

Chapter 3

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PROGRESSIVE HEALTHWORKER AIDS ACTIVISM, 1982-1994

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Introduction

This chapter focuses on how anti-apartheid healthworker organizations and activists- who commonly referred to themselves as being 'progressive' healthworker activists- took up the issue of AIDS in the 1980s and early 1990s. It argues that progressive healthworkers were central actors in the development of AIDS activism, who got involved with the disease by virtue of their professional experience and expertise in relation to it. Secondly, it contends that their political orientation as *progressive* healthworkers meant that they were adherents to the much older idea of Primary Health Care (PHC), which made them want to disseminate their knowledge about AIDS more widely in 'communities'. From 1990, South Africa's negotiated transition renewed earlier possibilities for the kind of state-civil society collaboration around public health as shown in the Karks' project.

The thesis of which this chapter forms a part explores the social and political origins of South Africa's AIDS movement. It focuses on the establishment of an AIDS-related social network between anti-apartheid activists and on how knowledge about the epidemic moved through this network in ways which were generative of this movement. It is not the first thesis to explore the early intellectual history of a social movement in this manner. For instance, Christopher Brown's history of the foundations of British Abolitionism explores the movement's

tentative beginnings, an exploration of the period when antislavery efforts developed cautiously and haphazardly, without unifying purpose or preset goals, before individual initiatives coalesced into a movement.¹

Documenting the early intellectual history of social movements is important because it can help historians to understand why people join movements. This is because participation in movements is not simply determined by which activists an individual knows, but also by their resonance with individuals' identities and their sense of meaning and place in the world.² For all these reasons it is valuable to trace earlier intellectual, social and political histories behind social movements.

This is also not the first project to address how South African healthworkers dealt with AIDS clinically or socially in the past. For instance, Gerald M. Oppenheimer and Ronald Bayer's book *Shattered Dreams? An Oral history of the South African AIDS epidemic*, uses oral history methods to document the social history of doctors' and nurses' experiences with AIDS.³ While this chapter is, similarly, partially based on key informant interviews with doctors, nurses and community AIDS workers, it also has an archival basis. To be more precise, it is also based upon media articles published in the period and records of the National Medical and Dental Association, PPHC Network and Centre for Health Policy held at the University of the Witwatersrand.

While *Shattered Dreams* presents a compelling account of how the advent and development of the South Africa's AIDS epidemic has changed the practice of the medicine in the country, it neglects two extremely important determinants of the political history of early healthworker AIDS activism. Firstly, it does not offer a detailed analysis of how some progressive doctors' experiences of AIDS in exile shaped their involvement in the Maputo Conference and the first National AIDS Plan following the National AIDS Convention. Secondly, the book discusses some doctors' progressive backgrounds as fuelling their disappointment of several prominent AIDS doctors at ANC government leaders' accusations they were racist to assert AIDS denialist viewpoints. However, it

¹ C. Brown, *Moral Capital: Foundations of British Abolitionism* (Chapel Hill, 2006),

² Brown, *Moral Capital*, p.2.

³ G. M. Oppenheimer and R. Bayer, *Shattered Dreams? An Oral History of the South African AIDS Epidemic* (Oxford, 2007).

fails to mention that an additional source of disappointment was that some of those doctors who remained in civil society had worked hard to help to draft the first National AIDS Plan and, therefore, firmly believed that the ANC government would take AIDS seriously once in power.

AIDS-related, advocacy-orientated social networks, were partially, but significantly constituted by and of progressive healthworkers from 1988. These networks of politicized individuals who wished to act on AIDS did not spring spontaneously from the ether, but built on older social movements, such as the progressive healthworker movement. Mario Diani has argued that earlier social ties and participation in other movements motivates people to participate in newer social movements.⁴ This theory can be applied to the emergence of the AIDS movement (TAC). In particular, the formation of AIDS-related advocacy networks matters in the history of AIDS activism because the public and private ties between individuals on the issue and pre-existing participation in the activities of other, related movements (such as the progressive healthworker movement) motivated people to participate in the AIDS movement when it formed.

In this regard, it is worth noting that Florence Passy has argued that as networks play a role in identity formation they are a powerful political resource for social movement formation: this is because

embeddedness in formal or informal networks close to that issue [under protest] helps individuals to create a salient identity which is an important cultural resource for joining the protest, and which facilitates the emergence of a political consciousness related to specific political issues...individuals who have been strongly socialized and who identify closely with a protest issue are likely to become more intensely involved in a social movement.⁵

To apply this to the history of AIDS activism, earlier AIDS-related advocacy networks which are discussed in this chapter are worthy of analysis because they translated earlier anti-apartheid, socio-political and cultural energy, identities and experience into the later AIDS-related social movement.

⁴ M. Diani, ‘Introduction: Social movements, contentious actions and social networks: ‘From metaphor to substance?’ in (eds.) M. Diani and D. McAdam, *Social Movements and Networks: Relational Approaches and Collective Action* (Oxford, 2003).

⁵ Passy, ‘Social networks matter’.

The group of anti-apartheid activists that this chapter focuses on were progressive healthworkers: as such, their initial interest in the issue was generated by both professional intellectual curiosity and involvement in research and treating patients living with the disease. Similarly, as politicized healthworkers they wished to spread their specialist knowledge about the disease and epidemic within progressive circles. Lastly, progressive healthworker activists held large conferences which were key to knowledge-dissemination in progressive circles and the formation of AIDS-related advocacy networks. As shall be argued in the penultimate chapter of the thesis these networks would then provide an important social and political basis for the emergence of the Treatment Action Campaign in 1998.

1) The influence of earlier ideas about PHC on the progressive healthworker movement and its approach to AIDS

Progressive healthworkers' approaches to the new disease drew on earlier ideas around the relationship between the apartheid political system and the racial patterns of disease distribution. Their goal of forming AIDS-related, advocacy-orientated social networks and their visions of post-apartheid AIDS policy built on older ideas about equitable, free universal health care. Community-orientated primary health care (PHC) has been a key part of the model for the free delivery of health care since the late 1930s in South Africa. This was an idea pioneered decades earlier by Sidney and Emily Kark. As we shall see in section 3 of this chapter, following the creation of the National Progressive Primary Health Care Network (the PPHC network), the idea of community AIDS workers mirrored the Kark's idea pioneered fifty years before of health assistants.⁶ Also, the PPHC network's idea of community involvement in AIDS policy-making and implementation drew heavily on the idea of community-orientated PHC. As the rest of the chapter goes on to show, the idea of progressive PHC would remain key to the vision of an unsegregated, free health system throughout the period. The origins and evolution of the idea of community-orientated PHC are prior to the main period under discussion in the thesis. However, because of its intellectual importance in the evolution of AIDS

⁶ The full acronym for the National Progressive Primary Health Care Network was NPPHCN, however, it is frequently referred to as PPHC or the PPHC network in archival material so the chapter adopts this shorter acronym for simplicity's sake.

activism- a later cycle of contention and movement formation- this chapter will now recount the history of PHC in South Africa, in brief.

The idea of PHC in South Africa had its genesis in the late 1940s, long before the discovery of AIDS. In 1939, Dr E. H. Cluver who was then the chief of the Union government’s Health Department and his Deputy Dr H. S. Gear, started a program to develop better health care for the ‘Native Reserves’. As part of this program they established three experimental Health Centres which would focus on the prevention and treatment of disease and health education.⁷ The first of these centers was the Pholela Health Unit which was run by Sidney and Emily Kark. This centre pioneered a new model of community-orientated PHC. The central aim of this approach was to train and empower the community to promote its own health. It aimed to provide an alternative to medicine which was solely hospital-based and curative in focus through its emphasis on community involvement in health and on preventative over curative medicine. As part of this new approach, the Karks trained community health assistants.⁸

Over the next few years, the Karks’ model of community-orientated PHC gained even greater government recognition. In 1944, the Gluckman Commission recommended that more local Health Centres be established at that they should be combined with a nationalized hospital system to comprise a National Health Service.⁹

As shall be discussed in section two of this Chapter, Mervyn Susser and his wife Zena Stein were epidemiologists who played an important early role in warning anti-apartheid health workers of the devastation that could be wrought by South Africa’s growing AIDS epidemic in 1990. However, in the early 1950s, as medical students they were friends with the Karks and visited Durban to study their model of community-orientated PHC. In the 1948 election, D. F. Malan’s National Party swept to power, a development which ultimately sounded the death-knell for the health centres. In 1958, the Karks went into

⁷ S. Kark and E. Kark, *Promoting community health: From Pholela to Jerusalem*, (Johannesburg, 1999).

⁸ *Ibid.*

⁹ M. Susser, ‘Foreword’, in (eds.) S. Kark and E. Kark, *Promoting Community Health: From Pholela to Jerusalem* (Johannesburg, 1999)

exile in the United States and Israel, where they continued to disseminate their ideas about community-orientated PHC.¹⁰

Despite these setbacks, the vision of free health care with special emphases on preventative and maternal and child health care continued to animate the anti-apartheid struggle within South Africa. For instance, the 1955 Freedom Charter called for a preventive state health scheme and free medical care and hospitalization.¹¹

The Natal University Medical School, became an important space for the politicization of a younger generation of black anti-apartheid activists.¹² The Black Consciousness movement had its origins at the medical school. This was because Steven Bantu Biko, the movement’s founder, was a student at the Natal University Medical School. His death in detention in 1977 focused the attention of doctors opposed to apartheid on the collusion of the medical profession in apartheid era human rights abuses. It also deepened anti-apartheid physicians’ antipathy towards the Medical Association of South Africa (MASA), which like the SAMDC was seen to having failed to censure Biko’s doctors’ for their failure to adhere to their ethical duties as doctors to provide medical care in a non-maleficent and beneficent manner.¹³

As a consequence, South African doctors opposed to apartheid set up an alternative association which was referred to as the National Medical and Dental Association (NAMDA), which was formed 1982.¹⁴ NAMDA’s core work included documentation and research of the effects of apartheid and health, advocacy for de-segregation of the health system and wider society and the provision of health services and first aid training through affiliated groups such as the Emergency Services Group (ESG). In the 1980s,

¹⁰ Kark and Kark, *Promoting Community Health*.

¹¹ “The Freedom Charter Adopted at the Congress of the People, Kliptown, on 26 June 1955”, Available at < <http://www.anc.org.za/ancdocs/history/charter.html>>

¹² The term ‘black’ is being used here in the manner of the black consciousness movement to denote people who were African, Coloured and Indian. M. Ramphela, *Across Boundaries: The Journey of a South African Woman Leader* (New York, 1995). S. Biko, *I write what I like* (London, 1996). V. Noble, ‘Doctors divided: Gender, race and class anomalies in the production of black medical doctors in apartheid South Africa’, (2005) Unpublished PhD Dissertation, University of Michigan.

¹³ Baldwin-Ragaven *et al*, *The wrong colour*.

¹⁴ Baldwin-Ragaven *et al*, *The wrong colour*.

the idea of PHC, an idea pioneered by the Karks over four decades before, continued to animate progressive healthworker activism. Indeed in 1987, NAMDA convened meetings of progressive healthworker activists and organizations, which culminated in the formation of the PPHC network in September of that year.¹⁵

The next section of this chapter examines progressive health worker activists’ initial professional engagements with AIDS and how this catalyzed the generation and dissemination of specialist knowledge around the epidemic.

2) Early professional engagements with AIDS

South African progressive doctors’ early professional engagement with AIDS differed depending on whether they were in the country or in exile. Progressive doctor-activists who were in exile often gained relatively privileged, early access to, or participation in AIDS research by top foreign Universities or medical research facilities. Those based in other African countries with the African National Congress (ANC) also gained insights into the threat posed by South Africa’s small but growing AIDS epidemic by observing the growing epidemics in their host countries. By contrast, while those based within the country were intellectually interested in the clinical manifestations of AIDS, they took longer to realize the high probability of a generalized South African HIV epidemic and the social devastation it could cause.

As discussed in Chapter One, the *South African Medical Journal* published articles on early AIDS cases in South Africa in the mid-1980s. Similarly, the epidemic’s emergence received widespread media coverage. However, for much of the decade AIDS was not even on the medical or nursing syllabuses.¹⁶

¹⁵University of the Witwatersrand, Historical Papers, National Progressive Primary Health Care Network Collection, Funding/Finances Box, Letters Etc File, “National Progressive Primary Health Care Network”, p.2.

¹⁶ Interview with Thoko Makhanya on September 13th 2007 at her home in Durban. Interview with Salim Abdool-Karim, 15th September 2003 at the Nelson R. Mandela Medical School, University of KwaZulu-Natal.

Exiled progressive doctors' intellectual interest in AIDS was nurtured by greater access to foreign colleagues, which was enabled by studying abroad and by the research resources offered by rich Northern universities. For instance, Zena Stein and Mervyn Susser knew about the emergence of the epidemic in San Francisco and New York 'almost as soon as anybody else did'.¹⁷ By the time the new disease emerged Mervyn held to Chair of Epidemiology at Columbia. He had worked as a consultant on a study searching for a vaccine for Hepatitis B with a Polish-American Epidemiologist by the name of Dr Szmunes. It turned out that 'bloods that were taken from men in San Francisco on that study turned out to be one of the key bits of information about the epidemiology of HIV infection and AIDS'.¹⁸ With the recognition that 'slim disease' in Uganda was HIV, and the discovery that it was caused by a sexually-transmitted virus, Stein and Susser knew 'for sure, it was going to blow, in the way syphilis did in Europe in the sixteenth century'.¹⁹

Jerry Coovadia was a paediatrician and an anti-apartheid activist at the Natal University Medical School who was less interested in AIDS. Throughout the 1980s, he knew about AIDS 'academically' by virtue of being a doctor and about the 'white male epidemic mostly in Johannesburg'.²⁰ In the 1980s and early 1990s, he didn't yet see AIDS as a social justice issue. Indeed, as a pediatrician he felt he already had plenty of work dealing with more traditional problems such as diarrhea and tuberculosis in black children and he

...was too divorced from the whole thing. I mean, I'm a paediatrician and I vaccinate and things like that. I didn't understand the full meaning of the cliché we are now familiar with that this is not fundamentally a medical disease- I mean problem- it's a social, economic and political problem and so on. I was sort of reductionist. That's why I ignored the problem because then I just had a nodding acquaintance because I'd seen a few patients.²¹

For Coovadia, while AIDS was a side issue with very little to do with the struggle, the push for a national health service- a dream which stretched back to the 1940s for

¹⁷ Interview with Zena Stein.

¹⁸ *Ibid.*

¹⁹ Interview with Mervyn Susser.

²⁰ *Ibid.*

²¹ *Ibid.*

progressive South Africans- was at its very core. This was a topic on the agenda of NAMDA's first meeting, which Coovadia attended. The creation of a National Health Service remained a central concern of NAMDA throughout the 1980s. For instance, in 1987, at its annual conference entitled 'Towards a National Health Service' Coovadia gave a paper presenting 'The case for a national health service: A framework for discussion'.²²

3) Advocacy-orientated network formation and the Maputo and NACOSA conferences

To return to the discussion of the formation of AIDS-related social networks in the late 1980s and early 1990s- small, AIDS-related discussion forums made up of progressive healthworkers began forming in different parts of the country. Simultaneously, AIDS began popping up as a minor item at NAMDA and PPHC meetings. For instance, an ad hoc PPHC AIDS Forum began meeting at the Wits University Medical School from late 1988.²³ Meanwhile, from 1988 a similar, progressive AIDS-related network began forming in Natal.²⁴ Similarly, in the Western Cape, a progressive network, led by healthworkers had formed in August 1989 which aimed to 'pull together organizations who support the PPHC [network]' and to 'lobby the state and challenge their AIDS strategy'.²⁵

1990 was also a watershed year in the political history of AIDS for a number of reasons. Firstly, the first national antenatal clinic survey was undertaken in 1990. This allowed epidemiologists to develop a much more detailed estimations of national HIV-prevalence,

²² H. M. Coovadia, 'The case for a National Health Service: A framework for discussion', in C. P. Owen (ed.), *Towards a National Health Service: Proceedings of the 1987 NAMDA Annual Conference Held at the University of the Western* (Cape Town, 1988), pp.11-22.

²³ Historical Papers, University of the Witwatersrand, NPPHCN, Funding and Finances Box, Conferences and Meetings File, 'Letter from Malcolm Steinberg to Prax dated March 25th 1989', p.1.

²⁴ Interview with Coral Vinsen and Stephen Knight; Interview with Thoko Makhanya.

²⁵ Historical Papers, University of the Witwatersrand, National Progressive Primary Health Care Network Collection, Funding/Finances Box, PPHC Memoranda File, 'AIDS IN PROGRESSIVE PRIMARY HEALTH CARE NETWORK (PPNCN)', P.2. This document is undated but only lists activities in 1988 and 1989, so was probably produced in 1989-1990.

which made it easier for progressive healthworker activists to argue that AIDS should be politically prioritized and that more national funding should be made available.

In addition, in 1990 with the unbanning of the ANC, exiles could return to the country. In addition, in 1990 with Mandela’s release from jail, exiles were allowed to return to the country. As Chapter 2 discusses AIDS had been an issue which had been addressed by the ANC health section in the ANC camps in Southern and Eastern African countries. The return of these cadres may have been a factor in the epidemic’s spread.²⁶ At the time of writing it was impossible, given available evidence, to verify this hypothesis. What is certain is that the return of ANC exiles certainly shaped the politics around the disease in South Africa. Many exiled progressive healthworker activists had been based in countries with more advanced AIDS epidemics. For instance, Nkosasana Zuma had recognized the threat posed by AIDS to the ANC cadres in exile while working as a Director of the Health Refugee Trust in England in the late 1980s and had worked for the ANC’s health desk in Lusaka for a year before returning to South Africa in 1990.²⁷

Judy Seidman was romantically involved with an Umkhonto we Sizwe (MK) operative who will be referred to as Z. to preserve his anonymity. Z. was identified as HIV-positive in December 1987.²⁸ He was at that stage mostly based in Lusaka and had been tested in preparation for a trip to East Germany which insisted on testing the thirty to forty MK soldiers it was going to admit. Eighteen of the operatives tested apparently tested HIV-positive. Operative Z. was in Angola at the time when the test results were announced. When he arrived back in Lusaka some weeks later

apparently there had been a typed list that was on the bulletin board saying that “the following people”... [are HIV positive] and I believe there was something like 18 people on the list. And his name was added in handwriting under that and he said when he came back there and saw that list he just thought it was a joke or somebody was, you know, whatever and he refused to deal with it. He didn’t ask anybody.²⁹

²⁶ Interview with William Malekapuru Makgoba. This is a prospect also pointed to in Mark Gevisser’s biography of Mbeki: M. Gevisser, *Thabo Mbeki- The Dream Deferred* (Johannesburg and Cape Town, 2007).

²⁷ M. Harnbridge, ‘A profile of the Minister of Health Dr Nkosasana Dlamini Zuma’, *AIDS Analysis Africa: Southern Africa Edition*, 5, 6, April/May 1995, p.3.

²⁸ Interview with Judy Seidman on December 4th 2005 at her home in Johannesburg.

²⁹ Interview with Judy Seidman.

He refused to believe that he was HIV-positive but was not sent to East Germany despite his desire to go, and instead went to Botswana. According to Seidman, he only became seriously ill on his return to South Africa in 1990 as one of Mandela's bodyguards as part of the ANC's advanced party.

In response to these rising infections, the ANC's health desk had produced a video entitled 'As Surely as an AK'.³⁰ The film opens with shots of MK soldiers in battle fatigues firing AK47s, wriggling under barbed wire and marching in formation. The first scene following this footage features ANC cadres stuffing envelopes and discussing the events of the prior evening where one male character boasts about engaging in unprotected, casual sex with another female cadre. When another cadre asks him if he is not scared of contracting AIDS through such behavior he brushes off the criticism as irrational paranoia. In the next scene he is shown to be AIDS-ill and contrite in the hospital. The moral of the film is clear: condomless, casual sex could result in HIV-infection and would render cadres unable to fulfill their duties in the struggle.

The film's credits list it as having been made by the ANC Health Desk, but do not list a scriptwriter or director. This is probably due to the fact that the ANC was a banned organization in South Africa in late 1989 or early 1990, when the film was probably made. According to Zena Stein it was filmed in an actual ANC office in Lusaka and made by Pallo Jordan's wife who was a British nurse who was also involved in work with the ANC.³¹ According to Cheryl Carolus, who was then an activist with the Emergency Services Group and the United Democratic Front, Nkosasana Zuma and Manto Tshabalala were also involved in the video's production.³² Either way, it was smuggled into South Africa and used by the UDF for political education purposes.³³ They were told that it was bring used in the ANC's camps.

³⁰ ANC Health Department, 'As Surely as an AK', Undated.

³¹ Interview with Zena Stein.

³² Interview with Cheryl Carolus on May 7th 2007 at Peotona Holdings in Rivonia, Johannesburg.

³³ Interview with Leslie London on January 15th 2007 at the Health Sciences Campus of the University of Cape Town.

Leslie London, a trade union doctor whose history as an activist is discussed in Chapter Two, valued the film screenings, which were used to form the basis of discussions between activists because,

I remember being struck, because it was a story about denial, and prejudice and stigma, it was all happening in exile and it was amongst ANC cadres and there was gender oppression and everything...it was the first time you found educational material and they stopped in the middle for discussion, but it was clearly intended to get people talking and we used it.³⁴ Cheryl Carolus who was a United Democratic Front (UDF) and ESG activist based in the country found the video extremely valuable as an educational tool. When she watched the video she I knew about the fact that AIDS was sexually transmitted and that condoms could prevent transmission but she appreciated that fact that 'quite a big message about responsible sexual behavior came through'.³⁵ Like other political education material sent in by the ANC for use by the UDF, the film also represented what 'the ANC thought we should be using in educating people in South Africa'.³⁶ Unlike London, she lost her copy when she went on the run because of state repression of the UDF opposition which was related to the State of Emergency.³⁷

The return of these ANC cadres certainly shaped the politics around the disease in South Africa. Due to their greater experience with large AIDS epidemics, exiled progressive healthworker activists were keen to push for the UDF-aligned progressive health organizations within the country and more senior leaders in the ANC to add planning for AIDS to the agenda of developing a post-apartheid health system.

The Maputo Conference on Health in Southern Africa was held in April 1990. It was organized and funded by the Committee for Health in Southern Africa (CHISA), which was an organization of health workers opposed to apartheid in the United States. It was established in 1984 and Mervyn Susser was the chair of the organization. The conference declaration envisaged that a Karkian 'progressive primary care strategy'

³⁴ *Ibid.*

³⁵ Interview with Cheryl Carolus.

³⁶ *Ibid.*

³⁷ *Ibid.*

would serve ‘as the basis for the provision of health and welfare services’ in a post-apartheid South Africa.³⁸

The discussions at the conference also focused on how to formulate urgent plans to address the country’s rapidly expanding HIV epidemic in the transition era.³⁹ According to Stein, at the AIDS session tensions emerged at the conference between inziles and exiles. At a certain point in the proceedings some of the delegates, such as Ivan Toms, Liz Floyd and Manto Tshabalala felt that some of the exiles, particularly ‘the Americans’ were dominating the proceedings.⁴⁰ Susser recalled that

Health-workers in South Africa were really focused on developing a national network of primary care, grassroots care for people so they didn’t want that issue- the HIV issue- to confuse their commitment to getting health services on the ground across the country. So, our priority was different because this is we thought this [AIDS] is a conflagration and building [the health system] is a slow business, so you’ve got to attend to the fire before you’ve burned all your houses down, that’s how we felt about it.⁴¹

So the whole agenda was changed in the light of this inzile-led ‘revolt’.⁴²

Nevertheless, the final Maputo Statement on HIV and AIDS in Southern Africa emphasized that AIDS was a political issue and that any attempt to deal with the epidemic had to be ‘situated within the broader struggle for socio-political change’.⁴³ The ‘senior political leadership within and outside South Africa’, particularly, the ANC had to become involved with the issue.⁴⁴ It also stated that networking between different sectors was vital to the development of a successful progressive strategy: ‘worker, youth, women’s, gay, religious, political and other community-based organizations’ had to be

³⁸ Historical Papers, University of the Witwatersand, NAMDA Collection, NEC Minutes Box 1986-1991 HIV/AIDS Issue File, ‘Declaration on on Health in Southern Africa. Maputo, April 15, 1990’, P.1.

³⁹ Interview with Zena Stein.

⁴⁰ *Ibid.*

⁴¹ Interview with Mervyn Susser.

⁴² Interview with Zena Stein.

⁴³ Maputo Statement on HIV and AIDS in Southern Africa’, in Z. Stein and A. Zwi (eds.) *Action on AIDS in Southern Africa: Maputo Conference on Health in Transition in Southern Africa April 1990* (New York, 1990).

p.137.

⁴⁴ *Ibid.*, p.137.

involved 'at all levels of work on HIV infection and AIDS'.⁴⁵ This was clearly influenced by the Karks' interdisciplinary approach of community-based PHC in Pholela.

In August of 1990, an American Democratic Party Congressman Jim McDermott visited South Africa to explore possible AIDS projects he could recommend for US foreign aid. PPHC assisted the ANC in preparing a submission for McDermott on the ANC's position on the epidemic and its recommendations for new programs which could be developed with US funding. The document clearly illustrates that AIDS activists in this period were forming advocacy networks. For instance, it mentions that gay healthworkers developed their own services voluntarily through GASA 6010 in Cape Town and at the HIV clinic at Johannesburg General Hospital. Similarly, it decries the fact that South Africa was 'a homophobic society with legislation' which made homosexual sex illegal which made it 'particularly difficult for gay people to campaign around AIDS'.⁴⁶ According to the PPHC network, Unions had played a 'leading role' in "'policy work'".⁴⁷ It also indicates that the PPHC network was aware about the fact that KwaZulu had 'encouraged a small group of healthworkers to develop AIDS work'.⁴⁸

Unsurprisingly, the PPHC network is listed in the document as having focused in developing regional networks. Even more significantly, it appears that for the first time in South Africa the term 'AIDS activists' is used as a self-descriptive term in the document: PPHC claimed that it involved 'more or less 80% of AIDS activists'.⁴⁹ This is a deeply significant development in that previously anti-apartheid activists of various types discussed in the thesis referred to themselves as gay, progressive health activists or trade unionists interested in, or working on, AIDS. The use of the term 'AIDS activist' as a self-descriptive term by indicates that for a noticeable number of these activists saw

⁴⁵ *Ibid.*, p.138.

⁴⁶ Historical Papers, University of the Witwatersrand, NPPHCN Collection, 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', P.2

⁴⁷ *Ibid.*, p.7.

⁴⁸ *Ibid.*, p.5.

⁴⁹ *Ibid.*, p.8.

their political goals and identity as becoming significantly tied up in trying to reduce new infections and improve the welfare of people already living with the virus.

The paper PPHC prepared for the McDermott visit noted that PPHC's AIDS Forums had 'no full time employees', which meant that coordination was sustained by volunteers who could not sustain neither networking nor campaigning at the desired level.⁵⁰ This is unsurprisingly, in a document which was written for fundraising purposes. By September 1990, the ad hoc AIDS Forums affiliated to PPHC had crystallized into an AIDS Working Group (AWG) of the PPHC. It was envisaged that monies which were promised by donors like USAID would be funded through the Matala Trust Fund, which was an independent trust fund 'set up on the initiative of the ANC'.⁵¹ The PPHC also funded national meetings of its AWG and gave ten thousand rand in seed money to each of the regional AIDS groups.⁵²

The return of the ANC exiles also created a racialized AIDS-related controversy, which played out very publicly and in the media. There appeared to be a real problem with AIDS in the ANC camps and in May 1990 following the April 1990 meeting in Maputo, the ANC convened a seminar on AIDS in Lusaka, Zambia, where its headquarters were based. *AIDS Analysis Africa*, an AIDS-related newsletter closely associated with Alan Whiteside, a health economist, and a journal whose genesis is discussed in Chapter Two claimed that

There have been reports that up to 25 per cent of Lusaka-based ANC operatives are HIV positive. This would be in line with the rate for young adults in that city and so it is hardly surprising. Data on the military wing are not available.⁵³

Initially, media coverage indicated that returning exiles would be routinely checked for HIV and other diseases. According to an article in the liberal Institute for a Democratic South Africa's newsletter *Democracy in Action*, pamphlets had been circulated by right-

⁵⁰ *Ibid.*, p.9.

⁵¹ Historical Papers, University of Witwatersrand, NPPHCN Collection, Funding/Finances Box, NPPHCN Minutes File, 'PPHC AIDS Working Group- S. Tvl, 21 Sept 1990', p.6

⁵² *Ibid.*

⁵³ A. Whiteside and J. van Niftrik, 'Aids in South Africa: Government and ANC response', *AIDS Analysis Africa: Southern Africa Edition*, August/September 1990, p.1.

wingers depicting returning exiles as “AIDS carriers” and these pamphlets were showered from planes.⁵⁴ An article in the Port Elizabeth-based newspaper *The Herald* entitled ‘Aids test for exiles returning to SA’ printed on 23 August 1990 claimed that a Mr Benson Fihla who is listed as being the ‘national chairman of ex-political prisoners...said [that] the subcommittee on health, established to deal with returning exiles would check each person for Aids and other diseases.’⁵⁵

This earlier proposal was later contradicted in an article in the same newspaper a fortnight later. The ESG, which was a group of healthworkers opposed to apartheid publicly stated its opposition to compulsory testing of exiles in an article published on 8 September 1990. This was apparently decided at a conference on how to receive returning exiles. In the article, a spokesperson for the ESG by the name of Dr Mbengashe was quoted as having stated that

“...The returnees must be looked upon as being a healthy group so when they return they must not be treated differently. Thus, a specific Aids programme for them is not needed...

At the same time we need to acknowledge that there might be health problems that need to be catered for. No returnees will be subjected to an Aids test or any questions related purely to the disease”.

If we make connotations with Aids that it is a certain race’s or group’s problem, it will derail the entire programme of awareness and the fact that it is a national problem”.⁵⁶ Mbengashe ended by saying that returnees would only be offered Aids tests if they asked for them.⁵⁷

The different positions taken in these two articles are interesting for three reasons. Firstly, they point to the fact that there may have been some debate within anti-apartheid circles over whether or not to test returning exiles, or disagreements over whose responsibility it was to determine this. Secondly, at the very least the different positions point to the possibility that the media had a lack of clarity over who the ANC’s spokespersons were on different issues, such as health and AIDS. Lastly, it is not totally improbable, given the ‘dirty tricks’ campaigns of the times that the comment by Fihla

⁵⁴ S. Armstrong, ‘Aids myths in black and white’, *Democracy in Action*, 15/07/94

⁵⁵ S. Holden, ‘Aids tests for exiles returning to SA’, *The Herald*, 23/08/90, p.1.

⁵⁶ S. Holden, ‘Aids tests for returning exiles are “not viable”’, *The Herald*, 8/9/90, p.2.

⁵⁷ *Ibid.*

was a part of a disinformation campaign against the ANC conducted either by right-wingers and/or the state. It is difficult, given available evidence to determine which of the above is true, but the fact that the truth of all three are probable points to the political fluidity of resistance politics at the time in relation to AIDS.

Indeed, the disinformation campaign using AIDS as a smear against returning ANC exiles continued as late as October 1990. The *Weekly Mail* reported that a fake ANC pamphlet was circulated across Southern Africa, which claimed to be signed by senior ANC leader Walter Sisulu and which was addressed to ‘all parents of South African exiles.’⁵⁸ It apparently warned parents of exiles that on their return to South Africa their children would have to go into quarantine and that they would have to be tested prior to their return because they may have contracted the ‘dreadful disease’.⁵⁹ According to the article, Joel Netshitenzhe denounced the document as a ‘spurious hoax’, and declared that the ANC was completely against the policy of testing returning exiles- the decision to be tested for HIV was ‘a private matter’ and ‘not something to be ordered by decree’.⁶⁰ The article ended by stating that ANC doctors had admitted that there was a high level of HIV seropositivity among the organization’s members in African countries and that the organization had ‘mounted an education campaign as part of a comprehensive AIDS policy’.⁶¹

The debate over whether returning exiles should be tested for HIV continued into 1991, when South Africa’s right-wing Conservative Party called for mandatory testing of returning exiles. It is clear that the position expressed by the ESG in Port Elizabeth against mandatory or routine testing in September 1990 prevailed as the ANC position, at least for a while. In January 1991, a spokesman for organization was quoted in *The Citizen* as stating its opposition to mandatory testing of returning exiles arguing that, if implemented the proposal would be ‘an infringement of human rights’.⁶² The ANC had researched the matter abroad ‘but [believed] tests should not be randomly imposed on

⁵⁸ ‘Sisulu’s name on fake ‘Aids’ leaflet’, *Weekly Mail*, 5/10/90-11/10/90, p.1.

⁵⁹ *Ibid.*, p.1.

⁶⁰ *Ibid.*, p.1.

⁶¹ *Ibid.*, p.1.

⁶² ‘ANC rejects CP’s call for Aids tests’, *The Citizen*, 16/01/91, p.12.

anyone’.⁶³ Instead, it believed that epidemic had no reverence for where a person resided which made the focus on exiles and immigrants in general ‘illogical’.⁶⁴ The article finished by reporting that the ANC supported cohesive AIDS projects and called on ‘individuals to act responsibly regarding the contracting and spread of the disease’.⁶⁵

The Conservative Party’s position was certainly held by some whites in wider society, as AIDS became a vehicle for arguing against de-segregation and for advancing the notion that it should be left unaddressed because it could address black ‘overpopulation’. For instance, a white businessman interviewed for an article on AIDS and race published in *Democracy in Action* opened with the following vignette

“Aids is a blessing in disguise.” Says the white businessman sipping expensive wine in a Johannesburg restaurant. “Isn’t it going to solve to problems of overpopulation and unemployment in this country?”⁶⁶

This attitude created a knee-jerk reaction among Africans, some of whom viewed AIDS as a white disease skillfully blamed on Africans. The same article later describes an AIDS awareness workshop where black gay men rejected their risk of contracting HIV arguing that it was a white gay disease, reasoning that because they didn’t have white lovers they weren’t at risk. Refiloe Serote of the NGO Alexander AIDS Action argued that condoms were seen by many Africans as a method of family planning favored by whites, which was seen to indicate that AIDS had existed among whites for a long time. She was even quoted as saying that

“Some [Africans] even believe that the reason the Immorality Act (which outlawed sex across the colour line) was scrapped in the late 1980s was to spread Aids to the black population”.⁶⁷

However, it seems that the matter may not have been entirely settled by the ANC in early 1991, as an article entitled ‘ANC to To Test its Exiles for AIDS’ in the August/September 1991 edition of *AIDS Analysis Africa* suggested that the ANC may have experienced a change of heart on the matter. The article announced that the ANC was to ‘test its exiles communities in Zambia and Tanzania for the HIV virus’ before

⁶³ *Ibid.*, p.12.

⁶⁴ *Ibid.*, p.2.

⁶⁵ *Ibid.*, p.2.

⁶⁶ Armstrong, ‘Aids myths’, p.14.

⁶⁷ *Ibid.*, p.14.

most of these followers returned to South Africa.⁶⁸ The decision apparently followed 'considerable criticism' that the ANC had 'been refusing to face up to the problem of HIV-positivity and AIDS within its ranks'.⁶⁹ The article argued that publicly the movement had

been reluctant to discuss AIDS and even where deaths have occurred as a result of the disease this has generally not been admitted. The recent death in London of 'Comrade Mzala'-Jabulani Nxumalo- a leading ANC figure and South African Communist Party theoretician...[appeared] to have helped bring matters to a head. Although no public mention was made of the causes of Mzala's death at 35 years of age, it strengthened the hands of those within the ANC who...[were] pressing for the movement to face up to reality.⁷⁰ Apparently, the ANC had decided to get an unnamed 'prominent medical researcher' to go the ANC camps to test cadres there and to get an AIDS awareness program underway.⁷¹ It is highly probable that this medical researcher was Nkosasana Zuma because of her early recognition of the threat posed by AIDS as discussed above. The history of this debate about whether the ANC should test its returning exiles highly is relevant to the history of progressive healthworker AIDS activism. This is the case because ANC medics like Zuma were caught between the rock of government and right-wing stigmatization of returning exiles as AIDS carriers and the hard place of ANC defensiveness around testing which stemmed from this stigmatization.

Meanwhile, internally, after the Maputo conference, ad hoc, voluntary AIDS forums organized by anti-apartheid healthworkers began to further crystallize from the PPHC AIDS Working Group into the AIDS program of the PPHC network. However, it is clear that the numbers of progressive healthworker activists interested in AIDS remained small in the early 1990s.⁷²

Fundraising efforts for the PPHC's AIDS program had borne fruit by mid-1991. Nikki Schaay, the manager of the PPHC's AIDS program in Cape Town wrote in the MRC's

⁶⁸ 'ANC to test its exiles for AIDS', *AIDS Analysis Africa: Southern Africa Edition*, 2, 2, August/September 1991, p.4.

⁶⁹ *Ibid.*, p.4.

⁷⁰ *Ibid.*, p.4.

⁷¹ *Ibid.*, p.4.

⁷² Historical Papers, University of the Witwatersrand, NAMDA AGM Meeting Minutes Box, File 3.2-Vaal, 'NAMDA S.TRANSVAAL CHAIRPERSON'S ADDRESS- ANNUAL GENERAL MEETING OF 1991', P.3.

AIDS Bulletin in 1992 that it had established its national office in Johannesburg in July 1991 and it soon had eight regional offices.⁷³ Schaay argued that the most important/innovative part of the program was that it was being implemented by Community AIDS Workers.

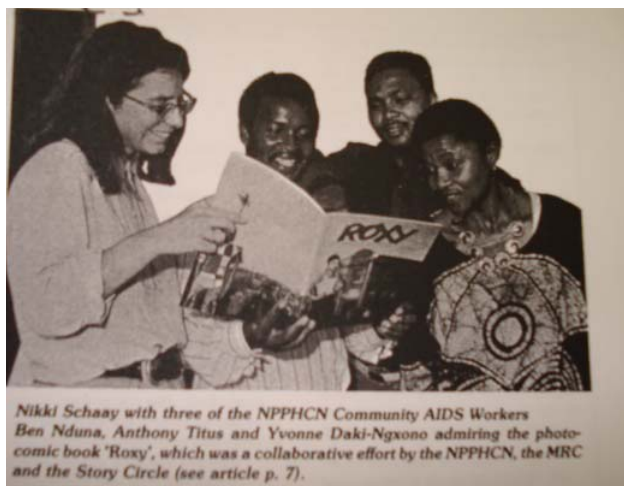


Fig 1: Picture of the NPPHCN AIDS Program's Nikki Schaay with NPPHCN Community AIDS Workers Ben Nduna, Anthony Titus and Yvonne Daki Ngxono⁷⁴

These community AIDS workers bore some similarity to the community health assistants trained by the Karks. Firstly, the Karkian health assistants of the 1940s and early 1950s were from the community of Pholela and other areas where similar community health centres were established. Similarly, the Community AIDS Workers either lived in the communities where they worked or had experience of 'community work' before.⁷⁵ According to the group interview with them in Schaay's articles, like Karkian health assistants, they saw themselves as both educators and organizers:

As organizers we are responsible for bringing people together within a community with the aim of raising awareness of AIDS. As educators we are responsible for

⁷³ Centre for Health Policy Resource Room, University of the Witwatersrand, N. Schaay, "The AIDS Program of the National Progressive Primary Health Care Network", *AIDS Bulletin*, 1,2, December 1992, p.1.

⁷⁴ This caption is part of the article cited above: *Ibid.*, p.2

⁷⁵ *Ibid.*, p.2.

empowering community members to be knowledgeable and active in their fight against AIDS.⁷⁶

Shan Ramburuth worked at the AIDS centre at the South African Institute for Medical Research (SAIMR) and was also a member of PPHC and an NGO representative on NACOSA. He remembers the production of posters and pamphlets to reinforce information communicated in PPHC workshops.⁷⁷

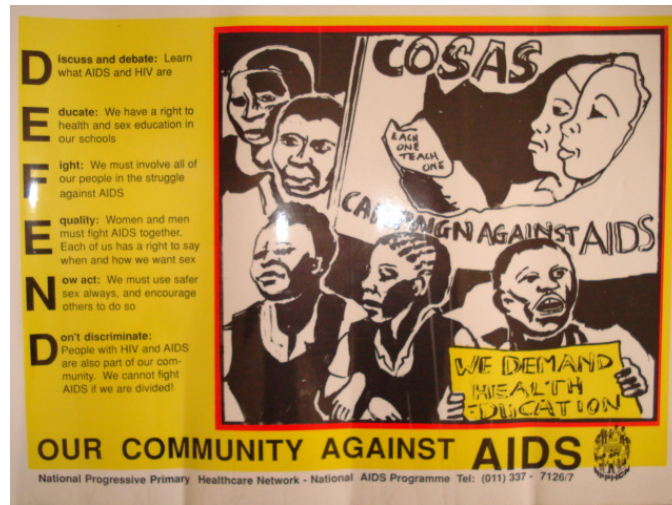


Figure 3: An early NPPHCN National AIDS Program Picture, which involves and invokes the youth organization COSAS: many of their members did not see AIDS as a serious issue.⁷⁸

⁷⁶ *Ibid.*, p.2.

⁷⁷ Interview with Shan Ramburuth.

⁷⁸ Warren Parker's personal collection, J. Seidman, 'DEFEND OUR COMMUNITY AGAINST AIDS'.



Figure 4: Mandela opened the NACOSA conference in 1992. As a potent struggle symbol he could add a great deal of legitimacy to AIDS awareness initiatives. His depiction with a child in this poster is clearly aimed at showing that casual contact could not spread HIV.⁷⁹

In practice this type of work was extremely difficult. Firstly, AIDS was not seen as an immediate 'bread and butter' issue unlike 'housing, education and employment' so the Community AIDS Workers had to 'fight to put it on the agenda'.⁸⁰ Thoko Makhanya was a nurse educator based at Kind Edward VIIIth hospital in Durban who was a member of the ad hoc AIDS committee at the hospital and later the PPHC AIDS group based at the medical school. In 1990-1 she remembers spending most weekends running educational workshops on AIDS in townships and informal settlements.⁸¹ However, while young people 'were interested...they would laugh about it', partly because they were not used to hearing adults discussing sexually explicit matters in public.⁸² Unlike problems such as shortages of housing, inferior education and unemployment AIDS was largely invisible.⁸³

⁷⁹ From Warren Parker's private collection of AIDS-related posters held in his garage.

⁸⁰ Schaay, "The AIDS program", p.4.

⁸¹ Interview with Thoko Makhanya.

⁸² Interview with Thoko Makhanya.

⁸³ *Ibid.*

While community AIDS workers were struggling to educate members of the public about HIV transmission, the ANC's health desk was negotiating with the government's Department of National Health and Population Development (DNHPD) to hold South Africa's first national AIDS conference inside the country. Slim Abdool Karim remembers that the idea of holding the first National AIDS Convention of South Africa (NACOSA) came from the DNHPD's Amanda Holmshaw. According to Abdool Karim, initially she had wanted to organize an international AIDS conference and

she started putting in place the processes to try and organize this meeting and the ANC heard about it and in relation to this whole academic boycott prevented it from sort of moving ahead, very early, as Amanda was still consulting people on it.⁸⁴ Holmshaw decided the best way around the impasse was to create a committee on the issue which had about half its members coming from the ANC and progressive organizations and half from the government.⁸⁵

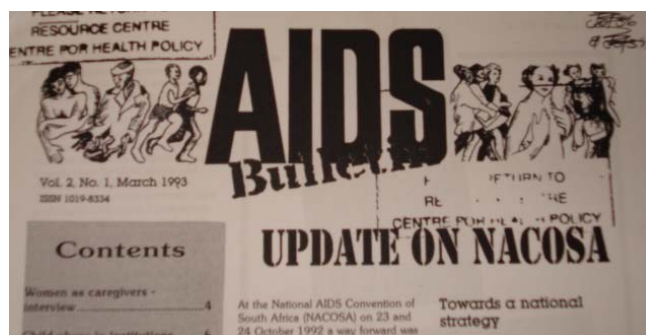


Fig 5: An early edition of the MRC's AIDS Bulletin.

Steinberg wrote an article in the MRC's *AIDS Bulletin* covering the NACOSA conference. It was held on 23 and 24 October 1992. Given wider political events in the country, it is miraculous that the conference jointly organized by the ANC and the government went ahead as planned, only a month after the resumption of negotiations following the Bisho massacre.

⁸⁴ Interview with Salim Abdool Karim.

⁸⁵ Centre for Health Policy Resource Room, University of the Witwatersrand, M. Steinberg, 'NACOSA: South Africa United Against AIDS', *AIDS Bulletin*, Vol 1, 2, December 1992.

According to Steinberg, Mandela opened the conference, arguing for a 'non-partisan approach' to HIV/AIDS control and prevention.⁸⁶ In keeping with the ANC health desk and NPPHCN's approach, Mandela took a progressive, primary health line that AIDS-like health in general- should not be viewed in a narrowly medical sense.

There were also presentations from representatives from the DNHPD, trade unions and church and NGO sectors. According to Steinberg the conference's main value lay in its provision of an early space for networking and knowledge-sharing, because 'It provided a forum for general discussion around key issues and an opportunity for informal exchange'.⁸⁷

At the end of the conference a steering committee was elected to develop regional structures and to establish a NACOSA Council. A National NACOSA Council was envisaged as 'the vehicle for the implementation of the National Strategy on HIV/AIDS'.⁸⁸ A three person team tasked with drafting the strategy comprised of Regina Mokgogong, Nkosasana Zuma and Manto Tshabalala.⁸⁹ A draft National AIDS Strategy was developed which was circulated for comments, which were discussed at a strategy workshop held in September 1993. The NACOSA National Council met on 27 January and approved the creation of an AIDS Task Team to draw up an implementation plan, which was finalized in June 1994.⁹⁰

The final plan included sections on education and prevention, counseling, care for people with HIV and AIDS, welfare services, human rights and law reform and research. The expense of implementing the National AIDS Plan was estimated by an external consultant as costing R256.77 million.⁹¹ The final National AIDS Plan stated that there was 'confidence' that it would be implemented by the new Government of National

⁸⁶ *Ibid.*, p.12

⁸⁷ *Ibid.*, p.12.

⁸⁸ NACOSA, *NACOSA: South Africa United Against AIDS: A National AIDS Plan for South Africa 1994-1995, July 1994*, (Sunnyside, 1994), p.3

⁸⁹ *Ibid.*

⁹⁰ *Ibid.*

⁹¹ *National AIDS Plan*, p.xii.

Unity.⁹² It was envisaged that NACOSA would ‘continue to function as a collaborator and watch dog on the government’s National AIDS policy and commitment’.⁹³ As discussed later in my thesis, it would be impossible for many AIDS activists to maintain both roles in the post-apartheid period- from the *Sarafina II* scandal onwards they increasingly became watchdogs and there was a diminishing collaboration.

Conclusion

Progressive healthworker activists were key actors in the early development of AIDS activism. They engaged with the issue early on by virtue of their professional experiences and expertise around it. Although the disease was new, some of the ideas they used to develop responses to it were much older, such as the Karkian idea of community-orientated PHC. This paper has also traced the early intellectual history of healthworker AIDS activism to show how AIDS-related advocacy- orientated social networks created by progressive healthworker activists were used to generate and share knowledge between individual activists and organizations. These networks are historically important because they provided social spaces for the rehearsing of new activist ideas and identities in the context of a new epidemic.

These AIDS-related, advocacy orientated networks thickened over the course of the period. Exiled South African progressive healthworkers such as Susser and Stein played a key role in sounding the alarm about the growing AIDS epidemic in the 1980s and early 1990s. By contrast, some progressive healthworkers, most of whom were based within the country, saw the AIDS issue as a irrelevant distraction from the work of building a national network of PHC organizations, and ultimately, a National Health System.

While older ideas about PHC shaped AIDS activism, the epidemic presented new communication challenges because AIDS was a heavily stigmatized new disease which the public often misunderstood. Another new front in the struggle against AIDS was determined by the political transition, which made the ANC prepared to negotiate with

⁹² *Ibid.*, p.4.

⁹³ *Ibid.*, p.4

the government on more specific developmental issues such as AIDS. These meetings culminated in the NACOSA meeting, which was South Africa's first national AIDS conference. Out of this process the first National AIDS Plan was developed- conflicts with AIDS activists over its implementation would soon dog the ANC government in the new South Africa, as Chapter Five of this thesis will show.