



Chris Kirchhoff



# Living with the stigma

**"The Miss HIV Stigma Free Pageant in Botswana asks contestants 'What are you going to do to reduce stigma in your community?'"**

With over two million inhabitants, Soweto is the most populated black urban residential area in South Africa. Poverty co-exists with pockets of wealth. Most people are working class, live in matchbox homes, shacks or rented rooms. Unemployment is as high as 50% among people aged 20 – 29. Single-parent families make up one third of all households. The HIV rate in the general population is estimated at 10% and is 30% in pregnant mothers. Although knowledge of HIV/Aids is widespread, 88% of people interviewed in a recent survey said no-one in their homes had HIV.

As part of a six-month study for the HIV/Aids and the Media project journalist **Philippa Garson** interviewed nine women to explore their experiences of stigma as people living with HIV. Garson found that despite the sheer numbers of people living and dying with HIV/Aids, and the public campaigns around Aids awareness, stigma has not diminished as much as one would expect.

She also found that some women are beginning to stand up to the tyrannies of isolation and rejection and in so doing, are acting as agents of change in their own communities. "In a climate where denial around HIV/Aids still prevails in both public and private spheres, and where women are often blamed for 'bringing the disease into the home', the burden they carry is immense."

Garson adds that research shows that the media's preoccupation with the politics around Aids in general continues while the personal experiences of people living with the illness continue to be ignored. However there is a hunger, particularly among those directly affected by HIV, for more media coverage on real life experiences of the disease.

## The following are the voices of some of the women:

**K** has disclosed to her partner but is unable to tell her immediate family. "The way my sister talks about HIV. She says 'I really hate them.' I said 'What if I tell you I have HIV.' She said 'Then I won't see you again in my house.'"

**D** with two children, has disclosed to her mother but not to her partner. "When I got the results I didn't tell him. It was just my secret ... You know, it's a question of who came with the disease or what happened, you know. I don't know whether I am the one who came with the disease with my first relationship or was he... At the end of the day I am the one to be blamed."

**Z** has a two-year-old and baby who is HIV-positive and sick. She has disclosed her status to no one. Because she was too scared to disclose to the hospital where she gave birth in Kwazulu-Natal, her baby wasn't given Nevirapine. "It's not easy to just disclose yourself. Ja, because you are thinking, eish, lots of questions. Maybe these people, they'll neglect me, you see, all these questions."

**D** is unable to tell her partner of her status because she fears a violent response. She has not told him that their first baby died as a result of hospital negligence; neither did she pursue the matter with the hospital, as she feared her status would be revealed. "He was just negative about this HIV thing, he doesn't want to know anything, even now. You see. There was a time last year when I tried to tell him, but he said if he can find out that he is HIV-positive he is going to kill himself,

so I can't risk that, I can't test that... So you won't know if he will kill himself only or he'll start with the baby and then me and then himself, those are the things that made me know I must never touch this, he will do something that is very hurting to the family."

**T** is a single mother of four children from three different fathers – two who have died of Aids. T has experienced ongoing rejection from her mother and sisters. She was forced to leave home several times and recently stayed in the HIVSA shelter. "My mother just said, 'Hey, she's got Aids, she's got Aids... I don't want her in my house.' Now my sisters came, all of them now, saying, 'Ja, she must be out, she must be out.' Now I was crying. I asked myself, 'where must I go now?'"

**J** discovered her status in 1993 when pregnant. Her child died three years later. To date she has never disclosed to the father of her child who had another baby in a subsequent relationship, who also died. The only person **J** disclosed to was her mother, who rejected her. "I don't know what she thinks but my mother doesn't like me from the age of three years. She even took me to the welfare, I don't know what's wrong with her, but I have been trying to come closer to her, you understand? ... I was living positive with my child, I didn't take any treatment because I was scared. (My mother) didn't even give me any support about this thing, the only mother, my biological mother. She is just avoiding and ignorant. I can't force her to understand this thing and accept it, and to face it. I just told myself it is with me and then I will face it myself."

**A:** "Disclosure has its advantages and disadvantages. For me I thought it was an advantage to disclose. I told my family and other friends. When they visited last Sunday we cooked and no-one wanted to eat the food because they thought it was infected with HIV. We had to throw away the food. It's better to disclose to someone you don't know. It's better to trust the support group than family members. Sometimes it hurts to disclose to family members and then you don't get the support you need."

**T** reports that suspicions around her status were confirmed when she bottle-fed her baby with Pelargon (issued as part of the PMTCT programme). "The problem started at my home when they said, 'Ja, you've got Aids now because mothers who have Aids, they get this milk, the Aids milk'. They knew before but now they didn't have proof, you understand, because I was fit and strong. But when they saw that tin now, they said, 'Here it is'."

**M** whose baby is negative, has the support of her mother in Lesotho but is trapped in an abusive relationship. "I am ready to confront everyone to say living with HIV is not a problem. I want people to know about HIV. I don't care whether the others are going to talk. I think we have to go house-to-house to teach the families – especially boys and men – about HIV/Aids. The people who have to go there must be the people who are HIV-positive. If you go there they say, 'She's lying. She's not HIV, see how healthy she is.' We must take our results. Explain why we are still living healthily, so they know everything about HIV."

**A** disclosed to her husband straight away. "What encouraged me is I was not alone. There were many others. There were 10 that day and seven were positive... I was in a hurry to tell my husband because I know my husband, he is faithful to me." ■

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