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INVITED COMMENTARY

Promoting public health in the face of disinformation

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Abstract

Disinformation hampered the response to both the HIV and Covid pandemics. Nevertheless, for the most part scientifically sound public health messaging prevailed: today millions of South Africans are on antiretroviral treatment and during the Covid pandemic most of the most vulnerable people in the country got vaccinated. The aim of this article is to describe what strategies in the author's experience were the most effective for communicating public health messages. Ten tips are provided for help health workers more effectively spread sound public health advice.

Promoting public health in the face of disinformation

We in South Africa are justifiably gloomy about our country's politics, the massive corruption, the huge amount of dysfunction in the civil service, the collapse of numerous institutions that once worked well. But there are some things we should be proud of, some fantastic achievements. I am not talking about our rugby team winning the World Cup a couple of weeks ago, though certainly that is a wonderfully unifying event for our often-fractured country.

It is this: we quite possibly have the largest public sector chronic medicine program for a single disease anywhere in the world. According to the Thembisa model, which is an excellent source of up- to-date and historical HIV demographic data for South Africa, there are nearly 5.9 million people on antiretroviral treatment. All but a few hundred thousand people get their antiretrovirals from the public health system. This is an incredible achievement.[1]

In 1990 South African life expectancy was just over 63 years. With the onset of the HIV epidemic, it eventually plummeted to under 54 years in 2004. It is now about 64 years – there was a sharp drop during Covid but we've now pretty much recovered.[2] That reversal is primarily due to the massive rollout of antiretroviral treatment and the largely successful implementation of mother-to-child transmission prevention of HIV.

According to the Thembisa model about 360,000 people started antiretrovirals while they were children. The model also estimates 2004 was the year in which the most number of children contracted HIV, over 75,000 mostly pre- or intrapartum or through breastfeeding. That has dropped to about 7,000 today, which admittedly is still far too high.[3]

This is a good news story, something that many people attending this conference were part of making happen. But it wasn't always so. It started off as a horror story.

This Congress has almost coincided with an important anniversary in South African history. Nearly twenty years ago, on 19 November 2003, the Cabinet approved an HIV treatment plan that included the rollout of antiretoviral treatment.[4] This was a major victory for activists, doctors and patients – people with HIV – as well as their friends and families.

For years under President Thabo Mbeki and his Minister of Health, Manto Tshabalala-Msimang, the government had been refusing to provide these life-saving medicines to people with HIV. The reason wasn't economic. The government had the money to implement an antiretroviral rollout.

The primary reason was because the president and his health minister doubted the causal link between HIV and AIDS. Instead, they indulged fringe, pseudoscientific theories and undermined the scientific response to the epidemic. Under President Mbeki the government carried out a misinformation campaign, and it killed many people.[5]

It required a massive, consistent, clever and passionate campaign to change government policy. Unfortunately, it was not before well over 300,000 people unnecessarily died because of the delays, according to analyses by Nicoli Nattrass[6] and Pride Chigwedere[7] carried out independently of each other, that the treatment plan was won.

The Treatment Action Campaign (TAC) was the organisation at the forefront of that campaign, but we couldn't have forced our government to change policy without the excellent science being done by scientists. In the field of paediatrics, there were the ACTG and HIVNET studies that showed the safety and efficacy of various different antiretroviral regimens for preventing mother-to-child transmission. There was the CHER study, run by people in this room, which showed that giving ARVs to infants immediately saved more lives than waiting for their CD4 percentages to decline. And much more.

I've been asked to talk today, based on my experience in the TAC and subsequently my experience running Ground Up, a human-rights focused news agency, about how medical scientists can successfully communicate public health messages especially in the face of disinformation.

Presumably everyone in this conference during the Covid pandemic witnessed the problems with disinformation in the media, but this was not new. It was a major problem during the battle for HIV medicines. What has changed are the technologies – social media didn't exist in the early 2000s -- but the fundamental principles, not so much.

I'm going to cover each of these briefly in my talk. Each topic could be a PhD topic and with limited time I can at best give a superficial overview:

- How the battle for HIV treatment was won
- What changed between then and Covid?
- Tips on how to deal with the media

How the battle for HIV treatment was won

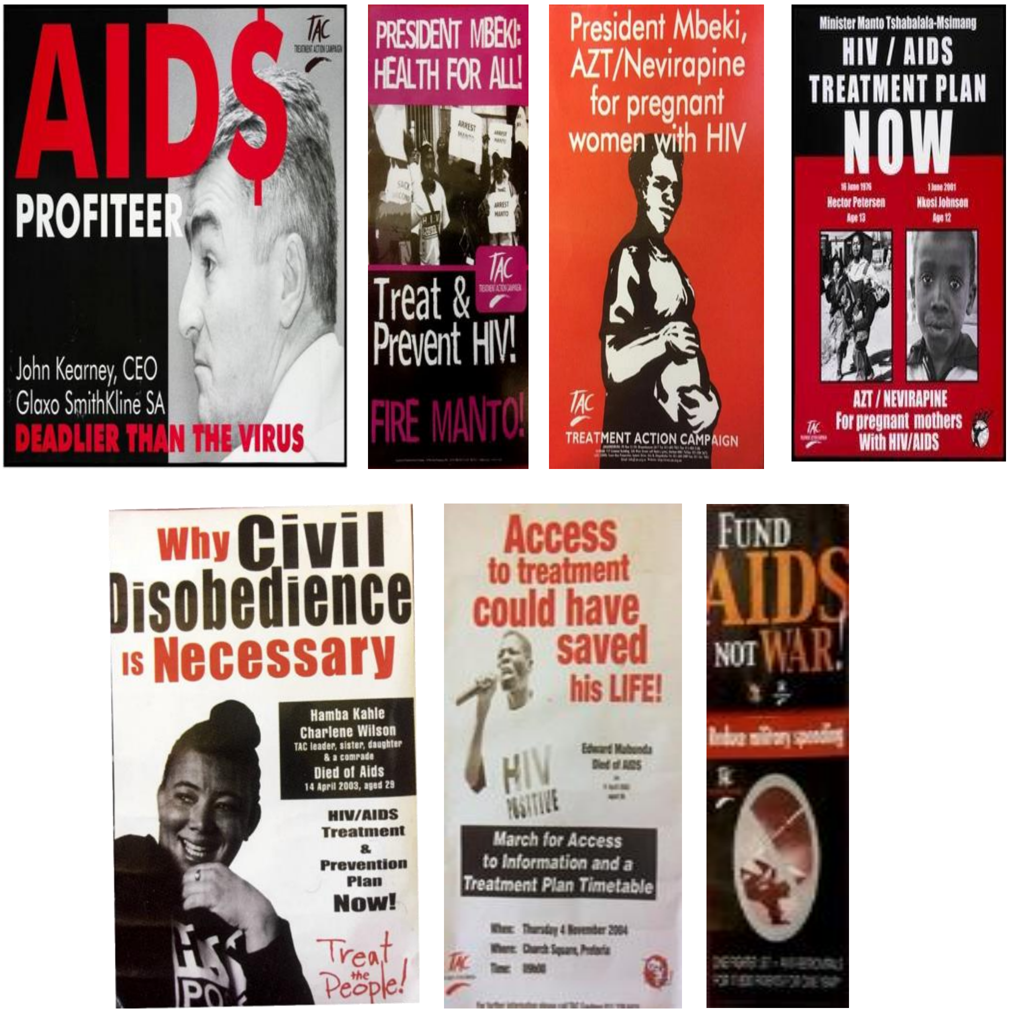
The TAC was largely made up of people with HIV, their friends and families. At its peak we had about 16,000 members. For this conference, it's important to note that leading voices in the campaign were women with HIV who wanted to avoid passing the virus onto their babies during pregnancy and breastfeeding.

I need to make a disclaimer here. There's a tendency to mythologies the TAC and I am as guilty of it as anyone. Unfortunately, a short talk like this and the fact that much of it happened 20 years ago exacerbates this. So, my disclaimer is this: Although the TAC was a highly successful campaign and a model of effective activism, like all social movements it was complex, it had warts and sores, and we made mistakes.

It's useful to divide the TAC's campaign into five areas:

1. **Research**: As activists we had to get on top of HIV science, to be able to explain to other members as well as journalists how HIV worked, how the medicines worked and how we knew they worked. We also ended up in debates with AIDS denialists.
2. **Mobilisation**: We organised branches in many places across the country. Branches, in theory, met regularly and differed vastly in size. At branch meetings people discussed their concerns with the health system (and much else) and learnt something about HIV. We also organised numerous protests and civil disobedience. The TAC literally held hundreds of protests between December 1998 and the beginning of the implementation of the treatment plan in 2004. On 9 July 2000, thousands of people marched to the opening of the International AIDS conference in this city to demand HIV treatment. Protests would take place all over the country and they ranged from a handful of people sometimes to well over 10,000. Most of the time we stuck to the law, but by 2003 we were, to use a South African phrase, gatvol with the lack of progress and embarked on a civil disobedience campaign in which we sat in at, for example, at police stations demanding that the police either arrest us or the health minister.
3. **Treatment literacy**: A large portion of TAC's budget went into running a highly organised campaign of teaching people, one-on-one, in branches, and in large workshops, about the science of HIV. We were assisted greatly here by HIV activists from the US and UK. On the paediatric side, I should specially mention the work of Polly Clayden, whom some of you will know.
4. **Law and courts**: We took the government to court. We battled pharmaceutical companies at the Competition Commission. We had excellent lawyers and almost always won. Our most celebrated court victory was to compel the state to implement mother-to-child transmission. Professor Haroon Saloojee, a paediatrician, deposed a vital affidavit on the science of mother- to-child transmission prevention. Professor Nicoli Nattrass, an economist, deposed an affidavit showing that mother-to-child transmission prevention would actually save the state money. We left the government with no rational answer and won first in the high court then, following an appeal by the government, in the Constitutional Court. You may look back on the case today and wonder why we asked for the very modestly effective single-dose nevirapine regimen. But it made legal sense at the time and the victory in this court case in 2002 was the gateway to compelling government to provide antiretroviral treatment a year and a bit later.
5. **Media**: We wrote a multitude of articles for newspapers and gave interviews all the time. We used the media to build a moral consensus across South African society that the government had a duty to treat people with HIV. We also ran advertisements. And we put posters up in health centres and on our protests.

Figure 1. Poster examples



What changed from a media perspective?

Covid struck South Africa hard. Based on the Medical Research Council's excess death analyses, the epidemic caused well over 250,000 excess deaths. It massively disrupted schooling and economic activity and worsened poverty.

The government has rightly been criticised for the slow pace it rolled out vaccines. There was no health organisation during Covid that had the community-based reach and co-ordination that the TAC had in the 2000s. By contrast there were a plethora of people spreading misinformation for various different purposes.

When the TAC ran its campaign in the 2000s the world was different in important ways. Social media was at best in its infancy and not yet widely used in South Africa. Radio, television and newspapers were still the main way people got their news. There were editorial walls. AIDS denialists sometimes got through those editorial walls but by and large they failed. I used the term moral consensus earlier and for the most part TAC was successful at building a moral consensus with journalists and editors that HIV caused AIDS and that the benefits of antiretrovirals far outweighed their risks.

Social media has collapsed the editorial walls or safeguards or whatever you want to call them. Every spreader of misinformation now has a choice of platforms. And if they've got charisma they'll get a following.

The misinformers now also network with each other much more easily.

It’s fascinating to see Covid vaccine denialists making common cause with some of the old AIDS denialists on Twitter, for example. This is obviously not good for public health. I have at times wondered whether the TAC would have succeeded in the age of social media.

But it works both ways. Social media has made it much easier for good young scientists, nurses and doctors to get public messages out. There are a plethora of such voices on social media. And the quacks/anti-scientists are not “winning”. Quackery and misinformation has always been around. Until the rise of scientific medicine and epidemiology in the 19th century, I would argue quackery was the norm. It won’t go away and it’s a continuous struggle to fight it. But more and more people are being taught scientific method.

Also while our vaccine rollout should have been better, more than 22 million people received at least one dose in approximately a year. That’s no small logistical feat. And at least in the big cities the vast majority of older people appear to have been vaccinated. To the extent that the vaccine programme didn’t reach enough people, I’m unsure if the anti-vaccination movement was a major cause of that; I suspect not but I stand to be corrected.

So it’s not all doom and gloom. Yes, depending on the country, vaccine hesitancy seems to range widely but nearly everywhere the majority of people continue to accept the advice of genuine public health experts most of the time.

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Tips

There is research being done into effective public health communication. It’s still a fledgling field and I’m currently a little sceptical of it. But at the same time the tips I am giving here are based purely on my experience and values. Maybe future research will show more effective methods, but this worked for the TAC.

1. **Be scrupulously honest.**

   We are in a battle for public trust. Don’t stoop to the tactics of the misinformers. All that separates us is honesty. Admit ignorance. Don’t bluster. Don’t speak about “science” as if it’s this final word decided by people in a committee. Keep the moral high ground.

2. **Don’t exaggerate or make hysterical statements. Err on the side of understatement.**

   The TAC at one point started a campaign whose slogan was the number of people dying in South Africa daily of AIDS. We debated extensively what X, the number of daily deaths should be in our posters and public discourse. We relied primarily on the Actuarial Society of South Africa’s AIDS model, but other models gave different estimates. At one point there were estimates of nearly 1,000 deaths daily, but later this turned out to likely be an overestimate. We eventually set X at 600. And our slogan was something to the effect of over 600 people were dying daily of AIDS, an unequivocally true statement at the peak of the epidemic. It was a also a considerable underestimate; over 700 people were actually dying daily at the epidemic’s peak, based on the Thembisa model. But had we overestimated, our detractors would have used it against us. By underestimating you appear more considered and remove the carpet from under the misinformers.

   When activists or scientists make hysterical statements, the public notices and confidence is lost. I see this frequently as a news editor – activist organisations overstating their arguments so blatantly that it undermines the possibly good case they are making.

3. **In general, don’t debate with antivaxxers, charlatans, quacks and especially unhinged people.**

   First, very few people are competent in a debate situation. Second, charlatans tend to make stuff up and it’s very hard to counter this kind of thing on the fly. Third, debates are usually far too short and superficial to properly air facts properly. Fourth, debating with charlatans gives them credibility. Fifth, debate is unlikely to be a way to reach the vaccine hesitant.

   There are exceptions to this rule though. If you’re very good at debating and completely on top of the topic it might occasionally be worth taking the risk.

4. **Differentiate between the leaders of misinformation movements versus ordinary members of the public who are genuinely confused, or vaccine hesitant.**

   The former need to be harshly criticised in public. The latter, often your patients or the parents of your patients, always deserve respect, understanding and patience.

5. **Be available and always be polite to journalists.**

   Having broken this rule many times at the TAC I am guilty of hypocrisy. Journalists can be pesky, relentless and annoying. They are often ill-prepared. But now that I'm an editor of a news publication I ask that you cut them slack. News is an underfunded industry, journalists are poorly paid, and they have to become instant experts on different topics every day. Many lack scientific training. They are rarely trained in statistical concepts. Don't alienate them or put them off trying to report on health. Often working with journalists to help them improve pays off in the long run even though it may seem hopeless when you first encounter them.

6. **If you communicate with the public through the media learn to speak and write in plain language.**

   This is perhaps the biggest frustration I deal with as an editor when commissioning scientific content. Writing for the general public is not the same thing as writing for the NEJM. Speaking and writing in plain language when dealing with technical fields is one of those things that is seemingly easy but actually extremely difficult. We are not taught to write in plain language at university, quite the opposite. It takes lots of practice. This is where editors need to be patient with scientists. But please be prepared to be edited because putting just one unexplained piece of jargon into an article, or when speaking on video or a podcast, can lose your audience.

7. **If you become a media figure, watch your ego.**

   Stick to speaking on subjects you know. Resist the urge to speculate continuously on things you are not an expert on. Say no to interview requests on subjects you are not qualified to speak on. This is all common sense but it's amazing how often one can lapse into making these mistakes.

   There was a US public health person who developed a huge following on Twitter during Covid. He would write the most outrageous, hyperbolic, hysterical tweets, always predicting doom, overstating the horrors and littering his tweets with exclamation marks. He developed a huge adoring following. But for every person who followed him, I suspect he alienated many others who found him intolerable. He eventually got vehemently criticised by other public health experts and I suspect he has rightly disappeared into irrelevance. Don't be this guy.

8. **Don't patronise people.**

   It's fine to use metaphors when explaining science. Prof Linda-Gail Bekker often uses the metaphor of an orchestra to explain the immune system to lay audiences. But she never makes the mistake of letting the audience think the metaphor is the thing. During my time at TAC we encountered HIV literature that would get lost in metaphors, describing the immune system using military terms without ever clarifying that this was a metaphor. This is not good. Most people can, if explained properly, eventually understand what CD4 cells are, what viruses are, what bacteria are, the rudimentary facts about vaccines. Explain the medical concepts using plain language, maybe a few times over, and most people, irrespective of their educational background, will get it

9. **Don't judge people.**

   The job of public health experts is to inform, to explain risks and benefits based on evidence. Leave moralising to priests, rabbis, imams and philosophers. As an example, there was a well-intentioned but daft public health campaign run by the Department of Health, especially in this province, some years ago which implored teenage girls to say no to "sugar daddies". This was based on the proposition that intergenerational sex was driving the HIV epidemic. Assuming that this was true, such a campaign ignores the complex socioeconomic reasons why intergenerational sex was common. But most of all the idea that teenagers will listen to the state tell them who to have sex with is frankly ludicrous.

Professor Francois Venter has much more of value to say on this topic than me. His particular bugbear at present are public health messages that subtly, sometimes not subtly, blame obesity on lack of willpower. He’s worth listening to.

10. **Media is often not the most important way to reach the people who really need to be reached.**

    Being involved with small patient groups, helping to do treatment or vaccine literacy workshops, often in townships is vitally important and will often help people who won’t be helped by you speaking on radio or television. In fact, a meta-analysis of strategies to overcome vaccine hesitancy by Singh et al published in 2022 indicates that such interventions are likely to be much more effective than media campaigns. During the TAC years, Dr Herman Reuter together with TAC activists such as Mandla Majola, Sipho Mthathi and Linda Mafu dedicated a great deal of his time to community meetings and setting up treatment literacy groups. This was very effective at improving antiretroviral uptake in Cape Town’s townships, especially Khayelitsha, but also remote areas like Lusikisiki and its surrounding villages in the Eastern Cape.

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