
UNIT 5 MORAL ISSUES ON HIV TESTING

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5.0 OBJECTIVES

In this block we have learned about the various routes of transmission of HIV as well as the what, why and how of HIV testing. Because of behaviour pattern, it is essential that we discuss about the moral issues involved in HIV testing. After studying this unit, you will be able to:

- understanding the concept of right to autonomy of HIV/AIDS patients;
- implications of testing entire population;
- issues pertaining to testing of specific groups; and
- issues involved in maintaining confidentiality.

5.1 INTRODUCTION

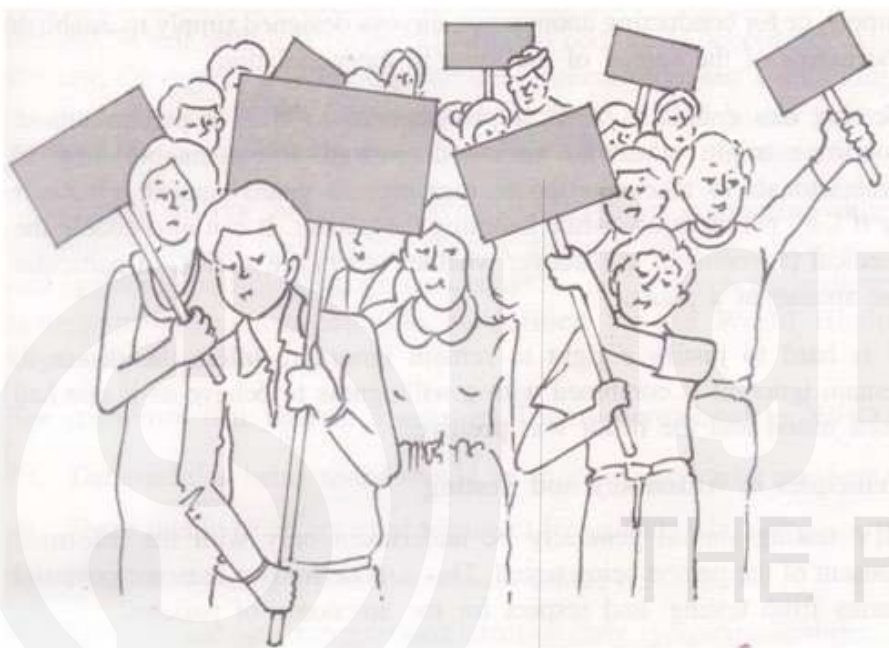
HIV/AIDS epidemic progresses differently in different situations. It is driven by individual behaviour which puts people at risk of infection. Their behaviour may in turn be driven by poverty, by relationship between same-sex men and women or between old and young people, or cultural and religious norms that leave people with little control over their exposure to the virus. The social, economic and cultural situation that creates this kind of vulnerability to HIV infection have not been adequately studied or explained. Perhaps there is virtually little information available for different social-cultural groups in India on the basic sexual and drug-abusing behaviour and patterns of sexual networking that determine the virus spread through a population. Whatever may be the situation, there is much that we all can do to face the existing situation.

Many people belonging to various social groups in the country are found to be infected with the virus. Several infected people seek medication. At the same time there are several others who continue to suffer because of discrimination, stigmatization and isolation due to the attitude of service providers as well as the widespread ignorance existing among the general population. Much of these behaviours can be changed if we learn about the ethical issues involved in HIV

management and HIV testing. In this unit, we shall examine the moral issues involved in HIV testing.

5.2 THE RIGHT TO AUTONOMY OF HIV/AIDS PATIENTS

Autonomy is a term derived from the Greek *autos* (“self”) and *nomos* (“rule”: governance”or“law”). It means self-governance. It is a widely accepted principle in medical ethics that competent patient has the right to autonomy. Intelligence and freedom are the basis of autonomy. Therefore, any patient who enjoys the gift of intelligence and freedom is competent to decide for himself/herself and has a right to autonomous decisions.



HIV/AIDS patient if competent also enjoys this basic rights of autonomy:

- “The right to knowledge” and “the right to ignorance”: with regard to understanding what is happening to them: the right to knowledge about to them, if they do not want to know;
- The right to know and accept what is being done to them with regard to the diagnostic and therapeutic procedures;
- The right to give informed consent; and
- The right to enjoy confidentiality.

It is quite evident that this right is not an absolute right. The rights and freedom of another person limit it. In the context of the special nature of HIV/AIDS, let us see how the right to autonomy applies to the questions of testing for HIV, right to confidentiality, etc.

The Ethical Advantages of Testing

Let us start reviewing the ethical advantages of testing for HIV:

Testing can tell the person tested whether he or she is carrying the virus or not. This may be useful to the individual in two ways: First it informs the individual

of whether or not to expect the onset of a serious illness. A person can take adequate precautions and treatment of the illness.

Second, it tells the person whether or not he or she is likely to transmit a lethal virus to another person by intimate contact. This is the ethics of right of knowledge.

No person welcomes the dreadful news that he/she has dreadful disease. People who oppose testing try to uphold the right to ignorance. It is true that the news that one is suffering from something that may lead to fatal illness is bound to be unwelcome. Enforcement of these rights tends to injure the second function i.e. precaution to infect others.

Second function often tends to override the right to ignorance. This right becomes relevant in relation to proposals for testing the blood supply, or for conducting anonymous surveys designed simply to establish the extent of the spread of the virus in the population.

Testing can enable a medical professional to treat a person whose condition might otherwise be mis-diagnosed. It can enable medical professionals to take appropriate measures to guard against infections or if they get an injury while handling the patient. It can also enable the medical professional to discover whether others are at risk, in particular the spouse of a patient.

It is hard to justify a right to remain ignorant, unless the desire to remain ignorant is combined with a willingness to behave as if one had been tested and the result was positive.

Principles of Autonomy and Testing

HIV testing should generally be undertaken only with the informed consent of the person being tested. This is done for two reasons: potential harms from testing, and respect for the autonomy of patients.

This, however, does not apply to the testing of donors of blood, organs, semen or similar bodily products. Here the intention is to provide a safe blood or organ donation. Ideally in all cases of donations, ethical approach is that prospective donors should be informed before the blood or organ is collected that an HIV-related test will be conducted on the tissue and given adequate information is performed as part of an anonymous HIV screening programme for epidemiological or research purposes.

General Principles for Testing: Voluntary or Mandatory

There are several general principles that should guide consideration of all testing proposals:

- First, the purpose of testing must be ethically acceptable. Treatment of the affected, protecting public health and preventing transmission of HIV are acceptable purposes. If the testing is done to deny services and express disapproval of certain groups then it is not ethical.
- Second, the proposed use of test results must contribute to the well being of the individual and the society.
- Third, the benefit to public health must warrant the extent of intrusion into

personal liberties. This principle does not suggest that public health should be sacrificed in order to protect civil liberties, but only that an uncertain or minimal public health benefit should not be used to justify gross invasion of personal rights.

The Question of Compulsory Testing

There have been repeated calls, however, for mandatory or compulsory testing of the entire population or of certain groups of the population, such as: pregnant women, newborns, prisoners, persons accused or convicted of sexual assault, prostitutes, health-care workers and patients, eunuchs and immigrants. Is it acceptable ethically?

Compulsory testing can be justified ethically in some situations. For example, when health care provider is at risk for HIV infection because of the occurrence of needle stick injury or a mucosal splash it is acceptable to test the patient for HIV infection even if the patient refuses consent. When testing is performed without consent in accordance with the law, the patient should be given the customary pre-test counselling. As post exposure prophylaxis is available to an injured health worker, right of the injured worker overrides the autonomy of the patient.

Mandatory testing programs have been used in combating other communicable and sexually transmitted diseases, such as tuberculosis and syphilis. The following are the conditions under which a mandatory testing programme acceptable as defined by the World Health Organisation in 1928:

Ten conditions that Warrant Mandatory Testing Formulated by WHO are:

- 1) The condition being tested should be an important health problem;
- 2) There should be an accepted treatment for patients who test positive;
- 3) Facilities for diagnosis and treatment should be available;
- 4) There should be a recognizable latent or early symptomatic stage;
- 5) There should be a suitable test for examination;
- 6) The test should be acceptable to the population;
- 7) The natural history of the condition, including development from latent to declared disease, should be adequately understood;
- 8) There should be an agreed policy on whom to treat as patients;
- 9) The cost of case-finding (including diagnosis and treatment of patients diagnosed) should be economically balanced in relation to possible expenditure on medical care as a whole; and
- 10) Case-finding should be an ongoing process and not a once and for all project.

Though not all of these ten conditions are fulfilled in the case of HIV/AIDS world-wide, the opinions about HIV-antibody testing has varied widely.

- There are those who recommend screening for all the population: their arguments seem to be irrational and are not based on scientific facts.
- Others show interest in screening targeted groups: the problem then lies in the choice of the groups and in the motives of that choice, which are often subjective.

- Last, there are those who recommend voluntary screening: they defend both human rights and scientific inquiry.

Which of these approaches can be considered ethical?

Over the years, calls for mandatory HIV testing have never stopped. Motivated by a mix of emotions and ideologist, they have re-echoed, citing new research findings and targeting different populations. Let us examine the question of mandatory testing and its merits and demerits further.

Check Your Progress I

Note: Use the space provided for your answers.

1) What are the ethical advantages of testing HIV?

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5.3 IMPLICATIONS OF UNIVERSAL TESTING

Early in the epidemic, it was recommended that the entire population be mandatory tested for antibodies to HIV. A popular misconception was that widespread or even universal HIV testing could identify **all who carry the virus** so that they could be isolated and the uninfected majority could be secure from any risk of transmission. The fallacy of this approach is that:

- Even if universal testing could be carried out, it cannot detect HIV: false negatives (persons are HIV positive but the test is negative) and persons still in the latency period (“window period”) when testing was performed will not be detected; repeat testing would be necessary to remedy those errors, and in the meantime those undetected might continue to spread the disease.
- There is a danger that the “uninfected” population would feel a sense of security and not pursue precautions against infections and are likely to be infected from patients who are in the window period.
- A universal or widespread testing programme does not represent a practicable approach because of the costs it would entail; and
- The HIV-negative persons in the population are not in fact at risk from HIV-positive persons living in their midst. However, wide consensus emerged that it would be a mistake to enact laws requiring the entire population to submit to testing: Concerns for protecting public health, support this conclusion, just as concerns for protecting fundamental rights do.

Testing of “High-Risk Groups”

Recognizing the problems raised by universal testing of the entire population, some have recommended that mandatory or compulsory testing be limited to members of the so-called “high-risk groups”.

However, such proposals were rejected on the basis that HIV is an indiscriminate virus that does not infect people along group lines: **it is a high risk activity, not identification with a group** that is decisive in the transmission of the virus. In addition, it was recognized that a mandatory testing programme aimed at the so-called “high-risk groups” would face obvious problems in identifying members of the targeted groups. Members belonging to the high-risk group may not access the health services. Finally, mandatory testing of these groups would have intensified the sense of polarization of “us” and “them” leading therefore to increasing discrimination towards “them” and giving “us” a false potentially dangerous sense of security.

Testing Specific Populations

There are problems both with forced testing of the entire population and with testing of “high-risk groups”. Some have called for more targeted mandatory testing programmes. One or more of the following factors seem to underlie the proposals for testing of certain groups:



- A perceived high risk of being HIV-positive
- A perceived high risk of infecting others with HIV; and
- Attribution of culpability due to involvement in criminal activity, so that being required to undergo the test can be considered a just component of punishment.

For example, some argued that testing should be required among prisoners, arrested prostitutes and drug users, and those who attend sexually transmitted disease clinics and de-addiction centers. In this view, these groups are not only at a high risk of infection, but they also pose a serious risk to the health of the

community and are likely to transmit the disease to innocent, healthy members of society. Each type of testing proposal raises a unique set of policy issues, and therefore it will be considered separately in section 5.4 below. For example, proposals to test all pregnant women raise different concerns and implications from proposals to test all prisoners.

Mandatory or compulsory testing, whether of the entire population or of specific groups, is generally opposed for the following reasons:

- Because of the potential for invasion of privacy and discrimination.
- Because of the stigmatization and discrimination directed at HIV-infected people, individuals who believe they might be infected tend to go “underground” to escape mandatory testing. As a result, those at highest risk for HIV infection may not hear or heed education messages about AIDS prevention.
- Testing without informed consent damages the credibility of the health services and may discourage those requiring services from obtaining them.
- In any testing programme, there will be people who falsely test negative – for example, because of laboratory error or because they are infected but have not yet developed detectable antibodies to HIV. Thus, mandatory testing can never identify all HIV-infected people.
- Mandatory testing can create a false sense of security especially among people who are outside its scope and who use it as an excuse for not following more effective measures for protecting themselves and others from infection. Examples are health care workers who do not follow universal precautions when all hospital patients are tested, and clients of sex workers who do not use precautions when they believe that all prostitutes are being tested.
- Mandatory testing programmes are expensive, and divert resources from effective prevention measures.

International organisations have made similar statements. For example, the Council of Europe adopted a recommendation stating “in the absence of curative treatment, and in the view of the impossibility of imposing behaviour modification and the impracticability of restrictive measures, compulsory screening is unethical, ineffective, unnecessarily intrusive, discriminatory and counter-productive.” The Joint United Nations Programme on HIV/AIDS (UNAIDS), in its 1993 Policy on HIV Testing and Counselling, also expressed its opposition to mandatory testing stating. “HIV testing without informed consent and confidentiality is a violation of humanrights”.

Finally, the International Guidelines on HIV/AIDS and Human Rights recommend that HIV testing only be performed with the specific informed consent of the individual tested, and that “exceptions to voluntary testing would need specific judicial authorization, granted only after due evaluation of the important considerations involved in terms of privacy and liberty.” This conclusion is consistent with WHO’s Statement from the 1992 consultation on Testing and Counselling for HIV Infection, which emphasises that “mandatory testing and other testing without informed consent has no place in AIDS prevention and control programmes.” The statement continues by saying.

‘There are no benefits either to the individual or for public health arising from

testing without informed consent that cannot be achieved by less intrusive means, such as voluntary testing and counselling.’ Public health experience demonstrates that programmes that do not respect the rights and dignity of individuals are not effective. It is essential, therefore, to promote the voluntary co-operation of individuals rather than impose coercive measures upon them.

Check Your Progress II

Note: Use the space provided for your answers.

1) Why mandatory testing for HIV is generally opposed?

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5.4 SPECIFIC GROUPS

Now, let us now briefly look the specific groups, which are often referred to as useful candidates for testing:

Pregnant Women

As with any other patient, pregnant women and women who are intending to conceive need to fully understand the advantages and disadvantages of HIV testing before deciding to undergo the test. The discovery of HIV-positive status has important implications for decisions to interrupt pregnancy, to take antiretroviral therapy to prevent mother to child transmission and to breast-feed the baby. These decisions are themselves mostly voluntary in nature.

Help must be given to meet the challenge of ensuring that all HIV-infected women who desire to continue a pregnancy are offered effective means to reduce the risk of HIV transmission to their babies. Ever since the discovery was made that administration of anti-retroviral therapy, such as Zidovudine (AZT), that significantly reduces that danger of HIV transmission from the mother to the child, the clamor for compulsory testing of pregnant women has increased. Ethically, however, the importance must be stressed of allowing women to make decision about testing as well as AZT use in a non-coercive atmosphere and based on the balance of the benefits and potential risks of the regimen to herself and her child.

The right question is: How can we offer appropriate counselling to all women and engage them voluntarily to learn their HIV status? If they are HIV-positive, how do we ensure that they receive needed care for themselves and potential interventions to prevent transmission to their foetus and, finally, that they provide care for their infants? With appropriate resources given to education and health care, the desired goal of early identification and treatment of HIV infected infants can be accomplished without mandatory new-born screening.

Newborns

Unlike programmes directed at offering voluntary HIV testing and counselling to all pregnant women that is coupled with voluntary treatment, the testing of newborns does not have the benefit of substantially reducing the risk of transmission from mother to baby. The test is not effective in identifying the infection in the newly born. Since, new born babies acquire all antibodies of their mothers, test for HIV antibodies can be beneficial only after a child has reached 18 months or more.

Prisoners

It does not seem that there exists any public health or security justification for compulsory or mandatory HIV testing of prisoners, or for denying inmates with HIV/AIDS access to all activities available to the rest of the population. Rather, prisoners should be encouraged to voluntarily test for HIV, with their informed, specific consent, with pre- and post-test counselling, and with assurance about the confidentiality of test results. As do people outside prison, they should have access to a variety of voluntary, high-quality, bias-free testing options, including anonymous testing.

Sexual Offenders

Testing sexual offenders like rapists, may not best serve to assist victims of these offenders. The issue of compulsory testing of persons accused or convicted of sexual assault has often been characterised as being one of choosing between the accused rights and victims' rights. However, an attempt to characterise the choice whether or not to require HIV antibody testing of accused persons as being either pro-woman or pro-criminal tends to obscure the real complexity of the issue and the tangible needs of the survivor's understandable feelings of anger, frustration and fear in order to advance a position that ultimately will not help her.

In contrast to persons convicted of sexual assault, persons accused of sexual assault are innocent until proven guilty. Therefore, it is not at all clear how compulsory testing could even be legally performed on them. Not having been convicted, testing could not be imposed as part of the punishment of the accused person. Merely having been accused of sexual assault are unlikely sufficient grounds to establish such a threat.

There can be no question that persons convicted of sexual assault have committed a serious criminal offence – if compulsory testing could further some useful objectives for the survivor of the assault, it might be appropriate to regard the convicted person's claim to autonomy as appropriately of less weight.

However, as demonstrated above, compulsory testing and disclosure of the test result to the survivor of a sexual assault provide little (if any) benefit to the survivors. Testing a person convicted of sexual assault cannot provide the survivor with useful information. At the time of conviction, she can find out whether she herself is HIV-positive by undergoing testing. If the test is performed during the window period, she will need to do a further test after six months especially if her previous test proved negative. In contrast, testing the offender would only provide her with information about the offender's HIV-status.

Commercial Sex Workers

Laws under which prostitute may be required to refrain from specific conduct, undergo specified treatment or counselling, submit to supervision, undergo treatment while detained, or, if infected with HIV and therefore, detained, may be counterproductive. These compulsory measures will dissuade CSWs to come forward for voluntary testing for HIV infection. Moreover, clients are absolved of any irresponsibility for not using precautions because the effect of the legislation leads them to assume that working CSWs will be 'clean'. Rather than such measures, interventions are necessary that would give sex workers the means to protect themselves against HIV transmission and would empower them to use them. The use of condoms must be evaluated in this context. In the context of CSWs continuing in their life-style, however, it can be considered as part of harm reduction efforts.

Health Care Workers

Should health-care providers be required to undergo compulsory testing for antibodies to HIV? If found positive, should they be excluded from practicing, or be required to disclose their HIV status to their patients as well as hospital authorities? The most appropriate way to frame the question is to ask **how best patients can be protected against real risks**, while not overreacting and excluding competent and safe practitioners. In order to best protect physicians as well as patients, the emphasis needs to be on strict adherence to infection control practices rather than on efforts to detect who is infected. HIV-positive health-care providers have saved and continue to save thousands of lives every year, and that excluding them from exercising their profession would endanger their patients' lives, and ruin the lives of thousands of dedicated medical professionals.

Check Your Progress III

Note: Use the space provided for your answers.

- 1) Should health care providers be required to undergo compulsory testing for HIV?

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5.5 HIV TESTING AND CONFIDENTIALITY

The right to confidentiality is one of the important rights of the patient. The information disclosed to a physician during course of the relationship should be kept confidential by the physician. The doctor patient relationship should be confidential to the greatest possible degree. The patient should feel free to make

a full disclosure for information to the physician in order that the physician may most effectively provide needed services. The patient should be able to make this disclosure with the knowledge that the physician will respect the confidential nature of the communication. The physician should not reveal confidential information without the expressed consent of the patient, unless required to do so by law.

The obligation to safeguard the patient's confidence is subject to certain exceptions which are ethically and legally justified because of overriding social considerations. Where a patient threatens to inflict serious bodily harm to another person or to him/herself and there is a reasonable probability that the patient may carry out the threat, the physician should take reasonable precautions for the protection of the intended victim, including notification of law enforcement authorities. If a physician knows that a HIV-positive individual is endangering a third party, the physician should, within the constraints of the law: 1) attempt to persuade the infected patient to cease endangering the third party; 2) if persuasion fails, notify authorities; and 3) if the authorities take no action, notify the endangered third party. Communicable diseases and suspected medico-legal cases should be reported as required by law. These principles regarding confidentiality in general apply to HIV-related information as well. The International Guidelines on HIV/AIDS and Human Rights say:

“General confidentiality and privacy laws should be enacted. HIV-related information on individuals should be included within definitions of personal/medical data subject to protection and should prohibit the unauthorised use and/or publication of HIV-related information on individuals. Privacy legislation should enable an individual to see his or her own records and to request amendments to ensure that such information is accurate, relevant, complete and up to date. An independent agency should be established to redress breaches of confidentiality. Provision should be made for professional bodies to discipline cases of breaches of confidentiality as professional misconduct under codes of conduct.”

The confidentiality of the results of HIV testing must be maintained as much as possible and the limits of a patient's confidentiality should be known to the patient before consent is given.

Obligation to Report HIV Status

Generally speaking, when law necessitates reporting of both HIV and AIDS, it should be done anonymously: nominal reporting is not warranted either for surveillance or for partner notification purposes. Test providers, ethicists, public health professionals, technical experts and others have to develop a system that collects only the information necessary, using unique or coded identifiers that ensure privacy and confidentiality is protected, the studies are going to be totally biased because of the non-cooperation of the general public. This type of system exists in United Kingdom. Also the communication media has to exercise a lot of self-discipline in this matter. The inhuman persecution that followed careless reporting by the communication media of some HIV/AIDS patients in our country is well known. ‘Do to others, as you would have them to do to you’ has been the golden rule of ethics down the ages.

Partner Notification

When a married person is tested positive for HIV, should the medical professionals or authorities inform the partner about it? If the person is likely to infect the partner, certainly there is an obligation on the part of the medical professionals to divulge the information to the partner. Convincing the person to share this information with the partner would be much more effective and conducive to prevent the spread of the disease. It would be a better policy to inform each person who requests HIV testing and counselling, under which circumstances the partner will have to be notified in case the test proves to be positive.

Effects of Breaching Confidentiality

While most agree that there are situations in which breaching confidentiality would be justified ethically, such breaches raise difficult questions: What will occur if it becomes generally known that clinicians breach confidentiality to protect third parties? Will patients cease to speak freely about their behaviour? Will the public health suffer as a consequence?

Here we are facing an extraordinary irony: the ethics of the clinical relationship, which usually favours strict confidentiality, appear to dictate a breach of confidentiality in the matter of partner notification, while the ethics of public health, which are usually less concerned with confidentiality, may dictate a stricter adherence to it.

It would be more beneficial to analyze the reasons why a client refuses to tell his or her sexual partner about his or her HIV-positive condition. Working through of deep-rooted issues of rejection, abandonment, loneliness, and infidelity may be more effective for prevention of the spread of AIDS rather than police-like reporting practices.

Confidentiality of HIV Status on Autopsy (post mortem) Reports

In the same vein, it is clear that health care professionals have a serious duty to maintain the confidentiality of HIV status on post-mortem reports. Physicians who perform autopsies or who have access to autopsy information regarding a patient's HIV status should be familiar with state law governing: (a) the reporting of HIV and AIDS to public health authorities; (b) obligations to inform third parties who may be at risk for HIV infection through contact with an HIV-infected dead person; (c) other parties to whom reporting may be required like funeral directors, embalmers, etc. This includes reporting to organ or tissue procurement agencies if any parts of the decedent's body were taken for use in transplantation.

Check Your Progress IV

Note: Use the space provided for your answers.

- 1) What do the International Guidelines on HIV/AIDS and Human Rights say regarding confidentiality on HIV related information?

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5.6 LET US SUM UP

In this unit we made an attempt to discuss a very important aspect with regard to the moral issues pertaining to testing for HIV/AIDS. The unit deeply analysed the right to autonomy of HIV/AIDS patients, the ethical advantages of testing for HIV, general principles for testing, implications for universal testing, testing of specific groups and HIV testing and confidentiality. This unit also dealt with certain pertinent issues like partner notification as well as confidentiality of HIV status on autopsy reports. All these issues are very important while dealing with issues relating to HIV/AIDS in any social setting as well as the medical setting in our country.

5.7 SUGGESTED READINGS

Almond, Brenda (1996 Ed.), *AIDS: Moral Issue. The Ethical, Legal and Social Aspects*. Macmillan Press Ltd, London

Overall, Christine and Zion, William P. (1991 Eds.), *Perspectives on Aids, Ethical and Social Issues*, Oxford University press, Ontario.

Illingworth, Patricia, (1990), *AIDS and The Good Society*, Routledge, London.

Thomas, Gracious, (2001), *HIV Education and Prevention: Looking Beyond the Present*, Shipra Publications, New Delhi.

Notes:

- 1) Recommendation No.R (89) 14 of the Committee of Ministers to Member States on the Ethical Issues of HIV Infection in the Health Care and Social Settings.
- 2) HIV/AIDS and Human Rights – International Guidelines, recommendation 28(b).
- 3) WHO, resolution WHA 45.35, 14 May 1992.