



## HIV/AIDS- Ethical/Legal Issues

Usha Arora, R.K Arora\*

HIV testing has brought out a number of legal & ethical issues to the forefront as HIV/AIDS is more of a social problem rather than a medical problem. There have been allegations of human rights violations across the globe and HIV infected persons have been discriminated against. HIV/AIDS has highlighted the inequalities, wide spread stigma, discrimination and denial of fundamental human rights. On the other hand, it is the denial of human rights that makes certain sub populations, more vulnerable to HIV than others like commercial sex workers (CSW), men having sex with men (MSM) and Intravenous drug users (IVDUs). Another important point to understand is that lab diagnosis is the only method determining the HIV infection status of an individual during the long asymptomatic period. HIV/AIDS affects life long and outcome is invariably fatal. There is no complete cure and no vaccine is available so far. Three main legal-ethical issues involved in a public health strategy to combat HIV, which arise in clinical and voluntary counseling and testing (VCT) settings, are: Consent for HIV testing, Confidentiality of HIV status and Discrimination on the basis of HIV in health care, employment & other services.

### Consent (1)

VCT is based on the requirement of informed and voluntary consent of the person being tested. This policy on consent is important because HIV is not curable, its implications are life threatening and the stigma attached to HIV is unprecedented. Knowledge of HIV positive status itself may lead a person to untold trauma including suicide. So, counseling is needed which is a confidential dialogue between a client and a counselor aimed at enabling the client to cope with stress and make a personal decision related to HIV/AIDS testing (2). The counselor should be aware of the GATHER technique, (Greet, Ask, Tell, Help, Explain and Revisit). Counselor should have empathy i.e. recognition and understanding thoughts and emotions. Counseling in VCTC consists of pre test counseling, informed and voluntary consent for testing and post test counseling before handing over the test result. The counseling process includes an evaluation of a personal risk of HIV transmission and facilitation of preventive behavior. Law also recognizes that in situations like a medical emergency where an unconscious patient is brought to a hospital, consent may not be taken. Here, doctrine of honesty permits doctors to interfere with bodily integrity of the patient. In others, proxy consent could be

taken where client is incapacitated (physically ill /mentally unsound /pediatric patient) and is unable to give consent). After testing, a reactive test result is confirmed by two more tests based on different principle/antigen (E/R/S) according to NACO guidelines (1). If the test result is negative and person is practicing high risk behavior he/she may be in the window period. He/she should be retested after 6 weeks to 3 months (after the end of window period). The test result is given only after post test counseling. This explains the need for counseling and testing center where adequate voluntary testing facilities, pre & post test counseling are available. Because of danger of vertical transmission to infants born to HIV positive mothers, prevention of parent to child transmission (PPTCT) centers are opened where pregnant women are counseled and made to realize the importance of test but are not tested without informed and voluntary consent. So, routine offer is not routine testing. UNAIDS/WHO does not support mandatory testing of individuals even for employment or for providing healthcare facilities except for safety purposes (screening donors of blood, semen, organs or tissues in order to prevent transmission of HIV to recipient of biological products). Informed consent is also a pre requisite for conducting research (2).

### Confidentiality of HIV status (3)

Confidentiality arises when there is a confidential relationship the nature of which may be dependent on factors of trust, knowledge and skill, e.g. a doctor-patient relationship or a relationship between a counselor and client. Confidential information, i.e. information that would otherwise not be divulged, which has the necessary quality of confidence about it and has been imparted in circumstances imparting an obligation of confidence. The principles of privacy and confidentiality are incorporated in Constitution of India (article 21) which states that confidence entrusted by a patient to a physician and defects/dispositions in character of a patient observed during medical attendance should never be revealed unless required by laws of the state. But in Goa, as per Goa public health (amendment) act 1986, Indians including foreigners can be forced to submit for testing for HIV at the discretion of health officer. Once tested, Section 51 of Goa public health act and local municipal laws provide for the notification of AIDS cases. Confidentiality is very important in VCT because of the stigma attached to the

From the Department of Microbiology Govt. Medical College and \*Orthopedic SGRD IMSAR, Amritsar Punjab, India

Correspondence to : Dr Usha Arora Professor and Head, Department of Microbiology, Govt. Medical College, Amritsar



epidemic. Maintaining the confidentiality of individual patients is crucial for protecting public health. People, particularly those at high risk, will access these services (including prevention, testing, care and support) only if they are sure of the confidentiality. It is stressed not only in medical and national ethics but has even been recognized in common law. Supreme Court of India has ruled on issue of the right of confidentiality of subjects with HIV infection and the breach of confidentiality in order to protect the health of third parties. In the opinion of the court, the right to privacy and confidentiality is not absolute. This right may be lawfully restricted in situations where third parties are at risk.

#### **Discrimination (4)**

Community education programs, legislation and public health policies can assist in reducing the discrimination experienced by HIV positive patients. Health workers may also require education with regard to discrimination and all the health services should have policies in place which prevent discrimination towards these patients by health workers. Otherwise the use of VCT services may be limited due to the fear of discrimination which may, also, reduce the rate at which people return to collect their results. In the context of discrimination in employment on the basis of HIV status, there have been several progressive judicial pronouncements upholding the right of HIV positive persons to work. The most notable among these is the Bombay High Court's decision that an otherwise qualified person cannot be terminated from service unless he is medically unfit to perform the job functions or poses a significant risk to others at work. Another significant judgement was that, such a person should be accommodated in another job commensurate with his skills so long as that does not pose undue financial or administrative hardship to the employer. However, there is no precedent in India till date. With respect to discrimination in Health services, Article 21 of the Constitution of India guarantees the right to life and liberty to all persons, including the right to health. State health-care institutions are obliged to provide medical treatment to all persons without discrimination. Some other areas where PLHA face discrimination include education, insurance, and travel. So, there is a need to institute an antidiscrimination legislation that will cover both public and private settings. No statute exists which requires the HIV testing of employees in work place or prisoners. Only, defense forces' personnel are being routinely tested for HIV. There are no specific criminal offences made out for transmitting HIV which need to be addressed. Draft for a law on HIV/AIDS 2006 is pending with the Government of India and is likely to be tabled in budget session of Parliament in 2009. Otherwise till now many of the laws on HIV/AIDS emanate from judicial precedence and are applicable

under common laws. Archaic laws & gaps in the legal area need to be looked into. There is also need to reform laws which marginalize women & children- the most vulnerable group in the HIV/AIDS Epidemic

#### **Research (5-6)**

In May 2000, the UNAIDS issued a guidance document regarding HIV preventive vaccine research. The document contains 18 specific guidance points regarding the conduct of research. Research regarding drugs & vaccine against HIV/AIDS involving human rights should also address legal and ethical issues. Highest ethical standards must be upheld when collecting behavioral or biological data on HIV/AIDS because of the stigma and human rights issues as study participants may experience psychological, social, physical and economical harm. Both the ICMR and Central drug standard organization have established guidelines for biomedical and clinical research in India. Much of the legal and ethical debate around HIV infection zeroes on the conflict between society's right to protect itself against the spread of disease and the rights of infected people to confidentiality and civil liberty. Measures intended to protect the individual also protect society. There is also a need in society to develop an attitudinal shift towards people and accept them what they are rather than what they do. In the face of AIDS- this new unheralded global crisis, we should all be humble. But we should be resolute. We should think of their families, parents and friends. We should spare thoughts for health workers who will toil courageously over them- often with no drugs, always with no cure. We should have strong, deterrent laws which should end discrimination and stigma should have no dominion. At this juncture we conclude by quoting McGeer : "*Knowing is not enough: We must apply*" "*Willing is not enough: We must do*".

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