ACTIVISM AND AUTHORITY: ACT UP AND TAC AS SUC-CESSFUL ARBITERS OF HIV TREATMENT POLICY CHANGE

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s AIDS became a frightening reality on the world stage and governments floundered, influential activist groups came to the forefront of AIDS treatment, policy, and advocacy. Two of these organiza-

tions were particularly well known – the AIDS Coalition to Unleash Power (ACT UP) in the United States, and the Treatment Action Campaign (TAC) in South Africa. While both set themselves in direct opposition to pharmaceutical companies, relationships with their respective governments differed dramatically. TAC, while very critical of its government, ultimately won its battles, and then devoted its energy to helping the government implement the new policy as effectively as possible; in contrast, ACT UP perceived itself to be in direct opposition to the American government and refused to show it any support. In this paper, I will argue that this dichotomy between the approaches and thus the outcomes of movements by TAC and ACT UP was in part defined by a divergent faith in the democratic processes which upheld the American and South African government. The TAC believed in the ability of South Africans to elect a representative government; ACT UP did not have the same confidence in Americans. TAC therefore perceived its government as an ally, while to ACT UP, the American government was an enemy. I will begin this paper with an overview of ACT UP and TAC as actors in their respective HIV epidemics, including in relation to public opinion. I will then describe the relationships ACT UP and TAC maintained with pharmaceutical companies and governments, using these relationships to illustrate the level of representation the organizations felt by the authority and how accountable said organizations felt that authority was to people living with HIV or AIDS.

TAC and ACT UP: An Overview

In July of 1981, a report was released about five gay men in Los Angeles who had an unusual myriad of infections. 1 Although 'Slim disease' had been reported affecting communities in Tanzania and Uganda since the late 1970s,² 1981 marked the moment western governments and organizations first took an interest in what would become known as acquired immunodeficiency syndrome (AIDS). Human immunodeficiency virus (HIV) destroys an individual's immune system until it is unable to combat opportunistic infections that would otherwise never take hold. HIV becomes AIDS when a person develops an opportunistic infection, or has a CD4 T-cell count of less than 200 cells per cubic millimeter of blood,³ which demonstrates that their immune system has fallen below the acceptable threshold.⁴ ⁵HIV continued spreading quickly after 1981, reaching an estimated 1 million cases in the US in 1989,6 and an estimated 34.3 million worldwide by 1999.⁷ In the United States, AIDS was quickly la-

beled a gay disease, and never lost that connotation, despite later revelations that HIV could be spread

¹ CDC. 1998. "Current Trends First 100,000 Cases of Acquired Immu- nodeficiency Syndrome -- United States." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention.

2 Eduard Grebe, 2016. "The Ambiguities of the 'partnership' Between Civil Society and the State in Uganda's AIDS Response During the 1990s and 2000s as Demonstrated in the Development of TASO." Global Public Health: an International Journal for Research, Policy and Practice: 11, no. 4: 498

³ HIV.gov. 2022. "What Are HIV and AIDS?" HIV.gov. 4 Li R, Duffee D, Gbadamosi-Akindele MF. 2022. "CD4 Count." In StatPearls. Treasure Island (FL): StatPearls Publishing. 5 I will use the term HIV when discussing transmission or HIV-status, and AIDS when referring to the physical effects of infection. 6 CDC. "Current Trends First 100,000 Cases of Acquired Immunodeficiency Syndrome -- United States."

⁷ De Zulueta P. 2001. "Randomised Placebo-Controlled Trials and HIV-Infected Pregnant Women in Developing Countries: Ethical Imperialism or Unethical Exploitation?" Bioethics 15 (4): 29

through many means other than gay sex,8 including straight sex, needle sharing, breast feeding, and contact with infected blood.⁹ Throughout the epidemic, gav men remained the group most affected by HIV/ AIDS in America, although prevalence rates were also very high among low-income communities and communities of colour. As a result of their visibility as the face of the epidemic, the association of HIV with queer communities led to a double stigma – people living with HIV were assumed to be gay and queer people were assumed to be HIV positive. 10 Furthermore, because being gay was often seen as a morally deplorable choice, queer people were perceived as having contracted HIV through their own immoral actions. Much of the American public blamed HIV-positive queer people for their status, and for subjecting American society to the nuisance of fixing a perfectly preventable problem. 11 Over and over again, queer people were told that if they didn't want to die, they should just stop having sex. 12 As a result, queer communities began to face increased rates of homophobia and violence. 13

ACT UP was born out of this cultural context in 1987. It aimed to provide necessary services for people living with HIV/AIDS, and to pressure the government into taking responsibility for the epidemic, but also to protect queer people from homophobia and fight HIV stigma. ACT UP fought evictions and dismissals based on HIV status, ¹⁴ released safe sex handbooks, ¹⁵ and organized dramatic protests to demonstrate that they would not be silenced or made ashamed of their identities. ¹⁶ The organization was able to respond quickly and forcefully to developments on the AIDS world stage, and to support its members and

other people living with HIV/AIDS through the disillusionment of the first fifteen years of the epidemic.

Finally, in 1996, highly active antiretroviral therapy (HAART) was developed, suppressing HIV in treated individuals and allowing them to remain healthy and avoid transmitting the virus.¹⁷ However, despite the existence of effective HIV/AIDS treatment, for most of the world, the patented HAART was prohibitively expensive. It is estimated that in 2000, HAART cost roughly USD \$10,500 per patient per year in the US.¹⁸ Even if the South African government, the African National Congress (ANC), had been willing to distribute antiretrovirals, it would have been an enormous, potentially even impossible, expense. Many in the government were wary of antiretrovirals and dismissed the link between HIV and AIDS.¹⁹ They suspected western science of ulterior motives, and the exorbitant price attached to ARVs certainly had the potential to constitute such a motive. Throughout the Apartheid era and before, governments used the institution of public health to perpetuate scientific racism and segregation,-

²⁰causing the public to distrust any governmental behaviour control, particularly with relation to reproduction. ²¹ The ANC could not afford to be compared to the apartheid government, so promoting HIV prevention was difficult. Officials were further concerned that by recognizing the prevalence of AIDS in South Africa, they would add fuel to the racist narrative of AIDS as a Black disease spread through crude Black sexuality. ²²

While the South African public did not conceptualize HIV as a gay disease, stigma against people living with HIV or AIDS still abounded. HIV was defined along class lines as belonging to poor, uneducated, rural South Africans, despite having a much

⁸ Adrienne E Christiansen, and Jeremy J. Hanson. 1996. "Comedy as Cure for Tragedy: Act up and the Rhetoric of Aids." The Quarterly Journal of Speech 82, no. 2: 160.

⁹ HIV.gov. "What Are HIV and AIDS?"

¹⁰ Robert W Hansen, Paul L. Ranelli, and L. Douglas Ried. 1995. "Stigma, Conflict, and the Approval of Aids Drugs." Journal of Drug Issues 25 (1): 134

 $^{11\} Adrienne\ E$ Christiansen, and Jeremy J. Hanson. "Comedy as Cure for Tragedy": 161

¹² David France. 2016. How to Survive a Plague. New York: Vintage Books Publishing: 332

¹³ Adrienne E Christiansen, and Jeremy J. Hanson. "Comedy as Cure for Tragedy": 161

¹⁴ David France. How to Survive a Plague.: 109

¹⁵ David France. How to Survive a Plague.: 156

 $^{16\} Adrienne\ E\ Christiansen,$ and Jeremy J. Hanson. "Comedy as Cure for Tragedy": 157

¹⁷ CDC. "HIV Treatment." Centers for Disease Control and Prevention. Centers for Disease Control and Prevention, July 14, 2022.

¹⁸ Chen, R. Y., et al. 2006. "Distribution of health care expenditures for HIV-infected patients." Clinical infectious diseases : an official publication of the Infectious Diseases Society of America, 42(7): 1003

¹⁹ Steven Friedman and Shauna Mottiar. 2005. "A Rewarding Engagement? The Treatment Action Campaign and the Politics of HIV/AIDS." Politics & Society 33 (4): 513

²⁰ Anthony Butler. 2005. "South Africa's HIV/AIDS policy, 1994–2004: How can it be explained?" African Affairs, 104 (417): 604

²¹ Quarraisha Abdool Karim, Salim S Abdool Karim. 2002. "The evolving HIV epidemic in South Africa" International Journal of Epidemiology, 31 (1): 38

²² Robins, Steven. 2004. "'Long Live Zackie, Long Live': AIDS Activism, Science and Citizenship after Apartheid." Journal of Southern African Studies 30 (3): 653

higher prevalence in urban areas.²³ Like in the US, HIV-negative members of the public believed HIV-positive people to have engaged in risky behaviour of their own will, reducing the responsibility of the nation to combat HIV/AIDS.²⁴ Also analogous to the US, such perceptions resulted in violence and ostracization of HIV-positive community members.²⁵ However, unlike the US, in 1998, South Africa had an HIV prevalence rate of over 10%, while in North America it remained around 0.56%.²⁶ In the US, AIDS remained largely contained to specific, and already ostracized, communities throughout the epidemic, allowing the American people to more easily otherize people living with HIV/ AIDS. In South Africa, rather than existing only in poor or otherwise stigmatized communities, HIV prevalence was also high among middle-class South Africans²⁷ and even the members of the ANC - according to activists, almost everyone knew someone who had HIV.²⁸

Unfortunately, the popular but nascent ANC government was otherwise preoccupied with navigating the complexities of a newly post-apartheid era, thereby effective HIV/AIDS policy could easily have been set aside as a luxury which the present moment could not afford. To eliminate this possibility, the Treatment Action Campaign (TAC) was created in 1998.

The TAC fought for HIV and AIDS treatments to be accessible to all South Africans, ²⁹ and as had been true for ACT UP, this battle required more than demonstrations against the government and pharmaceutical companies. TAC financed and distributed medication, ran treatment literacy programs, and combatted HIV stigma through education in schools, churches, and bars. ³⁰ TAC members are also known for loudly proclaiming their HIV statuses through brightly coloured t-shirts reading 'HIV-positive.' ³¹ They have been con-

sidered impressively effective at dissipating HIV/AIDS stigma, although their mission remains incomplete.³²

Both ACT UP and the TAC were able to respond to stigma, government inaction, and their own mortality with power and resilience. They both made admirable developments on all fronts; ACT UP applied enough pressure to expand HIV treatment research until HAART was discovered, 33 and TAC convinced the ANC to make antiretrovirals available in public health facilities. 34Both ACT UP and TAC successfully promoted condom use and safe sex. 35 36 They refused to make themselves invisible the way they were expected to: they forced their governments and fellow citizens to consider HIV/AIDS a societal problem.

TAC and ACT UP versus Pharmaceutical Companies

TAC and ACT UP maintained antagonistic relationships with most pharmaceutical companies. Companies with exorbitantly priced patented HIV treatments like zidovudine (AZT) and antiretrovirals were perceived by AIDS activist organizations as greedy and ignorant of the realities of HIV/AIDS. ³⁷They were, after all, companies which existed to profit from life-or-death medical conditions, existing without accountability to the public. In order to influence companies to lower prices for AZT and HAART, therefore, activists attempted to make it less profitable for them to resist than to submit to activist demands.

After the release of AZT (a promising but ultimately ineffective HIV treatment) in the late 80s, ACT UP made it their mission to force its distributor Burroughs Wellcome to reduce its price from \$8000-\$10 000 annually³⁸ to a level accessible to all people living with HIV/AIDS. Armed with a breakdown of company finances, ACT UP members Peter Staley and Mark Harrington arranged a meeting with Bur-

²³ Robins, Steven. "Long Live Zackie, Long Live": 653

²⁴ Anthony Butler. 2005. "South Africa's HIV/AIDS policy, 1994–2004: How can it be explained?" African Affairs, 104 (417): 612

²⁵ Robins, Steven. "Long Live Zackie, Long Live": 654

²⁶ UNAIDS. 1998. "AIDS Epidemic Update: December 1998." Data. UNAIDS.org. UNAIDS: 5,7

²⁷ Robins, Steven. "Long Live Zackie, Long Live": 653

²⁸ Fred Bridgland. 2003. "From Fred Bridgland in Johannesburg" ACT UP NY. The Sunday Herald.

²⁹ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 513

³⁰ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 514-515

³¹ The Guardian. 2003. "Call for 'Dishonest' Mbeki to Apologise for Aids Gaffe." The Guardian. Guardian News and Media.

³² Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 549

³³ David France. How to Survive a Plague.: 51

³⁴ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 514

³⁵ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 544

³⁶ Adrienne E Christiansen, and Jeremy J. Hanson. "Comedy as Cure for Tragedy": 157

³⁷ David France. How to Survive a Plague: 381-382

³⁸ Victor Zonana. 1989. "AIDS Groups Urge Firm to Lower Azt Price." Los Angeles Times. Los Angeles Times.

roughs Wellcome to discuss AZT prices. As they expected, the meeting proved fruitless, but it did provide Staley with the layout of the company headquarters. A few months later, ACT UP members barricaded themselves in a Burroughs Wellcome office, earning coverage by major US newspapers. When prices remained unchanged, ACT UP infiltrated the New York Stock Exchange with the slogan "We die while you make money. Fuck your profiteering" and "How many more must die?" The next day, Burroughs Wellcome cut AZT prices to the ranges demanded by the organization. This marked a profound victory for ACT UP and for all lower-income people living with HIV/AIDS, who could now more easily (and/or legally) access what they hoped to be a life-saving medication.

In this case, ACT UP did sit down with Burroughs Wellcome in an attempt to resolve matters civilly. Within ACT UP, however, not everyone agreed that such meetings were in the best interest of the organization. Disagreements were manifesting between those who felt that meeting pharmaceutical companies at their level was more productive, and those who rejected civil conversation with profiteers as an insult to ACT UP principles. Ultimately, the former group, including Mark Harrington, was purged from ACT UP, demonstrating that the organization refused to entertain what it saw as sacrificing its values. 41 Harrington and his group went on to form the Treatment Activism Group (TAG), which worked with drug companies to build medical trials and drug distribution programs.⁴² What worked, in this case, was not polite conversation with company executives, but rather public embarrassment for inhumane business practices. ACT UP needed to be loud enough to create a PR disaster of epic proportions. It needed to put Burroughs Wellcome in danger of losing profit if negative public opinion and media attention continued to snowball - ACT UP threatened to defame the reputation of Burroughs Wellcome by bringing their protest into the stock exchange itself. To win such a battle, ACT UP framed not only the act of profiting off of AZT as unethical, but also the entire

company as an enemy of people living with HIV/AIDS.

TAC achieved a similar goal against the Pharmaceutical Manufacturers Association (PMA) in 2001. In response to Nelson Mandela's 1997 amendment to the Medicines Act, which allowed importation of patented drugs from other countries, the PMA and 40 drug companies united to defend their intellectual property rights in the High Court of South Africa.⁴³ To demonstrate the outrageous difference in costs between generic and patented medication, TAC founder Zackie Achmat travelled to Thailand and returned with 5000 capsules of generic fluconazole for treating thrush, an opportunistic infection which could be painful and even fatal for people with AIDS.44 The media became a useful ally, spreading outrage that a drug that clearly cost so little to produce could be monopolized by a major international pharmaceutical company like Pfizer at such a markup. 45 Officially, TAC joined the court case in 2001 alongside the AIDS Law Project at the University of the Witwatersrand. 46 They successfully reframed the case as a defense of the rights of people living with AIDS in South Africa, rather than about the intellectual property rights of western pharmaceutical companies. 47 TAC mobilized AIDS activists around the world to pressure the PMA into dropping the case. They led a 5000-person protest past the South African Pretoria High Court, garnering international interest in the proceedings.⁴⁸ Later that year, the PMA dropped the charges against the South African government and Pfizer made its products available for free at South African clinics.⁴⁹

TAC's victories included many of the same elements as ACT UP's had a few years before. Although the court systems were involved, the case was never allowed to play out fully; PMA pulled its charges before that could happen, suggesting that TAC had been able to make enough noise to publicly shame powerful companies, forcing them to choose to reduce their profits before public opinion did it for them. Pfizer even

³⁹ David France. 2016. How to Survive a Plague. New York: Vintage Books Publishing: 340, 351-355

⁴⁰ David France. How to Survive a Plague: 381-382

⁴¹ Raan Medley. 1996. "MARK HARRINGTON WAS WRONG: ACT UP & TAG: A Brief History of AIDS Treatment ACTAGanism." The act up historical archive.

⁴² Raan Medley. "MARK HARRINGTON WAS WRONG"

⁴³ Section 27. n.d. "Chapter 2: Taking on Goliath: The PMA Case." Standing Up For Our Lives.

⁴⁴ Robins, Steven. "Long Live Zackie, Long Live": 664

⁴⁵ Robins, Steven. "Long Live Zackie, Long Live": 664

⁴⁶ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": $514\,$

⁴⁷ Section 27. n.d. "Chapter 2: Taking on Goliath: The PMA Case." Standing Up For Our Lives.

⁴⁸ Section 27. n.d. "Chapter 2: Taking on Goliath: The PMA Case." Standing Up For Our Lives.

⁴⁹ Robins, Steven. "Long Live Zackie, Long Live": 664

attempted to protect itself further by providing South Africa with free drugs – the large profit cut they were willing to endure suggests that TAC's tactics were exceptionally threatening. Here, TAC had the optics of the court system to visually place itself in opposition to the PMA. It was not negotiating or pleading. TAC was opposing the PMA through legal channels, and this sent the PMA scrambling into defensiveness. If pharmaceutical companies felt little accountability to their American customers, it is safe to say that they felt even less to customers in South Africa. ACT UP at least had the geographic capacity to protest at the headquarters of Burroughs Wellcome. If not taken seriously, they could at least make themselves directly visible to the company, facilitating some aspect of communication. Even if it was not common knowledge, American taxpayer money still funded Burroughs Wellcome's research and development. If ACT UP could not leverage some power from those advantages to promote the wellbeing of Americans living with HIV/AIDS, pharmaceutical companies would clearly feel no responsibility to their South African equivalents. In such a context, direct opposition was the only available option - no mutually beneficial solution would be reached.

TAC and ACT UP versus American and South African Governments

While ACT UP and TAC felt similarly about their positions in disputes with pharmaceutical companies, they employed different narratives when opposing their own governments. ACT UP maintained an antagonistic attitude toward the American government, similar to the one they levelled at drug companies. TAC, on the other hand, always demonstrated support for their government as a whole, even as they attacked specific government decisions.

ACT UP's main motto was to get 'drugs into bodies,' and yet, for years, AZT was the only approved drug on the market to combat HIV and AIDS.⁵⁰ ACT UP pressured the Food and Drug Administration (FDA) responsible for drug approvals to speed up testing and approval rates – they preferred that drugs be available for people living with HIV/AIDS as soon as possible, even if the FDA was not convinced of their efficacy. These were referred to as 'what the hell drugs,' meaning that

50 David France. How to Survive a Plague.: 334

an individual with AIDS might not still be alive by the time the FDA decided a treatment worked, and nothing else was working, so they might as well take it now, just in case. 51 ACT UP made its opinion extremely clear to the FDA through numerous protests and media campaigns with slogans such as "hey, hey, FDA, how many people will you kill today?"52 and "we're the experts, let us in!"53 In response, the FDA made a few important concessions. First, in 1988, the FDA agreed to expand the scope of the first and second phases of medical trials to eliminate the third phase, allowing HIV/AIDS medications to be released more quickly. 54 Secondly, in 1989, the head of the FDA, Anthony Fauci, began implementing the parallel track program suggested by ACT UP member Jim Eigo, which would allow HIV-positive people who were ineligible for clinical trials of an unapproved drug to access it (during efficacy trials) outside

of the trial system. 55 ACT UP members were even in-

volved in the task force which structured the program.⁵⁶

Despite Fauci's willingness to work with ACT UP members, and ACT UP members' grudging acceptance, this was not the start of an amicable relationship. In the same breath as Harrington discussed the collaboration of ACT UP and Fauci in "Comment" (1992), he declared that it wasn't enough, and that ACT UP members needed to be involved in every level of decision-making.⁵⁷Note that this is the same Harrington who later left ACT UP due to controversy over his relationship with drug companies, implying that the rest of ACT UP may have been even less enthusiastic about the partnership. First, Fauci appeared to have been pushed into making these concessions by ACT UP antagonism, rather than having accepted ACT UP into the decision-making process because he believed they had the right to be there. ACT UP therefore believed that they needed to fight to be in the room; rather than coming to the realization that the FDA was on their side,

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⁵¹ David France, How to Survive a Plague, directed by David France (2012; Sausalito: Mongrel Media, 2012), iTunes

⁵² Los Angeles Times. 1988. "Police Arrest AIDS Protesters Blocking Access to FDA Offices." Los Angeles Times.

⁵³ Robert W Hansen, Paul L. Ranelli, and L. Douglas Ried. "Stigma, Conflict, and the Approval of Aids Drugs.": 133

⁵⁴ Robert W Hansen, Paul L. Ranelli, and L. Douglas Ried. "Stigma, Conflict, and the Approval of Aids Drugs.": 133

⁵⁵ Mark Harrington. 1992. "Comment." Journal of the American Statistical Association. 87 (418): 573

⁵⁶ Mark Harrington. "Comment.": 574

⁵⁷ Mark Harrington. "Comment.": 574

ACT UP was reminded that their power over Fauci was only a result of their mobilization and hostility.

After ACT UP had been accepted into the parallel track task force, their relationship with the FDA changed. Personal, if not benevolent, relationships had been formed, and ACT UP could command Fauci's attention. An ACT UP meeting with Fauci in 1989, which from his perspective might have had the potential to soothe the FDA's relationship with the organization, clearly meant something different to the activists present. Fauci was accused of ignoring AIDS because the people most affected were queer and people of colour, and asked how he lived with the preventable deaths of AIDS victims on his conscience. Fauci would never be given the trust or support of ACT UP, no matter how much time he devoted to them.

Fauci was a man who had made mistakes in AIDS response and caused AIDS related deaths. But he was also a government official. As with pharmaceutical companies, who would always be subservient to profit, the head of the FDA would always be subservient to the politics of the elected government.⁵⁹ And just as ACT UP believed that companies felt no real loyalty to, or responsibility for, their customers, they also questioned the loyalty the elected government felt toward people living with HIV and AIDS. As mentioned, the HIV prevalence rate in North America was around 0.56% in 1998, and most cases were concentrated in communities already facing stigma and ostracization from the general public. With high rates of violence, hostility, and general indifference directed at people living with HIV and AIDS, it seemed clear that very few people outside of the communities affected would fight (or vote) to protect HIV-positive people. Ultimately, ACT UP did not win the affection of the public, and could not help to remedy that divide. 60 The elected government, therefore, was not a representation of people living with HIV/AIDS, and because they had little part in electing it, the HIV/AIDS community also felt little loyalty to them. ACT UP could never place trust in an institution which felt no responsibility to ensure their wellbeing, and so even when government

agencies chose to make steps in the right direction, they could never be fully trusted. ACT UP could certainly never openly support them, because they would always be illegitimate to the people they did not represent.

In contrast, TAC always made a clear distinction between their disdain for government policy and the government as an institution. Even while protesting government refusal to rollout antiretrovirals after the price cuts. TAC members declared themselves loval ANC members. ⁶¹They brought the government to the Constitutional Court to argue that access to treatment is the right of anyone living with HIV or AIDS, regardless of their ability to pay for the drugs themselves. 62 Of course, they also employed tactics to shame the government into agreeing by sending international organizations to protest at South African embassies⁶³ and by using the language of human rights, which the ANC itself had used against the apartheid government. 64 They won treatment for pregnant women to avoid mother-to-child transmission in 2002, and after further campaigning, in 2003 the court ruled that it was unconstitutional to deny anyone living with HIV and AIDS access to antiretrovirals.⁶⁵

Similar to ACT UP, TAC did not take this victory as an indication that the battle was over, or that the government would suddenly become a model arbiter of AIDS justice. Dissimilar to ACT UP, however, they did not hold the ANC's former reluctance against it, but rather poured their energy into making sure antiretroviral rollout was as comprehensive as possible. Activists were willing to proclaim their support for the new policy, stating that the organization's new purpose was to assist the government in the program implementation. This involved running awareness campaigns so individuals knew how to access treatment, visiting chosen hospitals to ensure they contained the equipment and staff necessary for proper HIV/AIDS care delivery, guaranteeing that hospitals were obtaining

⁵⁸ David France. How to Survive a Plague: 384-385

⁵⁹ Fernandez Lynch, H., Joffe, S. & McCoy, M.S. 2021. "The limits of acceptable political influence over the FDA." Nat Med 27: 188

⁶⁰ Adrienne E Christiansen, and Jeremy J. Hanson. "Comedy as Cure for Tragedy": $157\,$

⁶¹ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?":

⁶² Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 514

⁶³ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 546

⁶⁴ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 533

⁶⁵ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 514

⁶⁶ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 536

high quality informed consent from patients, and continuing to fight HIV stigma so people would be more comfortable accessing treatment. This was not framed in an oppositional way – activists did not imply that they were forced to do this work because the government refused to, but rather that they were offering their expertise to the government in the name of a common goal. Rather than attempting to take power away from the government, as did ACT UP, TAC saw itself as benefiting the most if the ANC was strong enough to uphold its HIV promises. Showing public support for the government was therefore mutually beneficial, just as the implementation of HIV medication would be.

As previously mentioned, unlike North America's 0.56% prevalence rate, one in ten people in South Africa were HIV-positive in 1998. Although HIV stigma was strong, almost everyone knew someone who was living with HIV or AIDS. Since a much larger portion of the South African voter public was either living with HIV or cared about someone who was, the question of AIDS treatment a much more heavily considered topic among voters, and among voters who would be voting for the ANC.⁶⁹ HIV and AIDS policy was therefore an issue about which the ANC needed a strong position. By reducing HIV stigma, using the court system, and mobilizing thousands in protest, TAC made the government recognize that truth. TAC managed to be respected by many South Africans, further influencing their voting positions. 70 TAC was therefore in a very different position from ACT UP, which felt ostracized from the voter public and convinced that the government felt no obligation to take the interests of HIV-positive people into account. In the case of South Africa, the government was supported by the majority of the population, including people living with HIV/AIDS, and through citizen mobilization, could be made to understand the will of its populace.

Conclusion

The TAC's policy of collaboration with the government toward positive change seemed extremely valuable in their context. Had they implemented the ACT UP approach, and used their voice to undermine the authority of their government in an attempt to achieve their goals, they may have negatively impacted the government's ability to act on their advice. However, had ACT UP been less careful about maintaining distance from the government, or used their voice to support the government when they agreed with its decisions, they may have undermined their position as marginalized by a government which did not represent them. The public begged and ordered ACT UP to quiet down and let the government work.⁷¹ Had they appeared to do so, all the other problems exacerbated by marginalization would have gone unnoticed – even if treatment for AIDS was found anyway, the system would have remained unreproached. Both organizations successfully employed the strategies which best suited their movements within the contexts they found themselves, under the measures of authority they were subject to. For ACT UP, that meant rhetorical animosity, both with relation to pharmaceutical companies and their own government. For TAC, it was equally important to set themselves in opposition to pharmaceutical companies, but they understood that their relationship with their government had the potential to be coopertherefore ative, and chose to pursue partnership.

⁶⁷ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 536

⁶⁸ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 538

⁶⁹ Steven Friedman and Shauna Mottiar. "A Rewarding Engagement?": 522

⁷⁰ Mark Heywood. 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): 323

⁷¹ Adrienne E Christiansen, and Jeremy J. Hanson. "Comedy as Cure for Tragedy": 157

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