HIV and confidentiality in India

Joe Thomas examines some ethical issues related to HIV management in India

A review of literature in the Indian database provides only a few anecdotal reports on the questions of informing the spouse of an HIV positive person, the role of blood banks and confidentiality in the workplace, with no comprehensive studies on the subject. One approach to the question could be to look at the mechanisms of discrimination, the cause and consequence of such practices and how we can combat the discrimination by health care providers.

The major malpractices of health professions toward people with AIDS (PWAs) are:

- testing patients without their consent or without pre-test counseling,
- denying treatment, discriminating, and
- breaching confidentiality.

There are variations in these practices depending on the affiliation of the doctors (private doctors as opposed to those attached to public hospitals, rural and urban practitioners, their specialisation, and so on). The most disturbing trend is the low level of knowledge about HIV among health care providers in many parts of India (we have data from a study in Bangalore) and in many other countries.

Health care providers’ discrimination against PWAs is usually due to a lack of professional skill. Some also discriminate because they are unable to treat them (so they are not valuable customers).

Secondly, in many countries the doctor-patient relationship is based on a social hierarchy, as a result of which patients are often forced to accept discourteous behaviour from health care providers. This is also true in AIDS.

In a Star TV programme on people with AIDS in India, a leading AIDS-related health care provider in Mumbai criticised the leader of a group of people living with AIDS in Pune. Many health care providers are not used to getting advice on treatment options from patients. Many people living with AIDS are capable of discussing their illness with their doctors or asking their health care providers critical questions.

The dilemma of disclosure is another area of concern. Unfortunately, there are no standardised procedures on this issue. (The latest AIDS policy document in India does not provide much guidance.) There was some consultation on this issue in Mumbai during the early 1990s, but it does not seem to have gone much further.

The role of blood banks in HIV status notification is a tricky question. Even though in India as many as 10-14 per cent of HIV transmission occurs through blood transfusion, blood banks will have difficulty disclosing the results as they do not have confirmatory testing facilities and counseling facilities. Perhaps pilot projects could be set up to test the efficacy of blood banks in dealing with HIV positive blood donors.

AIDS in the workplace is another area of concern for the rights and privacy of a person living with HIV. Many major companies do have an in-house mechanism to monitor their workers’ health. Consequently, they may be able to learn of their workers’ HIV status. This is true of other institutions such as the police, the armed forces, correctional facilities and so on. (Indian soldiers who were HIV infected during their peace-keeping mission in Cambodia were summarily discharged from the army.) The situation of paramilitary forces in the north-eastern states is also interesting in the context of AIDS and ethnic conflict.

The emerging PWA self help groups are a source of great hope. Often AIDS in India is a manifestation of the social vulnerability of the people living with HIV. Another area to explore is the human rights dimension of the deprivation of adequate care for PWAs due to monopolistic trade policies of many developed countries which keep treatment options very expensive.

Reference