

going first: a conversation with mdu nkosi

MDU NKOSI with LIZ CLARKE / south africa

Five months after Anthony Morris was vaccinated in Baltimore in *clinical trials* of a new type of AIDS vaccine (see chapter 42), the study expanded to trial sites in Durban and Johannesburg. The vaccine was the first one based on *clade C strains* of HIV (the most common family of strains circulating in South Africa) to enter clinical trials. And it was the first AIDS vaccine study to be launched in South Africa, followed in quick succession by two others.

Mduduzi Sabath Nkosi, age 28, was the first South African to be vaccinated in Durban. Nkosi, nicknamed Mdu, calls himself “a proud Zulu” and was born and raised in the northeastern region of the country, close to the Swaziland border. Here he speaks with journalist Liz Clarke, AIDS writer for Independent Newspapers in South Africa, about his experience as a trial volunteer.



TELL ME about yourself.

My home is in the rural area of Mpumulanga. My mother and father are simple farming people in their 60's, and I have a large extended family. I am Zulu speaking. In 1998 I came to KwaZulu-Natal to study electrical engineering. At the moment I am working part-time to earn enough money to finish my studies.

How did you hear about the vaccine trial?

One day I was listening to the Ukhozi Radio station when I heard staff from the Medical Research Council (MRC) invite people to their offices in Durban to learn about AIDS vaccine research. They gave a telephone number so I contacted the lady. That was in December 2002. I spent a full day there with others who had also heard the program. [The staff] explained everything about the *virus* and the importance of a vaccine that could one day help millions of people.

At that point, what did you know about HIV/AIDS?

I had read about this disease in magazines and how dangerous it was to have unprotected sex, but at that stage I did not know the science or what the virus did inside the body. None of my family is infected and I don't know a single person [living openly] with HIV. But this maybe is because people don't like to talk about it and wouldn't admit they have it. I know people who are ill, and yes, they could have the symptoms. But they haven't been tested for HIV, so it is difficult to say.

What do your friends think of this disease?

People are very frightened. They don't talk about it or call it by its real name. They sometimes call it "*Egameni Likayisa Nelendodana Nelikamoya Oyingcwele*," which means "In the name of God, the Son and the Holy Ghost." Because I have a lot of information I try to tell young people to take advice from nurses and doctors about prevention. I ask them if they are aware of the devastating things that can happen, and that there is no cure. It is very disappointing when they don't listen. Even when they start to lose weight and cough a lot, or have diarrhoea or sores in their mouths, they would not say anything. They are ashamed and know that people will look down on them if they are positive. Their families could also turn their backs on them.

Are you also frightened of getting HIV?

I am aware of the problem, but I have always been a very responsible person, and don't believe in having a lot of girlfriends. I always use condoms and will only be with someone I intend to marry. In the Zulu tradition the rules are very strict. If you meet a girl and it is serious, you take her home where *lobola* [money the man's family pays for the wife] is discussed. Sleeping around with one girl after another if you don't intend marriage is not acceptable in Zulu culture. If young people followed that rule there would be fewer people getting sick. When you have playboys there is no commitment, and that is where the problems start.

What do you see as the value of a vaccine and your role in the process?

If our people are going to survive we need something that will prevent this disease. If there comes a time when every baby born in the world is vaccinated against HIV/AIDS, this would be a good thing. I decided to join the study because I wanted to help prevent our children from becoming infected.

If our people are going to survive we need something that will prevent this disease. If there comes a time when every baby born in the world is vaccinated against HIV/AIDS, this would be a good thing.

What happened after you agreed to participate in the trial?

It took about 11 months between joining up and having the first injection. There were many meetings. It was explained what was expected of us during the trial period, and how the vaccine might work. We were told that the only people eligible were those between ages 18 and 60 who were HIV-negative and had no other diseases. But we would have to undergo an AIDS test and other blood tests. They told us that there were some risks of side effects from the vaccine, but this would be watched carefully. [Although there is no risk of infection from the vaccine,] if we became infected during the trial we would be offered treatment.

We didn't say yes or no right away. First we went back to our families and people close to us and talked with them about it.

What did your family say when you told them you were going to volunteer for an AIDS vaccine trial?

I didn't discuss it much with my father because it wouldn't really mean much to him. He is illiterate, so he has not read anything about it. My mother is also illiterate, but she is much more knowledgeable about everything and takes an interest. She knows about HIV from people explaining it to her. She said I was doing the right thing and I must continue. She was proud I had made this decision.

How did you feel on the day when you knew you would be making history as the first South African volunteer?

It's difficult to describe. When I got up that morning I was a bit nervous because I knew that this was a very important day for my country, my community and really for the whole world. I wanted to tell everybody what was in my heart, but there wasn't anybody who would really understand. On my way to the MRC I wondered about the injection. Would it hurt? Would I feel any different afterwards? But I trusted the staff, and they had prepared us well for this occasion.

At the clinic, everybody was very excited. It was a nice feeling knowing that this could make a big difference to people's lives one day. I know it is still going to be many years, but you have to take a first step. After the injection, everybody shook my hand. It was a strange feeling knowing that this vaccine was making its way through my body. I tried to imagine where it was and what it was doing. I also hoped my body would do the right thing.

One day when I have children and grandchildren I will tell them about this day. I think it will always be important in my family, maybe not now but in 10 years. I have also learned a lot from this experience about my own health and my body and also about research and vaccines.

Have you had any bad reactions to the vaccine?

No. I have been very well. I have had several blood checks and everything was fine.

Would you encourage other people to become volunteers?

Of course. But that is very difficult. The disappointing thing is that people are so afraid to be tested, which is the first problem in volunteering. I say to my friends that if they are HIV-positive it would be much better to know early on, when more can be done to help them. They shake their heads and don't want to talk about it. But I will go on trying.

What were the reactions when it became known you were the first volunteer?

After my picture appeared in the newspaper there was a lot of talk about it. A 15-year-old friend rushed back to her mother with the newspaper and said to her, “Look what my friend has done—one day I would like to do the same thing.” Her mother said I was a “good guy.” So it is important that more people read about the vaccine. Then they won’t be suspicious and think it is something bad.

What lessons have you gained from this experience?

It is that we must be in a partnership like brothers. The government must make sure that *antiretroviral* treatment is available at all the hospitals and clinics in our country. But we must also try [harder] to prevent [infections from] happening in the first place. Often I hear people saying there is not enough money for AIDS medicine, but when those same people get sick they don’t want to be tested or take any advice.

The only way to find solutions is to participate in the future. We can’t all be heroes, but we can make a difference.

[I also learned that] the only way to find solutions is to participate in the future. We can’t all be heroes, but we can make a difference.

What is your dream for the future?

To have a baby who grows up in a country free of HIV/AIDS. But perhaps that will be for my grandchildren.