



Chapter Seven

They Learnt about the Condom after they were Infected

The attitude of the Indian community towards AIDS is strongly reminiscent of the Roman emperor Nero who fiddled while Rome burnt to ashes. Martha and Assumptha, the two gender activists who undertook a collaborative research in Tamil Nadu on gender and HIV/AIDS, have made a strong statement in their report entitled 'Community Research on Gender and HIV/AIDS'. In an indicative, not exhaustive, study it is they who pointed out that the governmental and non-governmental interventions were not extensive enough. This seems a glaring lacunae at a time when an estimated four million Indians are suspected to be carriers of the HIV virus, a situation which the development community should be geared up to. The study also pointed out that information about the protective aspects of the condom was becoming available to women after they had been infected. These were wasted efforts at a time in development history when every step needed to be calculated and intentional. The service providers targeted only those at 'high risk' for providing information on condom use and this limited the access of the general population to this kind of crucial information.

The painful refrain

Martha and Assumptha are in fact echoing the common and painful refrain of a large number of men and women in India. A woman respondent from

Chennai, aged 28 years, put the situation in a nutshell. 'I did not know much about HIV/AIDS before testing positive. The knowledge that I had about AIDS was that AIDS is a dreadful disease of promiscuous people. You can get it even by touching a person with HIV. People with AIDS are thin, with skin diseases and die soon.' A male respondent, aged 25, expressed the same concern: 'I got to know about the use of the condom only after acquiring HIV.' Whether the research was undertaken in southern India or in the northern parts of the country, whether data were collected from the east or from the western parts of India, the concern was the same.

A 37-year-old graduate living in Kanpur had no knowledge about HIV prior to acquiring the infection, which was just some 14 months earlier, when he was 35 years old. These examples are only indicative of the larger picture. About 60 per cent of the respondents questioned in community-based research in India did not know about the causes and consequences of the epidemic until they were infected or affected. This finding holds across ages, across literacy levels, across socio-economic states and across gender. Men and women, young and old, rich and poor, educated or illiterate, are being caught unawares, as the epidemic enters its second decade in the country.

Awareness creation – can it be the ultimate goal?

The initial cases of HIV/AIDS in India were reported among the sex workers of Mumbai and Chennai and the intravenous drug users of Manipur, in the mid-1980s. Since then, the disease has spread into the general population, in both urban and rural areas. Recent statistics put out by the National AIDS Control Organisation (NACO) indicate that 90 per cent of the reported cases are occurring in the sexually active and productive age group of 18–40 years (NACO 1997–98). NACO has estimated that there are 3.5 million people living with HIV in India. Until 1991, 95 per cent of the national budget for HIV/AIDS was spent on testing services. Since then, although 'awareness creation' has seemed

to be the primary goal of a number of efforts in the country, the overall awareness in various sections of the population still remains very low. This low awareness about the causes and consequences of the epidemic in India could be due to the cultural sensitivity and inhibitions that hinder an open discussion about sexuality in the country. But it could also be attributed to the limitations of the awareness-raising approaches being adopted in the country by various development agencies. Not enough attention has been given to monitoring the quality of material produced and even less to assessing the impact of the different awareness-raising materials, media interventions and other approaches. Most of the visual material has failed to make the link between what was seen as a blood-borne disease and the use of condoms. The socio-cultural context, values and customs have not been adequately explored and programme implementers have failed to draw the link between these social realities and the information, education and communication (IEC) strategies that they developed to spread awareness about the epidemic.

As a result, blatant messages promoting condom use, on billboards along the highways, or on the rear bodies of buses and other public vehicles have failed to catch the attention of the Indian adolescent. As one respondent in our research rightly remarked, 'Even after getting HIV/AIDS, my husband brings home many girls and sleeps with them. I myself have seen it, but I cannot say anything about it. Since he has tied my 'tali' or wedding thread, I cannot speak against him. Being a woman, I have to accept it when he compels me to have sex with him.' And even if the anti-AIDS messages did make an impact on the young minds of boys and girls in India, could they be sure that such information would be adequate to guard them against the mutating virus when they were living in a world where young girls have little choice in the selection of their spouses? Revathy's testimony brings out the dilemmas and vulnerabilities of young women in India trying to live precariously in the twilight zone of the old traditions and the new social order.

Revathy was from a poor family married into an upper middle class family. Unable to gather enough resources to provide for the necessary 'dowry', Revathy's mother married her off to a man whose proposal for marriage had come through a marriage broker. Revathy was neither prepared for the marriage nor liked it, but had no choice. After her marriage, Revathy had just one unprotected sexual encounter with her husband. On the third day of her marriage, her husband started falling ill and had persistent fever. A routine HIV test was done and he tested positive for HIV/AIDS. He now remains in a semi-conscious state but is looked after day and night by Revathy, who does this not out of love or affection for the man but mere consideration. Revathy is convinced that her in-laws knew about the HIV status of their son even before he was married which is why they had got him married in a hurry without asking for dowry. Revathy cried bitterly the day she learnt that she had also tested positive. She had hoped that the result of her blood test would be negative, as the only exposure she had had to the virus was the one unprotected intercourse with her husband. Revathy is in love with another man, but does not want to remove her 'tali', or wedding chain, as she fears that such an act would cause the death of her husband.

I felt a sudden sting of pain, of anger, of hopelessness as I read Revathy's testimony. It was real. I had met and seen a number of Revathys in India but her words lingered in the air around me with a heaviness that is difficult to explain or put down in words. Facts and figures about the epidemic kept appearing and reappearing in my mind. There is usually a less than one per cent chance of getting infected per unprotected intercourse provided the woman has a healthy genital tract without cuts or lesions. Cuts and lesions are normally caused by sexually transmitted infections. Such infections in India are rampant, especially amongst people living in poverty as they can be caused by the inability to use a clean cloth during menstruation and lack of cleanliness in the genital areas in conditions of water scarcity. STDs in India are the third largest

cause of death after tuberculosis and malaria. And in spite of knowing that, we as development workers have failed to empower women with information and other resources that could help to guard them from the onslaught of the epidemic.

Still in the same pit

In 13 states surveyed in 1992/93, only one in six women said that they had heard of HIV/AIDS. In 1992, the level of AIDS awareness amongst women in three fairly densely populated states, where the so-called awareness efforts had been going on for more than half a decade, was dismal.

Table 5

	Population in millions	% who had heard of HIV/AIDS
West Bengal	68.1	10
Maharashtra	78.9	19
Tamil Nadu	55.9	23

Source: World Vision Relief and Development, Quarterly Report 1992. Article by Asha Bhende

Today, 8 years later, we are still stuck in the same mud pit. The research has revealed that in Assam 98.5 per cent of respondents have little or no knowledge about HIV. Reports from four Indian states read as follows:

'He left his job and broke all contact with his colleagues. One day he was found dead on a footpath.' Case c-10 – Assam.

'The first client that I met in the hospital informed me that he is HIV-positive and soon I found out that he was not sure what "being positive" entails. The hospital staff neglected him, nobody wanted to inject him, the injections are still lying there.' Case c-1 – Assam.

'His family members did not turn up when he was admitted to the hospital for treatment. She [his wife] alone had to take care of him. After his death, her mother-in-law asked her to leave the house and denied her

any share in the property. Her mother-in-law also told her to kill her three-year-old daughter. Even now she has to hear her neighbours say, "Your husband was a bad and dirty man". To avoid hearing this, and to stay away from unnecessary fights, she prefers staying indoors and has isolated herself. Her children do play with the other children but the neighbours fear that their house is infected.' Case 24 – Delhi.

'My aunt consulted the astrologer who informed us that someone had administered witchcraft to our family. Last time when I went to the village, I was asked to drink the juice of drumstick leaves. I vomited and they said the witchcraft was now out. I do not know whether to believe it or to doubt it.' 25-year-old woman – Andhra.

These instances can all be clubbed under one major concern – that of misinformation and disempowerment. How long will women and men continue to accept that their basic human rights can be ignored by those in positions of responsibility and at the cutting edge to make change happen? In a world where rights are seen as entitlements the blame for the number of lives and livelihoods at risk today lies squarely on the doorsteps of the change-makers, be they from the government or from the community. Armchair criticism may be an intoxicating pastime; it cannot be an antidote. We need to act and demand an adherence to ethical and human rights principles. We need to create a critical mass of empowered rights-seekers. With more and more women getting infected the women's movement will need to take this challenge by the horns – demanding information where information is due. Without this more mothers will be infected, more girls will be uneducated, more households will witness a feminisation of poverty. More women will be pushed out of families to live as single and deserted women.

This would be a rational attitude to adopt. Instead hysteria prevails. Outraged holier-than-thou moralists twist the entire argument with their chant – 'God's plan was for Adam and Eve, not for Adam and Steve!' All we hear is people arguing about homosexuals, prostitutes and higher

morality. We need to talk about how to provide succour to the patient, about pre-emptive measures, about how to fight a fatal disease, about institutional health care and a long-term policy to enable people to live and die with dignity. We need to revisit our own stereotypes, we need to reconceptualise the definition of the family to include those who are marginalised like, homosexuals and single women. Above all, we need to acknowledge that HIV/AIDS is a structural problem – a problem arising out of deep-rooted cultural settings in the society. Awareness creation in keeping with the individual's right to information is merely a first step. A series of initiatives needs to be launched to break and rebuild gender-friendly and more egalitarian structures. These require new alliances, expanded partnerships and innovative approaches that can create the ripples of change.