

Struggling to Survive

A South African teen talks about the stigma of living with HIV and why she decided to tell her story.

WEB EXCLUSIVE

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May 2, 2006 - South Africa has the highest number of HIV infections in the world. At least 5 million people—about one in nine—are living with the virus and an estimated 600 die of AIDS-related illnesses each day, according to the U.S.-based research group Africa Action. Yet 25 years after the virus was first identified, HIV and AIDS are still largely taboo topics in the country. Infected residents are often shunned by family and friends, driven from their communities and, sometimes, their jobs. In rare instances, they have been assaulted or killed.

Nor has the South African government done much to help. President Thabo Mbeki drew widespread international criticism for his refusal to accept the severity of the situation and for his suggestion that it was poverty, not HIV, that led to AIDS. Mbeki's response made it difficult for doctors to mount an effective campaign against the spread of the virus. Until recently, few patients had access to antiretrovirals, and AIDS educators are still struggling to spread their prevention message. A case in point: last month's courtroom comment by former deputy president Jacob Zuma, who told prosecutors charging him with rape that he'd lessened his chance of catching the virus by taking a shower after unprotected sex with his HIV-positive accuser.

Still, public education efforts are improving, thanks in part to the willingness of some who are infected to speak out. Thembi Ngubane is a young woman from Khayelitsha, a sprawling shantytown outside Cape Town. For the past year, the 19-year-old has carried around a tape recorder to document her struggles with the disease, capturing interactions with friends and family as well as conversations with health officials during her monthly trips to a clinic. Clips from her recorded diary aired last month as a documentary on National Public Radio and she and her boyfriend, Melikhaya, are now traveling with a New York-based production crew, Radio Diaries, **to speak in cities across the United States**. NEWSWEEK's Jessica Bennett spoke with Ngubane about life as a woman with HIV in South Africa. Excerpts:

NEWSWEEK: What made you decide to tell your story to the world?

Thembi Ngubane: I thought it would be fun. I'd never recorded my voice before. And I had this good feeling that if [people] could see where I live and hear about how other people live in other worlds, it would change their minds about stigma in relation to HIV and AIDS.

How long have you known about your HIV status?

I got tested four years ago. I started hearing rumors that my previous boyfriend was sick ... and then he died. I wanted to believe he died of something else, but I just thought that by the symptoms that he had, it might be HIV. I had to swallow my pride and get a test.

What was your initial reaction?

Well, when I was told I was HIV-positive, I didn't care. I said "OK." But as soon as I got out of the youth center [where the test was administered], I felt like everyone could see that I'm HIV-positive. I felt like I was losing weight by the second and everyone can see that I'm sick. I panicked a lot, and I felt very angry.

Were you treated differently by anyone?

A lot of people pointed [when I would walk down the street], and they were just like, "Oh my God, she's so thin." And I could hear that, so it made me feel like shameful, and I didn't want to go outside for people to see me.

How did you tell your family?

It was hard. When I told my mom, I told her because I felt like she had to know, because if I got

sick, [or] if I died, she's the only person who had to bury me. It was very hard because I felt like I had disappointed her, and I had brought the bad in to her. [But] she was very calm, although she was hurt. But she understood ... It took me a long time to tell [my father]. He was the only person I didn't want to tell. But when I started to do the diary project, I thought, "OK, if I'm going to tell the whole world, maybe he's going to hear the story on the radio, or by a neighbor, and that would be tougher for him. It's best if I tell him myself" ... And he was was hurt, he was shocked, all of that. But the thing with that was that there was nothing he could do. And he's fine now, actually. He's more loving and caring now than ever.

You were already in a relationship with your present boyfriend, the father of your 1-year-old daughter, when you got the results of your test. What was his reaction?

He didn't know anything about HIV and AIDS, so he panicked a lot. He said, "Oh my God you have AIDS, you're going to die." He just wanted to end things [because] he wanted to be safe. And I understood the way he felt. [Later] he went to take the test and he was HIV-negative. But they said he had to come back in two months for another test, and he [too] was HIV-positive.

But you have been able to work past that?

Yes. He's encouraging me, and he also thinks that I'm doing a good job with speaking out. We just don't care about the people outside. If our families have accepted our situation then it's just fine.

Your township, Khayelitsha, began receiving free antiretroviral drugs [ARVs] through a pilot program in 2001. Is it unusual to have access to these drugs?

Yes, I feel very lucky, because it's like I was at the right place at the right time. In other provinces they [did] not receive these drugs, and at first we [also] didn't have access to the ARVs, and a lot of people did die. But now, we [in Khayelitsha] have a lot of access and education, and you don't have to buy [the drugs], you get them free.

Even with these drugs, how common are AIDS-related deaths in your community?

There's a lot of death. But some are still pretending it's not AIDS, and say maybe, "Oh, it's another disease that killed them." Some don't want to [admit it], and they keep on taking traditional medicine and try to heal something that is AIDS. So it doesn't heal, it gets worse, and that person ends up dying.

Is it common for people to fear the stigma from their disease or not to accept the diagnosis at all?

A lot of people are in denial, and some are ignorant about the situation. If they do go for a test, they hide themselves because they're [afraid they will] be thrown out of the community, or sometimes they are going to lose their jobs. Sometimes if [people in a township] hear that someone has HIV, they burn their house down so they cannot live there. It doesn't happen much now, but it used to happen a lot.

Former deputy president Zuma enraged activists last month when he said he reduced his chances of infection by taking a shower after sex. How prevalent are such falsehoods?

There are a lot of [health] groups that go into clinics, the schools and the communities. And almost every day [in my township] they hold sessions after school for children to come and they teach them how to use a condom. But it's just that people don't listen.

You have been involved with the Treatment Action Campaign [TAC], an HIV-activist group that has often pressured the government to do more to provide crucial treatment and education. Do you think the South African government is doing enough?

I don't know a lot about the government, but I know a lot of people are joining TAC. But we also need to do things on our own. We don't need to depend on the government, we need to stand up for ourselves.

Are you scared about your own future?

I'm sometimes scared of dying, and I'm scared of getting sick. But I'm not always thinking about dying. I'm always telling myself that if I die, maybe I'm supposed to die that day. But what scares me most is becoming sick, because it's very painful.

How are you treating the disease?

I take three pills at night and three in the morning, and I'm going to have to take them every day

for the rest of my life...

What has been the most emotional part of this process for you?

With my family, since they already know my status, what was hard for me was when I got sick, they seemed so worried. And I thought that maybe I was going to die, and I'd created this problem for them, so I felt very bad. And I don't have the friends I had [before I learned I was HIV-positive] ... I could not do any of those things that they do. I could not go out at night; I had to think that I must not contract the flu. I had to stop drinking, and I had to get more sleep. So I just thought, "I should go to the people who are just like me. I must find the people that I'm comfortable with."

What do you hope others can learn from your story?

I just want people to stop being in denial of the situation. The more they pretend, the more it's killing.

What have you learned?

I've learned that it won't help to hide your sickness—especially AIDS—because it's something you can't hide. If you just believe in yourself, you have to stand up and say what you feel like saying, and that way you're helping someone else who's also quiet. I think we have to keep on educating.

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