Debate

The Treatment Action Campaign, HIV/AIDS and the Government

Zackie Achmat

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The struggle of TAC is, in the first and the last instance, a struggle about our constitutional rights to life and dignity and also to equity. Why do we say life? Life because without medicine – and also of course according to the Minister of Health, without food – people die. I don’t know how long it’s taken for the Minister to discover that. All of us have known it for a long time. Life, access to medicine and to good health care will extend the lives of many people living with HIV and AIDS. So life is the first thing to think about.

The second is the issue of dignity because dying of AIDS and dying of AIDS related illnesses is not a glamorous thing. It is not easy to die of AIDS. It is a horrible, undignified and really painful process for the people who go through it. It is a process that removes any vestige of dignity that a person might have. When you have diarrhoea, you lose control of your body. When you can’t move, you are relying on other people to carry things for you. When you can’t sleep, you are reliant on having a friend around. But most of all, especially for poor people, the big problem is the carrying of additional packages. There is, for example, the additional burden of carrying water for your mother when she’s ill. There’s having to give up important things when you are young – for instance, when you are a girl of 8 or 10 years old and have to leave school to look after ill parents. It’s about equality, because no matter what anyone says, it’s those of us with money who can afford to buy life. It is those of us who are employed, who are, incredibly, allowed access to life saving medicine. But it’s those who are poor who do
not have access to proper health provision. That is the case both in this country and in many other parts of the world – including Europe and the United States – where, although most people have access to good care, the poor and marginalised communities still remain outside of the formal health care services.

TAC started a civil disobedience campaign on March 20 this year [2003]. Hundreds of activists presented ourselves for arrests and demanded the arrest of the Health Minister and the Minister of Trade and Industry. We didn’t do this because we sought publicity. We didn’t do this because it was an easy thing to do. For four and a half years we have negotiated with the government. We have petitioned the government. We have used every instrument that our new democracy gave us – the Constitution, the Human Rights Commission, the Commission on Gender Equity, NEDLAC (the National Economic Development and Labour Council) – a body that most people forgot about until our debate with government began. We’ve used every single opportunity that the democratic government and our democratic constitution have given us. For us, that was not an easy decision because many of us, including myself, had previously put party politics before the right to life. And I think when one does that, one enters a zone of lack of comfort. After all, how can we speak of equality and the right to life when we ourselves put our party loyalty before people’s lives? And so, putting people’s lives first was a very, very difficult process and a very painful one in which we had to confront what we believed, still believe, is a legitimate government, a democratic government; and I believe one that is much better than those that went before.

Now let’s take this, what did we say happens? Six hundred people a day die. We note, ironically, that the government has not contested this figure. Why have they not contested it? Because we have taken the lowest figure out of all their documents. If you were to read the so-called five year strategic plan you will notice that it says that 250,000 people will die of AIDS related illnesses. If you read the requests for budgets from the enhanced care initiative, which is an internal department document, they say three to four million people will die by the year 2010. They tell you that 250,000 people will die this year of AIDS related illnesses. So we say that six hundred people a day, on average, die of AIDS related illnesses.

Most people die alone. Most people die incredibly painful and unglamorous deaths. And yet we continue to waste time. From our point of view, we would have liked government to liaise with us. We would have
liked to get anyone who wants to do something about AIDS in a room and say, ‘You don’t leave this room until you have a plan. You don’t leave this room until you deal with this issue’, because it’s about our lives. The issue of AIDS is about urgency. And it’s about our country and its future. No matter what people say, even the poorest woman in the rural areas with no employment adds to our social public and adds to our economy by transmitting values, by transmitting knowledge, by looking after her children and by looking after her community. So the loss that we will have is not only a loss to our humanity, but also a serious economic loss to the entire society and we would have liked government to show urgency. It didn’t and it still doesn’t.

So what has happened in TAC since we started our civil disobedience campaign? It was the most uncomfortable act that any of us have ever engaged in because it is a not nice thing to act against your own party in a way that we did. It was not nice for me personally to have lost my temper with the Minister of Health and to appear to be rude to her. I apologise for referring to her personal appearance. However, none of us in the Treatment Action Campaign will ever apologise for calling her a murderer. Nor will we ever apologise for saying that she and the cabinet and particularly the Minister of Trade and Industry are responsible for six hundred deaths a day.

We can no longer put our party loyalty before people’s rights to life. and so what has this done? What have we achieved? After years of existence, some government agencies suddenly woke up to the fact that there is an organisation called TAC and wanted to meet with us. Again, as all of you know, the government has sat on a report from the Joint Finance and Health Committee. I have seen this report. I was permitted to look at it – I won’t tell you the conditions under which this happened – but basically I wasn’t allowed to take it, or let anybody else see it or photocopy it and so on. But this report shows that the signs are that anti-retroviral therapy, when used correctly will save more lives than any other intervention. It also shows that the government has the option to do something about anti-retroviral treatment. It could go up to 20 per cent coverage, it could go to 50 per cent coverage, and it could go up to 100 per cent coverage. The report shows that government will be able to save many lives and that it will spend between R10–12,000 per year per person whom it treats if it uses brand name drugs. The report also shows that the benefit of each life saved is about R23,000 per year. For all of us it makes not simply social sense, humanitarian sense but it also makes economic sense.
That report is now finished. It was seen this weekend by the ministerial committee, the minister and provincial MECs (Member of the Executive Council) for Health. They have referred it to cabinet now. We hope that cabinet will take the right decision and will say, ‘Let’s start implementing!’ None of us here believes that government can roll out anti-retroviral therapy everywhere tomorrow morning. It is going to take us many years to ensure that our health care service gets it right. We have now called off our civil disobedience campaign, or rather postponed it, to give government the opportunity to take the correct decision. And from our side this is the last time that we will do it.

What do we want to do over the next few months and the next few years? We want to do the real difficult work and that’s what we need all of you here for. We need all of you here to help us train nurses. We need all of you here to ensure that there is treatment literacy programmes in all communities. We need all of you to contribute R50 a month to ensure that TAC and other organisations like us teach our own members and members of the community to ensure that we make up for where government can’t reach yet. We need all of you here to make sure that our health budgets in the provinces are spent correctly. So that is what we would like to do.

We don’t want to go back to the streets but we will if we have to! We don’t want to go back to confrontation with government on this issue. Although we are in a state of conformation at the moment, we do not want to ensure that across the globe in every capital of the world that – just as there will be candle light memorial services this weekend – there’s protest against the South African government. So from our side, we would like to help save 200, 300, 500 and maybe even more of the 600 lives per day that we lose. That’s what we need all of you to assist us with and that is what we need to assist the government with.

If the government doesn’t act, we will appeal to each of you to assist us. We will ask you to help us to go back to the streets; to assist us with a law case for a treatment plan to ensure that the national treatment plan, to ensure that the national process is respected. That is what we will ask of each of you.

But before I finish off what we want, let us see what global responsibilities are in all this. So far the United States government has given more money to the global fund than even the European Union. Japan and the Gulf States have not made their contribution to the global fund the way they should.
South Africa has enough money to treat people for the next four or five years, maybe ten years, but Malawi, Mozambique, Angola, the Caribbean countries, some of the countries in Latin America and Asia do not. It’s critical that the global fund gets the seven to eight billion dollars a year that it needs – which is less than the amount of money spent on ice cream in the US or in Europe. So it’s very important that we keep this pressure up.

But there’s one problem. We have to put pressure on the US. We have continually to deal with the Bush administration. We have to point it out if that unelected administration tries to put back the clock when it comes to prevention efforts and treatment efforts within the US itself. It’s time to attach conditions to the promotion of the pharmaceuticals and for the US government to stop taking grants away from gay and lesbian organisations. I think that it’s critical that we ask the Bush administration to put pressure on [right wing organisations] so that they don’t translate these kinds of policies into their global funding strategies. Such strategies, in terms of global funding, would mean that women don’t have rights to termination of pregnancies or family planning and that condom promotion is a serious problem and that we have to ‘address’ these issues. That’s not right! That is unnecessary interference. I also want us to say that we must put pressure on the EU, Japan and the Gulf States to contribute more to global funding for AIDS. They have enormous amounts of money that they misuse to fund all sorts of strange things.

We need an open public debate. Without it, without a rational public discussion about science, about poverty, about medicine and so on, we cannot advance and do the real work that lies ahead for us in the communities of Stanger, Mariannhill, in the communities around Durban, around KZN and throughout the country.

**Question and answers session**

Note: The questions to Zackie Achmat were inaudible on our tape, but we are reproducing Achmat’s answers insofar as they are able to stand on their own, without the questions.

1. TAC is trying to prevent an excessive pricing of drugs by the big pharmaceutical companies. They’ve now reduced their price of drugs and they claim to have given a voluntary licence to Aspen Phamacare, which is one of the generic manufacturers. We don’t believe that this so-called voluntary licence will work or end monopoly because only one generic company is allowed to produce the drugs. So what we’d like to do is this. Instead of taking the government to court to force them to
produce a treatment plan, we would really, really appreciate it if we could instead form a joint force with the government and get compulsory licences against the drug companies in order to bring the price of pharmaceutical products down.

In relation to private sector employers, I think here we need some more public debate about getting them to take responsibility for their workers. For example, Goldfields has started treating its workers because we said we were going to run a campaign calling it the ‘Killing Fields’

The real question that we have to ask ourselves about the private sector is whether we think that they’ve helped in pushing the agenda of getting treatment to people forwards. We must make sure that they make their contribution to the health care service in a proper way. The big problem that we have is that we don’t want workers to be bonded to their jobs because that is where they get their treatment. So we need a discussion about the privatisation of health care by allowing big companies to take responsibility for their workers, which can, in effect become a form of bondage of workers themselves unless there is proper protection for them via their trade unions and legislation.

There’s another area in the private sector that we are putting pressure on and that’s in connection with private medical schemes. Our new government, when it came to power, said that you can’t exclude people from medical aid when they have long-term illnesses like hypertension, diabetes or asthma. You can’t raise their premiums because the medical aid should be like a co-operative. It should share the cost among everybody. But unfortunately the medical schemes are private businesses and there’s no way of getting money out of them. And to give you a simple example, in 2000 R27.7 billion was spent on 38 million people in the public sector on health. At the same time R38.8 billion was spent on seven million people in the private sector. There is an attempt within the World Trade Organisation to help the drugs companies to cherry pick the middle classes in poor countries. They can make enormous amount of money out of them and leave the burden of the poor to the state with no proper way of sharing this burden between the rich and the poor. That is what is happening to our health care services in many ways. So what we want to ensure is that private medical schemes carry part of the burden. We know that less than one per cent of people who have coverage and require it, actually have access to private schemes’ anti-retroviral programmes at the moment.
Apparently, at the University of Natal, the medical aid scheme says, ‘it’s not our duty to let members know what their benefits are’. So you need to pressure your medical scheme here to publicise the benefits that they are offering so that people could be treated.

2. I want to pick up the question of gender equity impact and argue that this goes together with the question of race equity impact. Many of you would have seen the Minister of Health refer to my colleague Mark Heywood, as a ‘white man who directs Africans’. So the real question that we have to ask ourselves here is, ‘Who does HIV affect?’ HIV affects everyone in our country. The biggest problem is that there are not enough White, Coloured and Indian people in TAC who have HIV. The biggest problem that all of us have is that people who are carrying the burden of openness, the burden of justice, the burden of going to the streets and putting their bodies on the line, are the poor African women and men. The middle class people living with HIV still feel too stigmatised to come out. Middle class people of all races, African, Coloured, White and Indian, all of us feel much more ashamed – and I don’t know why – about having HIV, whereas poor people are prepared to take the burden of coming out with this disease. So this is a question that we need to address.

In the Treatment Action Campaign our members are made up as follows. More than 50 per cent of our members are aged between 16 and 24 and I have wondered why we have so many young people. Why is TAC a youth movement in that sense? And 50 per cent of our members are women. Now, it’s pretty obvious if you think about why. I met one of the young comrades, Lwazi, and he said, ‘I’m burying my brother next weekend in Transkei’. He lives in Cape Town and had to travel to Transkei to bury his brother who had HIV. And I realised that there is a political movement among young people on the question of HIV because they are at risk; because they are watching their sisters, their brothers and their neighbours get ill and they know that nothing is being done. So it’s very, very important to understand that TAC in essence has women membership, predominantly – although we do have a substantial number of men which is unusual for an AIDS organisation in southern Africa. Normally it’s the women who do the AIDS work and the men who do the ‘toyitoying’. So it’s a change in that sense. On the other hand it’s also primarily young people who are affected by this disease in ways that we cannot yet explain and it will have a huge impact on our society.
3. [The question of service delivery.] When this government came to power, it aimed to give health care to all. Now what did it do to implement that? It had some really great policies on primary health care, TB control and all those things, but fiscally it throws away posts. I remember Ronnie Thompson bragging in 1997 to the provincial health department saying, ‘I’ve saved so much money for keeping these posts frozen’. That’s what he said.

But our nurses are completely overburdened. They are emotionally drained. They have enormous pain that they carry in them. They also carry a burden, an apartheid deficient burden, lack of training and understanding of dealing with patients. They see many people die on a daily basis whereas in the past they were few. So if we talk about service delivery in the health care sector and in any sector, service delivery cannot be done without a mobilised civil society.

For instance, let’s take the question of housing. Why is there no movement to pressure the makers of cement, the makers of tin roofs, the makers of bricks to bring down their price because that will affect how government delivers housing, the quality, size and all those things? As activists, we need to understand that the price of drugs is a very important element for socio-economic action. But in every aspect of our work there is profiteering that is happening but which shouldn’t. We have a duty to bring the prices down to allow the government to afford to be able to deal with the needs of this country. I believe that service delivery in any part of society – and in every part of world – must go hand in hand with the mobilisation of civil society;: Young people who are studying have a duty to research, to find out and contribute their knowledge to our organisation, but also to the organisation of the homeless, to the organisation of the poor people, to the organisation of working people throughout the country.

4. [The last question was about the rural areas.] TAC has exploded as an organisation and we exploded after we had won the mother-to-child transmission prevention court case. We now have about 100 branches and they range from branches in some rural areas to those in urban areas. Our biggest problem is the Western Cape where we have a branch in every African township but only in two of the Coloured townships. And the point is there to strengthen and to provide knowledge.
Why do people come to TAC meetings? They come to TAC meetings because we can offer scientific literacy. We don’t condescend. We don’t pretend that because you are poor you must learn how to cook *pap* instead of learning about how the World Trade Organisation works. You can do both things simultaneously and for us I believe that everyone here can contribute to the process. But I want to turn the question back to you. We need your help to get to rural areas, or to places that we can’t reach in the urban area. There are many places in Umlazi and KwaMashu and so on around which we need help. We have got some people in Umlazi but it is so huge. So we need to expand. But the most important thing is to expand knowledge and to expand understanding because in that way we can deal with the epidemic.