



## COMMENTARY

# The Treatment Action Campaign's Fight for People Living with HIV/AIDS in South Africa: Reflections from a Leadership Perspective

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## 1. INTRODUCTION

The devastating HIV/AIDS epidemic that tormented a newly democratic South Africa was a new type of enemy that the ruling African National Congress (ANC) would have to defeat, an enemy which claimed the lives of 2.5 million people between 1990 and 2008.<sup>1</sup>

This coincided with a South African Government under the leadership of President Thabo Mbeki, which had neglected the widely accepted wisdom and science regarding the epidemic in favour of conspiracy theories and pseudoscience which entrenched the ideas, firstly, that HIV did not lead to AIDS and that AIDS was brought upon by social issues such as poverty and malnutrition, and secondly that antiretroviral (ARV) medication was a 'toxic poison' imposed upon African people to their financial and physical detriment.<sup>23</sup>

Additionally, this approach to the crisis by the Government occurred against the backdrop of long-standing societal stigmatisation and ignorance regarding HIV/AIDS. Despite these challenges, the overarching goal of society, especially the millions of people living with HIV, was to lobby the government, which was largely idle in addressing the issue, to provide education, prevention and treatment plans and policies that were robust, and which had a direct positive impact on the HIV/AIDS community. This overarching goal of society is best evidenced in the rampant proliferation of organisations from civil society and beyond involved in HIV/AIDS responses. Civil society organisations involved in the HIV/AIDS response have grown by 61% since 2000, while the number of faith-based

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<sup>1</sup> United Nations (n.d.). 'A Decade of Fighting for our Lives'. weblog.

<sup>2</sup> Ntaibosch (2016), 'Mbeki still believes his own AIDS propaganda'.

<sup>3</sup> Independent Online (2002), 'Manto Denies Poison Comment but Damage Done'.

organisations engaged in HIV/AIDS-related work has nearly tripled (275% increase).<sup>4</sup>

During this time, the Treatment Action Campaign (TAC) was founded and enjoyed immense support and success in shaping HIV/AIDS policy in South Africa. The proverbial birth of the TAC took place on the steps of St George's Cathedral in Cape Town on International Human Rights Day (10 December) 1998 with a group of just 15 people. These 15 activists, fed up with the prevailing rhetoric of doom and gloom regarding the epidemic, stood in the summer heat the entire day, drawing attention to the unnecessary suffering and death being caused primarily by the inaction of the Government to develop a treatment plan to combat the epidemic. By the end of the day, over 1000 signatures calling for the Government to immediately develop a robust treatment plan for all HIV/AIDS-affected people were obtained.<sup>5</sup>

There is generally a presumption that the TAC was constantly at odds with the Government, with engagements marred by a shared animosity. However, the relationship was far more complex, and the leaders of the TAC were able to recognise early on that the relationship with the Government would have to be far more dynamic and calculated. Collaboration, where allies could be found, was always preferred to a contentious approach. In the eyes of the public, this lent credibility to what could have been seen as the more antagonistic activities of the TAC, as the TAC's approach always seemed to be to follow established channels first before embarking on civil disobedience or judicial action.<sup>6</sup>

The emergence of the TAC directly led to the realisation of the shared vision of the affected communities, those being people living with HIV, which was to receive robust, dignified treatment from the State's health

apparatus and to combat stigmatisation and misinformation through educational programmes. Specifically, the TAC was concerned with three key demands or goals. They were, firstly, implementing a policy for medical treatment of people living with HIV using ARV treatments that had already proven safe and effective in other parts of the world. Second, the combatting of stigmatised, denialist and conspiracy-theory-based conceptions of HIV/AIDS, and finally, the roll-out of a national programme using ARV treatment to reduce the risk of mother-to-child HIV transmission (MTCT).<sup>7</sup> Initially, the TAC had emerged in response to the high prevalence of MTCT and subsequently began campaigns calling for the government to develop and implement a robust and cheap ARV treatment plan as only a few, mostly affluent South Africans, were receiving ARVs. Thus, the TAC was founded on the solution-driven premise of educating people on the available medical treatment for people living with HIV and eventually morphed into a highly respected organisation which undertook research and lobbying activities on the prevention and treatment of people living with HIV, using trite science and activism inherited from the struggle against Apartheid, as a central tenet of their interventions. The TAC also used its early partnerships with organisations such as the AIDS Law Project (ALP) to challenge the Government's position on ARV treatment in court to its eventual success.<sup>8</sup>

## 2. UNDERSTANDING THE TAC'S MULTIPLE LEADERSHIP STYLES

The TAC successfully became an organisation founded to represent the concerns and issues of a disenfranchised community, that being the massive community of people living with HIV/AIDS in South Africa. History now records that the TAC largely succeeded in its original mandate to ensure the 'right to treatment' for all

<sup>4</sup> Birdsall, Karen., & Kelly, Kevin. (2005), 'Community responses to HIV/AIDS: An audit of AIDS-related activity in three South African communities.' Johannesburg: Centre for AIDS Development, Research and Evaluation (CADRE). p. 6.

<sup>5</sup> South African History Online (1998), 'The birth of the Treatment Action Campaign'.

<sup>6</sup> Overy, Neil (2011), 'In the Face of Crisis: The Treatment Action Campaign Fights Government Inertia with Budget Advocacy and Litigation'. Partnership Initiative Case Studies. pp. 8-9.

<sup>7</sup> Heywood, Mark (2004), 'The Price of Denial', Interfund Development Update 93, 5(3).

<sup>8</sup> Our Constitution (2020), 'Speaking truth to power (TAC and HIV/AIDS)'.

people living with HIV through a strong understanding of the mutually linked concerns and interests of the affected communities, namely the need to provide ARV treatment to HIV-positive people, and to de-stigmatize and educate people regarding the spread, prevention, and treatment of HIV/AIDS. This understanding of the issues and concerns was shared by the TAC's leadership, which was made up of individuals who were also HIV positive and thus shared the exact same concerns and interests as the affected communities.<sup>9</sup>

This connection between leader and follower is an indispensable aspect of the process-based leadership approach. It also represents the thick mutuality that the TAC enjoyed with its followers. One may determine that the epidemic confronting South Africans was a "wicked problem", and as such, its complexity required the leadership to engage the collective to find a solution.<sup>10</sup> This is exactly the approach used by the TAC in their campaigns which were usually borne out of grassroots activism,<sup>11,12</sup> and the transfer of individual power to the collective was essential in delivering a solution. The TAC's grassroots activism can be seen through the targeted mobilisation of support for its strategic objectives, which was usually done through AIDS awareness and treatment literacy campaigns in schools, factories, community centres, churches, trade union meetings, sports events, and informal drinking establishments (known as *Shebeens*), but most importantly, through door-to-door community visits in South Africa's rural township areas.<sup>13</sup> Thus, the TAC had shown collective leadership in the face of a complex problem, which the government failed to do.

Various leadership styles and qualities become identifiable in this situation. Firstly, as mentioned

above, the process-based leadership approach draws on the strong mutuality between the TAC and its followers and is exemplified more by the campaigns (actions) of the TAC rather than the substance or skill of its individual leaders, such as Zackie Achmat. Indeed, Achmat, an openly HIV-positive and gay former anti-apartheid activist, played a figure head role in the early development of the TAC, with many grassroots members talking of him with high reverence. However, the TAC also included various other leaders, specifically HIV-positive black men and women who joined the organisation as volunteers and rose to leadership roles over time. Despite the purported reverence for Achmat, the TAC was, and continues to be, an organization with formal structures that provide for internal representative democracy. The branch level serves as the foundational element of the organisation. Each province in which the organisation is active has its own provincial executive committee (PEC), and the national executive committee (NEC) is the organization's primary decision-making body. National leadership is nominated at the branch level and elected every two years at a national conference in a vote overseen by the Independent Electoral Commission (IEC) of South Africa. Scholars have pointed to how the structural arrangement of the TAC is similar to many anti-Apartheid movements, including that of the ruling ANC, in the 1980s and 1990s and can be seen as a re-imagining of the radical advocacy techniques that proved successful during the struggle against Apartheid. Therefore, despite the dynamism and overwhelming popularity of specific leaders such as Achmat, the TAC remains a collective and democratic body underpinned by the imperative feature of a leader-follower relationship characterised by a thick mutuality.<sup>14,15</sup>

<sup>9</sup> South African History Online (1998)

<sup>10</sup> Grint, Keith (2010), 'Wicked problems and clumsy solutions: The role of leadership'. *The New Public Leadership Challenge*, pp 169-186. pp. 12-13.

<sup>11</sup> Heywood, Mark (2009), 'South Africa's treatment action campaign: Combining law and social mobilization to realize the right to health'. *Journal of Human Rights Practice*, 1(1), pp 14-36. p. 17.

<sup>12</sup> Overy (2011), p. 9.

<sup>13</sup> Robins, Steven (2004), "'Long Live Zackie, Long Live': AIDS Activism, Science and Citizenship after

Apartheid". *Journal of Southern African Studies*, Vol. 30, No. 3, pp. 651-672. pp. 664-665

<sup>14</sup> Friedman, Steven, & Mottiar, Shauna (2004), 'Rewarding Engagement?: The Treatment Action Campaign and the Politics of HIV/AIDS', *Globalisation, Marginalisation and New Social Movements in post-Apartheid South Africa (case study)* (Durban: University of KwaZulu-Natal), pp. 15-19.

<sup>15</sup> Robins (2004), p. 663.

A servant leadership style is also evident, which can be divided into two distinct categories, namely the leadership aspect, which is concerned with the vision or strategic role of the leader, and the servant aspect, which is focused on the implementation or operational role of the leader.<sup>16</sup> In terms of the TAC, the leadership aspect is satisfied by its clearly identified common vision by which it intended to exercise its activism, which was either in collaboration with the government or, if required, through the courts and other lobbying methods, including civil disobedience and defiance, in partnership with other formations such as trade unions and faith-based organizations.<sup>17</sup> The servant aspect can also be seen through the fact that the organisation was founded on volunteerism.<sup>18</sup> TAC volunteers played a crucial role in the organisation's grassroots activism, such as the AIDS awareness and treatment literacy campaigns (which formed a central part of the clearly identified common vision of the leadership), participating in marches and protests, distributing information and resources, and providing peer support to people living with HIV/AIDS. Volunteers also helped run TAC offices and clinics, providing crucial services to people living with HIV/AIDS in their communities. These volunteers, who were the primary drivers of the grassroots operations, were often young African women, many of whom were HIV-positive. As funding increased significantly volunteers began to receive stipends and the TAC expanded its paid staff, thus creating a new set of organizational challenges. Often, joining the TAC was seen as a solution to the issue of mass unemployment and poverty, causing competition and division within branches as well as alienation between the branches and the NEC.<sup>19</sup> Despite this, the TAC's approach to volunteerism was grounded in the principles of solidarity and social justice, emphasizing

the importance of collective action to achieve common goals, a central tenet of the servant leadership style.

A transformational leadership style, defined as a process through which leaders establish a bond with followers that increases the degree of motivation and morality in both the leader and the follower,<sup>20</sup> is also easily discernible. This becomes apparent in how the TAC worked to transform the hopes and motivations of followers, firstly, by educating them that treatments for HIV do exist and should be made urgently available to the affected communities,<sup>21</sup> as well as in the individual act of Chairperson, Zackie Achmat, when he refused to take his private sector acquired ARV's until the same was provided for those in the public sector, thus fomenting solidarity between leader and follower and motivating others to emulate this.<sup>22</sup>

Finally, the TAC has also shown elements of activist leadership, which as defined by Elzein,<sup>23</sup> is inextricably linked to leadership generally. The argument being that activism is indivisible from leadership in that activism uses the identity and commitment of activists to engage a broad base of followers to achieve societal change. There is no better example of the activist leadership behaviour of the TAC as when senior members of the organization smuggled generic ARVs from Brazil back to South Africa in act of defiance. Zackie Achmat, accompanied by Matthew Damane and Nomandla Yako of the TAC with Joyce Phekane of the Congress of South African Trade Unions (COSATU) travelled to Brazil where they acquired cheaper, generic ARVs from FarManguinhos, the Brazilian national pharmaceutical manufacturer, and brought them back to South Africa for use in an ARV treatment programme that was run by Medecins Sans Frontiers (MSF) - South Africa in Khayelitsha, a township of half a million people on the

<sup>16</sup> Blanchard, Kenneth, & Broadwell, Renee (2018), *Servant leadership in action: How you can achieve great relationships and results.* (Oakland: Berrett-Koehler Publishers). pp. 1-2.

<sup>17</sup> Heywood (2004), p. 18.

<sup>18</sup> Ibid, p. 4

<sup>19</sup> Heywood, Mark (2015), 'The treatment action campaign's quest for equality in HIV and health: Learning from and lessons for the Trade Union Movement'. *Global Labour Journal*, 6(3). p. 330.

<sup>20</sup> Northouse, Peter (2016), *Leadership: Theory and Practice.* (London: SAGE). p. 161.

<sup>21</sup> Heywood (2009), p. 16.

<sup>22</sup> Christie, Sean (2022), 'Profile: What happened to HIV activist Zackie Achmat?', News24.

<sup>23</sup> Elzein, Kareem (2021), *Activist Leadership Development: An engine for Social Justice Transformation* (thesis) (Los Angeles: UCLA), pp. 23-38.



outskirts of Cape Town. This subversive move was carried out with the intention of showing the lack of political will on the part of the South African government to investigate the feasibility of acquiring more affordable ARV medications from generic suppliers in India and Brazil as opposed to the multinational pharmaceutical companies in South Africa. In essence, this move coupled with the pilot project of MSF – South Africa in Khayelitsha proved that it would be feasible for the government to reproduce on a nation-wide scale what MSF was achieving on a small-scale.<sup>24,25</sup>

### 3. ACTIVIST LEADERSHIP TO SOCIETAL TRANSFORMATION

While other factors, such as both internal (from within the ANC) and external (from opposition parties) political pressure and international dissent<sup>26</sup> may have contributed to the route to a national ARV treatment plan, the activism of the TAC and its judicial action added the most impetus to the eventual societal change. The outcomes of this societal change included the 2002 Constitutional Court case, which ordered the government to make the ARV, Nevirapine, available to pregnant mothers at all public clinics, failing which they would be in contravention of the right to healthcare as enshrined in the South African constitution. Moreover, the court concluded that a robust and inclusive ARV treatment programme was a “realistic and reasonable demand” on the government.<sup>27</sup> The government's announcement followed that it had finally approved an ARV treatment plan in November 2003, which was implemented the following year.<sup>28</sup> Moreover, the TAC successfully contributed to the de-stigmatisation and education about HIV/AIDS. This is best evidenced by the simple device of the ‘HIV positive’ T-shirt, which proved to have significant power in confronting people's stigmas about HIV. It also served as an emblem of the activist community and demonstrated solidarity

between the living and tribute to those who had died.<sup>29</sup> Ultimately, it was through the symbolism of acts such as the t-shirt campaign, other educational initiatives of the TAC which focused on AIDS awareness and treatment literacy, and the roll-out of the national ARV treatment plan that served to generally avert stigmas related to HIV and AIDS, especially as it relates to social exclusion, discrimination in the workplace, bullying, and harassment. However, conversely, the consequences of the current day robustness of South Africa's ARV treatment plan, which reduces the visibility of AIDS-related symptoms in people living with HIV in rural communities where stigmatisation and ostracisation remain, has created a situation in which HIV-positive people often withhold the sharing of their status for fear of stigmatisation by their community and thus calls into question the overall effect of reduced stigmatisation as a result of the activism of the TAC.<sup>30</sup>

What is undeniable is that the emergence of the TAC and the leadership styles exhibited collectively and individually by people such as its foremost chairperson, Zackie Achmat, pressured the South African government into taking the requisite steps to improve its approach to HIV/AIDS. The eventual roll-out of South Africa's no-cost ARV treatment plan in 2004, which is now one of the most robust in the world in terms of the number of people served,<sup>31</sup> was and continues to be a major success for the TAC, achieving one of its key mandates. Ultimately, it was immense civil society pressure from the TAC and others, utilising activist and transformational leadership styles, which was able to effectively represent the mutual concerns and issues of people living with HIV, something which the Government had failed to do at the time.<sup>32</sup> The proficient delivery of justice complimented this pressure, and the courts, correctly interpreting South Africa's constitution, continue to be an ally to the TAC in its

<sup>24</sup> P. U. J. (2002), ‘Brazilian generic drugs in South Africa - the background: MSF’. Médecins Sans Frontières (MSF) International.

<sup>25</sup> Christie (2022)

<sup>26</sup> Overy (2011), pp. 10-13.

<sup>27</sup> Our Constitution (2020)

<sup>28</sup> Heywood, Mark (2015), p. 314.

<sup>29</sup> Heywood (2004), p. 7.

<sup>30</sup> Samuel, Krishen (2021). ‘As AIDS recedes, HIV stigma evolves in rural South Africa.’

<sup>31</sup> United Nations (n.d.)

<sup>32</sup> Overy (2011), pp. 6-7.

effort to shape HIV/AIDS policy in the country.<sup>33</sup> The good work of the TAC continues today, with the organisation continuing to represent the most marginalised users of the public healthcare system in South Africa while continuing to campaign and litigate on critical issues related to the quality of and access to healthcare.

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