Treatment Action Campaign: South Africa
Pioneering Human Service NGO
(1998-2009)

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Avuxeni, my name is Aaron Shabela I was born in 1962 and I'm from Gaza in Mozambique. I came to South Africa in 1990. I have two children here in South Africa. I discovered that I have HIV in 2007 and soon after disclosing to my wife, she dumped me. Now I am residing at Myakayaka village, few kilometres from Tzaneen Town in Mopani District. I have no Identity Document. It has been very difficult for me to get anti-retroviral treatment without an ID until I was assisted by Oscar Mabela who works for Treatment Action Campaign (TAC). I met Oscar at Dr CN Phathudi Hospital after hearing his presentation on how TAC can assist people to access treatment and I asked to speak to him alone. Oscar visited me at my home with a social worker who recommended me to get treatment at the hospital. He regularly visits me to teach me how to take treatment properly, stay healthy and maintain positive living. I want to encourage everyone to know their HIV status so that they can get treatment early if they are HIV Positive. Inkomu

INTRODUCTION

Treatment Action Campaign (TAC)'s vision is a unified quality health care system that provides equal access to HIV prevention and treatment services for all people. TAC's mission is to ensure that every person living with HIV has access to quality comprehensive prevention and treatment services to live a healthy life. TAC's strategic approach includes: securing comprehensive treatment and prevention services in selected focus districts as a model for other districts and informing and supporting national advocacy efforts through its branches by providing a platform for people to mobilize and organize around HIV and related health rights (TAC website). TAC uses a hybrid approach of advocacy, empowerment, and direct service provision.

HISTORICAL EVOLUTION

TAC was founded on December 10, 1998 in Cape Town, South Africa and advocates for increased access to treatment, care and support services for people living with HIV and campaigns to reduce new HIV infections. With more than 16,000 members, 267 branches and 72 full time staff members, TAC has become the leading civil society force behind comprehensive health care services for people living with HIV and AIDS in South Africa. Since 1998, TAC has held government accountable for health care service delivery, campaigned against the AIDS denial, challenged the world's leading

pharmaceutical companies to make treatment more affordable, and cultivated community leadership on HIV and AIDS (TAC website).

TAC's AIDS activists have framed their struggle for access to HIV treatment in terms of human rights where access to life-saving antiretroviral treatment for all HIV positive people is a right to life and access to health care. TAC is widely seen as one of the most effective examples of civil society pushing for South African and international/government policy to reflect the socio-economic and health rights of the post-apartheid era (Mbali, 2005). The founders of TAC agreed that while HIV is a virus, it symbolizes the deeper social and political crisis of poor people: "the growth of HIV to pandemic propositions is because HIV transmission is often via social fault lines created by poverty, inequality and social injustice" (Heywood, 2009). TAC worked to enforce the right to access to treatment through protest, mobilization, and legal action (Heywood, 2009).

TAC is viewed as a patient-driven, rights-based activist movement that evolved from the work of gay activists as Mbali (2005) noted, "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 them commonly phrased as the 'homosexual plague' " (p. 214). AIDS emerged in South Africa in 1982 and within a few years it was estimated that 10% to 15% of gay men in Johannesburg were infected (Mbali, 2005).

In the post-apartheid era, TAC is driven by people living with HIV/AIDS and can therefore be seen as "patient activism." They are rooted in the traditions of AIDS activism and gay rights activism that were established in the 1980s and early 1990s (Mbali, 2005). Action on HIV/AIDS was delayed by larger racial and political struggles in South Africa while AIDS was taken seriously by gay rights organizations, there was the overshadowing issue of apartheid and issues of institutionalized racism and legal segregation (Mbali, 2005). The militant patient activism of TAC in the late 1990s emerged from anti-apartheid, gay rights activism during the transition to the post-apartheid era (Mbali, 2005).

TAC's campaign for openness began in the early 1990s when Zackie Achmat called for the movement to be based on the public statements of HIV positive activists. This openness has been a key element of TAC's political strategy as a social movement (Mbali, 2005). The changing societal perceptions of HIV/AIDS have been essential to the rights-based approach: "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" (Mbali, 2005). AIDS activists in the early 1990s focused on patients' rights to confidentiality, while in the late 1990s, human-rights AIDS activists in TAC focused on openness in order to push for the socio-economic right to access to health care (Mbali, 2005).

TAC's efforts have resulted in many life-saving interventions, including the implementation of countrywide mother-to-child transmission prevention and antiretroviral treatment programs. On August 20, 2006 the New York Times named TAC

“the world’s most effective AIDS group” (TAC website). TAC has used political transformations to further its goals: “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” (Mbali, 2005). TAC’s work has received international acclaim, including a nomination for the Nobel Peace Prize in 2004.

TAC has recently tried to influence the U.S. role in the global fight against HIV/AIDS. TAC joined with ARASA (AIDS and Rights Alliance for Southern Africa) to urge the U.S. to act by recalling President Obama’s campaign pledge to drastically increase funding for the U.S. global AIDS program. The groups charged that Obama’s promise had been diluted by a call for an increase of only $100 million for PEPFAR and the lack of increases in funding for the Global Fund to Fight AIDS, Tuberculosis and Malaria. They argue that the increase is inadequate and represents a missed opportunity to strengthen African health and provide more effective HIV prevention. Prior to the letter, TAC had just launched a campaign in response to growing concerns about funding shortages for HIV/AIDS programs. TAC states that lack of funding causes health clinics to stop enrolling new patients onto antiretroviral medication. People get tested and seek treatment and then are turned away. Furthermore, the shortage of medication could result in patients sharing their drugs or lowering their doses, resulting in drug-resistant strains of HIV. The slowed funding stream hurts HIV prevention efforts and places increased burdens on women and children, suffering from HIV/AIDS.

On December 1, 2009, World AIDS Day, South African President Jacob Zuma announced new measures to combat HIV/AIDS. TAC welcomed the president's call for people to get tested and the president's personal admission of having been tested for HIV. The president announced that the government would provide all infants less than 12 months with antiretroviral treatment (ART) and provide ART to all people co-infected with tuberculosis (TB) and HIV with a white blood cell count of 350. Zuma also announced that the government would provide pregnant women with white blood cell counts above 350 with treatment to prevent mother-to-child transmission from 14 weeks of pregnancy. He also announced plans to more effectively integrate treatment of TB and HIV as many citizens have co-occurring infections (TAC website).

The new policy on treatment of pregnant women brought South Africa in line with World Health Organization (WHO) recommendations. By treating people with both TB and HIV earlier, when they are healthier, the WHO also believes that the new policy will reduce South Africa's death rate from those infections. Zuma argued that these policy changes will result in expanded treatment of HIV-positive patients, resulting in longer and more fulfilling lives (Dugger, 2009). These policy changes represent the core goals of TAC's advocacy efforts and were quickly welcomed by the organization.

TAC also applauded President Zuma’s recognition of the link between human rights and the treatment and prevention of HIV. Ensuring access to services and reducing the incidences of gender-based violence will reduce vulnerabilities to HIV infection and enhance access testing and treatment services. TAC continues to call on the government to strength health systems to implement the improved treatment guidelines. TAC is committed to working with government to improve the response to HIV. TAC further

supports the government call for all South Africans to take responsibility for their own health, get tested, and gain access treatment for HIV (TAC website).

PROGRAMS AND APPROACHES

South Africa's initial campaign for dealing with HIV/AIDS was fragmented, did not prioritize key interventions, and lacked leadership, particularly from the national government. Two possible approaches to HIV/AIDS involve either a coercive or human rights-based approach. A coercive approach includes forcing people to get tested or behave in certain ways. Prevention efforts would be portrayed as a war or moral crusade and people with the disease would feel isolated. Such an approach is discriminatory and often leads to the blaming and the social exclusion of people suspected of being infected. The coercive approach often labels HIV as someone else's problem, specifically a problem of those who are immoral. Such an approach would drive HIV underground and encourage its spread and so South Africa began to adopt a human rights approach instead (Kenyon, Heywood, and Conwayiii, 2001).

A human rights approach aims to empower individuals and communities with the knowledge and skills to avoid infection, encourage the entire country to recognize its vulnerability to HIV, supports voluntary HIV testing, and aims to provide infected persons with appropriate care and treatment. Such an approach provides more inclusion and respect for persons with HIV. This approach was endorsed in the national 2000 to 2005 HIV/AIDS Strategic Plan (Kenyon, et al., 2001). However, the South African government was slow to implement policies in line with such an approach.

The health activism and social action of organizations such as TAC has helped to counter-balance the absence of government leadership. TAC raised the profile of HIV/AIDS and helped to reduce some of the stigma for those living with HIV/AIDS. The work of TAC and similar organizations has also influenced other aspects of health policy and social development. For example, TAC's involvement in supporting the government against multinational drug companies in court helped to expose the public to the politics of the AIDS "profiteering of drug companies" (Kenyon, et al., 2001).

TAC takes a holistic approach of addressing service delivery in the forms of education and treatment access. TAC simultaneously employs a grassroots empowerment model to create structural change. TAC uses their provision of direct services as a starting point to train, activate, and empower members of the community to become more directly involved in demanding access to treatment and in lobbying to change government policy.

TAC has eight strategic objectives outlined in the organization's Constitution. First, TAC campaigns for equitable access to affordable treatment for all people with HIV/AIDS. Second, TAC campaigns for and supports the prevention and elimination of all new HIV infections. Third, TAC promotes and sponsors legislation to ensure equal access to social services for and equal treatment of all people with HIV/AIDS. Fourth, TAC uses litigation, lobbying, advocacy and all forms of legitimate social mobilization to challenge any barriers or obstacles, including unfair discrimination, that limit access to treatment for HIV/AIDS in the private and public sector (TAC website).

Fifth, TAC educates, promotes and develops an understanding and commitment within all communities of progress in HIV/AIDS treatment. Sixth, TAC advocates for access to affordable and quality health care for all people in South Africa. Seventh, TAC trains and develops a representative and effective leadership of people living with HIV/AIDS on the basis of equality and non-discrimination irrespective of race, gender, sexual orientation, disability, religion, sex, socio-economic status, nationality, marital status or any other ground. Finally, TAC campaigns for an effective regional and global network comprised of organizations with similar aims and objectives (TAC website).

TAC's human rights frame has created links with politically aligned transnational advocacy networks that provide an international political venue for its message: "The human rights frame offered a collective reservoir of meaning and symbols that served to bridge gay and AIDS advocacy struggles in the industrialized countries with AIDS struggles in Africa" (Johnson, 2006). TAC's focus on the right to access to treatment has resonated particularly with groups in the United States who have shared in the same struggle. The human rights frame work has also allowed TAC's leadership (primarily white, middle-class, and male) to build domestic support among its potential membership base composed overwhelmingly of poor blacks (Johnson, 2006). TAC pursued a strategy distinct from other human rights organizations. TAC does not consist of a small group of professionals advocating for a set of ideas, but instead, TAC has worked to create a social movement to empower poor people to become their own advocates. Rather than being composed of academics, moved to act out of conscience, TAC is composed of poor people for whom human rights are a personal necessity (Heywood, 2009).

TAC's service programs also have political dimensions. The treatment project helps provide medication for some community members and the treatment literacy campaign educates people receiving treatment. However, the literacy campaign includes consciousness-raising material and the treatment project informs people about the effectiveness of ARV programs, affirming TAC's role as a provider of effective treatment. These services both serve to reinforce TAC's relevance in the political landscape. TAC sometimes took political action as a means to provide services: "TAC also combined service provision with civil disobedience when, on occasion, it imported cheaper medication, ignoring pharmaceutical company patents" (Friedman, 2004). However, campaigning remains a primary focus of TAC's work.

TAC sees itself as politically multidimensional. One of TAC's founders, Zackie Achmat, states that TAC is not about a single issue: "we also deal with governance, corporate governance and domestic violence. We are aiming to reorder the health sector. We need to build a culture of complaint; we need communities to become more active. We have a progressive social democratic vision and shouldn't hide it" (Friedman, 2004). TAC has been involved in myriad non-AIDS issues from trade unions to social income grants to healthcare in general. However, it does seem likely that for the foreseeable future, HIV/AIDS will continue to consume most of their time and resources, limiting their involvement in other issues: "TAC will continue to face pressures from outside its ranks for involvement in other issues. But its constituency may judge it on progress in winning

treatment. Ensuring that it does not lose focus on their expectations will be a continuing challenge, as its mobilizing ability makes it a desirable ally for those seeking support for other campaigns" (Friedman, 2004). TAC's involvement in non-HIV/AIDS issues is evident from its website, which includes messages about criminal justice, the urban poor, homelessness, and global health in general. TAC has reframed the debate to an issue of fundamental human rights and wielded the human rights framework established by the government to pressure that same government to provide HIV/AIDS treatment.

TAC has three core programs.

- Prevention and Treatment Literacy (PTL).
- Community Health Advocacy (CHA).
- Policy, Communications and Research (PCR)

Prevention and Treatment Literacy

The PTL program provides high quality training and public health education on the science of HIV and TB prevention and treatment to patients and partner organizations. TAC's PTL program also monitors access to essential HIV and TB services and treatment at a facility-level in the districts in which they operate (TAC website). TAC not only provides people with access to treatment medicine but also the information necessary to remain healthy while receiving treatment. TAC's treatment literacy program provides the basis for both self-help and social mobilization. Access to health information and the linkage of this information to rights served to empower marginalized people who gained a public voice and visibility (Heywood, 2009).

Community Health Advocacy

TAC's CHA program strengthens awareness of, and advocates for greater access to, comprehensive HIV and TB prevention, treatment, support services, and social referral services, at a grass-roots community level. The CHA program also provides leadership and advocacy training to people living with HIV/AIDS, communities, partners and individuals in order to encourage and support social and community mobilization aimed at increasing access to and uptake of HIV and TB-related health services. In addition, TAC's CHA program has recently begun to intensify its women's rights work by leading campaigns to end violence against women and mobilizing communities around women's rights (TAC website).

Policy, Communications and Research

TAC's PCR department is responsible for monitoring and engaging with health policy processes at the national, provincial, and district level. The PCR department also disseminates information on the science of HIV and tuberculosis through the production of high-quality, accessible public-health education materials. TAC's PCR department communicates developments in HIV and tuberculosis policy and science to TAC's staff and membership base and they also liaise with media to promote TAC's advocacy and campaigns work (TAC website).

Collectively, TAC's programs facilitate access to comprehensive HIV and TB prevention, treatment, care and support services; provide scientific literacy training on prevention and treatment on an increasingly mass scale; coordinate, distill and disseminate scientific research and policy developments on HIV and AIDS and TB at the community grass-roots level; and organize and advocate with member communities to mobilize and take up issues of health policy and service delivery (TAC website).

GOVERNANCE

TAC has six district offices in Ekurhuleni, Gert Sibande, Lusikisiki, Mopani, uMgungundlovu, and Khayelitsha. Gert Sibande is one of the six model districts and is located in Mpumalanga province. It was established in March 2009 and the main campaign in the district has been the Resources for Health Campaign. They will also focus on Prevention-of-Mother-to-Child-Transmission of HIV (PMTCT), sexual assault, women's leadership, the expansion of the People with AIDS sector, branch inductions, and detailed research on service delivery with a particular focus on implementation in the public health system. This process will seek to ensure that there is collaboration on HIV/TB services, implementation of dual-therapy treatment, PMTCT, an end to stockouts and fully functional district AIDS and health structures (TAC website).

The Lusikisiki office was established in 2003 and has the following departments: Prevention & Treatment Literacy, Community Health Advocacy and Policy, Communications, and Research. The Mopani Office was opened in March 2008 and has been working to strengthen branches around Tzaneen Municipality. The Mopani office managed to place 20 PTLPs in Tzaneen and Letaba Municipalities. They have experienced the challenges of shortages of formula milk, condoms, and Voluntary Counseling and Testing kits. The Mopani office has done Prevention and Treatment Literacy workshops for partnering NGOs in the district (Hope Humana, Total Control of the Epidemic, and Vuyani Youth Project) and workshops for its branch members. The CHA program has been actively involved in organizing and running door-to-door campaigns of different issues such as TB and HIV, Cervical Cancer. The office also worked to mobilize the community for the district march (TAC website).

UMgungundlovu district was established in June 2002 and is coordinated by the the community-based organization Friends For Life. In 2003, the TAC District, funded by Oxfam UK, was formed under the supervision of Sbusiso, with only five branches: Mpophomeni, Ashdown, Sobantu, Bulwer, and Elandskop. It had a total of around 200 members. TAC uMgungundlovu was operating using Oxfam's small office. In 2004, the number of branches increased from five to ten branches with a total branch membership of 450, and five support groups were affiliated with TAC as subscribers. The uMgungundlovu district HIV steering committee was established under the coordination of Mr. Gwala (TAC website).

In 2005 TAC established partnerships with five NGOs and led a major campaign that was called "Fire Manto," where 2,000 people participated in a TAC-led march. In 2006, the district led the Access to Information campaign with another large march. The attendance by many from far-flung areas led to the decentralization of TAC office branches to

enhance accessibility. In 2008, the women's sector was established as well as a people living with HIV/AIDS sector. TAC is involved in an ongoing process of launching a civil society forum (TAC website).

TAC has a formal internally representative democratic structure with branches as basic units. Each active province has a provincial executive committee (PEC). There is also national executive committee (NEC) which is the prime decision-making structure for TAC. National leadership is nominated by branches and elected at a national congress every two years in a ballot that is supervised by the Independent Electoral Commission. At TAC's last conference, in August 2003, the chair and treasurer were elected unopposed, while elections for the deputy chair and the secretary were contested. PECs and branches meet on a monthly basis. Despite the fact that there are ambiguities about membership, participation at branch meetings is largely restricted to active members. According to interviews with TAC members Mvotho, Majali, and Xaba, TAC eventually created districts as the branches began to take on ever greater roles and the provincial office became too overwhelmed to oversee them all (Friedman, 2004).

FINANCES

TAC's website states that they do not accept donations from the U.S. Agency for International Development, the South African government, or from pharmaceutical companies and that donations from these entities will be returned. As of the end of the 2007-2008 fiscal year, TAC held R15,932,040 in total assets and R36,699,997 in income. TAC reported R37,268,958 in expenditures for the year, running a deficit of R568,961. Their cash flow statement shows R34,032,938 in cash received from funders and donors with cash paid to programs, suppliers, and employees of R36,984,838, significantly exceeding cash donations.

TAC lists several organizations under deferred income, including: Anglo American, Atlantic Philanthropies, Dfid – United Kingdom, Dfid – South Africa via Constella Futures, European Union/Hivos, Ford Foundation, Global Fund, Levi Strauss, Medicins Sans Frontieres – Lusikisiki, OXFAM Australia, Sigried Rausing, South African Development Fund, Stephen Lewis Foundation, Treatment Action Group (TAG), and UNAIDS. TAC also received and held funds for the Pan African Treatment Access Movement pending the establishment of its own independent financial management system. Furthermore, TAC also received additional grants from ActionAid International, Belgium Development Cooperation, Brot fur die Welt, Comic Relief, Secours Populaire Francais, Engender Health, Open Society Foundation for South Africa, OXFAM – UK, Public Welfare Foundation, Royal Netherlands Embassy, Swedish International Development Agency, and the other organizations listed previously under the deferred income category. The majority of TAC's funding comes from outside of South Africa, including some foreign governments but also many non-profit organizations. TAC is a tax-exempt organization under South African law.

FUTURE VISION

According to an article written by TAC's founder, Zackie Achmat, TAC is guided by several core human rights principles: "What has guided TAC's mobilisation in nearly seven years of existence and our work over the last two years? First, and most important, is the fact that we stand uncompromisingly for the rights to life, dignity, equality and access to health care for all people. In our work, we affirm the rights of the weakest, most marginalized and vulnerable people in society. TAC is unashamedly pro-poor and working class, pro-feminist and pro-human rights" (Achmat, 2006). TAC's goals for the future include continued access to treatment for everyone with HIV/AIDS, regardless of income, and improved human rights and dignity for all South Africans.

Integrating a human rights perspective into public health is vital to address growing global health disparities. According to Leslie London, Director of the School of Public Health at the University of Cape Town in South Africa, there are three aspects of health as a right that are germane to a human rights approach to health. The first aspect is the indivisibility of civil/political rights and socio-economic rights. The second aspect is meaningful for those who are vulnerable to human rights limitations or violations. The third aspect is the powerful role of human rights in providing accountability for protections and freedoms. Institutional accountability for the protection of human rights is critical to prevent placing responsibility solely on a health professional. Establishing human rights-based health policies requires both social mobilization and legal remedies. Changes in policies are required, but active monitoring of government through community mobilization is imperative in order for those rights to be realized (London, 2008). TAC embodies the principles of an effective agent for change toward a human rights-based health system in South Africa.

DISCUSSION QUESTIONS

1. What are the advantages and disadvantages of TAC's holistic approach?
2. TAC has an informal membership base but a formal governing structure. Are these approaches consistent?
3. How does TAC raise funds and avoid government and drug company funding? Does TAC have a strategic plan for financial and political growth in the next decade?
4. What is the future vision for TAC in light of the new government of Jacob Zuma?

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