Introduction

This past September has marked thirty-five years since the Center for Disease Control recognized the legitimacy of HIV/AIDS, a disease that claimed the lives of around one-hundred people that same year. The HIV/AIDS crisis reached epidemic levels as the 1980s persisted, peaking in 1993 with around three-hundred thousand newly-reported cases that year (CDC 2001). Thankfully, due to the presence of effective education and preventative measures, HIV/AIDS instances have become mostly contained throughout the developed and developing world. Unfortunately, efforts in containing HIV/AIDS in Sub-Saharan Africa haven’t been nearly as successful, as hundreds of millions of dollars have been invested into treatment development in this region of the world with limited positive results. In fact, even today, Sub-Saharan Africa, a region of the world that accounts for less than 15% of the overall population, possesses over 70% of the total occurrences of HIV/AIDS globally (Kharsany & Karim, 2016). South Africa is of particular interest when analyzing this epidemic, as a history of colonial oppression and racial discrimination has led to modern-day health inequities specifically pertaining to HIV/AIDS. With this in mind, we decided to pose the following question: are the programs that are aimed at tackling the persistent HIV/AIDS epidemic in South Africa in conversation with the needs and sensitivities of the communities’ understanding of the disease, and how do these health initiatives play out in a society that is influenced and marred by a history of colonial oppression?
History of Apartheid

The global importance of South Africa began around 1650 with the Dutch colonization of what is now Cape Town. Control of South Africa wavered between the Dutch and the British for the next 200 years. This was because both countries wanted power over the highly-profitable slave trade, as every slave that was brought from Africa, Asia, or Australia to the Americas via the transatlantic slave trade first went through the city of Cape Town. This colonial presence led to much racial diversity in the country, and by the end of World War II, South Africa was almost 20% white and about 78% black or colored (2011 Census). Though the racial minority, the white population rose to immense power when the National Party, a political party of Dutch origins, imposed a system of racial apartheid where whites enjoyed a very-high quality of living (arguably the highest in all of Africa) while black and colored individuals were left disadvantaged in terms of income, educational opportunities, access to healthcare, and pretty much every other metric of importance. This system persisted until 1991, but almost 30 years after the dismantling of Apartheid, institutionalized segregation persisted, unemployment for those who identified as black or colored increased, and health outcomes of the population of South Africa as a whole decreased largely due to the HIV/AIDS epidemic. Today, around one in every eight South African has HIV/AIDS, but people of color in the country are thirty-one times more likely to have HIV/AIDS than white South Africans. Whether or not these disparities resulted from a misunderstanding of the region’s needs is what we are trying to discern here.

The Global AIDS Response and PEPFAR

In 2007 there was an estimated 5.7 million South Africans living with HIV out of a population of around 50 million (Ghanotakis, 2009, pg. 357). These estimates indicated that South Africa’s AIDS epidemic was one of the worst in the world, the same of which can be said about the epidemic today.
Over the years, national public awareness of HIV/AIDS increased through the advocacy and activism of medical communities, civil societies, and media outlets within South Africa. Simultaneously, global health initiatives with significant funding from outside countries presented as powerful forces in the targeting of HIV/AIDS. These global health initiatives are focuses on “a performance-based funding framework, including objectives, operating procedures and outputs, global health initiatives are perceived to attract additional funding, increase political visibility and create a sense of urgency and impetus around the issues that they support” (Ghanotakis, 2009, pg. 357). Below is a summary of some of the key programs that interact with the South African government directly, or act as sources of funding to support one another.

Table 1. Summary of Global AIDS Response Programs and Funding Sources Present in South Africa

<table>
<thead>
<tr>
<th>Program</th>
<th>Description</th>
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<tbody>
<tr>
<td>The Global Fund</td>
<td>Founded in 2002, the Global Fund is a financing institution that is in partnership between governments, civil society, the private sector and people affected by AIDS.</td>
</tr>
<tr>
<td>President’s Emergency Plan for AIDS Relief (PEPFAR)</td>
<td>Founded in 2003, initiative started by the United States to address the HIV/AIDS epidemic on a global scale by implementing on the ground support.</td>
</tr>
<tr>
<td>World Bank Multi-Country AIDS Program (MAP)</td>
<td>Founded 2000, contributes billions in pooling of funds to the UNAIDS program on HIV/AIDS.</td>
</tr>
<tr>
<td>United Nations Program on HIV/AIDS (UNAIDS)</td>
<td>Founded 1996, works on the ground with locally based staff to build a system to prevent transmission, provide care, remediate social instability.</td>
</tr>
<tr>
<td>South African National AIDS Council</td>
<td>Association that receives funds from the Global Fund to enhance South Africa’s AIDS response by building a consensus across civil society and government.</td>
</tr>
<tr>
<td>Treatment Action Campaign</td>
<td>Founded 1998, a civil society organization that campaigns for access to AIDS treatment and currently focus on quality and access to healthcare.</td>
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The largest contributor to the Global AIDS response in South Africa is The President’s Emergency Plan for AIDS Relief, or PEPFAR. PEPFAR began in 2003 under the Bush administration with the intention of addressing the HIV/AIDS epidemic by serving as a funding program that directs funds to many different HIV/AIDS initiatives globally. PEPFAR singled out 15 countries heavily burdened by the HIV/AIDS epidemic, South Africa being one of them (Ghanotakis, 2009, pg. 360). From 2004 to 2008, PEPFAR disbursed over $18.8 USD in these 15 countries of focus, becoming the largest donor in history to fight HIV/AIDS.

The goal of PEPFAR is to control and end the HIV/AIDS epidemic that is present all over the globe. Much of the efforts of PEPFAR are channeled into the Sub-Saharan African continent where the HIV/AIDS epidemic is the most concentrated and the least equipped to meet the demands of the sick and vulnerable. Some of the major goals of PEPFAR are that the programs are to be “country-owned and country-driven” (Ghanotakis, 2009, pg. 359), placing much of the health system building in the hands of the countries that are facing the epidemic. PEPFAR’s long term goals, beyond curbing the rate of HIV/AIDS transmission in vulnerable countries, is to provide infrastructure to sustain and maintain a high level of health care beyond the AIDS epidemic. Building up the national health program in the countries where PEPFAR is located has far-reaching implications. In summary, the main goals of PEPFAR are to:

1. “Transition from an emergency response to promotion of sustainable country programs.
2. Strengthen partner government capacity to lead the response to this epidemic and other health demands.
3. Expand prevention, care, and treatment in both concentrated and generalized epidemics.
4. Integrate and coordinate HIV/AIDS programs with broader global health and development programs to maximize impact on health systems.
5. Invest in innovation and operations research to evaluate impact, improve service delivery and maximize outcomes”
PEPFAR has had its own criticisms of implementation and oversight since its inception in South African society that led to the comprehensive agenda listed above. Elena Ghanotakis’ work on elucidating the effectiveness of PEPFAR programs in the Western Cap also gives insight into the implementation style of the U.S. led program. For one, PEPFAR funded programs have the goal of working closely with the health departments to make decisions, but in reality practice decision making power in isolation from the health leaders in society. Ghanotakis’ work focuses on PEPFAR’s effectiveness in providing more than just preventative HIV/AIDS treatments, but extending that funding to addressing issues like Gender-Based Violence (GVB) that contributes greatly to the HIV/AIDS prevalence in women in South Africa. Through a series of interviews with officials, it is clear that the views of the program distort their involvement in initiatives to combat GVB simultaneously with HIV/AIDS, a conflict of interest that stems from the U.S. having a conservative, abstinence-based approach to sexual health. In an interview, a South African official said:

“PEPFAR won’t fund anyone that does abortions. We have given women this right for twenty [sic] years. We have data to show our programs have prevented septic death. It would not be acceptable for our province to apply for PEPFAR funding because of the PEPFAR prescripts, which are not in line with our government policies” (Ghanotakis, 2009, pg. 362)

PEPFAR-South Africa officials will dispute the above statement, asserting that funding decisions and programming decisions are made in tandem with the leaders of South African healthcare. Yet in practice, the doors are closed off to these actors, leaving the decision-making process in the hands of US citizens representing institutions like the CDC and USAID, not South Africans (Ghanotakis, 2009, pg. 359). This allows for the viewpoints of the US government to become the driving force in decisions involving the external factors that contribute to HIV/AIDS, one such as GVB. One can imagine this over-reach of the PEPFAR program having an effect on other, more nuanced and deeply rooted factors that greatly perpetuate the HIV/AIDS epidemic in South Africa.

Overall, $44 billion dollars had been spent by 2012 by the PEPFAR program with an overall 10.5% decrease in HIV/AIDS mortality (Katz, 2013). But with issues with poor implementation and
ideological differences in countries like South Africa described above, the HIV/AIDS epidemic still remains the worst in Sub-Saharan Africa. Through criticism of the program’s implementation style not only in South Africa, but program-wide, sparked a change in the aims and structuring of PEPFAR. Do the U.S. concerns of funding capabilities down the road, and the overall sustainability of the program, a transition away from the “emergency” model of providing HIV/AIDS treatment, to a system devoted to building health systems that lift up community health on all fronts, was the main focus (Katz, 2013).

By supporting community health clinics with PEPFAR dollars means that there can be more involvement by the South African community in the treatment of HIV/AIDS, allowing a deeper level of understanding to the community with the importance placed on community-based healthcare workers. Yet, the reality of the transition is once again not aligned with the goals of the program, and on the ground implementation leaves something to be desired for the people of South Africa due to lack of access to physicians in the community, poor attention to care, and organizational issues. Additionally, the people of South Africa fear deeply rooted stigmatization of HIV/AIDS and have an overall distrust of aid from Western societies as a result of long-lasting effects of racial apartheid (Katz, 2013). Seeking treatment has always been avoided due to fear of being recognized by family and peers in the community, but amplified as PEPFAR influence has become available at the local level (Katz, 2013). Moving forward, the PEPFAR program must strengthen the relationship with the South African community, address issues of cultural overreach, as the U.S. led program does set goals based on the viewpoints of the U.S. government, and work to build health systems that address not only the HIV/AIDS epidemic, but the confounding societal factors that prevent South Africa from advancing the fight to end HIV/AIDS transmission and mortality.

**TAC: A local advocacy movement**

Treatment Action Campaign (TAC) has been one of the most effective health and human rights movements rooted in South Africa itself, altering the response to the HIV/AIDS epidemic that has infected 6 million people just in that country. TAC was founded in 1998 in an effort to
campaign for access to HIV/AIDS treatment. With 8,000 members, they are able to “represent users of the public healthcare system in South Africa, and to campaign and litigate on critical issues related to the quality of and access to healthcare” (“About”). TAC created a shift in South Africa from political denial to one of praise and progress surrounding this relevant global health issue. By utilizing a human rights approach, TAC was able to start a grassroots mobilization effort and utilized local talent to educate the local communities. By empowering marginalized communities, TAC went “beyond the traditional spheres of advocacy and used innovate approaches to enable social change” while focusing on “sympathy and compassion rather than judgement and antagonism” (Ahmad, 2013, p. 18). Lucie White’s three dimensions of lawyering could potentially be a framework for other organizations to base their approaches off of, as TAC “unequivocally succeeded at each individual dimension” (Ahmad, 2013, p. 19). This framework consists of three layers that each bring a new dimension of lawyering to the table: advocacy through litigation, advocacy in stimulating progressive change, and advocacy as a pedagogic process. TAC’s multidimensional approach followed White’s characterization of activism, as they employed each of the previously mentioned dimensions of lawyering to “mobilize traditionally marginalized societal segments in the process of self-empowerment and education to combat the HIV/AIDS epidemic” (Ahmad, 2013, p. 19).

By beginning with understanding the Constitution, TAC was able to “effectively litigate in a previously established power structure that has inherently created class, race and gender imbalances” (Ahmad, 2013, p. 19). Fighting for the fundamental principle that everyone has the right to have access to health care, led to TAC suing the government for not the making the drug nevirapine available in public hospitals. By not having this drug available, there was no guarantee of prevention of mother-to-child transmission; this went against Section 27(1)(a) of the
South African Constitution since not all had access to this service. TAC also began a lawsuit with the Department of Correctional Services (DCS), demanding access to HIV/AIDS treatment for infected prisoners. Once they had a report detailing the cause of an inmate's death, they had real-life proof that a lack of access to ARVs contributed to infected prisoner’s deaths (Ahmad, 2013, p. 20). TAC’s claims benefitted disempowered groups and challenged the established injustices, rather than questioning the biases and injustices inherent in the legal system. Ensuring that South Africa met its constitutional obligation to provide sustainable and quality healthcare to its citizens was the best first step they could have taken, providing leverage and evidence to build off.

Given South Africa’s history of apartheid and systemic marginalization, the second step TAC had to take was delving deeper into the causes for suppression that shapes society. By discovering the barriers that inhibit specific issues from being challenged, they were able to attack them at the core and dismantle some power dynamics. “TAC has utilized the adversarial legal system to promote social progression by pursuing already enshrined rights while also challenging unjust norms to achieve further rights for HIV patients” (Ahmad, 2013, p. 20). The Christopher Moraka Defiance Campaign was evident of their adherence to this; the Pharmaceutical Manufacturers Association challenged the government’s right pursuant to the Controlled Medicines and Related Substances Act to lower the price of fluconazole, a brand name drug created by Pfizer. TAC submitted a “brief in favour of the government’s decision,” while raising three issues: access to essential medicines, patent rights and health service transformation (Ahmad, 2013, p. 20). They were able to use Christopher Moraka’s death to illustrate the sharp inequality in the South African healthcare system: “the private sector accounted for 75% of public expenditures on health care while serving only 20% of the
population” (Ahmad, 2013, p. 21). TAC also touched on how there were monopolies maintaining high drug costs that prevented essential medicines from reaching public sector patients. Since the patents were the barriers to equal access to a public good, this was legitimized and looked at closely by the government. TAC dismantled the power imbalances that created these barriers through print and digital media in order to promote social progress. TAC also acknowledged that the issue of high marked-up prices on fluconazole was not an isolated incident, but an injustice that affects the whole healthcare system. The government ended up complying and lowered the price of fluconazole, “an ARV treatment scientifically proven to combat the opportunistic infections caused by the HIV virus”; this made it more affordable to HIV patients as the drug was previously unavailable through the public healthcare system (Ahmad, 2013, p. 20). Taking it a step further, White commented that a movement requires continued interactions between those in power and those who are speaking on behalf of those who lack formal representation in the government. TAC used a legal claim to stimulate progressive change and were able to “bridge the age-long inequalities between the formal employment sector that was privileged to have access to medical schemes subsidizing health care and the informal sector, which relied on the grossly inadequate underfunded public system” (Ahmad, 2013, p. 21). They worked on engaging powerful pharmaceutical companies to speak on behalf of patients. Their pressure on this issue led to Pfizer supplying fluconazole free to public healthcare clinics in South Africa. Breaking down the inequalities that kept previously marginalized groups disempowered by inhibiting their improvement to health care, has made a world of difference for all HIV/AIDS infected persons.

Advocacy as a pedagogic process enables an ongoing process of “reflection, action, and improvement in which a disempowered group strives to recognize and collectively change its present reality” (Ahmad, 2013, p. 22). By constantly reflecting, acting and improving small
groups are able to reflect together on the current conditions of their lives. TAC first illustrated people’s rights as HIV/AIDS patients and fought for them, as they have little power and voice. Then they emphasized active participation and held AIDS literacy campaigns in townships across the country in order to challenge the myths, rejection, and misinformation surrounding the virus. This really fostered an environment of reflection in the local townships. Another campaign was developed to inform “poor South Africans about the injustices of generic drug price increases” (Ahmad, 2013, p. 22). If HIV/AIDS infected people are not aware of the issues revolving the virus they have, they cannot speak up in attempt to create change. Knowing this small bit of information could seriously alter the span of their lives. TAC played the role of catalyst, intervening between the government and marginalized communities who were seeking increased access to HIV/AIDS treatment. In addition, TAC fostered non-institutional citizenship, promoting self-empowerment. Instead of having an outsider attempt to understand the nuances of socioeconomic issues in relation to HIV/AIDS in order to educate local communities, TAC had representatives from its Literacy and Treatment Program (LTP), who were also residents of Khayelitsha, visit Khayelitsha clinics three times weekly to give presentations about adherence to treatment schedules and safe sexual practices. This legitimized the information people were receiving, as it was from one of their own; they were hearing information “rooted in cultural and historical congruency” that they could personally relate to (Ahmad, 2013, p. 23). After many of TAC’s campaigns and five years after formation, the Cabinet approved the Operational plan for Comprehensive HIV/AIDS Care and Management and Treatment for South Africa. In 2005, the government became committed to improving public access to ARVs, even for HIV-positive foreign nationals who live in the country. In 2009, once Jacob Zuma became president, all children exposed to HIV would be tested and given ARVs, getting rid of the culture of denialism
under the former president, Thabo Mbeki. One year later, the government then launched an
HIV/AIDS Counseling and Testing media campaign that utilized door to door visits and
billboards to promote the availability of free testing and counseling in health clinics. This
dismantled the myths and stigmas surrounding the disease, allowed the government to be more
active, and engaged citizens in their own circumstances (Sabi & Rieker, 2017, p. 62).

TAC has been so effective because it differs from humanitarian aid (which tends to
address temporary, urgent needs) and instead uses rights arguments (which are concern broader
structures such as liberties and opportunities). “Although nothing is infallible, the point of
establishing rights is to try to rebalance the power relationship, and to produce long-term,
reliable structures that will remove the need for humanitarian concern in the future… that is why
rights are worth pressing for, even when humanitarian aid is, for the moment, forthcoming”
(Wolff, 2012, p. 16). TAC used a bottom-up approach to break the silos between government,
healthcare, and the people of South Africa. By working with existing political structures,
challenging the roots of various barriers, and empowering HIV/AIDS infected persons, TAC was
able to mobilize a post-apartheid generation of South Africans to fully participate in all aspects
of society to combat injustices perpetuating the HIV/AIDS epidemic so familiar to them.

Comparison of Approaches to HIV/AIDS epidemic in South Africa

Table 2. Comparison of PEPFAR and TAC

<table>
<thead>
<tr>
<th>PEPFAR</th>
<th>TAC</th>
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<tbody>
<tr>
<td>Top-down approach</td>
<td>Bottom-up approach</td>
</tr>
<tr>
<td>International umbrella humanitarian organization</td>
<td>Grassroots national social advocacy movement</td>
</tr>
<tr>
<td>Funded entirely by U.S. Government</td>
<td>Funded through outside sources, such as donor countries</td>
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</table>
As evident in previous sections, there have been a multitude of different approaches and tactics taken in attempting to decrease the amount of people at risk of or living with HIV/AIDS in South Africa. Many of these approaches, such as PEPFAR and TAC, have made significant progress in combatting the epidemic in South Africa. It is also true, however, that both programs have their criticisms and drawbacks. In South Africa in particular, it is important to ensure that the programs addressing the HIV/AIDS epidemic are best suited to helping the community and fulfilling their needs, given the social determinants of health and colonial history context particular to the country. There is extensive history that shows that without taking into consideration the specific circumstances of a situation, implementing generalized strategies can actually end up doing more harm than good. For example, the implementation of neoliberal policies by the World Bank through structural adjustment programs (SAPs) in Latin America had extremely detrimental effects on many economics and social practices. In comparing the two approaches to fighting HIV/AIDS in South Africa, it is important to keep in mind what actual effect they have on not only the epidemic but the targeted communities and individuals affected by the disease.

PEPFAR is an umbrella organization, funded primarily by the U.S. Government, which would fall into the category of international humanitarian aid and intervention. In contrast, TAC is a bottom-up, grassroots national social advocacy movement, which could be construed as a national non-governmental initiative. The foci of these programs also differ in many ways. As PEPFAR’s main goal is to control and end the HIV/AIDS epidemic worldwide, much of the focus in South Africa is on health-care system building and providing resources (i.e. health care
workers and medications) to help abate the effects of the epidemic. TAC, on the other hand, utilizes the pedagogy of advocacy as the main way to affect change, through influencing government policy regarding equitable access to treatment of HIV/AIDS, and creating awareness of certain issues. While both of these initiatives differ in their approach to the HIV/AIDS epidemic in South Africa, they have both been relatively successful in achieving their goals.

PEPFAR has had immense success in providing treatment and medication for those living with HIV/AIDS in South Africa. PEPFAR has provided South Africa with more than 3 billion dollars, in order to train doctors, construct clinics and provide medications (McNeil, 2014). This has resulted in many more people receiving the treatment needed, increasing the number of trained healthcare professionals and the number of drugs available. TAC has also had success in their approach; holding the government accountable, as a duty-bearer, for the health of its citizens, including those living with HIV/AIDS. TAC has had a huge effect on how the South African government perceived the HIV/AIDS epidemic, and has litigated for the availability of resources for those living with HIV/AIDS. TAC has also increased advocacy and awareness in specific communities by focusing on prevention through their literacy campaigns in order to foster self-empowerment.

Both TAC and PEPFAR have had some positive effect on combatting the HIV/AIDS epidemic in South Africa, though there have been some drawbacks and criticisms of each program. PEPFAR has reduced the prevalence of HIV/AIDS, but many argue that it has fallen short in some areas. For instance, PEPFAR has not reduced stigma against people living with HIV/AIDS. Another criticism regards PEPFAR’s lack of concern for the underlying structural violence and social issues that affect not only people living with HIV/AIDS, but the epidemic and prevalence of the disease itself. In this vein, PEPFAR has failed to address the issue of
gender inequity, and the lack of education available to young people. The argument can be made that as PEPFAR is a huge, umbrella organization, and since the main funding and initiatives come from Washington D.C., it is not completely in tune with what the communities need in terms of long-term solutions and/or what will be most beneficial.

TAC was also able to affect change and “utilize a multi-pronged advocacy, legal and activist approach to improve health policy and service delivery in South Africa” (Sabi & Rieker, 2017, p. 63). However, it can be argued that TAC has a too narrow focus on the right of access of individuals to ARV medicines and that it would be more beneficial if TAC broadened its scope and goals. In addition, TAC has less stable funding as compared to PEPFAR, and therefore is not always as reliable as PEPFAR is. At its founding, TAC was very influenced by the current context at the time, that of the rights-based rhetoric utilized in the Anti-Apartheid movement. Therefore, while TAC many more more in-tune with the needs of specific communities and individuals, it is simply unable to provide resources and training on the large-scale that PEPFAR is.

*Rights-Based Approach*

By applying a rights based approach to the HIV/AIDS epidemic in South Africa, it gives “people the ability to claim what is rightfully theirs as opposed to simply receiving aid” (Beracochea, 2011, p. 11). With this framework, the goal of these organizations should be to transform those infected with HIV into right-holders and turn the government of South Africa into duty-bearers. Although these programs provide support and advocacy for change within this region, there is a gap when it comes to making the government of South Africa engaged and accountable to their position as duty-bearers.
With this in mind, PEPFAR and programs that follow similar structures, provide the region with ample resources, but fall short in holding the government of South Africa accountable. Because PEPFAR’s focus is on providing resources to the communities that are deeply affected by HIV/AIDS, it does not maintain anything sustainable once the funding is removed. TAC, on the other hand, empowers those impacted by HIV/AIDS and focuses on advocacy to influence the government.

**Conclusion**

Overall, it can be concluded that these programs and organizations aimed at tackling the persistent HIV/AIDS epidemic in South Africa have made a significant impact in the region. However, when looking at this issue from a human rights-based perspective and with historical context in mind, PEPFAR does not appear to meet the needs of the community in South Africa. Because of TAC’s bottom up approach and grassroots nature, it is more sensitive to the community’s needs and its history of colonial oppression.

**References**


