Thembi’s AIDS Diary

Transcript

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Host Intro: No country in the world has been harder hit by the HIV/AIDS epidemic than South Africa. More than 5 million South Africans are living with HIV, the virus that causes AIDS. Three quarters of all new infections are among girls between the ages of 16-25. Thembi Ngubane is one of them. She lives in the township of Khayelitsha outside of Cape Town - a sprawling sea of houses and shacks made of wood planks, tar paper, and sheets of tin. Thembi was 19 when she first met audio producer Joe Richman. He gave her a tape recorder and for the past year she made an audio diary of her life. This is Thembi’s story.

Thembi Ngubane: Testing, testing, 1-2, 1-2 test test test, ok. Hi, this is Thembi. It’s time for my prayer. Every morning when I wake up I run off to my drawer, take out the mirror, and look at myself. Than I start to do my prayer. I say it every day. Every time when I’m feeling angry, like when you are angry at someone you always have that thing in you that you need to tell that someone what you feel. I say, hello HIV. You trespasser. You are in my body. You have to obey the rules. You have to respect me, and if you don't hurt me, I won’t hurt you. You mind your business, I’ll mind mine. Then I’ll give you a ticket when your time comes.

[music]

Thembi: I never thought I would worry about HIV and AIDS. It was the last thing on my mind.

[sound of clinic]

Thembi: Ok, right now I’m at the doctors office. Hi.
Doctor: Hello,
Thembi: How are you?
Doctor: I’m fine, thank you. How are you.
Thembi: I’m feeling great.
Doctor: You’re feeling great, no problem.
Thembi: I’m fine no problem.
Doctor: Ok, Let me just take your weight.

Thembi: I’ve known that I’m HIV positive for two years. I’m considered stage 4. When you are stage 4 you are no longer HIV positive anymore, they say you’ve got AIDS.

Doctor: I see your CD4 count - you know what it is? CD4 is an indication of how good you immune system still is. It was 167 in March of this year.
Thembi: Yes, Yes.
Doctor: You know its going down all the time and when it is below 200 it is dangerous for you.
They know. But...

I haven’t thought about that. I was very surprised to know that my CD4 count was below 200, It is 167. But at the same time I’ve never been sick.

You are very much at risk of getting sick. It’s very much like swimming in a lake where you have crocodiles. You can swim for some time without getting bit, but if you stay for a long time at some point you are going to get bitten.

OK, I understand.

You sure?

Yes, I’m sure. Thank you.

[sounds of clinic fade out]

Ok, I’m going to tell you how I was infected. I had this boyfriend and then we broke up. I went my own way and he went his way. A year later I heard that he died. When I went to his house his family was gathered there. I said, what happened? Was he shot? Or Was he stabbed? His sister told me no, he was sick. I said what? She said he was very thin and he couldn’t talk and then all of a sudden he just lost a lot of weight. Then I asked her what if he had AIDS. She said I don’t know. That’s when I started to get really worried. So I decided ok, I’m going to go for a test. I went to the clinic. They bring all of the equipment in front of me and just prick all of my fingers. Then 10 minutes passed by. The counselor came back and said we need to have another one. He started to do another one and another one. They did all my five fingers. And I started to worry. I was like, why is he testing me 5 times Then he said ok, now its time for your report. He said, when your blood looks like this - it means you have the virus. You are HIV positive and you’ve been positive for many years. I just stared at him, and said ok.

[dogs bark] Now I’m at home. Oh, Hi. This is Melikhaya my boyfriend. Say hi.

Hi.

Hi.

I was just telling them about how cute you look.

We live together. We’ve been together for 2 years. And Melikhaya is obsessed with music.

Come Melikhaya lets dance [singing]

We are very close. Everyone knows we are very close. If they see Melikhaya they see me. We are always together. He met me and I met him and that was it. [singing] I remember when I find out about my HIV status it was very painful to tell him. I thought, what if I’ve also infected him? Now I’ve ruined my life and I’ve ruined everybody’s life.

Melikhaya, do you ever wish that maybe you would have never met me?

No, [laughs] just because the only thing is that I love you. You know that?

Yes, but I am the one who has infected you.
Melikhaya: I don’t want to blame you. You didn’t chase after AIDS. You didn’t go to the top of the mountain and say you want to have AIDS, you know? And I don’t want you to blame yourself. Just be strong.

Thembi: OK. For me what scares me most is I think we are not going to die at the same time if we die.

Melikhaya: I know that you think that if you die first I’m going to have another girlfriend. [laughs]

Thembi: No! [laughs] No! Really I’m thinking if one of us dies, how would it be. At least if we were going to die [Thembi and Melikhaya speak simultaneously] die at the same time [laughs]

Melikhaya: Give me a kiss for that. [kiss]

[sound of clinic]

Doctor: Hi Thembi, my name is Dr Abrams. How are you doing?

Thembi: I have pains here and in my neck and head [coughing]

Doctor: I’m just going to take your blood. I’m going to examine you now for any other signs of any other opportunistic infections. I’m opening your mouth and looking for thrush on the tongue - which there isn’t. Ok, now I’m going to listen to your chest. [tapping] So you can hear it’s more dull in there. Right inside, fluid in the lung, covering the whole lung. Ok, can you just sit up here. You’re very thin very short of breath. You need to be on anti-retrovirals. You do need the ARVs to bring up your CD4 count. Ok? To bring down the virus. Alright. [Thembi coughing]

[sound of clinic fades]

Thembi: Testing 1-2, 1-2, This is Thembi again. Its been a few months since I’ve been talking to you. The reason that I didn’t record was that I didn’t want to hear my sick voice. I didn’t want people to see me like this and hear me like this. I couldn’t even look in the mirror. The way that I looked, my face was sort of becoming like bones, you see, and dark, and my eyes were kind of big and I was shaking. I couldn’t walk. All the things that were happening I thought they would never happen to me. And my boyfriend Melikhaya was very, very worried. He would plead with me to go to the hospital, but I just wouldn’t want to go. I was afraid of the way people were going to look at me. People would stare and start to point - look at her, look at her. I just wanted to hide myself in the bed. Then my mother showed up. When she came into the house she kind of stared at me. Because the last time she saw me I was fine and now I’m thin like this. Then she said [speaking in Xhosa]. And that means, child, why are you like this? I just looked into her eyes [begins to cry] she was very afraid. And I just looked at her and I said, I don’t think I’m going to live for long. And she said ok, don’t worry, I’m going to take you to the hospital. Then she put me on her back and took me to the hospital.

[fade]
Thembi: [cell phone rings] Oh, hold on a minute. This is Thembi again. That was my cell phone alarm. It does that everyday at 9am and at 9pm. When it rings [sings along with the cell phone] I take my ARVs. I am very lucky to be in a community that supplies ARVs because in some areas they are not available. ARVs stands for anti-retrovirals. Anti-retrovirals are medicines that help to fight the virus. You must take them the rest of your life. Ok. I swallow them. [swallows] That’s it. [throat noise] I wish I didn’t have to drink these. It’s been about a month now since I started ARVs. In about two weeks time I could walk and breath and do things. So when I look back I just, think it was some sort of miracle or something.

[sound of door]

Thembi: Let me see outside, what the day looks like. I’ll show you around my neighborhood. [music] It is a bright beautiful day. People are starting to wash their laundries, putting them on the line. Music is coming from every house. I just love it today. My neighborhood is very crowded. There’s this shack behind another shack. Or there’s this house and behind the house is a shack and behind the shack is another shack. A lot of people.

[greeting, laughing, speaking in Xhosa]

Thembi: And now here’s my friend. [laughs] Ok see you later. bye.

Thembi: Noxola is one of my friends. She lives nearby. She was diagnosed HIV positive in 1999. She has two daughters. There are a lot of us here in Khayelitsha who are sick, but they don’t disclose because they are scared of discrimination. People do talk, do point, do whisper. Sometimes if they hear that someone is HIV, they burn your house down so you can’t stay there anymore. [street sounds] In the past our parents were suffering from apartheid. They wanted to be free and now it is the same with HIV and AIDS. This is the new struggle.

Thembi: Knock, knock. Right now I’m at my mother’s house. Hello everyone. This is my mother. Hello. Hi Onwabo, I’m back! [speaking in Xhosa] [kisses]

Thembi: Now I have to tell you something now that will come to you as a surprise. My boyfriend Melikhaya and I have a baby. This is Onwabo, she is almost one year old. She’s got many toys and this one is her favorite. It makes a sound like this [boing boing sound]. I know what people might be thinking, but Onwabo is fine. We gave her a drug called AZT when I was in labor. She’s been tested and she is HIV negative. Isn’t that true Onwabo? [baby coos] [laugh] She says yes.

Thembi: At first I didn’t want people to know that I was pregnant. What I thought was I didn’t have the right to have a baby. I thought if I had a baby, maybe in the hospital they are going to arrest me. Sometimes I think maybe it wasn’t the right thing to do. But I just, I just wanted it so bad.

Thembi: [speaking to mother] Did you understand why I wanted to have a baby? Mother: My daughter I did understand, but can you explain it to me.

Thembi: Ok, I, I felt like I needed to have something to live for - something I could call my own.

Mother: Oh, you didn’t care you have me?
**Thembi:** [laughs] No! You are old, and you are not my real mother’s baby. So I wanted my own. [both laugh]

**Thembi:** The way that I care about Onwabo and the way that I love her, it makes me think about how my mother feels about me. My mother has clothed me, fed me, raised me, and now, at the end of the day she must also bury me. I was supposed to be the one that is going to look after her. She put me on her back when I was young, and now that I am old she must again put me on her back. That is not right.

[sound of rain]

**Thembi:** My parents don’t live together. They live in different townships, but not far. My father is kind of old fashioned person. Its like to him, I am this child. He really adores me, but my dad doesn’t know that I have AIDS. I haven’t told him. I felt like I could tell the whole world, but not him. And now I feel like I’ve been hiding for so long I just have to tell him because he’s my father. I just want him to hear it from me.

[greets dad, kiss]

**Thembi:** Here we are at my dad’s house and it is raining a lot. My father’s shack – the roof is made of tin, you can hear because the rain sounds so loud. [speaking in Xhosa] He has just asked me whether I’m going to go back to school. Yes, I am going to go to school. Ok, dad...

**Father:** Yes,

**Thembi:** Before, in the past, there was no epidemic like AIDS. But now people are suffering from it. How do you and the other old people think about it?

**Father:** Ok. It’s hard for us, we old people. You grow the kid up now, tomorrow the kid is dead. You see, that’s why I get angry of this disease. There was no problem before, but now there becomes a big problem. Jesus.

**Thembi:** Ok, I have news that I have to tell you, I was trying to tell you but I just couldn’t. But I don’t want you to feel as if I am hiding something from you.

**Dad:** Ok my kid. Ok,

**Thembi:** 3 years ago I was discovered HIV positive. I have AIDS.

**Dad:** No, man.

**Thembi:** Everything is under control. I’m on ARVs my health is fine. I’m going to the good doctors. So I don’t want you to worry about anything. Just for you to know. Because it has been kept a secret for a long time.

**Dad:** [sighs] Ok.

**Thembi:** I felt like I have disappointed to you. I felt like it was going to break you into pieces

**Thembi:** [speaking in Xhosa] How do you feel?

**Dad:** I feel, umm, I feel bad. You see. But what can I do? I have to accept it, what can I do? Ok, my kid.

**Thembi:** Ok.

[sound of rain fades]

**Thembi:** My mother always said that you must be tough. Even if you are feeling hurt. You must not always be jelly belly, cry, cry, cry, cry. Telling my dad was one of the hardest things that I have ever done. But I didn’t want to cry. He must see
just, a tough face. I wanted him to see that I was not afraid. That I was going to be ok.

[baby sounds]

**Thembi:** Right now I am making a bottle for Onwabo. [sucking sound] This is her sucking the bottle. Ok, now its almost half past 10 and we are preparing ourselves for sleep. Goodnight. [kiss] Where is the other blanket? She is already asleep. Melikhaya is already in bed, as always, I’m the last person to sleep.

**Thembi:** I’m just imagining what this world would be like without me. I’m not scared of dying, but I’m scared of not being here. Leaving my baby behind. I just want enough time to see her grow a little bigger.

[baby sounds]

**Thembi:** Oh, you are awake now.

**Thembi:** AIDS is not going to bring me down. I am the one whose got hands and feet and mind. And it is only something that is inside my blood. So it will try to rule maybe inside, but outside I’ll be the boss. I want to study further. I want to have a great job. There are a lot of things I want to get done. I’m just going on with my life. I’m just going on with my life.

[baby cries]
[Thembi sings softly]

Visit the Thembi’s AIDS Diary website to hear the story, see photos, and download the AIDS Action Toolkit: http://www.radiodiaries.org/aidsdiary