

THE SECOND STRUGGLE / LOST DECADE DOCUMENTARY

INTRODUCTION

The testimonies so far gathered by the DiraSengwe oral history project document the grave mistakes made in the South African political / policy responses to the epidemic in the first hand experiences of prominent, central figures in the unfolding HIV/AIDS drama. There is a general consensus in the interviews that ideology and power struggles interfered with sound public health science and practice, in part because the competing priority of broader political transformation overshadowed concerns about health. Few commentators deny that toxic politics drove what is currently the world's highest prevalence of HIV infection. This is not unusual; few societies confronted by HIV/AIDS have avoided controversy in some form, and this is duly shaped by cultural politics and political culture.

What perhaps sets South Africa apart, in both its policy 'mistakes' and their civil society responses, is the proximity of a traumatic past. The post-apartheid Truth and Reconciliation Commission tried to expose the systematic abuses of an opaque and tyrannical regime, to document them for posterity so that they should never be repeated, and so future generations should understand their consequences. A central feature of the TRC, and of other memorial projects, has been testimony: the personal experiences of tyranny, brutality, humiliation and loss that forced us to look human suffering in the face, to gaze at it free of commentary, intellectualization and politicization. This is the moment in which we are united as members of the human race – where politics and theory and culpability and even victimhood are stripped away – and we see bare human suffering. This is a powerful foundation for consensus, among people, communities, nations and beyond and has given rise to the most important instruments we currently have for protecting human rights.

Graphic memorialization is central in award-winning documentaries the Nazi Holocaust, the Rwandan Genocide, of catastrophic famines and of 9-11. While there are always political sub-stories, the central, most powerful message of these documentaries is “never again.” The aim of the Lost Decade /Second Struggle documentary should be to pose the question “have we truly faced the reality of AIDS in South Africa?” There are two parts to posing this question.

1. THE “WHAT” QUESTION: STARING DEATH IN THE FACE

[...] for the middle class who were controlling the media, they got tired of HIV and they stopped – they tried to ask us to do other stories – not HIV related stories. So it was really a challenge to report on what was a national tragedy, effecting millions of people, but to try and find interesting ways to do that, and different ways to do that all the time because in a lot of ways, it was the same story being played out in households throughout the country [...]. [Kerry Cullinan]

The first, and arguably most important part of the question is “what really was the human cost?” This is where we ask the audience to look, to not turn away, to see the graphic horror of hospitals becoming mortuaries in the absence of treatment, of what death from AIDS really looks like, of the hundreds of thousands of graves being dug, funerals, and the decimated and grieving families that made up hundreds of dying communities. Anyone who has watched a documentary on Rwanda or Nazi Germany cannot help but be haunted by the evidence – stacked bodies and bones – the signs of

mass death without dignity. In the precursor to this project, which was my MPH thesis, I interviewed doctors, many of them young and inexperienced, who faced these wards-cum-mortuaries helplessly, their years of training rendered useless and their confidence shattered. Many doctors effectively become the overseers of death-houses – health care facilities devoid not only of treatment but often short of basic supplies needed to give palliative care to the dying. There are stories of health workers suffering from post-traumatic stress disorder. Others fought back however they could, becoming activists in their own ways, but because of the political stance on HIV/AIDS, were unsupported and even persecuted. There are many untold stories that can help us to do what South Africa has perhaps not yet done as a nation – to stare death in the face and understand its scale and impact – like an aerial photograph of the aftermath of Hurricane Katrina, the piles of rubble where the twin towers stood or the stacks of bones and bodies that are the aftermath of genocides. We need to de-intellectualize and de-politicize AIDS long enough to stare the suffering and death in the face - something we have never been allowed to do in South Africa because it is STILL, to this day, a politically incorrect, anti-ANC thing to do. It is “divisive” to refer to the AIDS holocaust. This is an injustice to the victims, the survivors and to those who continue the struggle.

2. THE “WHY SOUTH AFRICA?” QUESTION: THREE POSSIBLE NARRATIVES

I fear that if it's not HIV, something else is going to come along and we're going to have the same sort of crisis because we haven't dealt with the foundational problems we have in this society. [Brad Mears]

The existing collection of oral history transcripts reflects the experiences of prominent activist and high-level health professionals who articulate and reflect mainly on the governance issues around AIDS denial. Here we have an incredibly rich collection of memories and reflections of people who were at the heart of the political AIDS struggle. A review of these transcripts yields many important themes that can help the audience consider the ‘why’ question.

These hundreds of pages, along with the video footage will need a fine-toothed analysis, but there are prominent recurring themes that raise important questions about South African history, culture, governance and the many pressing social problems we face today. Any one of these major themes can be used as a sub-narrative – a political, scientific and historical commentary that contrasts the naked reality of mass death. These are the themes that have also been explored, to some extent, in the sociological and political literature on HIV/AIDS.

The themes are important because they were buried, swept under the rug – denied, even – when the battle against HIV/AIDS finally took on the cloak of rational scientific and policy discourse with the end of the Mbeki Presidency and Minister Manto’s reign of terror. But they recur, daily, in the on-going social unrest, violence against women and corruption that have dogged this country for two decades of freedom.

What this documentary *should not be* is yet another message-of-hope-soccer-world-cup-Mandela-moment that ropes us into another act of collective denial by suggesting that we have miraculously overcome the epidemic while ignoring intractable governance issues and enduring social injustice. The age of miracles passed on and was laid to rest with President Mandela.

Sub-narrative 1: An epidemic waiting to happen.

Is this Darwinian? Is this so dramatic it will change society? [Alan Whiteside]

We didn't actually confront that a lot of what we called Social Religious or Cultural Values were actually colluding with the epidemic and they were part of the problem and so in reinforcing a kind of morality, what we were actually doing was not challenging the epidemic at all. [Mary Crewe]

We need to learn from Rwanda, we need to learn from Cambodia, where there have been these events. [Alan Whiteside]

In this narrative we explore the historical, economic and gender drivers of the epidemic. As historian Shula Marks pointed out, HIV in South Africa was an “epidemic waiting to happen.” We look at the migrant labour system and how economic growth under Apartheid successfully externalized the social costs of labour reproduction, entrenching gender inequality and exploitation. This system perseveres – where the Freedom Charter aimed to abolish tribalism as an evil and insidious instrument of colonial indirect rule, the Zuma regime has resuscitated it in full force – allowing the existence of a system of governance that is practically extra-constitutional, rarely accountable but indispensable for controlling the poorest and most vulnerable (i.e. potentially politically volatile) sectors of the population. Today, the parts of South Africa with the highest rates of HIV, malnutrition, unemployment and where gender discrimination is *de-facto* legal, are the former homeland areas under strong traditional authority. The distortion and reinvention of “tradition” is an important driver of the epidemic, symbolized by a President beleaguered with corruption charges while offering multiple concurrent partnerships as a model for family life. To balance this out, we ask why the traditions of female authority have not been revived and celebrated. Where are the strong South African women fighting back?

Sub-narrative 2: The political culture of an uncontrolled epidemic.

Our country has been influenced a lot by these Messianic figures, like Mandela. [Dr. Coovadia]

[...] well the President denied the link between HIV and AIDS, and I think for most of us, we were so happy to have this new government and we wanted to be loyal to it and we couldn't really believe, to begin with, that [...] they took us this position on HIV, we didn't want to believe it so I think we were probably slow to begin with and slow to report on it initially. [Kerry Cullinan]

[...] we were made to feel very unpatriotic for the things that we did at that point in time. [Brad Mears]

[...] and then she [Health Minister Manto Tshabalala Msimang] said, which I will not forget, “Don't you understand, they don't even vote for us in Khayelitsha, that's the Cape where they're not ANC, so how dare you go into a province where there is no support for the government”. [Steven Lewis]

The triumphant, post-Apartheid political context of the denial era is reminiscent of Leni Riefenstahl's propaganda film "Triumph of the Will," showing the glorious march of Aryan athletes to Olympic victory while the horror of the concentration camps was quietly beginning. The German people were both caught up in the fanfare, and, at that point in their history, so desperately wanted another dire

ction in which to look. Caught up in ANC victory, South Africans did not want to see the rot beneath the fanfare. In this narrative, we contrast two very powerful sets of images - the celebration of victory versus slow and tortuous AIDS death. The 'victory' declined rapidly into cheap populism because the Apartheid regime left in place a political legacy of denial: at all costs, keep everything looking nice on the surface while hell is breaking loose underneath. This ugly aspect of Apartheid political culture remains largely intact (see the Brad Mears interview) - why do we need Mandela and Soccer to make us a nation? Maybe because as a nation we only behave nicely when we think someone is watching? Where does this ethos come from – the inability to admit fault and maintain the appearance of order at all costs? Consider how frighteningly few and terrifyingly influential were the leaders of Apartheid and how deeply they branded South African political culture with their personal morality. Zuma's government is a cult of personality. The state is reverting to authoritarianism in its inability to accept criticism and its failure to create space for real civil society. In the absence of this space, for coherent and articulate social movements, we have inarticulate, violent, tyre-burning mobs. I call this "post-fascist syndrome." AIDS activism was the last gasp of the Anti-Apartheid struggle and the swansong of our political consciousness.

Sub-narrative 3: Where Thabo was right and where he went wrong: the cultural politics of HIV/AIDS.

It was quite astonishing that in a modern society, in the latter part of the twentieth century, that an anti-scientific campaign, which is almost medieval...is allowed to take place. [Dr. Coovadia]

I think that Mbeki is a very troubled person intellectually, I think that he has a whole lot of race issues and I think that because of a limited scientific understanding of HIV which if he'd troubled himself enough to learn he would have realised he didn't need to be quite so defensive around there. [Francois Venter]

Many of the Ministers were colleagues who fought with me in the struggle...they were brave, they were willing to die... And comes independence and they cover to this madness of Mbeki. [Dr. Coovadia]

In this narrative we explore the intellectual and counter-hegemonic roots of denialism. What perhaps began as an exploration of South Africa through a post-colonial lens went terribly wrong somewhere. The pharmaceutical industry is, in fact, driven by profit and neo-liberal orthodoxy. There have been unethical experiments conducted on developing country peoples. South Africa is deeply scarred by unconscionable attempts at social engineering, for example "Project Coast." There has been far too much emphasis on the sexual and behavioural aspects of the epidemic, a legacy of gay activism in the USA. There is an element of "lost in translation" here. Prefabricated, imported HIV/AIDS discourse-in-a-box was rejected like an incompatible liver transplant. For example, America went through a 'sexual revolution'; South Africa did not, so out-and-proud style activism would simply not work, nor would current treatment protocols work in a debilitated health system, or behavioural interventions in a heterosexual epidemic. Add to this equation the isolation of the preceding decades and resulting xenophobia. The consequence was the wholesale dismissal of current understandings of the epidemic by both the South African people and the leadership. The emphasis on freedom of sexual expression as part of the rights-based approach to getting treatment not only fell flat; it alienated our pre-sexual revolution society. Ordinary people readily absorbed the message that AIDS was an American invention to control African behaviour. It also cast the spotlight on deeply racist and colonial constructions of African sexuality. Thabo's

counter-hegemonic questioning opened space for scientific dissidence, and the line between science and politics got blurred. But Thabo saw the historical *cordon sanitaire* between North and South; the racist, colonial construction of African “otherness” that justified exploitation in the past and continues to justify it today: in the global economy, Africa is a *terra nullus* populated with hapless, unproductive people, an empty space waiting to be filled by investment, technology and economic growth. Even AIDS is a commodity to be exploited if you look at it the right way. An interesting footnote here: Thabo was responsible for a number of deaths reaching genocidal proportions, and yet he remains a solidly respected intellectual and political figure. How does that work?

Moving forward

We have, in the existing interviews, more than enough material for any of the three proposed sub-narratives. More needs to be done under the “what” section of the documentary. There are several places to look for this:

1. Interviews with doctors and nurses – ordinary health workers who presided over the hospital-cum-mortuaries who can give graphic and personal accounts of what they saw. Many of these were young doctors, already faced with too much responsibility having been thrown into a health system in disarray, even without the epidemic.
2. Facts and figures – plotting the explosion of the epidemic alongside the unfolding political drama could be quite powerful. There are catchy ways to portray death tolls, for example, UNICEF uses groups of children, making their faces disappear one-by-one as they die of malnutrition-related disease.
3. Imagery – cemeteries with a startling number of fresh graves are reminiscent of the mass burials after genocides. They show the scale of death. The trappings of death – funeral parlours, coffin makers, the explosion of charismatic and messianic religious movements, burial societies, the popularization of the life insurance industry – all the symptoms of a country re-organizing itself (in a strikingly stoic and orderly fashion, if we think about it – why was there not a violent uprising against denial? Imagine if it had been food shortages – the scenario would have been quite different) to accommodate mass death.
4. Continuity – are there enduring symptoms of denial? Here we can pursue the sub-narratives accordingly; how denial manifests in the governance, gender, political issues we are still facing. How do we wrap up the commentary?

Direction

This subject matter could benefit from the direction by someone experienced with similar subject matter – holocaust, genocide, famine – who is able to portray the reality graphically but not *pornographically*, i.e. sensationally. This does not mean sanitizing it – enough of that has been done already. It’s about fearlessly showing the magnitude and scale of death, which contrasts with the intellectual debate going on in the sub-narrative. We want to show the ‘fiddling while Rome was burning’ but also that that the fiddling persists – the denial years were symptom of a greater and enduring crisis of governance that we have not yet resolved. The director needs to be somewhat cognizant of South African political culture in order to sensitively and coherently tell the story, but I feel the more important part is the main story – the exposure of mass death that we are made to look away from, because “there is no point in digging up the past” or “we need to move

forward” or “we have can’t jeopardize the consensus” even if it is counterfeit. The outcome of the documentary should be *never again*.