

By Max Martin

Women in Karnataka talk about the stigma and discrimination they face because of their HIV-positive status

Heena is a sprightly woman in her early-20s. When she returns to her village in Karnataka her neighbours stare at her as if seeing an apparition. “Are you all right?” someone will ask coldly. “I am still alive, not dead,” Heena replies before going on to counsel women living with HIV in and around her village. Some are widowed; many are dispossessed and ostracised by their families.

Heena’s message: Do not spiral down to a life of depression, never even think of suicide. Fight the stigma.

A UNAIDS study of Bangalore and Mumbai, capitals of Karnataka and Maharashtra respectively – two high HIV prevalence Indian states – found that issues such as inheritance, housing and care-giving were particularly fraught with problems for women. The report, ‘2004 Report on the Global AIDS Epidemic’, brought out by UNAIDS recently confirms that such attitudes prevail across the developing world.

At the 15th International AIDS Conference in Bangkok on July 11–16, UN secretary general Kofi Annan urged the world to recognise the “Terrifying pattern” of HIV spread to young women, and the prevailing discrimination against those infected by the virus.

When she came to Bangalore, Heena did not know her HIV status. The news, when it came, shattered her. Its follow-up was even worse. Health workers at the hospital where she went for tests asked her bluntly: “How did you get it?”

This is the norm rather than an aberration, explains her friend Sheba, another young woman living with HIV. “They put a red star against your name,” she explains. “The woman dispensing medicine would throw the tablet sachet at me from the other end of the desk.”

Heena describes how a government hospital refused to terminate her pregnancy before it reached three months, despite complications. “The foetus died in my womb,” she says.

If this can happen in south Asia’s technical hub, Bangalore, the experience elsewhere can be worse. Often people do not know what HIV is. The minute they know it is sexually transmitted and incurable, the persecution begins.

Meena, a mother of four, says her husband’s family with whom she lived turned hostile after he tested HIV-positive and eventually died. “They minimised contact with us, and would drop our milk in a box.”

Many women say that their husbands’ family blames them even when it is a clear case of the man bringing home the infection. Meena agrees. “One day my husband’s brother dropped us at a care home in the city, saying it was for a few days of treatment. They never came back and I was not allowed to go.”

Later Meena realised that she and two of her four children were HIV-positive. “The first

question the doctor asked me was: 'How did you get it?'"

"In villages, people do not distinguish between HIV and AIDS, the last stage. They treat us worse than 'untouchables,'" says Anasuya, another widow in her 20s. "We get scared and feel very, very bad."

"Even after an AIDS patient's death, people are often scared to touch the body, making the last rites a problem," explains a social worker who works with people living with HIV and AIDS in Karnataka.

Children abandoned by infected couples suffer even more. The issue of AIDS orphans has yet to receive attention in India and elsewhere in south Asia. "We do not take such infants as we do not have the support system and other children may not like to live with them," says the regional representative of a children's charity working in Latur, a district in Maharashtra ravaged by an earthquake in 1993.

Several HIV-positive women working in garment units or in homes as domestic help say they would rather hide their positive status than risk being stigmatised or losing their jobs.

"In many places, there are compulsory medical checkups. Or when the entire staff goes for regular medical checkups they conduct HIV tests without their consent," says Jayna Kothari, a lawyer with the Alternative Law Forum in Bangalore. "An employee cannot be dismissed at the whims and fancies of the management. The law requires disciplinary proceedings. So they make up false charges."

At first, many governments saw HIV/AIDS as a public health menace that warranted the isolation of those infected. In traditional south Asian cultures, where sex is often a taboo word, an initial high-voltage campaign amounted to scare-mongering and contributed to the discrimination of those affected by HIV. "Skull-and-crossbones posters contributed to the dreaded image of the disease," says Ashok Rau, executive trustee of the Freedom Foundation, a voluntary group working with HIV-positive people.

Of late, however, there has been a trend to broadly interpret the law to uphold people's rights, and in India there are now national efforts to formulate legislation to protect these rights.

The most powerful weapon against stigma may well be HIV-positive people demanding their rights. And it is brave women like Heena who will be leading the way.

Denial of healthcare

The provision of healthcare remains largely unregulated by legislation, and there are countless examples of people living with HIV/AIDS being denied treatment because of their status, notes a new United Nations Development Programme (UNDP) study 'Law, Ethics and HIV/AIDS in South Asia'.

The study underscores five points about stigma and discrimination

- Wrong ideas about the spread of HIV and the risk of infection.

- Blaming those living with HIV/AIDS.
- Undue stress on 'risk groups' such as sex workers.
- Denial of healthcare and social support to those affected; breach of privacy, loss of job.
- Gender inequality and power imbalances in sexual relationships.

The UNDP also notes that the media in south Asia, like much of the general public, is largely ignorant about the basic facts of HIV transmission. At the same time, constitutional provisions are rarely used to protect the rights of those affected by HIV and AIDS.

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