵⁴ *Ibid.*, p.47-49.

Other literature on changes in African sexualities in South Africa, such as Mark Hunter and Suzanne Leclerc-Madlala have pointed towards the collapse of *lobola* leading to the commodification of sexual relationships in the 1990s.⁵⁵ In contexts of gendered poverty and inequality some poorer African young women were having sex with wealthier older men in exchange for gifts. Indeed, poverty and inequality, which could be ameliorated for some young women through such transactional sex, were more immediate issues than a stigmatized, largely invisible and poorly understood disease. Similarly, the PPHC AIDS Working Group's Community AIDS Workers (CAWs) found that many Africans in the communities where they worked did not see AIDS as a "bread and butter issue" unlike issues of housing, education and employment.⁵⁶

Confidentiality was seen by PPHC activists such as Nikki Schaay as "hindering" the Community AIDS Workers' work as they could not encourage HIV positive people to draw on their existing support structures:

Another problem is HIV-positive people or people living with AIDS are discriminated against and often isolated by the community. There is a lot of pain and silence that that person would have to live with...The issue of confidentiality often hinders our work...What can we do if we know someone is HIV positive and we know that he/she is unable to tell his/her lover, family or friends? That person needs support...Because of the potential discrimination that that person could face if his/her HIV status was known, and because we respect the individual's confidentiality we feel our work is slowed down.⁵⁷

In her 1996 critique of the Kwa-Zulu Natal Health Department's policy of confidentiality (which was in line with the National AIDS Plan devised by NACOSA), Gill Siedel argued that many patients and health workers in the province interpreted their right to confidentiality as meaning "your status is your secret", akin to the secrecy of an individual's vote in the first democratic election, an interpretation which may have

⁵⁵Mark Hunter, "The Materiality of Everyday Sex: Thinking beyond prostitution", *African Studies*, 61, 1 (2002). Suzanne Leclerc Madlala, "Silence, AIDS and Sexual Culture in Africa", *Women's International Network News*, 27, 1 (2001).

⁵⁶CHP Resource Room, Nikky Schaay "The AIDS Programme of the National Progressive Primary Health Care Network". *AIDS Bulletin*, 1, 2 (1992), p.4.

⁵⁷*Ibid.*, p.4

reduced prospects of de-stigmatising the disease.⁵⁸ The flip side of this interpretation of confidentiality was evident in gay AIDS activists who began revealing their status at an early stage, a political strategy, which enabled them to get anti-discrimination onto the agenda of NACOSA if not (yet) out onto the streets.

In a similar way, Dr Noddy Jinabhai of NAMDA highlighted the challenges facing community AIDS workers in a paper given at the 1990 NAMDA Conference. He cited a black social worker, a certain Mrs Mkhobo, as having argued that convincing black youths that AIDS was a risk was difficult: AIDS was a new disease, with foreign concepts of causality, without signs and symptoms appropriate to STDs requiring management. Sexism and the male dominance in sexual relations were the norm.⁵⁹

It is worth quoting at length the difficulties cited by Jinabhai involved in HIV prevention promotion work in 1990:

Prevention strategies require a certain social milieu, with a collectively accepted value system and norms...In reality a semi-permanent state of military destabilisation- prevents any effective community based prevention programmes. The townships and rural areas are a seething cauldron of mass mobilization, political agitation, rising waves of expectation and brutal police and military action. In such a volatile climate such issues are pushed even lower down the list of priorities. In such a context it may be unrealistic to expect community members to leave urgent and burning issues, such as police action, refugee care and poverty; to spearhead an AIDS campaign.⁶⁰

The lofty rhetoric of the NACOSA negotiations was world away from the reality of AIDS and the socio-economic and political context in which it existed. For activists such as Worsnip, NACOSA was an irrelevant and abstract 'talk-shop' of the 'high-ups', which happened in Johannesburg.⁶¹

⁵⁸ Gill Siedel, "Confidentiality and Gender Status in KwaZulu-Natal, South Africa: Implications, resistances and challenges", *Health Policy and Planning*, 11, 4, (1996), p.423.

⁵⁹ SAHA, NAMDA, Conference Proceedings and Publications Box 85-90, N. Jinabhai, "AIDS: Community Perspectives and Organisational Issues", *Health Priorities for the 1990s: Proceedings of the 7th Annual National Conference, University of Natal, Durban, 13, 14, 15 July 1990*, pp.32-33.

⁶⁰ *Ibid.*, p.33.

⁶¹ Interview with Michael Worsnip, 3rd July 2003, Johannesburg.

Prevailing social attitudes in relation to the epidemic limited the possible parameters of any progressive AIDS activism. Promise Mthembu, in an interview with me, argued that she did not see AIDS as a political priority until she became an AIDS activist in 1995 and joined the National Association of People Living with HIV/AIDS (NAPWA) after finding out her positive HIV status. She had different priorities as President of her school's Student Representative Council, which was aligned to the ANC Youth League. For such a young comrade, the momentum generated by liberation movement's push for democracy could not have been stopped to fight AIDS, which was widely understood in her community as a white gay disease or a disease of coloured and white prostitutes.⁶² Indeed, for a young comrade such as Mthembu, the struggle could not be stopped to fight AIDS:

I mean to be quite fair, I would have challenged them, because to stop the liberation struggle to focus on HIV/AIDS you know, the most important thing for me at the time, the late 80s priorities, were for Nelson Mandela to be released and for the first democratic elections on April 27th and that was the most pressing need.⁶³

After learning of her HIV status in 1995, Mthembu would become one of the most outspoken openly HIV positive women activists on issues of HIV treatment access and gender inequality and AIDS in the post-apartheid era. However, in the period when she probably became infected she had other political priorities and in her community, the predominant understanding and representation of AIDS was as a white disease that was not a threat to 'ordinary' young Africans like herself.

The ANC as a political organization was constrained by the attitudes of its membership, and could not have been seen to have been focusing on AIDS at the expense of the negotiations. Furthermore, widespread societal homophobia and perceptions of AIDS as a white, gay disease, as discussed in Chapter One could have meant that had the ANC focussed more on AIDS they would have been seen to be beholden to minority, white, gay interests at the expense of focussing on the goal of 'one man, one vote' and 'bread and butter issues'.

⁶²Interview with Promise Mthembu, 19th August 2003, Durban.

⁶³*Ibid.*

The Legacy of the AIDS Plan and Charter of Rights: The New Government and the Problems Implementing The Plan

As Chapter Three has shown, AIDS had made it onto the political agenda of the liberation movement, even if in a very limited sense, in the 1990-1994 period. Even if it was not at the very apex of the new government's agenda, its urgency as a political issue would only get stronger in the post-apartheid years, where activists equipped with the new Constitution would continue to fight against AIDS-related discrimination, which continued to exist well into the new democracy. While AIDS activists pushing for a protection of the rights of people living with HIV they would still defend the right to confidentiality, HIV positive AIDS activists increasingly agitated for their rights by a new strategy of openness about their HIV status.

As Phillips has shown, activism by people living with HIV/AIDS, which was enabled by years of relatively good health after infection prior to development of 'full-blown' AIDS, made AIDS activism unique in South Africa's epidemic history, in that unlike earlier epidemics such as polio and TB, where only one or two specific NGOs were formed to fight the disease AIDS. By 1993, in contrast, there was over seven hundred AIDS-related NGOs.⁶⁴ Indeed, there was now a whole generation of relatively fit and active people, some of whom were middle class, articulate and well-educated, and many of whom had learned the art of political mobilisation in the anti-apartheid struggle, infected with the disease whose potential as a political force to be reckoned with only began to be tapped in the late 1990s.⁶⁵

Massive shifts in the broader political context of the early 1990s certainly impacted on AIDS activism, but the social terrain in which it operated remained one where the disease was blamed on racial and sexual Others. Activists become better linked and formed new alliances on new issues like AIDS. Whereas, at the beginning of the decade there were only relatively weak links between doctor and health-worker activists and gay rights

⁶⁴ Phillips, "AIDS in South Africa", p.22.

⁶⁵ *Ibid.*, p.22.

activists, a mere two years later they formed a Consortium against AIDS related discrimination. However, doctor activist organisations such as NAMDA and PPHC disbanded, leaving gay rights organisations one of the few remaining critical voices on AIDS which may account for the prominence of gay rights activists in post-apartheid groups such as the TAC. Indeed, the visible and vocal presence of gay rights activists in this vacuum in the immediate post-apartheid era may explain why they as opposed to other civil society groupings such as NGOs and trade unions have taken up the mantle of leading militant rights-based AIDS activism as espoused by groupings such as TAC.

On the other hand, any gains made in the transition era should not be over-stated, as whilst the National AIDS Plan incorporated principles of non-discrimination on the grounds of HIV infection or membership of “high risk groups”, social attitudes remained more conservative as homophobia and white racism, and ‘knee jerk reactions’ amongst Africans to it, led to continued AIDS stigma and discrimination. Discrimination and stigma in turn led to secrecy and denial, for while gay activists were more likely to be open about their status and acknowledge the personal impact of AIDS, for most South Africans AIDS was not their personal problem, it was something other racial or sexual groups got.

In this hostile, stigmatising context, white gay men began revealing their status to highlight AIDS related discrimination, but they were in a tiny minority. This was due to the fact that respect for the right to confidentiality and privacy was often interpreted as a necessity for those infected with the virus to keep their HIV status a secret (as secretive for citizens as their votes), which made AIDS invisible. Indeed, HIV infection was largely publicly unspeakable in the first person in a political and social sense. However, doctor and HIV positive (patient) activists would hold the new government to the promises of non-discrimination in the National AIDS Plan and the new constitution they had fought so hard for, as unequal access to powerful and effective new anti-HIV combination drug therapy which emerged in the mid-1990s drove many activists to use the legal and political tools of their new political freedoms to push for the rights of HIV positive people as citizens of the new democracy.

Indeed, the post-apartheid era presented fundamentally different possibilities and challenges for AIDS activism, which is why I will end my thesis on the eve of a fundamentally new phase in AIDS activism. AIDS activism was also fundamentally transformed in 1996 by a scientific breakthrough in treatment of HIV, in the guise of powerful combination anti-HIV therapy, which changed HIV from an irrevocable terminal illness to a manageable chronic condition. The post-apartheid Constitution, enshrining as it did socio-economic rights, such as the right to access to healthcare, provided a powerful new legal and political tool.

Moreover, with the ‘people’s government’ in power, who had increasingly shown their concern about AIDS and were ostensibly in favour of rights-based AIDS policy, anti-apartheid doctor and patient activists had every reason to have high hopes for post-apartheid AIDS policy. However, these hopes were dashed during the post-apartheid era, most dramatically as a result of the government’s espousal of AIDS denialism and its related refusal to introduce anti-HIV combination therapy into the public sector of the health system, as has been well-documented elsewhere.

Recent struggles between AIDS activists and the post-apartheid government over AIDS policy can be contextualised and understood through examining the evolution of AIDS activism “from both sides of the bed” during the late apartheid and transition eras, which has been outlined in my thesis. At the time of writing, activist struggles for humane and rights-based approaches to the epidemic are still unfolding due to their primary focus being the tragedy of high and rising levels of AIDS-related illness and death, as a result of the government’s refusal until recently to roll-out anti-HIV drugs in the public sector. Such AIDS activist struggles are still unfolding, so there are no neat conclusions to the history I have outlined. However, the persistent and ongoing nature of AIDS-related stigma and discrimination in the post-apartheid era (as discussed in the Postscript), suggest that rights-based AIDS activism may not become merely confined to historical literature for some time to come.

Postscript

Thus does it happen that those who consider themselves to be our leaders take to the streets carrying their placards to demand that because we [black people] are germ carriers, and human beings of a lower order...we must perforce adopt strange opinions, to save a depraved and diseased people from perishing from self-inflicted disease.
President Thabo Mbeki. Speech at Fort Hare University, October 2001¹

While SAMA welcomes any debate on health it is obliged to point out that the view that HIV may not cause AIDS has been thoroughly discredited...This view is dangerous and its propagation may lead to cases of AIDS that otherwise would have been prevented.
Statement in the SAMJ 2000.²

To talk about human rights but not mention treatment and that's basically like saying talk about other rights and not talk about right to life, which is ridiculous.
Interview with Promise Mthembu³

The AIDS tragedy in South Africa has deepened and its dreadful impact has become fully apparent in the post-apartheid era. As I argued in Chapter Four, I cannot hope to come to any neat conclusions on how this history will end or what the full implications of the history charted in this thesis will be for future AIDS activism: therefore, this thesis ends with a Postscript. Indeed, some of the most significant events in socio-political mobilisation around the disease have only occurred in the last ten years. However, the history outlined in this thesis can be used to partially understand the nature of contemporary AIDS activism and recent conflicts between AIDS activists and the government.

More especially, contemporary AIDS activism needs to be understood as building on late apartheid and transition era rights-based, anti-apartheid gay rights (patient) and doctor activism, which arose in response to racist and homophobic stigmatising framings of the epidemic by the government and in the media and the material AIDS-related discrimination that these framings caused. This brief postscript will revise the main arguments made in this thesis about rights-based doctor and patient AIDS activism in the

¹ This quote is taken from an account of Mbeki's speech from the *Mail & Guardian*: Drew Forrest.

"Behind the Smokescreen", *Mail and Guardian*, October 26th 2001.

² This SAMA statement appeared in the SAMJ in 2000. "SAMA Official: HIV causes AIDS", *South African Medical Journal*, 90, 5 (2000), p.461.

³ Interview with Promise Mthembu, August 19th 2003, Durban.

late apartheid and transition eras and analyse the relevance of this history to an analysis of recent conflicts in AIDS policy-making. Before doing so I will sketch out the main AIDS policy-making events and points of contention between government and civil society in the post-apartheid era.

Conflicts Between Former Comrades

As I briefly discussed in Chapter Three, NAMDA disbanded due to the fact that ‘their government’ was in power, which many members saw as obviating the need for an independent and critical political doctor organisation. Some anti-apartheid health workers went into government, such as Quarraisha Abdool Karim, who became the Head of the Health Department’s AIDS Directorate, and Nkosasana Zuma, who became the first post-apartheid Minister of Health. However, AIDS policy-making conflicts occurred early on which alienated some former anti-apartheid doctors from the new government on the issue.

Sarafina II

High hopes for post-apartheid AIDS policy were partly tempered by the reality that the new ANC government ‘was still learning how to govern’. In this context, it scrambled to find ‘quick fixes’ to the problem of AIDS, such as *Sarafina II*. *Sarafina II* was an AIDS-awareness musical, which was written and produced by playwright Mbongeni Ngema in 1995. The new Department of Health chose the musical as the centrepiece of its AIDS prevention campaign. A scandal quickly arose in civil society circles and amongst opposition parties and some in the ANC over the unfair tendering procedures for the musical, which had an excessive budget of over fourteen million rand.⁴ Many critics argued that the play’s budget could have been better spent on funding community-based drama groups.⁵ The scandal made it clear to many AIDS activists that they would not

⁴ Vuyo Mvoko and Justin Pierce, “Health minister defends Aids musical”, *Mail and Guardian*, 9th February 1996.

⁵ Quarraisha Abdool Karim, for instance, resigned over the fall-out from the scandal. Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban

be consulted on important policy decisions as they had in the NACOSA process in the transition era.

Virodene

The disagreement over improper government championing of the experimental drug Virodene as an ‘AIDS cure’ in 1997 suggested that the government would be prepared to support unorthodox science on AIDS over proven, consensus positions on AIDS science. The drug was developed by scientists linked to the University of Pretoria, who were given the opportunity of an audience with the Cabinet where they obtained support of the Health Minister and Deputy President to proceed with further human trials. However, the Medicines Control Council (MCC) banned any further human tests of the drug on the grounds that the researchers had not allowed peer review of their research and had insufficient grounds to claim it was safe and effective.⁶ Indeed, chemically, it turned out to be little more than an industrial solvent, which had been blocked internationally due to its dangerous side effects.

Government AIDS Denialism

However, both these disagreements paled in comparison to the bitter and drawn-out struggle between government and AIDS activists over government denialism and HIV treatment access, which lasted from 1999 to 2003. As I have documented elsewhere, President Thabo Mbeki, supported by Health Minister Manto Tshabalala Msimang questioned HIV as the viral cause of AIDS, the accuracy of HIV tests, and the safety and efficacy of anti-HIV drugs, a set of beliefs that AIDS activists referred to as denialism.⁷ Government endorsement of AIDS denialism, due to its rejection of the safety and efficacy of combination anti-retroviral drug therapy, was in turn a crucial factor blocking equal access to combination anti-HIV drug therapy for people living with HIV.⁸

⁶ The MCC is South Africa’s pharmaceutical drug regulatory body, which is equivalent to the American Federal Drug Administration (FDA). For more on this see Charlene Smith and Aaron Nicodemus, “More human guinea pigs for Virodene”, *Mail and Guardian*, 19th March 1999.

⁷ Mandisa Mbali. “HIV/AIDS policy-making in post-apartheid South Africa”, in Daniel, J, Habib, A and Southall, *State of the Nation: South Africa, 2003-2004* (Cape Town: Human Sciences Research Council Press), pp.318-320.

⁸ The other important factor being the pharmaceutical industry’s refusal to permit production and importation of cheaper generic drugs. Mbali, “HIV/AIDS Policy-making”, pp.321-3.

For many former anti-apartheid doctors, the denial of basic tenets of the medicine explaining AIDS at a biological level represented a deep affront to the medical profession and their deep concern for the well-being of their patients. Some doctors paid dearly for their opposition to denialism and support for wider access to anti-HIV drug therapy. For instance, Dr. Janet Giddy lost her teaching post at the Medical University of South Africa (MEDUNSA) for disagreeing with her boss, Professor Sam Mhlongo, on denialism: Mhlongo was one of the President's most outspoken supporters on the denialist issue.⁹ Dr. Thys Von Mollendorf was fired from his post as Super-Intendent at Rob Ferreira hospital for allowing a rape survivor support NGO to distribute anti-HIV drugs as prophylaxis to rape survivors.¹⁰

However, the disbanding of NAMDA and its merging with the more conservative MASA to form SAMA had meant that there was no longer a politically mobilised, critical doctor voice. Illustrative of this is that while SAMA did criticise denialism as early as 2000, it only affiliated itself with TAC in 2002, two years into the debate. Still, the historical irony of being forced to be sharply and publicly critical of the government they had fought for was lost on few former anti-apartheid doctors.¹¹

However, by contrast to SAMA, major gay rights organisations whole-heartedly supported TAC from the outset: it was formed by the head of the National Coalition for Gay and Lesbian Equality Zackie Achmat, in 1998, partially in response to the death of a stalwart of the gay liberation movement, Simon Nkoli.

⁹ Interview with Dr Janet Giddy, 15th September 2003, McCord's Hospital, Durban.

¹⁰ I discussed this case in my BA Honours thesis. Mandisa Mbali, *'A long illness': Towards a History of Government, Medical and NGO Discourses around AIDS Policy-making* (Unpublished Bachelor of Arts Honours thesis, 2001).

¹¹ In all my interviews with former anti-apartheid doctors who are now AIDS clinicians I picked up a sense of profound disappointment and disbelief that relations over AIDS policy had reached such a low in the late 1990s.

TAC's Campaign

TAC itself was established in 1998 to widen access to anti-retroviral drugs for prevention of mother to child transmission (MTCT), post-exposure prophylaxis following sexual assault and for use in combination drug therapy. TAC is not entirely historically unique, like the AIDS Consortium, it is a broad-based network, which includes unions, churches, gay rights groups, health-workers and doctors. Also in common with the AIDS Consortium it frames its campaigns in terms of rights-based discourse. TAC has also used similar tactics, such as openness about HIV infection, litigation, and attracting media attention for its campaigns albeit, on a much grander scale involving mass-openness, the international media and the Constitutional Court. This demonstrates further the value of seeing recent events in the context of the history of AIDS activism in the first decade of the epidemic.

However, TAC is historically unique in terms of its militancy. On the back of its success in forcing the government to roll out Nevirapine for prevention of MTCT, at its 2002 Congress it decided to push government to adopt a National Treatment Plan to roll out anti-retroviral combination drug therapy in the public sector. Through its trade union federation ally, COSATU it forced its Plan onto the negotiating table of National Economic Development and Labour Council (NEDLAC), a major socio-economic policy negotiating forum involving government, labour, business and civil society. When government withdrew from the negotiations in 2003, TAC embarked on a civil disobedience campaign, where its members volunteered to be arrested for non-violent protest and accused the government of culpable homicide, reminiscent of those of its American ally ACT-UP in the early 1990s.¹²

¹² I have described and discussed all these events elsewhere. See: Mbali, "HIV/AIDS Policy-making".

Agency and Resistance and Representation in Doctor and Patient AIDS activism

This thesis has shown that anti-apartheid doctor activists in NAMDA and PPHC and gay rights activists in OLGA, GLOW and the AIDS Consortium, exercised their agency to resist stigmatising framings of the epidemic and related discrimination by the apartheid government and media. This undermines a Foucauldian medical historiographical characterisation of patients as mere passive ‘docile and useful bodies’ and doctors as destined to be active oppressors in modern disciplinary power.¹³ Instead in a Habermasian/Fraserian sense doctor and patient activists exercised their agency to resist AIDS related discrimination using human rights-based discourse.

While early doctor and patient AIDS activists in the late 1980s and early 1990s were not as militant in their strategies and tactics, and did not use the ACT UP style tactics of the TAC’s civil disobedience campaign in 2003, they nevertheless used the media, courts and NACOSA AIDS policy negotiations to resist racist and homophobic readings of the epidemic and real discrimination that resulted from these framings.

In its charting of the history of doctor and patient activism, this thesis has critiqued Foucauldian medical historiography’s inherent binaries of doctor/patient, active/passive and oppressor/oppressed by arguing that both doctors and patient AIDS activists have resisted AIDS-related human rights violations in the history of the epidemic in South Africa. However, I do not entirely reject Foucauldian approaches to medical history: in particular, as Triechler has shown its emphasis on issues of representation in the exercise of modern power can be used to show how AIDS has been an epidemic of signification, where power has been written onto patients’ bodies. As I argued in Chapter One, in common with Triechler’s characterisation of the early history of AIDS in America, the early epidemic in South Africa was an epidemic of signification.¹⁴ However, in South Africa as in America activists exercised their agency to resist stigmatising representations of AIDS as a ‘gay plague’ and later as a ‘black death’.

¹³ I discussed the applicability of these theories in the Introduction. Michel Foucault, *Discipline and Punish: The Birth of the Prison*, Transl. A. Sheridan, (Tavistock: Penguin, 1977), p.136.

¹⁴ Paula Triechler, *How to Have a Theory in an Epidemic: Cultural Chronicles of AIDS* (Durham and London: Duke University Press, 1999), p.19.

In the central period of this thesis's investigation, 1982-1994, the full potential of this activism was not manifest for several compelling reasons, which largely relate to how both groups of activists responded to the political centre of gravity at the time, the apartheid system, as Chapters One and Two have shown.

Firstly, as discussed in Chapter One, the Gay Association of South Africa (GASA), the country's first national gay rights movement, emerged in the same year as the epidemic arrived in the country. This movement responded early to the epidemic and gay-related discrimination around it. This may have been in a large part due to the fact that for much of the decade, gay men were the primary group infected and affected by AIDS. However, its response was limited due to the fact that the group, whose membership were mostly politically conservative white men, wished to remain 'apolitical' and had an accommodationist relationship with the apartheid government. The detention of Simon Nkoli, one of the organisation's few black members, for anti-apartheid activity revealed the organisation's racism and refusal to condemn apartheid. This in turn led to splits in the gay rights movement and the formation of several new explicitly anti-apartheid gay rights organisations, such as OLGA and GLOW. By the late 1980s this in turn enabled the first nascent links on AIDS with anti-apartheid doctors in NAMDA and PPHC. Moreover, such links were enabled by the rise of militant anti-apartheid gay rights activism, which located the fight for gay rights within universal rights-based discourse and the broader anti-apartheid struggle. This is due to the fact that such a broadening of the gay rights agenda in turn enabled the development of gay rights AIDS activism, which located the struggle against homophobic AIDS-related discrimination within the struggle against *all* AIDS-related discrimination and for a protection of the human rights of *all* people living with HIV.

Similarly, NAMDA was preoccupied with opposing apartheid and its ill-effects on medicine and the health system. This meant that for much of the 1980s whilst many of its members saw AIDS as an academically interesting subject, it was far from the top of the organisation's agenda, as outlined in Chapter Two. NAMDA was a UDF-affiliated

anti-apartheid organisation whose membership included doctors and dentists. Unlike GASA it was highly political and politicised and some of its members paid a high price for their opposition to apartheid medicine and health policy. From the distance of exile, doctor activists such as Zena Stein and Mervyn Susser saw from an early stage the threat that AIDS posed to South Africa's future well-being and tried to push the issue higher up the organisation's agenda. By the late 1980s there were small AIDS discussion groups within NAMDA its new off-shoot the PPHC, who held regular meetings on AIDS. Despite pockets of domestic interest in AIDS, the catalyst for AIDS to be placed on the agenda of the Maputo Conference largely the insistence of exiled doctor activists such as Susser and Stein. In turn, Maputo catalysed the first serious rise in interest in and activism around AIDS in the liberation movement in the transition era.

De Klerk's political reforms, which began in 1990 ushered in the transition period which brought about the release of Mandela and other political prisoners from jail, the unbanning of the ANC, the return of exiles and the political negotiations. The drastic changes in entire political landscape fundamentally impacted upon AIDS activism. As Chapter Three demonstrates, the return of exiles enabled stronger links between the ANC, NAMDA and the PPHC on AIDS, to the point where in negotiations with the government and foreign donors they often formed joint positions on the issue. This was most significantly the case at the NACOSA negotiations, which formed the first post-apartheid National AIDS Plan. The government in turn sought out such negotiations with the anti-apartheid organisations as, in the spirit of the CODESA negotiations, it realised that it lacked legitimacy on AIDS. The earliest discussions between anti-apartheid NAMDA doctors and the government on AIDS revealed very different readings of the unfolding epidemic, for while NAMDA saw AIDS as a result of the political and socio-economic injustices of the apartheid system, the government rejected such an interpretation. However, by the end of the main period of investigation, in the spirit of the bigger compromises being made at the CODESA negotiations, they had managed to formulate joint right-based policy positions on AIDS.

In turn, the ANC's rise to power, through the CODESA negotiations and the democratic constitution and elections which they precipitated, also led to the demise of NAMDA in that many of its members no longer saw the need for an independent doctor organisation. Indeed, for doctor activists in NAMDA, the rise of the 'people's government' to power held out the hope of finally achieving a legitimate and rights-based AIDS policy which would inspire public confidence. However, as discussed above, in power, the ANC did not live up to these high expectations, as during the Mandela Presidency it was "still learning how to govern". Furthermore, during the Mbeki Presidency, the denialist scandal briefly discussed above revealed the ongoing need for an independent and critical political doctor organisation. Despite this ongoing need, the demobilisation of NAMDA and its merger in SAMA meant that such an organisation took time to be re-constituted, with the effect of weakening doctor activist voices on AIDS in the post-apartheid era.

Rights-talk in AIDS activism

As Chapter Four has shown, the multi-sectoral and inclusive NACOSA also provided a space for gay rights AIDS activists to forward a rights-based AIDS policy agenda and to work more closely with anti-apartheid doctors on the epidemic. Gay rights activist Edwin Cameron, who had fought against racism within GASA and homophobic apartheid policies and laws was central to forming the AIDS Consortium, which developed an influential *Charter of Rights for People Living with AIDS and HIV*. As discussed above, the AIDS Consortium was the first multi-sectoral activist coalition targeted towards fighting AIDS-related discrimination. It also prefigured TAC tactics such as: using legal action, wider national forums to forward its views (it used NACOSA in a similar way as TAC used NEDLAC in the post-apartheid era) and publicising its views in the media. It is significant that the AIDS Consortium was based at the University of the Witwatersrand's Centre for Applied Legal Studies where the AIDS Law Project is based at the time of writing. The AIDS Law Project is one of TAC's allies and has played a key role in assisting TAC with its litigation.

As Chapter Four shows, negotiations towards developing a new democratic constitution created several draft Bills of Rights which Cameron used to argue, in a legal opinion

produced while he was still an advocate, for the right of AIDS activist organisations such as ASET to distribute explicit gay AIDS awareness literature. This latent potential of the new Constitution being developed for AIDS activism was more fully explored by the TAC. In particular, the TAC the socio-economic rights it enshrined, to obtain a Constitutional Court ruling in early 2002 for the government to provide anti-HIV drug Nevirapine to prevent mother to child transmission. As I argued in the Introduction, the legal and political force of rights-based language to make normative claims was revealed in the Transition era: this potential was even more dramatically unlocked in the post-apartheid era by the Constitutional Court's TAC ruling and rulings outlawing discrimination on the grounds of sexual orientation (a right which anti-apartheid gay rights activists had successfully lobbied the liberation movement to include in the country's post-apartheid Constitution).

Confidentiality Versus Openness and First Person AIDS Activism

Many of the key battles undertaken by activists such as Cameron and organisations such as the Consortium were over the issue of confidentiality, as shown in Chapter Four. The Barry McGearry trial and debates over notification showed that they believed in protecting the right to doctor-patient confidentiality. Similarly, anti-apartheid gay rights activists such as Shaun Mellors and Peter Busse were opting for the opposite strategy of public and political openness about their status to combat AIDS related stigma and discrimination. This was in a period when only a mere handful of gay, white AIDS activists were opting for this strategy as many South Africans may have interpreted the right to confidentiality as an obligation to maintain secrecy.



(Mass openness in action. Picture of TAC demonstration on February 14th 2002)



(Zackie Achmat, background, hugs Promise Mthembu wearing a TAC “HIV positive” t-shirt, foreground. They both live openly with HIV and have led the struggle for the realisation of the right to HIV treatment access)

The future fruitfulness of openness was demonstrated by the early 2000s TAC’s strategy of mass-openness, where at mass demonstrations a human sea of HIV positive and HIV negative activists would wear “HIV positive” t-shirts. Seen in the light of subsequent shifts towards mass-openness as a strategy of post-apartheid AIDS activism, activists in the period faced a strategic dilemma: whether HIV positive people should retain the privacy of their status to avoid AIDS-related discrimination, or whether they should reveal their status to tackle AIDS-related stigma and increase understanding of the disease and compassion for people living with HIV.

While it is easy to see the rewards of the wider adoption of such a strategy in the post-apartheid era, the risks have in cases been enormous: it is important to remember that Gugu Dlamini, one of the first African women to reveal her HIV positive status in the post-apartheid era, was stoned to death in KwaMashu township in Durban for her openness. However, it is also interesting to note that this horrific act of AIDS-related discrimination in turn mobilised HIV positive activists in the KwaZulu-Natal region, such as Promise Mthembu, to begin lobbying for equal HIV treatment access, which in turn linked them with the Treatment Action Campaign simultaneously being formed in Cape Town.¹⁵

¹⁵ Interview with Promise Mthembu, 19 August 2003, Durban.

Indeed in the post-apartheid era, for many activists, medical breakthroughs in treatment and prevention of HIV increased the stakes in fighting AIDS related discrimination. Conclusive studies were released in the mid 1990s, which showed the efficacy of AZT in prevention of MTCT and of anti-retrovirals used in combination in suppressing the virus and allowing immune system recovery. However, anti-HIV drugs were unavailable in the public sector and prohibitively expensive even for those with private health insurance.¹⁶ In 2000 Edwin Cameron, by then a Supreme Court of Appeals judge revealed his HIV positive status to protest at the fact that only a tiny minority of extremely wealthy people living with HIV, such as himself, could afford drugs: he had essentially bought something which he thought should be freely available to all, the right to live.¹⁷ The TAC blamed the government indifference and denialism and pharmaceutical industry profiteering for unequal access to the new drug therapies.

Whereas, in the early 1990s, HIV infection was viewed as having predictably debilitating and lethal health outcomes, it became widely viewed as a manageable chronic illness by the late 1990s. This had profound impacts of rights-based AIDS activism because while in the early 1990s, the activists saw confidentiality and non-discrimination as the goal, by the end of the decade, they came to see their activism as pushing for the right to life itself (as the quote from Mthembu above reveals). For many TAC activists, fighting for the right to live through treatment made openness worth the risks it entailed. Mass openness put a 'human face' on the epidemic and made the arguments for treatment access as basic an appeal at an ethical level as "a person dying of starvation asking you for bread".¹⁸ But generation of compassion or pity was not the number one goal, it was the realisation of rights to life and health as equal citizens.¹⁹

¹⁶ When I joined the TAC in 2000, it cost a bare minimum of R4000 to be on combination anti-retroviral therapy.

¹⁷ Cameron famously revealed both his gay sexual orientation and his HIV positive status during hearings on his appointment to the Supreme Court of Appeals. Given his years of dedicated gay rights and AIDS activism, in hindsight the revelation of neither fact should have come as a particular surprise.

¹⁸ This apt characterisation came from my interview with Salim Abdool Karim: Interview with Salim Abdool Karim, 15th September 2003, University of Natal, Durban.

¹⁹ For instance Zackie Achmat argued at a public lecture at University of Natal Durban in April 2003 that HIV positive people do not demand pity, they demand rights. He was in turn implicitly arguing for a shift

The Persistence of Stigma

However, this thesis has aimed to avoid writing a hagiographical Whiggish history of AIDS activism as catalysing an ever-upward spiral towards rights-based social and political responses to the epidemic. The murder of Gugu Dlamini and more recent incidents of assault, rape and murder of openly HIV positive TAC activists shows, the persistence of social stigma, despite the contemporary existence of rights-based AIDS policy documents and the democratic Constitution legally underwriting them.

As Chapter Four has shown, in the early 1990s, as the NACOSA negotiations were taking place cases of AIDS-related discrimination continued and racist and homophobic characterisations of the epidemic remained widespread. The McGeary case, the Boksburg Council's attempted closure of St Francis's Home, and numerous letters to editors in leading newspapers revealed that social attitudes were far from in line with the rights-based tone of the NACOSA negotiations.

Significantly, the fears of white racists of 'being drowned in an Aids sea' with desegregation and the return of exiles, catalysed a 'knee-jerk reaction' among African young people who, as community AIDS workers found, were apt to represent AIDS as the 'American' or 'Afrikaner Invention to Discourage Sex'. This reverse Othering, fed into social denial, which coupled with the secrecy surrounding the epidemic in this early period exposed African young people to HIV infection. As I demonstrated in my Honours short thesis, post-apartheid government denialism was driven by a desire to refute colonial and apartheid racist understandings of African sexuality which it characterised as fabricating the viral causation theory of AIDS to racially discredit Africans. The nature and scope of AIDS activism in resistance to government denialism and for treatment access has been determined by the social and cultural contexts in which it exists, as these contexts determines how people in societies interpret and represent AIDS. In terms of this, evidence of the existence of social denial and reverse Othering in

away from early tear-jerking 'AIDS testimonials' given by NAPWA activists in the late 1990s towards more militant TAC style activism.

the early 1990s could be a possible factor explaining why there was not wider resistance to government denialism: it is certainly one which requires further investigation than could possibly be offered within the scope of this short dissertation.

However, the social disruption experienced by many young Africans in South Africa in the late 1980s and early 1990s also made AIDS feel like an irrelevant issue, which the liberation movement could not be distracted by: even though HIV was beginning to spread rapidly among the African ‘heterosexual’ population, mass imprisonments, torture and killings committed by the apartheid regime, coupled with civil strife were simply more immediate issues than a largely invisible disease, whose full devastating impact was yet to be seen. Young African *comrades*, a major constituency of the ANC, felt the ANC should focus on ‘bread and butter issues’ such as unemployment, housing and land and the democratic transformation of the country not what was perceived to be a white, minority, gay disease. Yet paradoxically, although the anti-apartheid movement focussed on the broader struggle at the expense of AIDS may have hastened its spread, the fight for democratic freedoms enshrined in Constitutional rights enabled contemporary AIDS activists in the TAC to legally use the media, courts and streets to forward their aims.

At the time of writing, in January 2004, TAC had successfully forced the government to relent on developing a National Treatment Plan to provide anti-retrovirals in the public sector. It remains to be seen whether the government has the political will to provide adequate budgets, infrastructure and human resource development required to make the plan a success. In achieving this concession, TAC has been one of the most successful post-apartheid social movements, and has even been nominated for the prestigious Nobel Prize.

A comprehensive oral and archival history of TAC has yet to be written, however, as I have tried to demonstrate, there is a longer history of rights-based AIDS activism by anti-apartheid doctors and gay rights patients, a legacy which has formed the socio-political basis for contemporary activism. As I argued in my Introduction, the tragedy of AIDS

has followed the tragedy of apartheid in South Africa. The first two decades of the epidemic in South Africa were characterised by AIDS-related discrimination and stigma and resistance to such dehumanising approaches to AIDS. The history of AIDS activism demonstrates that history can be made through the exercise of agency in struggle. It remains to be seen whether AIDS activists exercising their agency will continue in the epidemic's future to successfully push for further rights-based AIDS policy gains and if so, what effect it will have on socio-cultural attitudes towards the epidemic.

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Box A

Box A.6: ASET

Box A11: NACOSA

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