

THE TREATMENT ACTION CAMPAIGN AND THE HISTORY OF RIGHTS-BASED, PATIENT-DRIVEN HIV/AIDS ACTIVISM IN SOUTH AFRICA

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Introduction

Over five million South Africans today are HIV positive.¹ In the post-apartheid era, the AIDS policy-making process has been characterised by a well-documented conflict between AIDS activists aligned with the Treatment Action Campaign (TAC) and the government over official denialism and inadequate access to HIV treatment.² Contemporary AIDS activists aligned to the TAC have framed their struggle for HIV treatment access in terms of the human rights of people living with HIV/AIDS. They insist that access to such life-saving combination antiretroviral drug treatment for all HIV positive people is a human right, in as much as it fulfils their rights to life and the socio-economic right to access to health care. As a result of the TAC's campaign, in September 2003 the South African Cabinet instructed the health ministry to develop a comprehensive HIV treatment and prevention plan. The government has since begun to roll-out HIV treatment at public health care facilities across South Africa. TAC is now seen by many commentators as perhaps the most successful example of civil society pushing for South African – and indeed international - government policy to reflect socio-economic and health rights in the post-apartheid era.³

What receives less attention is the way in which the history of HIV/AIDS activism in late apartheid and transition South Africa fundamentally shaped TAC's strategies, tactics and use of rights-based rhetoric. This Report explores two ways in which the history of AIDS activism in the 1980s and 1990s shaped TAC's politics. Firstly, it examines the influence of 'patient driven', anti-apartheid, gay rights⁴ activism on TAC. Secondly, it looks at how the early openness of gay rights activists living with HIV has shaped TAC's work against HIV-related stigma and its creation of a large and visible constituency of HIV positive people demanding their rights.

In asserting these continuities, it is not this Report's aim to underplay the discontinuities between anti-apartheid, gay rights activism in the 1980s and early 1990s and TAC's militant AIDS activism in post-apartheid South Africa. Conservative gay AIDS activists affiliated to Gay Activists of South Africa (GASA) tried and failed to gain access to the apartheid government's AIDS committees during the 1980s. In the early 1990s, anti-apartheid gay AIDS activists used transition-era negotiating spaces such as the National Aids Convention

1 A figure extrapolated from the Department of Health's 2004 annual ante-natal clinic survey.

2 I have documented and traced the possible reasons for this disagreement extensively elsewhere. M. 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).

3 For instance Friedman and Mottiar recently argued that TAC is a 'success-story' as a social movement and that TAC shows that 'It remains possible to use the rights guaranteed and the institutions created by liberal democracy to win advances for the poor and weak'. Steven Friedman and Shauna Mottiar, 'A moral to the tale: The Treatment Action Campaign and the politics of HIV/AIDS', (2004:28). Available at <www.ukzn.ac.za/ccs> Heywood's chapter in this same volume cautions that it is too early for TAC to proclaim 'victory' in its struggle for a roll-out. Mark Heywood, 'How South Africa's National Treatment Plan was won: Sustaining a civil society campaign for socio-economic rights', in (eds.) Stokke, K and Jones, P, *The politics of socio-economic rights in South Africa*, (Pretoria: Martinus Nijhoff, forthcoming).

4 I am using this term to describe the movement for equal rights for gay, lesbian, bisexual, transgender and intersex (GLBTI) people. Some queer theorists prefer to use terms such as 'queer activism' or the acronym GLBTI. I will use the term 'gay rights movement' for ease of reading and because it is the only term used in all archival and oral sources I consulted throughout the period under discussion.

of South Africa (NACOSA) to further their aims. However, the post-apartheid era brought much greater scope for AIDS activism as it brought with it a free press and the Constitutional Court, which were used to maximum potential by TAC activists, especially in advocating HIV treatment access for all, as the second and third sections of this Report argue. In using these democratic institutions, TAC defended and extended 'first generation' political rights.

It should also be noted that South African AIDS activists used rights-based discourses to attain different goals in different periods. Whereas during the early 1990s the focus was on confidentiality, by the late 1990s openness was used to push for access to treatment. This suggests that activist uses of rights-based discourse are contested and changing. Despite these historical legacies of AIDS activism of the late 1980s and early 1990s, TAC's formation in 1998 was based much more upon distinctly post-apartheid democratic cultures and institutions. Similarly, TAC's success in pushing for wider access to HIV treatment using the language of socio-economic rights poses wider theoretical questions about the potential power and meaning of discourses of human rights, when used by new social movements to fight for socio-economic justice in post-apartheid South Africa.

Theorising human rights and civil society

In considering the history behind TAC's emergence as a rights-based, civil society movement, there are a few relevant theoretical debates on human rights and civil society which need to be briefly highlighted. Although activists in TAC talk about human rights as if they are absolute, true and universal, human rights are instead contested, constructed and given different meanings in different contexts.

In the international context, human rights have been central in discourses against unfair discrimination against people living with HIV since at least the early 1990s.⁵ As TAC's lobbying and advocacy successes show, human rights remain one of the most important ways of asserting political and normative claims in contemporary post-apartheid South Africa. Moreover, South Africa's constitution is revered as being one of the most progressive in the world for its inclusion of socio-economic rights, and the rights to gender equality and non-discrimination on the grounds of sexual orientation. However, human rights discourse is not without its critics and the interpretation of human rights, or constitutional law depends very much on the socio-economic, political and historical context in which they are interpreted and invoked.⁶

5 Jonathan Mann famously invoked human rights-based discourse to argue against AIDS-related stigma and discrimination, see: Jonathan Mann. 'Medicine and public health, ethics and human rights' in (eds) Gruskin, S, Grodan, MA and Annas, G *Health and human rights- A reader*. (New York: Routledge, 1999). In a similar tradition Paul Farmer has more recently invoked human rights discourse to argue for access to HIV and multi-drug resistant tuberculosis treatment for poor people in poor countries such as Haiti. Paul Farmer, *Pathologies of power: Health human rights and the new war on the poor* (Berkeley: University of California Press, 2003).

6 For instance, Marxist critics of civil society have framed it as the realm of individual egoism and self-interest, as 'bourgeois society' which limits the power of the state and protects the right to private property. S. Ashenden, S., 'Chapter 5: Questions of Criticism: Habermas and Foucault on Civil Society and Resistance'. In Ashenden, S., Owen, D. (eds). *Foucault contra Habermas: Recasting the Dialogue between Genealogy and Critical Theory*. (London: Sage, 1999), p.143-46.

As I have argued elsewhere, Jürgen Habermas's understanding of civil society as constituting and protecting the public sphere and rights-based discourse, in his book *Between Facts and Norms*, is a useful way of understanding organisations such as TAC.⁷ TAC is an example of Habermas's idea that communication in civil society sustains the public sphere itself and, simultaneously, the maintenance of this public sphere entails the ongoing defence and extension by civil society of the right to freedoms of speech, expression and opinion.⁸ Differently put, in fighting for 'second generation', socio-economic rights such as the right to access to health care, TAC has defended and extended 'first generation', political rights such as the right to freedom of speech and opinion and the right to peaceful demonstration.

Despite the power of the invocation of rights-based discourse by civil society in post-apartheid South Africa, it has not been immune to post-structuralist and post modern critiques. Such critiques of rights-based discourse have argued that in a Derridean sense the law is part of the myth of modernity.⁹ Fitzpatrick has argued that 'Myth is the mute ground which enables 'us' to have a unified law and which brings together law's contradictory existences into a patterned coherence'.¹⁰

As I shall try to demonstrate in the following sections of this Report, as fabricated, contested and context bound as it is, rights-based discourse can be made and remade over time by activists in changing political and historical circumstances. In terms of this, the next section of this Report will demonstrate how gay rights, anti-apartheid activists invoked human rights discourse in the late apartheid and transition eras to fight racism in gay rights organisations and homophobia in anti-apartheid organisations, government policy and institutions and broader society. Some of these activists later became prominent in AIDS activist organisations such as TAC and applied political lessons they had learnt in their experiences in earlier anti-apartheid and gay rights struggles to their work in groups such as TAC. In contemporary South Africa, TAC shows that rights-based discourse can be a useful political strategy to articulate normative claims of civil society at particular social, political and historical moments, even if it is essentialised for rhetorical force.¹¹

7 M. Mbali. 'Researcher/activist engagements with AIDS policy-making after the death of objectivity', Available at www.ukzn.ac.za/ccs.

8 J. Habermas. *Between Facts and Norms*. Transl. Rehg, W. (Cambridge: MIT Press, 1996), p.367-69.

9 P.Fitzpatrick, 'Introduction'. *Inside and Outside the Law: Anthropological Studies of Authority and Ambiguity*. (London: Routledge, 1996), 10-12.

10 *Ibid.*, p.2.

11 Here, I am drawing on Marie Benedict Dembour's arguments against an outright rejection of strategic essentialisation of human rights discourse to realise normative political goals. See: Benedict-Dembour, 'Human rights talk'.

The legacy of 1980s anti-apartheid, gay rights activism

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 1983¹²

In historically contextualising TAC as a patient-driven, rights-based activist movement, it is worthwhile revisiting the earliest years of the epidemic in South Africa, over two decades ago. In the earliest years of the epidemic, there were only a handful of white gay men dying of AIDS and 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 men in New York and San Francisco in its Weekly Morbidity and Mortality Report.¹³ In South Africa, as in the United States, shocking headlines announced that the ‘homosexual’ disease or the ‘gay plague’ had arrived in South Africa.¹⁴ 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.¹⁵

The early location of HIV/AIDS activism in the gay rights movement has had significant implications for the formation of the TAC. It provides a partial explanation of why the movement is led by gay rights activist Zackie Achmat and why gay rights activist Edwin Cameron has been one of the most passionate advocates of wider HIV treatment access and non-discrimination on the grounds of HIV status. Furthermore, the emergence of anti-apartheid, gay rights activism situated in universal rights-based discourse, provided the basis for such gay rights activists to form broad-based, human rights-focussed alliances such as TAC in the post-apartheid era.

As Howard Philips has argued, HIV/AIDS occupies a unique position in South Africa’s epidemic history as the years of relatively good health following infection before the onset of ‘full-blown’ AIDS have enabled a much higher degree of activism than around other

12 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.

13 Paula Treichler has offered an excellent account of the homophobic panic generated by the emergence of AIDS in the US. Treichler has argued that AIDS is an epidemic of signification, where multiple stories have been generated focusing on the text of the body of the male homosexual. See: Paula Treichler, *How to Have a Theory in an Epidemic: Cultural Chronicles of AIDS*, (Durham and London: Duke University Press, 1999), 19-26.

14 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

15 Ruben Sher, ‘HIV infection in South Africa 1982-1989- A review’, *South African Medical Journal*, 76, (1989), p.314-318.

infectious diseases in South Africa's epidemic history.¹⁶ Even in its early years the HIV/AIDS epidemic created a large number of relatively fit and active young people, some of whom were articulate, well-educated and schooled in the art of political mobilisation in the gay rights and anti-apartheid movements. In the post-apartheid era, TAC is in many senses driven by people living with HIV/AIDS and can therefore be framed as what I will call 'patient activism'.¹⁷ As I will argue in this section of the Report, this patient activism by people living with HIV/AIDS is rooted in traditions of AIDS activism in gay rights activism, established in the 1980s and early 1990s.

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 infected with HIV, not least through social support networks established for members of gay organisations who were HIV positive. Also they were concerned about both the issue of AIDS itself and 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 anti-discrimination patient activism by gay AIDS activists.

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 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 others¹⁸ 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'.¹⁹

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

16 Howard Philips, 'AIDS in the context of South Africa's epidemic history', *South African Historical Journal*, 45, (2001), P.22.

17 I am drawing here on the work of social medical historians such as Roy Porter who have argued for medical histories to be written from patients' perspectives. See Roy Porter, 'The Patient's View: Doing Medical History from Below', *Theory and Society*, 14 (1985), p.175.

18 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.

19 'Gay plague: More victims? Source?'

history of AIDS, in particular.²⁰ For instance, posters went up in Natal urging ‘gays’ and ‘moffies’²¹ or people who had had sex with ‘gays’ and ‘moffies’ not to give blood to prevent transmission of AIDS.²² This discrimination was informed by the dominant late apartheid, public health constructions in the *South African Medical Journal* (SAMJ) and 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 were operating in complex socio-cultural contexts, as I have demonstrated elsewhere.²³

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’.²⁴ In South Africa, the discrimination against people living with AIDS in the early years even included some private hospitals refusing to admit AIDS patients.²⁵

As histories of the epidemic in the West have shown, there were similar AIDS-related discrimination and relative apathy on the part of governments to the problem in Europe and North America in the early 1980s.²⁶ However, in the United States, AIDS-related discrimination, especially the refusal to spend sufficiently on developing HIV treatment, catalysed much more radical action. Some of this influenced TAC’s activism. In particular,

20 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). Lois Grundlingh, ‘Government responses to HIV/AIDS in South Africa as Reported in the Media’, *South African Historical Journal*, 41, (2001)

21 A derogatory and prejudiced 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.

22 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.

23 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), p.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), p.158-159.

24 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, ‘AIDS, Homophobia and Biomedical Discourse’, p.21-23. Simon Watney, *Policing Desire: Pornography, AIDS and the Media* (Minneapolis: University of Minnesota Press, 1987).

25 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.

26 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).

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.²⁷ 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!'.²⁸

There was no such placard waving on the part of GASA, South Africa's main gay organisation during the early 1980s. GASA actively eschewed militancy, in a context where gay and lesbian sexual activity was criminalised 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 men. GASA believed in a different, 'apolitical' model of organisation, which mainly focussed on providing social support.²⁹ 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.³⁰ 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 accommodationist strategy.'³¹

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 such gay men.³²

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 in Cape

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

28 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*.

29 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 prerequisite to gay political organisation.

30 Gevisser, 'A different fight for freedom', p.50-51.

31 Gevisser, *Ibid.*, p.51.

32 Gevisser, *Ibid.*, p.48.

Town was, by contrast, a ‘shrill voice in the dark’ providing a range of AIDS prevention and care services;³³ and it used its newsletter to decry homophobic AIDS-related discrimination.

Fundamentally, however, with its accommodationist and nonmilitant strategy, GASA’s answer to this crisis was not to wave banners and toyi-toyi. It was to meet with the late apartheid government’s National Department of Health and Population Development’s National AIDS Advisory Group. For GASA, recognition by the minister of health of GASA as the ‘official mouthpiece of the gay community’ with which the National AIDS Advisory Group was to liaise was seen as ‘a positive development’.³⁴ However, consultation did not translate into representation on policy-making bodies, as 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

While AIDS was taken seriously by gay rights organisations, there was the overshadowing issue of apartheid and issues of institutionalised racism and legal segregation. The organisation’s racism and ‘apoliticism’ on apartheid were highlighted by its manner of dealing with the 1984 arrest and incarceration of one of its members, Simon Nkoli. Nkoli was detained for anti-apartheid activity with other United Democratic Front (UDF) activists who were tried in the Delmas Treason Trial. Nkoli became a *cause celebre* for anti-apartheid gay rights activists around the world. As a result of their efforts, GASA was suspended from the International Lesbian and Gay Association (ILGA) for its ‘apolitical’ stance and refusal to condemn apartheid, which crystallised in its refusal to support Nkoli.³⁶

In the years when GASA was trying to respond to AIDS, the political divide in GASA between a handful of militant anti-apartheid activists such as Nkoli, Edwin Cameron, Sheila Lapinsky and Peter Busse³⁷ and accommodationist non-militant apolitical activists would become so great that GASA ceased to exist as a national movement. Speaking of this period, Achmat has argued that there was ‘a moral failure of the white lesbian and gay community with very few exceptions...to speak out against apartheid and racism’.³⁸ 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.³⁹ Yet simultaneously, these conflicts created new kinds of radical, more militant gay rights activism, which was located explicitly in human rights-based, anti-apartheid politics, a development essential for the later involvement of some of these activists in the TAC.

33 Gevisser, *Ibid.*, p.59.

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’.

36 Gevisser, ‘A different fight for freedom’, p.56.

37 Busse was later a founder member of the National Association of People Living with HIV/AIDS, which was formed in the mid-1990s.

38 Zackie Achmat ‘Appendix to Edwin Cameron’s Address to the HIVOS Symposium on *Homosexualities, HIV/AIDS and HIV-Why?*’, 21st October 2004.

39 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*’.

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'. Significantly, the article argued that gay rights were inseparable from human rights in general and *for all*.⁴⁰

There are ongoing racial, class and gender-based cleavages in the gay rights movement and in the communities it represents today, which is by no means socially or culturally unified or uniform. Indeed there remains a great deal of racism and sexism and classism in these communities, which pose ongoing challenges to the movement.⁴¹ Still, the importance of even a small handful of gay rights and anti-apartheid activists having located gay rights within wider discourses of universal human rights and in broader progressive movements such as the UDF in the mid-1980s must not be understated.

There were several legacies of their early location of gay rights within wider human rights discourses of the anti-apartheid movement. It would later politically enable the National Coalition for Gay and Lesbian Equality (NGCLE) to succeed in lobbying for the enshrinement of non-discrimination on the grounds of sexual orientation into the country's post-apartheid Constitution. The Equality Project would also later manage to obtain thirty-five pieces of legislative reform, based upon this strategy of invoking wider human rights discourse.⁴² These successes may have enabled gay activists to turn their attentions to wider struggles such as TAC's and to apply lessons on the power of invoking human rights discourse in a broader-based movement like TAC campaigning for wider access to HIV treatment.

Significantly, the move by Simon Nkoli into AIDS activism and his early openness about his HIV status and his subsequent death from AIDS over a decade later, became a catalyst for the formation of the TAC. This was the case as anti-apartheid gay rights and head of the NGCLE, Achmat, promised 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.

An instance of the new anti-apartheid, gay rights activism was the work of Cameron in the 1980s. 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 early to mid-1980s, he was a trade union lawyer who 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 Tomms) when they were imprisoned for anti-apartheid activity. 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

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

41 Teresa Dirsuweit, 'The problem of identities: The lesbian, gay, bisexual, transgender and intersex social movement in South Africa', (2004), CCS Research Report for the Globalisation, Marginalisation and Contemporary Social Movements in South Africa Project. Available at <www.ukzn.ac.za/ccs>

42 Dirsuweit, 'The problem of identities', p.8.

and oppression that they faced as gay people and the overwhelming racist oppression that black South Africans faced.⁴³

GASA's refusal to support Nkoli during his detention, which revealed its 'apolitical' and 'accommodationist' nature, precipitated the collapse of GASA as a national organisation. In its place several explicitly militant, anti-apartheid, gay rights political organisations were formed, which were not only focussed on fighting homophobia, but were also directly opposed to both GASA and its tacit support of apartheid such as The Rand Gay Organisation and the Gay and Lesbian Organisation of the Witwatersrand (GLOW) and the Organisation of Gay and Lesbian Activists (OLGA).⁴⁴

It was a messy fracturing 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 imprisoned and tried with him because of his sexual orientation. 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.⁴⁵ It has been documented elsewhere 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.⁴⁶

This history could help to illustrate why TAC activists such as Achmat from an anti-apartheid gay rights background have come to see gay rights as closely related to a broader struggle for the realisation of social justice and human rights for all. Also, a case could be made that Achmat's notion of campaigning for treatment access from within the ANC as a 'loyal, card carrying ANC member' may relate to the tradition established in the late 1980s and 1990s typified by Nkoli of anti-apartheid gay rights activists lobbying for gay rights from within ANC and UDF structures.⁴⁷

The origins of a TAC's 'campaign for openness' in the early 1990s

On Friday night at Simon [Nkoli]'s funeral I made a call for ten people with HIV/AIDS, their families, friends and allies to start a symbolic fast for access to treatment on 10 December 1998... Openness and Treatment are two pivotal issues... A campaign for 'Openness' is in reality a call for activism and the assertion of identity.

43 Gevisser. 'A different fight for freedom', p.60.

44 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', 57.

45 Nkoli, 'Wardrobes', p.256.

46 Gevisser, 'A different fight for freedom', p.70-71.

47 For more on this and the activist debates it has generated see Annie Devenish and Mandisa Mbali 'A critical review of Zackie Achmat's Wolpe Memorial Lecture, March 2004', Available at www.ukzn.ac.za/ccs.

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.
A letter from Zackie Achmat to HIV/AIDS activists, 1998.⁴⁸

In one of his first letters to AIDS activists calling for the formation of TAC quoted above, written when he was the head of the NCGLE, Achmat called for TAC's campaign for treatment to be based on HIV positive activists being open about their HIV status. Openness about HIV status has been a cornerstone of TAC's political strategy as a social movement.

Despite the fact that the first few HIV positive AIDS activists publicly revealed their status to fight AIDS-related discrimination in the early 1990s, Achmat's call for openness was a bold step even in the late 1990s. However, the full political potential of this strategy of disclosure to push for human rights-based AIDS policy was not fully realised when the first activists disclosed their status in the early 1990s and would only become apparent when it was adopted *en masse* in the post-apartheid era by TAC. From a mere handful of openly HIV positive white gay activists in the early 1990s, in the first years of the twenty-first century, AIDS activists' would heed Achmat's call and TAC's 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 as I have begun to argue above, the seeds of TAC's militant patient activism of the late 1990s grew largely from anti-apartheid, gay rights activism in the late apartheid and transition eras. The transformation of HIV/AIDS from an unspeakable and invisible epidemic in the early 1990s to one which affects a highly politically vocal and visible constituency in the early 2000s has been absolutely fundamental to the success of TAC as a political movement. Whereas human rights-focussed AIDS activists in the early 1990s were largely focussing their efforts on pushing for wider respect for patients' rights to confidentiality, in the late 1990s, human rights-focussed AIDS activists in TAC were using openness to push for the socio-economic right to access to health care. This clearly points to the changing and contested nature of human rights discourse. Similarly, AIDS activists' strategic use of spaces for political negotiation of AIDS policy provided to them in the transition period, such as NACOSA, suggests how civil society contributes to the creation and extension of democratic public spaces.

Openness about HIV status was and remains a significant and courageous step because of HIV/AIDS-related stigma. This stigma has been articulated with pre-existing racist, homophobic and sexist readings of disease and sexuality.⁴⁹ As with many other previous

48 Centre for Health Policy (CHP), University of Witwatersrand, Resource Room, 'A Letter from Zackie Achmat', Zackie Achmat, *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*. Zackie Achmat 'A Letter from Zackie Achmat'.

49 I demonstrated the history of such stigmatising discourses in the apartheid era in my BA Hons thesis: Mandisa Mbali. 'A long Illness': Towards a history of government, medical and NGO discourses around AIDS policy-making'. Available at www.ukzn.ac.za/ccs.

epidemics, both internationally and in South Africa, outsiders and minorities have been unfairly blamed for the spread of AIDS.⁵⁰

Just over a decade ago, in the early 1990s, 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.

In terms of early patient activism, the Maputo Conference on Health in Southern Africa, and NACOSA process it catalysed, 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*.

In the early 1990s, the first handful of gay AIDS activists got the ANC to denounce AIDS-related homophobia. 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, which influenced South Africa’s post-apartheid democratic Constitution. The origins of the first-person, patient-driven AIDS activism, which has driven TAC’s campaign based on the discourse of socio-economic rights is a significant, under-documented and unique phenomenon in South Africa’s epidemic history. 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.

AIDS was an ‘invisible epidemic’ in the early 1990s, which, due to stigma, was largely unspeakable publicly in the first person. The epidemic’s invisibility was assured by stigma and discrimination that had led to activist demands for the protection of the right to doctor-patient confidentiality. Doctors were professionally and ethically obliged to maintain secrecy on the patient’s condition. However, this right may have been interpreted by patients as *necessity* to maintain secrecy, as opposed to the *right* of the patient to decide on whether to publicly disclose their HIV status. Illustrative of the contradictions and dilemmas posed to activists in this period, is AIDS activist Cameron, who was working flat out and very publicly for human rights-based policy and legislation (largely to uphold confidentiality). Yet Cameron was terrified to reveal his own HIV positive status (which had been diagnosed in 1986) and only did so in 1999.

That being said, the reasons why gay men remained virtually the only patient voice in

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

the early 1990s are suggested by several factors in the period. Firstly, the epidemic affected the gay community early and hard.⁵¹ As discussed above, AIDS was first represented as a 'gay plague' and homophobic AIDS related discrimination swiftly followed such representations. Although this representation receded as it became clear it would mainly affect heterosexuals, the memories of the early 'gay plague' representations remained.⁵² Also, there was a well-developed, militant, gay, anti-discrimination, AIDS activist movement established in the United States by the late 1980s which inspired South African anti-apartheid gay activists organising against AIDS-related discrimination. While South African gay AIDS activism would not reach such a fever pitch until the late 1990s, freed from the shackles of GASA's moderation and 'apoliticism', gay rights activism including AIDS activism became more measurably militant and outspoken. Early openly HIV positive AIDS activists pushed 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.

Cameron, who had fought against *both* regressive amendments to criminal law discriminating against gay people *and* against racism in gay organisations in the 1980s, turned his brilliant legal and political mind to fighting AIDS-related discrimination in the 1990s. By 1992, he was based at the University of Witwatersrand's Centre for Applied Legal Studies (where AIDS Law Project, a close ally of TAC's is based today), and played a key role in founding The AIDS Consortium Project.⁵³ Several anti-apartheid organisations, which had played a vital role in pushing for AIDS policy to be rights-based, were involved in the AIDS Consortium. The AIDS Consortium was central 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*⁵⁴. 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.

This was by no means the extent of rights-based AIDS activism in the period. 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-

51 *Ibid.*, pp.3.

52 Edwin Cameron, 'Address to the HIVOS Symposium on *Homosexualities, HIV/AIDS and HIV-Why?*', 21st October 2004. In his address, Cameron went on to argue that many anti-apartheid, gay activists threw themselves into fighting the epidemic in the 1990s as if it were solely 'straight epidemic', thereby ignoring the need to struggle for prevention services and programmes designed for, and cognizant of the specific vulnerabilities of, gay, lesbian, bisexual, transgender and intersex people.

53 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.

54 *Ibid.*, p.1.

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.⁵⁵

McGeary was a patient infected with HIV, which was then heavily stigmatised 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.⁵⁶ 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’.⁵⁷ 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 I would argue was partially caused by the earlier 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 declaring their status to tackle stigma and promote HIV prevention 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 to prevent occupational exposure: that is, an infectious disease where doctors would have to notify the authorities when patients were found to be HIV positive.⁵⁸ On the other hand, the earliest proposals for notification met with some resistance on the grounds of existence of the ‘window period’ of the earliest months of infection, where HIV infection may not be detectable and against the breaching of doctor-patient confidentiality in the case of such a stigmatised disease.⁵⁹

55 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), p.54-69.

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

57 SAHA, 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.

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

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

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: in the transition period, discrimination against gay and lesbian people remained legal. Moreover, 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.⁶⁰ 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.⁶¹

In October 1992, 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.

Significantly, in the history of patient activism, a 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 two 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 emphasise 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 wrote: '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 consequences of heterosexual and vertical transmission.'⁶²

60 SAHA, 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).

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

62 *Ibid.*, p.1.

However, this reading of the speech is contingent on and 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 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, 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:⁶³ 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 their power to the doctors treating them; they had the right to either hide or reveal their HIV status, showing their agency in forming 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. By the late 1980s, militant AIDS activism by people living with HIV for the development of HIV treatments had reached fever pitch in the United States: with heckling of 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.⁶⁴ This kind of militant treatment activism would be echoed a decade later in TAC's 2003 civil disobedience campaign, which attempted to place charges of culpable homicide against Health Minister Manto-Tshabalala Msimang and Trade and Industry Minister Alec Erwin.

Just over a decade ago, the NACOSA 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.⁶⁵ Whereas the AIDS Consortium would have been a natural candidate 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

63 *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.

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

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

men expressed their disapproval of this confusing of two issues and their personal commitment to the campaign in response to the heterosexual epidemic.’⁶⁶

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 Progressive Primary Health Care Network (PPHCN), representatives from both groups were later elected to represent the NGO sector on the NACOSA steering committee.⁶⁷ Early AIDS activists tested the democracy and potential of transition era political and legal spaces just as TAC activists would, just under a decade later, test the potential of democratic institutions and legal spaces to deliver on socio-economic rights outlined in the new Constitution which was fashioned in the mid-1990s under a gathering dark cloud of steadily rising new HIV infections.

Yet while a tiny group of gay rights activists were being open about their status to combat AIDS-related discrimination, it was heavily stigmatised among straight African young people who were increasingly becoming infected. Indeed, HIV positive people were routinely counselled that their status was confidential, which may have been interpreted as meaning an enforced secret. 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.⁶⁸

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 reduced prospects of de-stigmatising the disease.⁶⁹ 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.

66 ‘Report’, p.4.

67 CHP Resource Room, ‘Update on NACOSA’. *AIDS Bulletin*, 2, 1 (1993), p.1.

68 *Ibid.*, p.4

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

Out and open in the streets: TAC as a post-apartheid, rights-based and patient-driven movement

To talk about human rights but not mention treatment and that's basically like saying talk about other rights and [do] not talk about right to life, which is ridiculous.

Interview with Promise Mthembu⁷⁰

In earlier sections of this Report I have tried to show how TAC shares historical continuities with late 1980s and early 1990s anti-apartheid gay rights activism such as the emphasis on universal human rights-based discourse and early openness of such activists about their HIV status. However, it is important to note that despite its roots in early AIDS activism in the late apartheid and transition eras TAC is also fundamentally a *post-apartheid* political creature, which has used entirely new political and legal spaces created in post-apartheid South Africa. There are two main historical developments post 1994, which I wish to point to which have fundamentally contributed to TAC's emergence, agenda and the strategies it adopted: the development of a powerful combination of antiretroviral drug therapy (HIV treatment)⁷¹ and the adoption of South Africa's democratic Constitution enshrining socio-economic rights.

As has been discussed above, TAC was formed in 1998 by Achmat, partially in response to the death of a stalwart of the gay liberation movement, Simon Nkoli. Simultaneously, the stoning to death of openly HIV positive AIDS activist Gugu Dlamini for revealing her HIV status mobilised HIV positive activists in the KwaZulu-Natal region, to begin lobbying for equal HIV treatment access, which in turn linked them with TAC simultaneously being formed by anti-apartheid, gay rights activists in Cape Town.⁷²

TAC aimed 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 in the early 1990s, TAC 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.

TAC's post-apartheid campaign for wider access to HIV treatment was necessitated by two factors blocking access to HIV treatment: pharmaceutical industry profiteering through protection of patent monopolies, and the rejection of the efficacy and safety of HIV treatment

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

71 This is generally referred to in medical circles as Highly Active Anti-retroviral Therapy (HAART), it can also be referred to as ART (antiretroviral therapy) or ARVs (antiretrovirals). TAC has tended to refer to it simply as 'HIV treatment'.

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

by several key figures in government, such as the President and Health Minister, due to their adherence to AIDS denialism.

The new, powerful and very expensive HIV treatment worked by suppressing viral replication and allowing for immune system recovery. This scientific breakthrough, which was announced in 1996, changed HIV from an irrevocable terminal illness to a manageable chronic condition in the wealthy Northern countries. However, the pharmaceutical industry kept the price of these medicines unaffordable in developing countries in the South with a high HIV prevalence, such as South Africa, through abusing their patent monopolies.

In 2001, the Pharmaceutical Manufacturers Association representing 47 multinational pharmaceutical companies took the South African government to court to block the passing of the *Medicines Act* of 1997, which would have allowed for the production and importation of cheaper generic essential medicines, such as antiretroviral drugs in South Africa. TAC supported the government in the case acting as 'friend of the court' and helped to mobilise local and international activist support and global public opinion in favour of the government. Due to international public pressure and the negative perceptions the case generated about the pharmaceutical industry, the case was dropped. TAC subsequently successfully pursued action against industry abuse of patent monopolies to inflate prices at the Competition Commission against GlaxoSmithKline (which produces antiretrovirals such as AZT and 3TC) and Boehringer Ingelheim (which produces Nevirapine).

Wider treatment access was also blocked by the bitter and drawn-out struggle between government and TAC activists over government denialism and HIV treatment access, which lasted from 1999 to 2003. 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 HIV treatment, a set of beliefs that AIDS activists referred to as denialism.⁷³ This denialism was driven by Mbeki's belief that AIDS was a post-colonial, racist conspiracy to discredit African sexuality.⁷⁴ 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.⁷⁵

While TAC may not be the first instance of rights-based, patient-driven AIDS activism in South African history, it is certainly 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 TAC 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, the Congress of South African Trade Unions (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,

73 M. 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), p.318-320.

74 M. Mbali. 'AIDS discourses and the South African state: Government denialism and post-apartheid AIDS policy-making', Forthcoming *Transformation* (2004).

75 The other important factor being the pharmaceutical industry's refusal to permit production and importation of cheaper generic drugs. Mbali, 'HIV/AIDS Policy-making', p.321-3.

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.⁷⁶

TAC's militancy in the post-apartheid era, as expressed in its civil disobedience campaign can be partially explained by the fact that medical breakthroughs in treatment and prevention of HIV increased the stakes in fighting AIDS related discrimination. Whereas previous struggles were about confidentiality and equality, in the struggle for treatment life itself was at stake, which meant more radical strategies had to be adopted. In 1999, 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.⁷⁷

For many TAC activists, fighting for the right to live through access to treatment made openness worth the risks it entailed. The brave openness of activists like Achmat and Justice Cameron 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'.⁷⁸ But as Achmat argued from the outset, generation of compassion or pity has not been TAC's number one goal. It is the realisation of the right to life and health for HIV positive people, as equal citizens.⁷⁹ Similarly, TAC is unique in its ability to use the post-apartheid Constitution, enshrining as it does socio-economic rights, such as the right to access to healthcare, as a powerful legal and political tool. A tool which it successfully used in a 2001 Constitutional Court challenge which forced the government to roll-out Nevirapine to prevent mother-to-child-transmission.⁸⁰

At the time of writing, in November 2004, TAC had successfully forced the government to relent on developing a National Treatment Plan to provide anti-retrovirals in the public sector. Critics such as TAC argue that government appears to lack the political will to provide adequate infrastructure and human resource development required to rapidly roll-out the treatment and make the plan a success. Its most recent 'Right to Know Campaign' has also criticised the government for not being transparent about its patient targets and the timetable for the roll-out. Despite the roll-out's ongoing shortcomings, in forcing the government to develop a National Treatment Plan and being the roll-out of HIV treatment, TAC has been one of the most successful post-apartheid social movements.

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

77 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.

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

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

80 For an excellent account of this see GJ Annas, 'The right to health and the Nevirapine case in South Africa', *New England Journal of Medicine*, 348, 2003.

Concluding remarks

Placing TAC in the longer history of rights-based, patient-driven AIDS activism can help to explain its political nature in several crucial ways. Firstly, the fact that anti-apartheid, gay rights activists played such an important role in early patient driven AIDS activism helps to explain why the movement is led by a former anti-apartheid gay rights activist. TAC's emphasis on universal human rights also mirrors the location of gay rights within universal human rights discourse by anti-apartheid gay rights activists in the late 1980s and early 1990s. Also, the emphasis of TAC activists such as Achmat on fighting for treatment 'from within' ANC structures mirrors Nkoli's gay rights strategy in the 1980s and 1990s of pushing for gay rights from within the UDF and later ANC structures. Similarly, Achmat's call for TAC's campaign to be based on openness was not the first time the strategy had been used. Anti-apartheid gay rights activists living with HIV had first begun to reveal their status at political forums such as NACOSA to push for AIDS policy to be rights-based in the early 1990s.

What is new and specifically *post-apartheid* about TAC are its demands for access to new drug therapies which did not exist until after 1996 and its use of South Africa's new democratic constitution to forward its aims. Furthermore, it is far more militant than any earlier forms of rights-based, patient-driven activism and it has had far greater success in encouraging mass-openness.

As legally, philosophically and politically contingent as rights-based discourses may be, TAC has powerfully deployed this rhetoric to push for policies that have literally saved lives. Human rights-based discourses have also been used differently by AIDS activists over time in South Africa. Whereas they were initially invoked mainly to promote confidentiality, the rights arguments are now used by a movement led by openly HIV positive activists to push for access to treatment. This shows that the invocation of human rights-based discourse by civil society is contested, changing and context bound; which is not to discount its potential and a political strategy. This history of patient-driven, rights-based AIDS activism also demonstrates that in a Habermasian sense communication in civil society sustains and maintains the public sphere and gives meaning and substance to first generation political rights; just as AIDS activists in the transition era tested the lobbying and advocacy potential of new transition-era negotiating spaces such as NACOSA, TAC has taken its fight to new democratic spaces such as the Constitutional Court.

It is unclear whether TAC's success in invoking rights-based discourses in new democratic spaces will be replicated by other new social movements pushing for the realisation of socio-economic rights. For instance, will they be able to marshal the kind of funds and legal support TAC has used in its court challenges if they wish to pursue similar action? What sort of success could new social movements which contradict aspects of the Constitution, such as the Landless Peoples' Movement, which argues for expropriation of land (which contradicts the Constitution's property-rights clause) expect in such court action? Certainly, TAC reveals how socio-economic rights on paper can in certain instances be translated into rights in reality through civil society activism.

A comprehensive oral and archival history of TAC has yet to be written, however, as I have tried to show, there is a longer political history of rights-based, AIDS activism by anti-

apartheid gay rights, HIV positive patients, a legacy which has formed the socio-political basis for TAC's patient-driven, contemporary activism for the realisation of the socio-economic right to access to health care. The history of rights-based, patient driven AIDS activism demonstrates that history can be made through the exercise of agency in struggle. However, it remains to be seen whether AIDS activists exercising their agency will continue to successfully push for further rights-based AIDS policy gains, and it also remains to be seen how successfully the roll-out of HIV treatment will proceed.