



SOUTH AFRICA: Fear of stigma still prevents disclosure

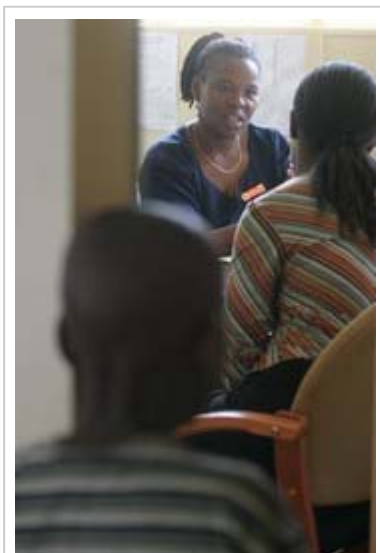


Photo: IRIN

Most women do eventually disclose to a family member or friend,

JOHANNESBURG, 13 June 2005 (PlusNews) - [All names have been changed]

Zeni's baby arrived prematurely while she was visiting her mother in the KwaZulu-Natal province of South Africa and was rushed to the nearby Edendale Hospital.

She had been scheduled for a caesarean section at Chris Hani Baragwanath Hospital in the country's largest township, Soweto, near Johannesburg, but gave birth by natural delivery at Edendale, about 500 km away.

Zeni was too scared to tell the hospital staff there that she was HIV-positive, so her baby boy didn't receive the nevirapine he needed. "He didn't get the syrup; maybe if he got the syrup he would have been fine," she said.

On her day off she had come to spend some time with nine-month-old Thabo, who was in Baragwanath hospital again, where was feeding him formula in a crowded paediatric ward.

His eyes were bright and he smiled readily but, with his stick-like limbs and an oxygen tube attached to his nose, he was the image of vulnerability: he is HIV-positive, has tuberculosis and is in and out of hospital with chest infections.

"My heart was very sore because at least I have had a chance to experience life - what about my son? He doesn't know anything; he is still young," she said, hugging her baby closer. "When I look at Thabo I feel like crying. I just tell myself one day he's going to get thin, because most of the people who've got this HIV thing, they get thin."

Despite her difficulties, Zeni, 30, sparkles with enthusiasm and zest for life. She has now sent Thabo off to KwaZulu-Natal to be looked after by her mother, while she tries to hold on to a poorly paid job and care for her elder son, who is HIV-negative.

So far, she has kept her status to herself - her partner, family and friends are still in the dark; only the hospital staffers know why her baby is so sick.

Like so many other women, Zeni is too afraid to disclose her status because of the persistent stigma around HIV/AIDS. "It's not easy to disclose yourself ... you are thinking ... maybe these people, they will neglect me, you see."

She is one of the roughly 25,000 women who have tested HIV-positive at Soweto's 13 public clinics over the past three years. Counsellors at the PHRU, based at Baragwanath and one of the largest AIDS research organisations on the continent, report that the inability of women to disclose their status is one of the biggest obstacles in the fight against HIV/AIDS.

PHRU psychologist Ray Lazarus noted: "Many of our counsellors feel completely frustrated and disempowered by the fact that the client won't disclose." However, as he pointed out, "experience around the world suggests that we have to think of disclosure as a process and not an event".

According to a PHRU study conducted last year, most women do eventually disclose to a family member or friend, but many still stall when it comes to their partners.

Dolores, 34, a mother of two, explained why she could not tell the father of her second child, John, that she was HIV-positive. "You know, it's a question of who came with the disease - I don't know whether I am the one who came with HIV from my first relationship, or whether John had it all the time. At the end of the day I am the one who will be blamed."

The fear of stigma and the resultant rejection is often greater than the actual experience of it. "Usually the fear in the mind is greater than the reality - women think that if they disclose they will be chucked out, but very few actually experience this," noted Zandile Myeni, director of the prevention of mother-to-child transmission (PMTCT) project at the PHRU.

Nevertheless, the dread of being ostracised, kicked out of home or blamed for passing the virus to a baby are enormous barriers to disclosure, and the stress of keeping the secret often appears to hasten the onset of illness.

HIV is merely the latest of many diseases, including leprosy, cancer and TB, to be stigmatised, but what makes it particularly intense around HIV/AIDS is that it concerns the usually taboo subjects of sex, death and bodily wastes, such as the diarrhoea that plagues many people with AIDS-related illnesses.

Research shows that people living with HIV/AIDS are all too frequently perceived as sexually promiscuous, the 'walking dead', or

contaminated and unclean.

Several women interviewed by Philippa Garson, a research fellow at 'the HIV/AIDS and the Media Project', run by the Perinatal HIV Research Unit and the school of journalism at the University of the Witwatersrand, said they would not disclose their status to family members or friends, because of the "way they talk about people with HIV".

Karabo, a receptionist who has just given birth, said she would never disclose her status to her sister, who has told her she "really hates them [people with HIV]".

"When I said to her, 'What if I have HIV?' she said, 'Then I will not see you again in my house'."

Many expected that the launch of the government's plan to provide free antiretrovirals at public health facilities would help diminish stigma by presenting HIV a chronic, manageable illness rather than a death sentence. But the pace of the rollout has been slow.

About 45,000 people are receiving the drugs, and the government is now close to meeting its target of providing treatment to 53,000 - admittedly a few months past the March 2005 deadline.

For Evelyn Keswa, who coordinates the PMTCT programme at Soweto's Lillian Ngoyi community clinic, education is the only way to eradicate stigma. "People need to understand that if I'm positive it doesn't mean I slept around more than the person who is negative; people need to accept positive people and understand that it can happen to anybody."

Themes: (IRIN) [Care/Treatment - PlusNews](#)

[ENDS]

Report can be found online at:

<http://www.irinnews.org/Report.aspx?ReportId=38687>

[This report does not necessarily reflect the views of the United Nations]

Services: [Africa](#) | [Asia](#) | [Middle East](#) | [PlusNews](#) | [Radio](#) | [Film & TV](#) | [Photo](#) | [Live news map](#) | [Interviews](#) | [E-mail subscription](#)

Copyright © IRIN 2009

The material contained on www.IRINnews.org comes to you via IRIN, a UN humanitarian news and information service, but may not necessarily reflect the views of the United Nations or its agencies.

All IRIN material may be reposted or reprinted free-of-charge; refer to the IRIN copyright page for conditions of use. IRIN is a project of the UN Office for the Coordination of Humanitarian Affairs.