

“Is there still denialism about HIV/AIDS in South Africa?”

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I'm pleased to see so many people here. Suresh Roberts is promoting his book tonight with Dennis Davis and I thought everyone would be there. I hope you don't buy the book! I also thought the Hon James Ngcucu, chairperson of parliament's health committee, would be here. I am disappointed, because parliamentary privilege doesn't extend to this meeting and I wanted to challenge him on some key issues.

The topic for today is denial – I asked Tracy a while ago – are we denying the silence about the true impact of HIV/AIDS and its consequences in SA? Are we, all of us, denying the silence around HIV/AIDS? For me, as an activist of 10 years, it is one of the most depressing things to deal with every day. It's a new traditional cure or a new statement by a minister or a new purpose for garlic, while you know medicines are available and people don't have access to them.

I will present some thoughts on this and then expect you to draw your own conclusions- of course for me it is a resounding *yes*. Whether it is denial at a political or individual level the consequences of not accepting the hard truths are staring us in the face today. Our country is being torn apart by this epidemic but we act as if everything is fine – we have the soccer World Cup, some gold medals, won the cricket, Black Economic Empowerment, tax relief, and the economy is stable.

So first, I must ask: is there any ANC MP openly living with HIV and openly using ARVs – and if not why not? Given that there are 5, 5 million people living with HIV and about 500 000 who need access to lifesaving treatment, one wonders how parliament can be immune to AIDS. In fact, why do so many middle and high income earners think they are immune to AIDS? How many of us have tested for HIV in the last year?

The question then is: if not, why not? What is going on? We seem to be living in some other world removed from reality, where we continuously get involved in an artificially misleading dichotomy between garlic and medicines. When I met the Director General of Health on Monday he suggested the latter falls into the category of conventional medicines – or western orthodoxies -- whereas the former brings with it the hope of generational indigenous knowledge which western orthodoxies are closed to. This, from the DG of Health.

Secondly, I must ask: are we in denial about our sexuality and sexual practices, and how do we as a nation respond to complex gender issues where prominent leaders admit to having multiple sexual partners but do not practice safe sex? Why do they not? Is it because they believe that they are immune (individual denial) or because they simply do not believe that HIV/AIDS exists (political denial)? Or because they already have assumed the risk?

The answer really is a bit of everything. The case of the former deputy president and former head of SANAC (the agency responsible for the country's coordinated response to AIDS) is disturbing, because it signals that our prevention efforts are failing us. ABC (Abstinence; Be faithful; Condomise) has failed us.

In Queenstown we were marching on Frontier hospital and the police called our marchers, women with HIV/AIDS "bitches with AIDS", hitting them with batons and shooting rubber bullets. Nobody made a big noise .

So let me unpack some of the reasons why many of us, including the international and donor community, keep silent about the silence,—about our leadership's denial and about our own individual denial.

Many of you may think, well we have an ARV programme -- some of the best policies on paper, a strong legal framework for protection against unfair HIV/AIDS discrimination – so really we are on track and there is no problem. But we are not – yes 120 000 people are on treatment (with substantial donor support) and about 100 000 in the private sector) but there are hundreds of thousands who are still waiting.

And for those of you who think that everything is fine now that we have an ARV programme, let me forewarn of even greater imminent confusion and denial. Let me refer you to excerpts from legal papers filed in March 2006 by the Minister/ government/ Department of Health in a case pending at the Cape High Court dealing with government's failure to act decisively against Matthias Rath and his associates for promoting vitamins as a cure for HIV/AIDS and for conducting human experiments without approval.

Excerpts:

It's a case that tells of government's failure to act against Rath. One of the first statements he makes is that "the minister and I have no desire to be involved in the dispute between the TAC and Rath. We are wary of attempts by anyone to use the state's machinery to further self interest."

The applicants allege government has failed to take steps to stop Rath. "The minister and I (she never signs statements) take issue with the claims by the TAC. We have done all we are required to do in terms of the law and the constitution."

In other words, read "nothing".

"I asked that specific ARVs be registered with the MCC but they are not the only way of dealing with HIV/AIDS and they are for conventional treatment programmes."

Nowhere in this statement will you find any statement that says ARVs work.

"HIV is a major public health challenge in South Africa, not a crisis."

In referring to issues around data and statistics, "since HIV is not a notifiable disease there are all sorts of figures presented coming from medical models. As regards allegations (that ARVs work) it is not a matter on which the minister or I wish to engage the TAC. Some members of the scientific community take a different view and we believe such disagreements between scientists cannot be resolved by the courts".

“It would be wrong to conclude that Rath is conducting human clinical trials in South Africa.”

“The department has decided to distribute ARVs in the public sector while recognising the choice of treatment is a matter for the patient and his doctor.”

“With regard to the marginalisation of the TAC: the contents of this paragraph are irrelevant. The TAC has made it a special interest to ensure the minister is embarrassed, insulted and lampooned as much as possible.”

Now this tells you something – see that lurking suggestion that AIDS is not a crisis but a challenge; that dominant models of science and western orthodoxies are preventing broad-minded approaches to combating HIV/AIDS; that government is meeting its constitutional obligations and really that everything is on track; that lobby groups are lampooning the minister and have their own personal agendas against Rath or whoever.

It does not tell us that ARVs work – or that AIDS is ravaging this country with new infections and massive adult and paediatric deaths. It fits in quite nicely with the President’s approach of “crisis- what crisis”. See, the President himself is in denial – and all of us know this. He has refused to accept hard evidence of the crisis in the public sector (teachers, police, nurses), of increased mortality as a result of AIDS (death statistics prepared by government-commissioned agencies) He has openly flirted with known denialists before and after the Presidential Advisory Panel. Strange, then, that denialists from other parts of the world get an audience with the President and not social movements of people in this country.

He has only mentioned AIDS in two of his last three addresses. In the 2004 address he said we have an ARV programme and that we would treat 53 000 people by March 2005. March 2005 came and went and the target was missed – and he conveniently forgot to mention that in his 2005 speech. In fact 2005 had nothing about AIDS. This year he mentioned the word AIDS once in passing reference to the Operational Plan (the title uses the word AIDS) which, ironically, government is now claiming as a political victory, which it was forced through civil disobedience to adopt. It boasts that it has the largest programme in the developing world it boasts. But more paragraphs were devoted to the soccer World Cup bid and poetry.

The government claims it has the largest ARV treatment programme in the world. It hasn’t. Most of the patients are funded by international donors and we have only 120 000 patients. Without the donors the government couldn’t claim those numbers. And government refuses to speak to the private sector anyway.

The consequences of this are the very responses we received from the DG – if you want your job you toe the party line (and this is not the first case where DOH officials have taken the rap or signed affidavits eschewing the denialist line). Ironic, because many ANC MPS have privately lambasted the minister, but aside from Ben Turok and Kader Asmal no one else has had the courage to publicly draw themselves into this debate.

Fear is silencing us. Many ANC health committee MPs see the Minister’s approach, as a liability, but no one dares say this in public. They are denying the denialism. Many donors and people working for multilaterals have said, “This is an embarrassment, your minister is undermining the struggle in Africa”, but none, save for (United Nations special envoy on HIV/AIDS) Stephen Lewis have publicly berated the SA government. Why? Well the Lewis example is clear – you will be lambasted,

marginalized and refused any meaningful engagement with government. The dogma is quite pervasive.

At a community level the consequences are far reaching and even more dangerous. People are confused because we have no proper leadership – they are starting, stopping, starting ARVs with and without high dosages of vitamins. So while government says “back off, we have an ARV programme in place”, they are doing very little to promote it or speed it up (they took over a year to order drugs) and they are adding to the confusion.

This false debate has meant that very sick people are getting sicker and coming to seek help very late in their infection. And while the programme is in place and many health workers in several provinces are working tirelessly to make it work, there is no promotion of it. Yet there is with (the traditional remedy) Ubhejani -- two statements in the space of about 10 days telling detractors to back off because they do not support traditional knowledge.

That is quite convenient. It is western vs traditional, yet where is the research, investment, money and support for TCMs? In fact, where are those promised regulations so that the MCC can start affording the same “respect” to all types of medicines? And where is government when multinational corporations engage in wholesale biopiracy?

The problem is that until something is proven to work in an acceptable and reasonable manner, citing Indian and Chinese examples will not help. Promoting a product in such a stark manner is simply not acceptable – especially given that there seems to be some involvement of the current deputy president’s mother with the company promoting the product, and mainly when the research into its efficacy is still underway.

Not so with ARVs though – try finding a positive statement by government about the use of ARVs ...it is almost impossible. You see the ARV programme is a nice comfortable hiding zone – no one can point fingers because, yes, our government is paying for ARVs – but it is doing so slowly, reluctantly, without any great vigour or creativeness. In fact, it is deliberately stalling on its own programme.

International pressure has stopped because we have ARVs in the country. The government is doing everything slowly on its own programme.

And then lets us look at individual denial. . Men are seeking treatment too late. They are in denial about their status and are coming into an overloaded health care system too late. Why is there a low uptake by men on VCT programmes? In the mining and manufacturing sectors they are not coming forward. Yes, there is stigma, but we have a bigger problem of denial on our hands.

They are in denial. SO Until all of us take responsibility for the denial of our health and the denial of our elected leaders do, this epidemic will continue to ravage this country. It will undermine all of our development of the last ten years.