HIV / AIDS : Social and Ethical Issues

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The social issues associated with AIDS can be understood in two ways. Firstly, they may refer to the social determinants of the pandemic. Secondly, they relate to the social impact of the pandemic. Ethical questions present some of the most vexing problems associated with HIV infection [1]. Ethics cannot be considered in a vacuum. The social context dictates how the principles of ethics are applied and interpreted.

Spread of HIV is linked to certain patterns of human behaviour. Hence, it has both biological and socio-cultural determinants. Any attempt to control its spread must take into account the complex social, cultural, economic and environmental factors in which the disease is embedded. India has a large migrant population. Rapid urbanization coupled with poor housing facilities in city areas leads to migrant labours staying away from families. Illiteracy and poor awareness exposes them to high risk behaviour. Occupational groups such as truck drivers are especially vulnerable.

Mass uprooting of people by ethnic conflicts may also be related to an increased incidence of HIV infection. In a study among drug users [2], it was found that 80% of the respondents, many of whom migrated following ethnic clash, reported having sex with non-regular partners. Two-thirds of these respondents reported sex in exchange for money or drugs.

The unequal status of women in most societies also makes them vulnerable to HIV infection. Gender inequities preclude the women on insisting the male to wear a condom even when she suspects him of high-risk behaviour. In many parts of the world, commercial sex is an important source of HIV infection. Even if commercial sex workers (CSWs) are willing to adopt safer sex practices, their clients may object [3]. Thus, for promotion of condom use, AIDS prevention programmes should target not only CSWs, but their clients as well.

Interventions aimed at establishing safe sexual practices among CSWs have shown remarkable results. In Thailand, the decline in new infections has been very marked and attributed to universal condom use by CSWs

[4]. The 'Sonargachi' project in Kolkata red-light area has demonstrated that such interventions are possible in India also [5]. Successful targeted intervention projects in Kolkata have kept the HIV prevalence at a low level among sex workers. Participation of sex workers in programme planning and the resultant empowerment were the key elements of these interventions along with condom promotion, STD management and clinic services for clients as well as sex workers. The other targeted groups in and around the city were the fishermen, migrant labourers and truck drivers.

The first case of HIV seropositivity in an intravenous drug user (IDU) was detected in Manipur in 1989. Subsequently, within a decade, 44.7% of IDUs were found to be positive for HIV in Manipur. Injectable drug abuse is rapidly spreading in India and has been found to be prevalent in North East India, Maharashtra, Tamil Nadu, Punjab, Chandigarh, Delhi and other metropolitan cities. IDUs also often indulge in various sex related risk behaviours. Condom use is also low in the group [6].

At the family level, an adult with AIDS will severely compromise household resources as the functional capacity to work is reduced, medical expenditures increase and the income of both the infected individual and those who care for that person is lost. Reduced income in turn threatens food supply, the ability to pay for the education or health of surviving family members. The entire social fabric of the family is potentially disrupted.

The effects of HIV/AIDS multiply far beyond the infected individual. In the long run, it has the potential to affect whole sectors of the economy and societies as resources will be required for increasing number of people living with HIV/AIDS and for the care of increasing number of orphans.

The four pillars of medical ethics are autonomy, nonmaleficence, beneficence and justice [1]. These are general guidelines, which leave room for interpretation and judgement in specific cases. Many of the ethical issues that confront us in the context of AIDS are not new. However, the AIDS pandemic has given a sharp

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focus to issues such as confidentiality, discrimination, access to health care, prenatal testing/abortion and the conduct of clinical/vaccine trials.

The ethical issues relating to confidentiality and partner notification within the context of HIV infection are complex. The right of the individual to confidentiality can be in conflict with the right of the partner to be protected from the risk of infection. Confidentiality is essential to prevent discrimination. On the other hand, the seriousness of the threat to the health of unsuspecting third parties resulted in the debate on informing people at risk, also known as 'partner notification'. The National AIDS Control Guidelines for HIV counselling encourages motivation of the HIV positive person to disclose his/her status to the sex partner.

The Supreme Court of India has ruled on the issue of the right to confidentiality of subjects with HIV infection and the breach of confidentiality in order to protect the health of third parties [7]. The opinion of the court is that the right to privacy and confidentiality is not absolute. This right may be lawfully restricted in situations where third parties are at risk.

According to the National AIDS Control Organization (NACO) policy, no person is to be tested for HIV without voluntary consent. The NACO policy rules out any mandatory testing for HIV. It encourages voluntary HIV testing with appropriate pre-and post-test counselling.

Ideally, the disclosure of HIV status of the person should not in any way affect his rights to employment, position at the workplace, right to medical care and other fundamental rights. Unfortunately, one of the biggest problems faced by HIV positive person is stigma. People, even doctors, are sometimes afraid of dealing with HIV positive persons leading to discrimination in medical care. This stigma can prevent people from being tested. It can result in individuals unknowingly transmitting HIV.

HIV positive women should have complete choice to make decisions about pregnancy and childbirth. There should be no forcible abortion or even sterilization. Proper counselling should be given to pregnant women to enable her to decide whether to continue or terminate the pregnancy.

Even the selection of study sites for clinical and vaccine trials are fraught with ethical complications. Sometimes, researchers have chosen developing countries for such trials to avoid the ethical constraints faced in the developed world [8].

The highest ethical standards must be upheld when collecting behavioural or biological data on sexually transmitted infections, including HIV/AIDS. Because of the stigma and human rights issues around HIV/AIDS, study participants may experience psychological, social, physical or economic harm, even when precautions are

taken. Data collection protocols or procedures should include an explicit description of the measures that will be taken to protect the subjects. Both the Indian Council of Medical Research (ICMR) and the Central Drugs Standard Organization have established guidelines for biomedical and clinical research in India [9,10].

The global burden of HIV infection in the years to come will be borne overwhelmingly by people in developing countries. Increasingly, inequalities of gender, race and wealth will dictate the course of the pandemic, with infection rates increasing among the vulnerable groups. Social and economic dependence will be the major determinants of the future course of the HIV/AIDS pandemic.

Input from social research field is urgently needed for planning and evaluation of AIDS prevention programs. Social, behavioural and legal research will improve understanding of the dynamics of the pandemic and its impact. It will translate into public health and societal action for fostering understanding of the intricate relationships between the individual, public health and society. It will also help in resolving some of the complex social and ethical issues.

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