

Treating AIDS with Activism in South Africa

The Treatment Action Campaign (TAC) has become South Africa's most influential AIDS advocacy group within a decade of its founding in 1998. The TAC has mobilised protesters, confronted policy makers in their offices, waged war in the press and hired teams of lawyers to sue the South African government and the global pharmaceutical industry.

When these techniques have failed to persuade the government to change its policies or fulfil its promises, it has joined up with Médecins Sans Frontières (MSF, or Doctors Without Borders) and dispatched activists and health workers to local villages to directly provide the medicine and care that patients need.

The TAC has also provided a way for people living with HIV/AIDS to overcome social stigma by allowing them to assert new, more positive identities, as their emblematic t-shirts suggest.

These multiple strategies have begun to turn the policy tide in South Africa, where dissident scientific views about HIV and AIDS held by the former president and health minister had deterred the provision of life-saving anti-retroviral drugs, with devastating consequences.

Myth, stigma and shame

The politics of HIV and AIDS in South Africa, especially the dissident views of public figures, was driven by a strong distrust of the scientific establishment and a desire to use 'indigenous knowledge' and 'African solutions' to confront the problem. The public discourse, unfortunately, legitimised many of the popularly held AIDS 'myths' and contributed to the stigma and shame associated with the disease. This has led to a defensive posture and widespread denial about AIDS among the general public.

When TAC activists accompanied workers from MSF on a visit to a small village in the Eastern Cape Province, the headman's wife told them they could not possibly carry out their work in the area because none of the residents would admit to having HIV/AIDS.

She was staggered to be informed that most of the visiting group were themselves living with HIV/AIDS, and that residents need not feel ashamed. TAC and MSF have since made the village and its surroundings a model for how to provide anti-retroviral treatment, though the project continues to face entrenched forms of stigma, denial and rampant AIDS myths.

In 1998, when the TAC was established, it looked as if anti-retrovirals would not become available to the vast majority of poor people living with HIV in South Africa or the rest of the continent. In 2008, only an estimated 370,000 (42 per cent) of the 890,000 South Africans needing treatment were receiving anti-retrovirals through the public health system. Clearly, the struggle to provide effective HIV treatment continues.

From above and below

TAC has been unique in engaging with a range of stakeholders: scientists, academics, health professionals, the media, the legal system, South African and international civil society organisations, and local, provincial and national government officials. Citizens at the community level were mobilised through AIDS treatment literacy and awareness campaigns. TAC's main objective was to pressure the South African government to provide AIDS treatment, but in so doing it was forced to address a much wider range of issues. These included tackling the global pharmaceutical industry in the media, the courts and the streets; fighting violence and discrimination against HIV positive people, women, and gay and lesbian citizens; challenging AIDS-dissident science; and taking the government to court for refusing to provide drugs that prevent mothers from transmitting HIV to their unborn child.

TAC activism straddled local, national and global spaces, using the courts, internet and media, and networking with South African and international civil society organisations, in its struggle for access to cheaper AIDS drugs. Widely publicised acts of 'civil disobedience' also provided TAC with visibility within a globally connected public sphere.

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Fortunately, TAC now has a new ally in government with a health minister that strongly supports the kinds of policies that TAC has promoted over the past eleven years.

Positive results

TAC used the courts to compel the Ministry of Health to provide anti-retrovirals at public health facilities. They also campaigned to defend the rights of people living with AIDS and to protect the autonomy of scientific institutions from government interference.

As a result of a highly successful global and national media campaign, TAC managed to convince international public opinion and the Pharmaceutical Manufacturers Association that it was immoral and unjust for drug companies to maintain their prohibitively high prices and to prevent developing countries from manufacturing generics.

In July 2000, HIV-positive TAC volunteer Christopher Moraka died, suffering from severe thrush, an opportunistic infection caused by AIDS. The drugs to ease the pain of thrush and prolong his life were unavailable through the public health sector. TAC visited Thailand and bought 5,000 capsules of a cheap generic version. When this was announced in a press conference, there was a national public outcry against the pharmaceutical giant Pfizer and their inflated name-brand medications. Meanwhile the cheap generic drugs were successfully prescribed to South African patients. By March 2001, Pfizer made its drugs available free of charge to state clinics.

TAC mobilised poor and working class communities. It encouraged HIV positive people to be knowledgeable and empowered about their condition: to be, in effect, patient-activists. People who may have been very close to death may seek biomedical treatment of opportunistic infections, join a TAC support group and enrol for anti-retroviral treatment with MSF. The patient-activist learns basic scientific knowledge about HIV and AIDS, including its symptoms and

anti-retroviral treatment and will have to wait to find out if the drugs will work. Recruitment into TAC allows them access to a supportive community and non-hierarchical social space. When the patient starts to recover physically and psychologically, they usually get incorporated socially into TAC and possibly the wider community and society. While there is no guarantee, these processes can transform a stigmatised and dying patient into an activist-citizen empowered with knowledge about HIV and AIDS and an ability to speak out in public spaces.

When I go to my doctor I tell him exactly what medicines I need. He asks me if I've trained in medicine at the university. No, I say to him. It was TAC that taught me. Black woman in her thirties.

What are the lessons for mobilising citizens?

- TAC employed a variety of strategies and engaged a wide range of stakeholders across race, class, ethnic, gender and education divides to raise awareness of their cause and thereby leverage pressure.
- TAC deployed highly effective strategies of mobilization at local, national and global levels that can best be described as 'grassroots globalisation' or 'globalisation from below'; these strategies drew on litigation and media campaigns alongside grassroots mobilisation.
- Through grassroots mobilisation, people living with HIV and AIDS are becoming knowledgeable and responsible active citizens, accessing their right to adequate health care and medicine and interacting with biomedical professionals with accurate information at their disposal.
- Medical treatment is important but so is creating empowered citizens who understand the connections between biomedicine, the wider social world and the political economy of health.