LIVING OPENLY

STORIES AND IMAGES OF HIV POSITIVE SOUTH AFRICANS
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The Living Openly Project is about the experience of HIV positive South Africans who have publicly declared their HIV status.

The project was born out of discussions around media portrayals of people living with HIV/AIDS, and the understanding that so often these images were harsh and stereotyped. Where people were ill, they were portrayed in bed, emaciated and downcast. Where people were healthy, instead of their faces we saw their heads turned away, more often than not, to protect their identities.

There had to be another way to create images around HIV/AIDS, and perhaps the starting point lay in taking photographs of HIV positive people who were living openly with the disease. The photographs and stories were brought about through the dedicated work of photographer Giséle Wulfsbohn and writer Susan Fox, and this book is one of a number of outcomes of the project.

HIV/AIDS is a disease that is seldom associated with openness, yet these stories, told in the first person, give insight into the courage and strength required when confronting HIV infection. Furthermore, they give insight into the greater courage required to be open about one’s infection – open not only to friends and loved ones, but to the general public.

We cannot ignore the fact that many millions of South Africans are infected with HIV, and that most are unaware of their infection. For many of those who know their status, public openness is difficult, for it requires a safe environment and support for being open about HIV. In many instances such support does not exist. However, the more we are open about HIV/AIDS, the better equipped we are to tackle the epidemic head on.

In reading these stories we can begin to understand the complexities of being open about a disease that is, for the most part, hidden. Now we can see the images and hear the voices of those who have chosen openness over silence.

The Living Openly Project is one of a number of activities of the Beyond Awareness Campaign of the HIV/AIDS and STD Directorate, Department of Health. The campaign set out to explore alternative approaches to communicating around HIV/AIDS, and has allowed for greater understanding of aspects of the disease that often fall outside of the framework of conventional campaigns. This focus on living with HIV forms part of an increasing emphasis on care and support issues that is vital to an expanded response to the epidemic.

This book is dedicated to all those living with HIV/AIDS.
Diagnosed 1993. Disclosed six months later.

I decided to keep quite for some time until I was ready and I had accepted my status. It didn’t take too long. It was tough to talk alone to myself, to get the information alone and not have anyone that I could speak to. It was the most difficult thing to keep it inside me. It was the anger that actually drove me to want to say something to someone.

So from that point I did my first interview on TV with Shaun Mellors. My face was hidden. People, who knew me, like my family, knew my hands. Usually when I talk I use my hands a lot, so even though my face wasn’t clearly visible, people who knew me knew it was me, and that’s how my mother and father found out. I did not come home to disclose to my family. They started seeing me on TV. I felt, this is me and this is what I had to do. I cannot face them, but I can face the world. By facing the world maybe they can see.

When my mother saw me and my son said, “Momma, I saw your hands on TV,” the whole thing started coming out. From that day I never really stopped. I carried on talking. I was one of the first women in South Africa to disclose. At that time there were only two women who were open about their status amongst a group of gay men, so it took a lot of strength to get to a point of disclosing.

I didn’t have courage to tell my mother at that time, because she was very sick. But my concern was, I have brothers, I have sisters, I have cousins. I have a huge extended family and if I don’t do anything, I would never live with the guilt of hearing my brother saying he had been diagnosed HIV positive. Maybe, if I had told him three years ago, I could have done something to protect him.

All I could say to my family was that I was doing this because I’ve got a son who has to grow to become a man. I have to contribute whatever information I have as a parent. I’m a resourceful person in terms of education programmes, I have to ensure that my life does help.

In a way it helped me to be someone I wanted to be and it would contribute to the quality of life of people living with HIV/AIDS. Maybe they can take something the same way that I took from Shaun Mellors, the same way that I took from Peter Busse. Some of these guys started disclosing years before and I thought if they can do it, so can I. Thabang faced a lot of complications after my disclosure. After his father died, I told his teacher I was HIV positive. All the teachers at the school said, “Don’t touch this child, his mother has AIDS”. After that Thabang said to me, “Don’t touch me, mommy, you’re going to give me HIV”. I asked him who told him that and he said it was the teachers. The next day I went into school and spoke to them. Thabang never wanted to go to school again so he actually stayed back a year. I had to try and be the teacher in the house with the little time that I had.

One day, I came home and spoke to my brothers and some other guys and said, “You are young, what have you done for your community? The young kids are contracting HIV. They are not going further with their education. You guys have learned so much but you are not sharing with the community.” And they said to me, “What do you want us to do?” And I said, “I want to have an AIDS campaign on Human Rights Day because my family has a right to live in society peacefully”. I had to accept that I was the one to put them in this position, I’m the one who had to get them out of it.

Then we started getting ready for a huge campaign. That was the first campaign in our township. We invited the people living with HIV that most of them knew already. My father was there. I launched a campaign that was called “disclosure and acceptance” on that day because I wanted my family to be accepted the same way that I was accepted. I was accepted with HIV, whenever I walk around here everyone shows me that I’m accepted. I can’t walk from one corner to another corner without anyone coming to me hug me and I could not understand why they would not accept my family the same way.

So in a way, AIDS was an experience for this family and that’s how we took it. It’s an experience to learn how to be better and deal with it. People always say to me, “What are you doing? Are you strong? Are you taking medication? Why are you so brave?” And I always say, “No, it’s love.” I believe love heals anything. The love that I received from my family is just too much, it’s more than I can imagine. I cannot ask for more.

Diagnosed in March, 1999. Disclosed the following week.

Basically my dad had a hard time with my HIV status and the people at his office. He told his senior colleagues. I had to face it full on and tell everyone else because I knew they would find out anyway.

I was annoyed but my dad was angry – angry at me and at the disease. I think my parents took it a lot worse than I did. I don’t think my dad really knew how to handle it. I told him that he was not allowed to go and tell the world. I don’t think he realized the serious implications of what it could do. It could have had a negative outcome but it didn’t .... Instead, it turned out to be positive.

There was a lot of support from everyone at work. Nobody has changed their attitude towards me. I mean I went to the kitchen staff and said, “Okay, this is basically the story, and just wear a condom in the future for yourself.” And that was it.

I would say that I was a little more apprehensive than anyone else. I was still in shock the week after and if I cut my finger I’d go through paranoia, thinking, “Oh my God, somebody’s going to touch my blood!” Little things like that I had to deal with.

Attitudes haven’t changed in the sense that they’re not saying, “Oh be careful of Brett,” and if they are, they are hiding it very well.

I’ll be honest that I haven’t bumped into anybody who has been negative about it. I think they are exactly like I was, thinking it wouldn’t happen to them. But I would say that since then, this whole building has changed. A lot is now happening. If anything, I think the people who work with have woken up to the fact that there is a disease out there and we need to do something about it. I got a whole lot of red ribbons for everyone in the office and I make sure they are more proactive about AIDS.

For me, talking about my status was my saving grace. I’m expecting the day that some ignorant idiot will say something rude to me, but I think South Africa is finally waking up to this disease. As much as I don’t believe in notification, I do believe that South Africans do need to get ready for people to start talking. The only way that that is going to happen is for people to realize that disclosure is a healing process. To come out and take control of the disease rather than letting the disease take control of you. Your life doesn’t necessarily have to change and you just wait to die. I’m not planning on dying for a long time.

What my father did wasn’t right, but in a way it was a good thing for me in the sense that I didn’t have to hide it. I didn’t have to come out with it myself. Although, if he didn’t do it, I would have disclosed anyway. I think talking about it was the best thing that helped me through it and to come to terms with it. I’d still say to anybody else not to hide away. The sooner you start talking and mixing with other people and learning about the disease the better.

Empower yourself.


When people think of HIV/AIDS, they think about careless individuals who get infected so they think it’s a disgrace and try to hide it. In my mind, the minute you talk about it you are free.

When I disclosed, I did it both for my benefit and for them as well. It was at a high school in northern KwaZulu-Natal. It was at a rural school where there is a lot of ignorance because of the lack of access to information and illiteracy. These were the first people I thought of to disclose to because I thought to myself, “Let me just go out where the world is gloomy.”

I spent three days at the school. It was a must for students to attend when I disclosed and there were about 500 kids there. First, I gave them a talk about AIDS to educate them about what it is all about. I fitted myself in with them during the first few days, playing sports and eating with them. On the third day I disclosed as I was about to leave. I was nervous about telling them, but the truth just came out. After I told them, I reminded them about the activities I did with them and I asked them if they thought they were infected now. “Remember where we ate, played sports, shared toilets. Now are you infected?” I asked them.

They showed a lot of interest but questions mushroomed that highlighted the lack of education in the area. I had to show them my results because they didn’t believe me. I always carry the piece of paper with my results on it so I can produce it to prove that an individual with HIV can look like me. Most people don’t believe me because they say I’m tough and they see my energy. They think AIDS is something that will come and they will be able to see it. They shouldn’t confuse healthy or thin with HIV because it has nothing to do with loss of weight.

We as the youth are the pillars of this country’s future so we had better start taking things seriously. Kids usually doubt that they can get it. I think we should talk about it. HIV isn’t this monster that eats them.

There was a time when I felt like I was drowning, but today I’m back to normal. Telling people has actually brought me back to the real me. Now I tend to see the impact on other people but not on me. I feel like I can conquer this through power and hope. I can overcome obstacles. I flow with the wind but let it know that I’m resisting.

Interviewed in Durban, September 1999. Age 22.

Coming back home after the doctor told me I was HIV positive, I asked myself what I was going to do? Could I tell my people because I know that in the Muslim community it’s a big sin to have AIDS, so what was I going to do? I told one of my friends and he also told me not to tell my family unless I was prepared for it.

After a few months I built up the courage to tell my family and they were very supportive. They told me not to blame my husband because we believed that this was put out for me from God and I have to make the best of it. But I still felt like I put shame on my family.

After a year I realized that I should come out because even our people, we’re not perfect. We all have sins. In my case, I was married to this man when I was 26 so they can’t really point the finger at me. But when people hear you are HIV positive there is a stigma attached to it. It was almost a year that had passed and I’d been searching for other Muslims who were positive but I couldn’t find any. I was fed up because I belonged to a support group of staunch Christian people who were very supportive – I can say they supported me more than my own people – but I wanted to be with my own people. I couldn’t find anyone and it was heartbreaking. The group was talking about how God feels about you and I was asking myself why can’t my people accept me like that?

I went public on our local public Islamic radio programme. I didn’t tell anybody that I was going to be on the radio but some of my aunts listened to the programme and they came and told me I should have told them. I just told them, “Listen! I myself am not very used to having this disease and I was finding it very difficult telling you people because I know how you are. I know that some of you might think badly of me now”. They said that they didn’t think badly of me because they knew what kind of person I was but I could still feel that things had changed with my family.

Every time the radio station calls me in to give a talk about AIDS and every time someone else in my family criticizes me, saying why did I have to go public, I always say, “Why must I keep quiet? I’ve done nothing wrong!” We people, we always believe that we are superior but we are not superior, we all make mistakes. It’s time that someone in our community should come out and be open about this because we are actually endangering the lives of others if we keep quiet about it. There are lots of other Muslims out there who are positive but won’t come out about it.

Then again, I can understand why they don’t want to come out. I went through a tough time and I’m sure in other communities it’s the same thing. But still, today I’m involved with organizations and some of my family doesn’t like it. I tell them that I’m the one with the virus and at the end of the day you are on your own. I’m happy with what I’m doing.

Sometimes I do feel down. After I appeared on television I actually expected other people to come forward and when no one actually did, I felt that my time was useless. Then I received a call from another Muslim guy who was diagnosed five months previously. He said to me when he saw my programme he was feeling very down and was afraid to go out in to the community, knowing that they would reject him. He said when he saw my programme, he gave him the courage to live, and without knowing it, by telling me this he also gave me the courage to carry on again.

Diagnosed in 1995. Disclosed six months later.

I think it was the anger that made me go public. I grew up in a family that was strict about boyfriends. When I came to Welkom, I started having many friends and got involved with a boy. He proposed to me. He was the only one that I slept with. Even if you say you will protect yourself, you don’t know what kind of person you are in love with.

I was crying a lot then because he was my first boyfriend. I was so angry at lots of things. Then I started thinking, why should I hide it because I didn’t do anything wrong! I didn’t sleep around with many boys! If I was sleeping around, people would point a finger at me, but I wasn’t. I only had one partner. Why should I hide it? It’s something that you can’t shake. It just happened, so I had to speak out.

After I found out I was HIV positive, I said to myself, “If I can get HIV with one boyfriend, what happens to girls who have two or three?”. I have a younger sister and I had to do something to protect her. When I disclosed, it was six months after finding out I was HIV positive. I was invited to speak to people at a World AIDS Day event. When they invited me, I didn’t feel well and was depressed. I said, “No ways, how can I speak to people? How am I going to live my life after that?”. I finally said I would think about it.

About two days ahead of time, I told them, “Yes, I want to come out!”. There were about 700 people there. It was a huge campaign that day in Welkom. There was the Minister of Health, the Minister of Education, and ministers from many different churches. I felt important because all the people were listening to me – even the ministers. I was nervous at first but as time went on I wasn’t nervous. I was crying because I wasn’t really sure whether the people would accept me. I had some friends there and I didn’t know that if by doing this, they would still accept me afterwards.

I was nervous because I was angry. I was hoping that by speaking, it would get rid of my anger. And it did work. After I heard I had HIV, I think I overloaded on stress. I didn’t speak out for an entire six months, so something in me was relieved to speak. After I spoke to the audience, I felt great. I know they listened to me because after I spoke they asked questions. In 1995, AIDS was not really something people accepted. When they saw me they wanted to see someone with AIDS. So when I spoke to them they were surprised. It was the first time here in Welkom for them to see someone with HIV. Some believed and some didn’t believe me when I told them. Some people responded well. They wanted to hug me and tell me things would be OK. “God will be with you,” they said. Some people came and wanted to touch me to see how HIV feels.

At the time that I spoke, I was having skin problems. They saw I had skin problems and I was a little bit thinner so it was easy for them to believe. So if someone approached me, they said, “Yeah, you can look at her and see she’s HIV positive”. Then when I started to get better and got rid of the skin problems, they said, “How can you be HIV positive anymore?”. After I spoke to them I started to gain weight and relax. All the questions I was asking myself …………… the answers were there. I had been asking myself why God chose me because I was working for Him as a Sunday school teacher. There is a Bible passage in the Scriptures that says “sex without marriage is a sin”. As a teacher I knew this, but I didn’t take it seriously. I don’t know what I was thinking about. After I became sick, I started to ask questions like, “Why didn’t I listen to the Scripture or take some measures to prevent it?”.

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At church, the minister threw me out when he heard I was HIV positive. Other churches were accepting, but I grew up at that church so I thought they would hear me. If God is with me, he can pull me through this thing. My friends rejected me. They didn’t say anything. When I saw somebody passing I said “Hi”, they didn’t care that I greeted then. I still have to speak to them about it because I want to know the truth.

It was worth speaking up because some of my friends are dying because people didn’t care. They committed suicide just because their relatives didn’t show support. Some people are wearing a mask because they don’t want to see the truth. Sometimes I feel angry because people don’t take AIDS seriously. They say government has sent me to come out and lie to them and that’s not true! We’re coming out for the sake of them.


It took me such a long time before I disclosed. I was employed by a company that requested me to take an HIV test. I went for the test and found out I was HIV positive. Thereafter I felt angry. I even decided to commit suicide. I tried to inform one of my colleagues. After a couple of months, it spread over the company so I decided to leave and join another company. I was lucky because within two weeks I found another job. And there the same thing happened. I tried to inform another colleague after a year and it spread in the company. I decided to leave my job and stay at home. People were discriminating against me.

I disclosed to my family. They too rejected me. After my family rejected me, I was running out of support from the community and my friends. I had only my sister who supported me. Last year I met a certain lady who was positive too. She’s the one who encouraged me to join a group in Orange Farm. That’s who I asked to come and visit my family and counsel them. They then later realized that what they did was really wrong. They hadn’t accepted me as part of the family.

I was staying with a lady who I called my wife because we were married through lobola. She left when she learned I was HIV positive. I requested that she take a test but instead she left.

What happens with the community as a whole is they point fingers at you, saying you’re HIV positive and what not. You’re a whore, a prostitute. When you come into contact with such words, really, you feel shy. You feel you don’t want to go outside or meet anybody.

I went to live with a lady who is also HIV positive and we decided to make our own group. HIV positive people in the community were running short of support. As HIV positive people, we decided to keep and support them since we knew that it would be difficult. It’s rare that they are accepted in the community. We try to counsel them so they can accept it because even for those who are positive, it’s very difficult for them to accept that they’ve got AIDS.

HIV can come no matter how good you are. It’s just an illness which anyone can get. It doesn’t only go to people who don’t protect themselves. It can still happen.

Most people don’t know how to use a condom because they don’t have good information on how to use them. I try to talk to most of the people and educate them about AIDS and how a person can prevent it and make people aware of it. Most of the people do accept it and like what I’m doing and some want to join our group.

I was afraid because some people tried to stone me when I told them of this illness. I tried to talk to them. I remember at certain schools I was taken out by the principal when I told them I was HIV positive and the crowd wanted to attack me. I was protected by the principal. They said I was coming to spread the illness and I should go out of town to live. I think they were afraid for themselves. Most people don’t know their status. If you tell them to go and take a test, they think maybe their result will be bad, so they don’t go.

I’m still going out to tell people because every person should know about this. I also give them protection. When I go up and down in the township, wherever I go, people ask me for condoms. “Brother, where are the condoms?” they say, because they know now that this virus is very serious. It kills a lot of people right in South Africa and overseas and everywhere. If you, as a human being, don’t want to protect yourself, really it is going to take you.

We who are infected accept it and protect ourselves from further infection. There are a lot of people who are positive in Orange Farm. They are silent, but some of them want to disclose. I try to show them that even though you talk to her or him about their status, they don’t want it.

It isn’t easy because some only pretend to support you. They know deep down in their heart that the don’t support you. They are angry. They do accept but not wholeheartedly. Even at home, I have my own plate and if I use theirs just once, they won’t use it again and put it aside for the next time I come to visit. They still don’t understand, even though the say they do.

Sometimes I feel like I want to leave this place and go somewhere that I’m unknown to the community. I do feel angry about my situation but I have to accept it. It wasn’t my choice.

PADDY NHLAPO

I wanted so long to disclose because basically it’s lack of understanding of HIV and not having the right information that kept me in the closest for a long time. I didn’t undergo any counseling; I was just diagnosed and was told to go. I went to a clinic for an STD and my blood was taken so they could find out what I had. When I went back the nurse just said, “It’s bad news, you have HIV.” And that was it …… no post-test counseling. I went for the results of the STD and it was a shock and that’s it.

So I didn’t tell anyone, I just kept quiet. During that four years, I was collecting lots of information. I didn’t miss anything that happened with HIV/AIDS and I was reading a lot. I started becoming slowly confident. I confided in a friend of mine. She was the first person who knew. That was two and a half years later after I was diagnosed. We kept quiet about it, both of us. After people were busy coming out, I talked to quite a few people who were out. I started undergoing counseling, then I decided, “I’m coming out too”.

I had various stages of disclosure that I had to go through. I thought I should tell my mom and dad and the rest of my family. Unfortunately, I couldn’t do it, so I started telling people at work first. My then-Director, Zackie Achmat, was the first person to know. Then I spoke to my manager and two or three months down the line I spoke to the staff. It went through stages. After they knew, and other closer people started to know, I felt I was ready. It was the right time to disclose at home so that they could start taking care of themselves and I could help them to understand what was going on.

I had very serious problems at home with my dad. Then I got very sick. I think my being sick brought so many things in their minds, like, “It’s possible that we may lose him and if we continue fighting about this, it won’t help anyone.” After that, I started a group counseling session for my family because they didn’t want me to go public. That’s basically what we fought about …… my dad and I. He told me, “You’re not going to go public about this because it’s an embarrassment to the family”. So the counseling sessions took quite a long time.

Already I was telling people in organisation that I am part of, like the African National Congress (ANC), and comrades that are close to me. Finally I told my family that I was doing this TV programme and it was going to be shown to everyone. I told them, “I’ve already started doing it, so you will have to get over your fears and problems”. My dad just kept quiet and said, “Do what you think is right”.

Sometimes you cannot do what parents want you to do. You have to take charge of things. It’s advantageous for me to be out and I think I’m playing a certain role in making other people feel comfortable with their status. I’m making other people feel that they are not going to die tomorrow, as people think HIV/AIDS is just a death sentence. You aren’t kept from a happy life, a positive life, a productive life for that matter, just because you are HIV positive.

I came out for a few reasons. One was a political reason and the other is a personal thing. Personally I wanted to be free and do what I wanted to do. There were times that I was with my friends and they would be having Coca Cola and I’d be asking for juice. People came to my house and asked why I bought filtered water, why did I like 100% juice? People see the difference in you, even if you might not notice it, they will see. They will keep on asking questions and its better that people know and you are free with them.

Also they can confide in you. You don’t know how many young people have come to me and said, “I want to go have a test. I had a partner who died of AIDS and we were careless”. People come to me, lots of them. I want people to understand the realities about HIV/AIDS.

Another reason is some of the youth that I grew up with on my street, my neighbours, about three of them passed away and two are very sick. People will have to know that leading a positive life and eating healthy helps people a lot.

It’s a small-scale type of achievement, but in the long run it helps people’s lives. It enriches people’s thinking. I like to lead the way, and give advice. I love to be a part of development and an improved situation.


My disclosure is a weird story because I was disclosed publicly in the United States. I didn’t bring myself out, I was brought out. I was dragged out, screaming, I might add.

The long and the short of it was that my partner was in the military and we were diagnosed on the same day. He was a doctor, and somebody in his clinic leaked the news to the media. The media picked up on it, and in those days it was called Gay Related Immune Deficiency Syndrome (GRID)…..it wasn’t called AIDS.

Amazing huh, as gay men we had our own diseases, specific to us! So it hit the newspaper and I was brought out by association because I was his partner. Someone spray-painted “fags” on the side of the house, and bricks were thrown at our windows. Somebody poisoned our dogs. The telephone, when it did ring, was usually somebody making some derogatory statement about killing a bunch of faggots and, “This is God’s way of killing you”.

I was immediately discriminated against at work, as was Bill. He was court martialed. It was an 18-month fight, and the long and the short of it was that we were able to set precedent.

I was working at a travel agency at the time. There was a woman at the agency who had seen an article in the newspaper about Bill, made the association with me, reported it to the powers-that-be in the travel agency and, the next thing I knew, I was called in and told I was a shoddy worker and I must please leave.

Then I was discriminated against again about 18 months later when I was working hush-hush in someone’s home as a private chef. The news leaked again, I was no longer living in Vegas at that time and had subsequently moved to Florida. They found out and required me to have an HIV test done, which I did, and they fired me. We then took them to the Constitutional Court of Florida and had precedent changed there.

So as far as coming out is concerned, I came out, I went back in the closest the minute I left Vegas, and it wasn’t until I hit Florida when I said, “This is bullshit”. The reason I said so was that Bill had won his case with the military and they then tried to screw him on his veteran’s pension, and that was absolute crap. “This is wrong”. I’ve been out ever since.

I don’t have a problem with anyone knowing my status at all. I’m clear on the fact that its my body that has a disease, not me. I’m not a diseased person. My body has got this thing called HIV and so far I’ve been able to beat it. I’m looking at 17 years since I was diagnosed and there’s no sign of it reactivating.

When I was diagnosed, my first response was, “I’m not going to die from this. This is not how I’m going to die”. Based on my reality now, I’m probably going to live until I’m 70. I’m going to be walking around having a great old time and people will be saying, “Oh that smelly old man”. Or maybe I’ll die of a heart attack from smoking too much. But I don’t think its going to be AIDS, I really don’t.


When I was diagnosed with HIV I was angry, and for the first time in my life I thought of suicide. I thought maybe if I died, things would be better for my son. After a few weeks, I realized I was making a big mistake because it was better to live and teach people how to live with AIDS. I started seeing social workers to help me get through this.

The first time I disclosed, I was staying in Lenasia and I was working at a Children’s Home as a child-care worker. There were two children there who were HIV positive but the staff were not treating them correctly, it was not like the other kids. They used to swear at them and sometimes they didn’t even wash their clothes.

I felt depressed and angry because they didn’t invite this disease…it just happened to them. Nobody knows how this disease comes or how it started. I was angry and I had to fight back for those kids because they were small and couldn’t fight back for themselves.

The people I was working with started to suspect maybe there was something wrong with me. By that time my husband had just died of AIDS and I thought I had to tell them the truth. They rejected me, they said I’m a loose woman and I sleep around. It was very painful because I was faithful to my husband and didn’t know he was infected until after he died.

I think that by being silent I made myself ill and depressed. I first got courage after I saw other people soon after they were told they had HIV. These people became very ill and they died because of silence. By that time I was angry because I didn’t know about this disease and what it was doing. I used to go to support groups to be with other people to express my feelings. After that I felt better.

Immediately after I told everybody, I was relieved and I began to live a normal life. But it took seven months to tell people. Telling people was the hardest thing to do because you don’t know whether they are going to accept you or not. It wasn’t easy, believe me.

I think it was the best thing to do because each and every time after I talk with somebody, I feel okay. As long as you accept it, it’s like other diseases. As long as you accept yourself, people will also accept you. If you don’t accept yourself, you’re hiding from yourself. In a way you don’t want other people to help you, or to learn more about this virus. So by talking to other people, visiting other people who are HIV positive, talking to each other, discussing your problems, you become relieved.

LUNGISANI BIYELA

I started talking about my HIV at schools in KwaMashu. Then I went out to talk at a church and a Christian Centre in KwaMashu. Then I went to other schools in Umlazi.

I was asked many questions. People wanted to know how did I feel when I heard that I had this disease. I told them that it’s like I’ve admitted that I’ve got this disease. I was in church and people read some verses in the Bible to console me. When they were reading the Bible verses for me, it was painful for everybody. They cried and felt sorry for me.

They asked me about my relationship with my girlfriend. Did I tell her about this and what did she say? I told them I didn’t tell her I’m positive because we were separated and I never saw any need to go back and tell her to take a test. I was afraid she would say I’m the one who infected her with this disease.

I told my family that I’m infected. At first they made a noise at me, but everything passed. I even told my friends and other people around I know and they tell everybody else that I’m positive. I never worry about that because I’ve already admitted it.

Men listened to me even though some of them didn’t like what I was saying. They were always telling me they didn’t want to use condoms because they said a person must do ‘flesh to flesh’. But they do listen to me. I always carry condoms and give them away so that these men can protect themselves.

My mother was hurt when I told her about HIV and it was very painful for her. She cried and she tried to chase me away. When I was diagnosed, those same people who diagnosed me told me they wanted to talk to her. She never wanted to go to them because she knew herself that she wasn’t treating me right and was afraid about what would be said about her. I didn’t want the health people to sit her down and talk to her either. Finally I sat down with her and explained to her about my infection and she admitted and apologized for how she acted, and she cried.

An important thing is that when people know that someone has this disease, they shouldn’t go around telling everybody that so-and-so is infected because that makes me, as the person who is infected, feel like I’m not free. It makes me feel like someone who is different from other people when the truth is, there is nothing different; we are the same.

Some people say someone who has HIV should be a skinny person. They want to know why I’m not skinny. They forget there is a difference between HIV and AIDS. I don’t have AIDS, I am HIV positive.

I wish people should treat us right because we are the same as them. To say I’m HIV positive, it is just my blood, not my mind. My mind is not HIV positive, it’s only my body. Only blood. In my mind I know what is wrong and what is right.

Interviewed in Durban, September 1999. Age 31.