ignou
THE PEOPLE'S
UNIVERSITY

Indira Gandhi
National Open University
School of Social Work

BFE-101
Basic of HIV/AIDS

Block

2

HIV TRANSMISSION AND TESTING ISSUES

EXPERT COMMITTEE (ORIGINAL)

Prof. Abdul W. Khan
Former Vice-Chancellor
IGNOU

Prof. Thomas Kalam
Director, St. John's National
Academy of Health Sciences
Bangalore

Dr. Padam Khanna
Health Consultant
New Delhi

Dr. Glory Allexander
Chairperson
Asha Foundation
Bangalore

Ms. Enish Sareen
Sharan, New Delhi

Shri George K. Jose
Advocate, Supreme Court
New Delhi

Prof. Gracious Thomas
SOCE, IGNOU

Prof. VS. Prasad
Former Pro-Vice Chancellor
IGNOU

Ms. Bimala Kapoor
SOHS
IGNOU

Dr. Ritu Priya
Centre of Social Medicine &
Community Health, JNU
New Delhi

Dr. Rabia Mathai
International Federation of Red
Cross & Red Crescent Societies
New Delhi

Prof. Jose Puthenvedu Head,
Deptt. of Psychology
F.M.N. College, Kollam

Dr. Joseph Alencherry
Director, CANA
Kottayam

Dr. A.S. Guha
IGNOU Regional Director
Shillong

Dr. Suniti Soloman
Director, YRG Care
Chennai

Dr. A. Padmavati
Indian Social Institute
New Delhi

Fr. George Pereira
CBCI Centre
New Delhi

Dr. Anita Dighe
Direcrtor, CEE
IGNOU

Dr. V. Vasudevan
IGNOU, Regional Centre
Cochin

EXPERT COMMITTEE (FIRST REVISION)

Prof. Sanjay Bhatt
Delhi University, Delhi

Prof. Anjali Gandhi
Jamia Millia Islamia, Delhi

Dr. Rama V. Baru
JNU, Delhi

Dr. Ritu Priya
JNU, Delhi

Prof. Gracious Thomas
IGNOU, New Delhi

Prof. A.R. Khan
IGNOU, New Delhi

Prof. Santosh Panda
IGNOU, New Delhi

Dr. R.P. Singh
IGNOU, New Delhi

EXPERT COMMITTEE (SECOND REVISION)

Prof. Gracious Thomas
IGNOU, New Delhi

Prof. Jyoti Kakkar
Delhi University, Delhi

Dr. Bina Antony
Delhi University, Delhi

Dr. Suresh Pathare
CSRD, Ahmednagar

Prof. P.K.N. Ghosh
Viswa Bharti, Santi Niketan

Dr, Sanjoy Roy
Delhi University, Delhi

Dr. Habeebul Rehman
Jamia Millia Islamia, Delhi

Dr. Archana Kaushik
Delhi University, Delhi

Dr. Kaushalendra Pratap Singh
Rajiv Gandhi Universty
Arunachal Pradesh

COURSE PREPARATION TEAM (ORIGINAL)

Units Writers:
Prof. Thomas Kalam
Dr. Subhakanta Mohapatra
Dr. G.D. Ravindran
Prof. Gracious Thomas

Block Editor & Course Coordinator
Prof. Gracious Thomas
SOCE, IGNOU

COURSE PREPARATION TEAM (FIRST REVISION)

Contributors
Prof. Thomas Kalam
Dr. Subhakanta Mohapatra
Dr. G.D. Ravindran
Prof. Gracious Thomas

Revised by
Dr. G.D. Ravindran
Prof. Gracious Thomas

Content Editor
Prof. A.K. Agarwal
IGNOU

Block Editor & Programme Coordinator
Prof. Gracious Thomas
SOCE, IGNOU
New Delhi

COURSE PREPARATION TEAM (SECOND REVISION)

Original Contributors
Prof. Thomas Kalam
Dr. Subhakanta Mohapatra
Dr. G.D. Ravindran
Prof. Gracious Thomas

Content Editor
Dr. Rambabu Botcha
Rajiv Gandhi National Institute of Youth Development, Sriperumbudur

Programme Coordinators
Dr. Rose Nembiakkim
Prof. Gracious Thomas

PRODUCTION

Mr. Kulwant Singh
Assistant Registrar (Publication)
School of Social Work

January, 2019 (Revised Edition)

ISBN: 978-81-266-3115-5

Further information on the Indira Gandhi National Open University courses may be obtained from the University's office at Maidan Garhi, New Delhi-110 068 or the official website of IGNOU at www.ignou.ac.in
Printed and published on behalf of Indira Gandhi National Open University, New Delhi by Director, School of Social Work, IGNOU.
Lasertypesetted at Tessa Media & Computers, C-206,7 A.F.E-II, Jamia Nagar, New Delhi-25

INTRODUCTION TO BLOCK 2

Block 2 of the course on "Basics of HIV/AIDS" is an important block. It has explained the different ways of the transmission of HIV/AIDS. There are five units in this block. This block on "HIV Transmission and Testing Issues" will help in clarifying many doubts and misconceptions prevailing in several groups and communities regarding HIV/AIDS transmission. **Unit 1** explains the 'Transmission of HIV through Sex'. It will help you to understand how HIV is transmitted through sex and various other factors that contribute to HIV infection through sex. It also gives description about various vulnerable sections of population who indulge in high risk sexeual activities. **Unit 2** deals with 'Transmission of HIV through Blood'. This unit explains details about various modes of HIV transmission through blood and the vulnerable groups of population for HIV transmission through blood and blood products. **Unit 3** deals with 'Mother to Child Transmission of HIV'. From this unit you will understand various means of mother to child transmission of HIV. This unit also deals with some of the preventive measures associated with mother to child transmission of HIV. **Unit 4** is on 'HIV Testing and Issues Involved'. This unit will help you to learn how HIV can be detected in a human body, the various types of HIV tests used as well as the need for pre-test and post-test counselling in HIV. **Unit 5** is a very important lesson of this block. It deals with the 'Moral Issues on HIV Testing'. In this unit the right to autonomy of HIV/AIDS patients, implications of testing entire population and issues involved in maintaining confidentially have been explained.

The five units of this block provide comprehensive understanding about the what, why and how of HIV testing and the strategies involved.

UNIT 1 TRANSMISSION OF HIV THROUGH SEX

Contents

1.0 OBJECTIVES

The aim of this lesson is to create awareness about the transmission of HIV through sex. This will give us ideas on how to avoid various types of risky sexual behaviour.

After studying this unit you will be able to:

- know how HIV is transmitted through sex;
- analyse the factors responsible for the risk of becoming infected,;
- state various vulnerable sections of population who indulge in risky sexual activities; and
- interpret the relationship that exists between the modes of transmission and carriers of HIV through sex.

1.1 INTRODUCTION

There are several ways in which one can get infection with HIV. It is very important to know the routes of HIV transmission. This will help us to avoid the spread of HIV. In other words, understanding how HIV passes from one person to another will enable us to protect ourselves. It will also help us to plan and implement programmes for the prevention and control of HIV/AIDS.

Persons infected with the HIV can pass on the virus to those who are not infected. Most transmission occurs from patients who are without symptoms of AIDS. Therefore, it is essential that everyone is aware about the transmission of HIV. It is also important to know who can get infected and how one can get infected. HIV is present in all body fluids, tissues and organs. HIV has been found in almost all body fluids like blood, genital secretions, (semen, cervical and vaginal) saliva, tears and breast-milk. The HIV/AIDS virus can pass on to an individual through three routes. These are:

i) Sexual exposures;

ii) Contact with HIV/AIDS contaminated blood and blood products; and

iii) Mother to child through pregnancy or childbirth.

In this unit, let us examine how HIV spreads among people through risky sexual exposure.

1.2 MODES OF TRANSMISSION THROUGH SEXUAL ACTIVITIES

Sexual activity, whether homosexual or heterosexual, is the major route of transmission of the HIV throughout the world. The virus can be transmitted by any penetrative sexual act in which HIV-infected semen, vaginal or cervical secretions or blood is introduced into the body through a break in the mucosa. The sexual activities where this type of transmission occurs include:

a) Penetrative penile – vaginal intercourse;

b) Penile – anal intercourse; and

c) Oral – genital contact.

Detailed epidemiological studies throughout the world have documented that sexual transmission occurs through exposure to semen and vaginal or cervical secretions. Exposure to any of these fluids may also occur during other sexual activities.

The precise risk of HIV transmission from a single act of sexual activity is not known. Population-based estimates suggest that the extent of risk through penile-vaginal or penile-anal contact is generally less than one infection per hundred exposures. However, such statistics describe the average within a group of people and cannot be applied to an individual case. While some people have had multiple sexual contacts with infected persons without acquiring HIV infection, others have become infected following a single sexual encounter. Repeated sexual activity with an infected person increases the risk of infection. Let us discuss various types of sexual activity and the risks involved in transmitting HIV during those acts.

Penetrative Penile-Vaginal Intercourse

This is the most common form of sexual activity. Transmission of HIV from men to women and from women to men is well documented. However, transmission rate through heterosexual contact is reported to be high among females.

The transmission from men to women is fairly well understood. Semen from an infected man contains HIV that is most likely associated with infected lymphocytes. HIV introduced into the vagina must make its way into the lymphatic to initiate viral reproduction. Small breaks in the linings of vagina are presumed to be portals of entry to the lymphatic. Women are more susceptible to infection than men after a single exposure to HIV. This difference may be because the vaginal mucosa has a larger surface area and the vagina acts as a vessel for the seminal secretions. The seminal fluid has a greater contact time with the vaginal mucosa. Moreover, small cuts or break in the mucosa go unnoticed.

Other factors that increase the transmission during the sexual act are the presence of ulcers on the male and female genitalia. Women who have infections in their pelvic organs are more prone to develop infections. Chemical irritation of the vaginal mucosa that occurs due to use of barrier contraceptives may increase the chance of the women getting infected. Although male to female transmission clearly occurs, the means of transmission of HIV from women to men is less clear.

Penile-Anal Activity

This means penetration of penis into the anus. It appears to be the primary means by which HIV is transmitted among men having sex with men. This is sometimes referred as rectal activity and in turn often leads to breaks in the lining of rectum. The rectal mucosa is delicate. These breaks in the rectum linings make it easier for HIV to enter into the lymphatic. Laboratory studies suggest that cells that line the rectum may also become directly infected with the virus.

Male to male transmission through anal intercourse occurs at the rate of one infection per 10 sexual acts. Surveys of the homosexual populations indicate that a partner who inserts his penis in to the anus of another partner (active partner) seems to have a lower chance of becoming infected when compared to the partner into whose anus he has inserted (passive partner). When these activities are performed without any physical barriers, it must be considered as high risk for transmission of the virus.

Usually penile-anal activity is not recommended even between a mutually faithful husband and wife on health grounds. It is against dignity for the man to force his wife to agree for penile-anal sex against her will. Every human act whether in public or private has its implications on the behaviour and character of the individual. One must have regard and respect for every human being including a sex worker. Dignity and worth of the individual must be given utmost importance.

Oral-Genital Contact

This means contact between the mouth and genitals. The role of oral-genital sex as a route of transmission of HIV is poorly studied in populations other than homosexuals. It is because individuals who engage in oral genital sex rarely do so to the exclusion of other forms of sexual contact. It is difficult to attribute transmission of HIV to oral sex and not to other types of sexual exposures.

The possibility of transmitting HIV from the vagina to the mouth seems possible, although it is not documented. Similarly, the feasibility of transmitting of HIV from the mouth to the genitals is unclear. One can speculate about plausible roots of transmission in any type of oral-genital contact. HIV bearing lymphocytes present in semen could contact damaged mucosa in the mouth and allow the entry of HIV into tissue. Likewise, traces of menstrual blood or vaginal discharge containing HIV could severe as conduct of infection from the genitals to the mouth. Virus is shed in the saliva. Saliva is not infective as the dose of virus needed to transmit the infection is very low. Saliva also contains an enzyme that inhibits the virus. Hence, it does not easily transmit the infection.

Oral sex is very rare amongst most people in the Indian sub-continent for various reasons. Some of these include:

i) Lack of adequate privacy. Almost 70 per cent people live in rural areas in small houses along with several family members (children, joint family, etc.) where privacy for intimate sexual activities is limited.

ii) Almost half the populations in most urban areas live in slums which comprise a small room without any privacy and safety.

iii) Most men and women from the above mentioned categories return home tired and wanting rest after a day's work. They eagerly wait for darkness to set in so that their sexual urges can be satisfied in fleeting moments.

iv) Most people in India are not exposed or oriented to various forms of sexual activities described above due to their family, cultural, religious, educational, traditional and social background.

v) Husband and wife hardly talk to each other on sex and sexuality.

It may be noted that very few studies have been conducted on the sexual behaviour of people in India. Therefore, most of the concerns discussed in this unit may not be relevant for most people. However, adequate information on various aspects with regard to sexual activities which are risky in nature need to be made known so that the last person in the country is enabled to take necessary precaution to void transmission of HIV/AIDS/STDs. Twenty first century is witnessing unprecedented development in technology. Through social media network one is exposed to all types of pornographic activities that influence young minds. As a result, approaches to sexual behaviours changes can not be ruled out.

Check Your Progress I

Note: Use the space provided for your answers.

1) Describe how HIV transmission occurs through sexual activities.

.....

.....

.....

.....

.....

.....

1.3 FACTORS RESPONSIBLE FOR CAUSING INFECTIONS

Some of the risks of becoming infected with HIV as a result of sexual activities include:

i) Whether the sexual partner is infected;

ii) The type of sexual contact involved;

iii) The amount of virus present in the blood or secretions of the infected partner; and

iv) The presence in either partner of other sexually transmitted diseases or genital lesions.

Probability that Sexual Partner is HIV Infected

The prevalence of HIV infection among sexually active people varies in different areas and among population sub-group in those areas. The probability that a person has acquired a sexually transmitted HIV infection is, in general, proportional to the number of sexual partners the person has had in recent years. In areas where the mode of transmission is through heterosexual activity, the higher prevalence of infection has been found among female sex workers. The probability in such cases increases.

The probability of a homosexual man encountering an HIV infected sexual partner ranges from a few per cent for those with only a few male sexual partners in areas of low HIV/AIDS prevalence to several fold for men who have many sexual partners in areas of high HIV prevalence. Unlike several permissive societies in the world, the percentage of homosexuals and lesbians in India are significantly less. However, we do have reported cases of the prevalence of HIV among the minority homosexual population of the country having different sexual orientation.

Type of Sexual Contact Involved

Sexual Intercourse

All forms of sexual activity in which any type of contact with body fluid is involved carries a risk of HIV transmission. While existing data suggests differences in the relative risk of various forms of activity, the precise level of risk associated with each is not yet known. Trauma to the mucous membrane of the rectum or vagina may facilitate transmission of HIV, but is not essential for transmission to occur.

The highest risk for HIV infection occurs amongst men and women who engage in receptive anal activity with an HIV-infected partner. Vaginal intercourse carries a higher risk for heterosexual men and women than oral activity. Oral-genital contact may transmit HIV, but the available data are too limited to permit quantification of the risk from such contact.

Kissing

Kissing has been shown to pose a risk of transmission in some cases. Nevertheless, while not substantiated, there is a theoretical risk of HIV transmission during 'wet kissing' in which saliva is exchanged and if there are cuts and pores in the mouth.

Masturbation

Self-masturbation obviously poses no risk of HIV transmission. However, mutual masturbation, which may involve exposure to semen, or cervical and vaginal secretions, may pose a theoretical risk of HIV transmission if there are cuts, wounds etc. in parts of the body, which may be exposed to such body fluids.

Amount of Virus Present in the Blood or Secretion of the Infected Partner

HIV infected individuals are thought to become more infectious as they progress to overt disease i.e. AIDS. Similarly during the window period the concentration of HIV is the highest and the person is highly infectious. Therefore, exposure during window period can be highly risky.

Presence of other Sexually Transmitted Disease (STDs)

There is increasing evidence that the presence of another sexually transmitted disease in one or both partners may increase the risk of HIV transmission. Genital ulceration may occur with chancroid, syphilis or herpes virus infection. Ulcerative disease appears to increase the susceptibility to infection of uninfected individuals and to enhance the infectivity of those who are already infected.

Commercial Sex Workers

It is always risky to have sex with Commercial Sex Workers (CSWs) in India. Reports indicate that most of the sex workers suffer from STDs and a large number of CSWs are also found to be HIV infected across the country. The only way to avoid HIV is to remain faithful to one partner or practice abstinence. Sex education is the need of the hour.

Check Your Progress II

Note: Use the space provided for your answers.

1) Describe in brief about the various risk factors involved in the transmission of HIV through sex.

.....

.....

.....

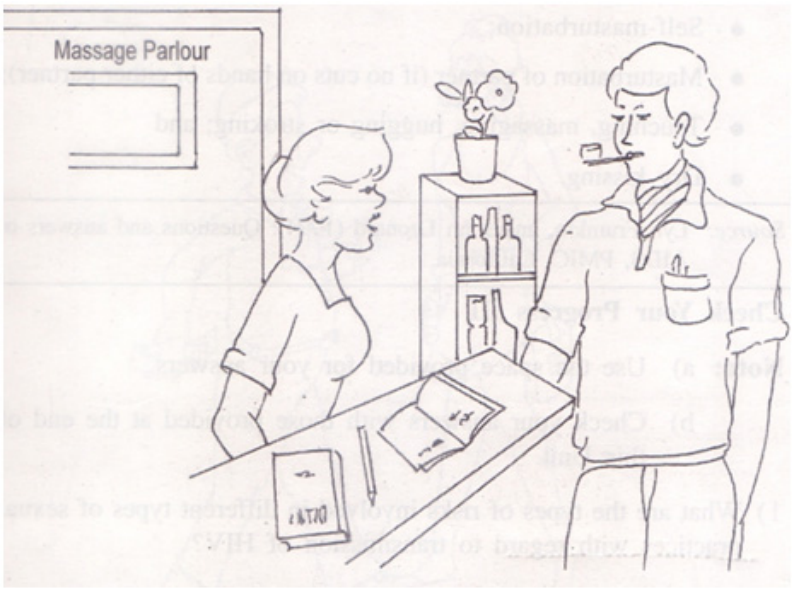
.....

.....

.....

1.4 HIV TRANSMISSION RISKS FOR DIFFERENT PRACTICES

In the previous sections we discussed various factors responsible for transmission of HIV. In this subsection we have presented risks involved in the transmission of HIV for difference practices in a tabular form. Different types of practices are grouped under four categories. Unsafe practices with high risk, unsafe practices with unclear risk, low risk practices with some risk and practices with probably no risk.



HIV Transmission Risks for Different Sex Practices*

1) Unsafe practices with high risk of HIV transmission:
   - Numerous sex partners;
   - Unprotected anal receptive sex with an infected partner;
   - Unprotected anal penetration with hand (fisting);
   - Anal douching in combination with anal sex;
   - Oral-anal contact; and
   - Vaginal intercourse without a condom with an infected partner.
2) Possibly unsafe practices with Unclear Risk of HIV Transmission:
   - Fellatio (Oral contact with male genitals and contact with semen);
   - Cunnilingus (Oral contact with female genitals); and
   - Sharing sex toys and implements.
3) Low Risk Practices with some Risk of HIV Transmission:
   - Anal or vaginal sex with proper use of intact condom;
   - Wet kissing (French kissing); and
   - Fellatio interrupts (contact with male genitals without ejaculations)
4) Practices with Probably No Risks of HIV Transmission:
   - Abstention from sexual contact;
   - Monogamous relationship in which both the partners are uninfected;
   - Self-masturbation;
   - Masturbation of partner (if no cuts on hands of either partner);
   - Touching, massaging, hugging or stroking; and
   - Dry kissing.

* *Source:* Lyn Frumkin, and John Leonard (1994): Questions and answers on AIDS, PMIC, California.

Check Your Progress III

Note: Use the space provided for your answers.

1) What are the types of risks involved in different types of sexual practices with regard to transmission of HIV?

.....

.....

.....

.....

.....

.....

1.5 VULNERABLE POPULATION

Sex Workers or Prostitutes

The HIV virus is primarily transmitted from one person to another through sexual activities. There are various categories of persons who are vulnerable to HIV infection through sexual contacts. In every culture, and society one does come across sex workers. They are mostly women who sell their bodies for a price (money). Some men may also involve in male prostitution. There are various forms of sex work:

i) **Organised Sex Work**

In big cities and towns, they live in certain areas known as Red Light Areas or Red Light Districts. Women who practice prostitution live in groups in such areas. There are also sex workers who live in brothels. Brothel keepers may keep them in brothels by force. They have no freedom to go out of the brothel premises. Very often they have to provide sexual satisfaction to several men in a day.

ii) **Call Girls**

The second category is call girls. Call girls are those who live a more comfortable life. They usually serve customers in their homes or hotels and earn handsome amount.

iii) **Certain Tribals**

Another category comprises women from some of the tribal communities who practice prostitution as means of livelihood and as their traditional practice. Some of these tribes are Rajnat, Bediyas, Gadia, Lohares, Kanzars, Bheel etc. Most of these tribes are found in Rajasthan and some other north Indian states who mostly stay along the Highways.

iv) **Religious Traditions**

There is also another group of young girls who are called Devadadis. These are young girls usually from very poor families who are offered to temples. Almost always, these dancing girls are sexually exploited and they also become sex workers later in their lives. It is a common practice in northern parts of Karnataka and several other states in India.

Same Sex Relationships

Same sex sexual relationships are very high-risk activities. In fact, the very first cases of HIV were found among people involved in same sex relationships. This trend continued in the United States of America until recently. Oral penetrative sex as well as anal penetrative sex are high-risk activities. This causes bleeding and breaks in the mucosa or the skin covering the sex organs. In case of oral sex, sex organs get hurt with the teeth. In case of anal sex, penetration becomes painful for both active and passive partners, as the anus cannot receive an erect penis. In the process, both the penis as well as the rigid rectum suffers injuries or tears causing bleeding as well as transmission of HIV/STDs.

Several reports reveal that a passive partner is very often forced into doing a particular sexual act. Sex can never be enjoyed by force. It then becomes cruel or sadistic act done without concern for the dignity of the individual. Several cases of homosexual rape have been reported.

Same sex relationships are commonly found in:

i) Massage parlors

ii) Hostels where people of the same sex live

iii) Prisons

iv) Welfare Institutions taking care of clients belonging to same sex like Nari Niketan, Beggar's Home, Juvenile Homes, Orphanages etc.

v) Camps of armed forces

vi) Among street children

vii) Among child laborers kept in camps; and

viii) Circus camps etc.

Eunuchs

Involvement of eunuchs in the flesh trade is not a new phenomenon in any country. They are a high-risk group in India today. They are estimated to be over one million in India. They run brothels that serve particularly the homosexuals and also cater to bisexuals.

Sperm Donors

There are some documented cases from various parts of the world where HIV has been transmitted through artificial insemination. People who donate sperm can also pass on HIV if they are infected. There are several sperm banks located in various parts of the country. The usual donors of the sperm in the country are poor labourers, beggars or street vendors who make a living out of it. Many drug addicts also donate sperms for a price to buy drugs. There are also reports of students from some of the professional colleges and educational institutions who donate sperm for making additional pocket money.

Check Your Progress IV

Note: Use the space provided for your answers.

1) Explain briefly same sex relationship in the context of HIV transmission.

.....

.....

.....

.....

.....

.....

1.6 LET US SUM UP

In this unit various means of transmission of HIV through sex is discussed. Sex is one of the known sources of HIV transmission. This is also the largest mode of transmission. This mode of transmission generally occurs in three ways.

These three ways are: Penetrative penile-vaginal, penile-anal and oral-genital contact. Amongst these three ways penetrative penile-vaginal activity is the most common. In penetrative penile-vaginal activity, transmission from male to female is known.

The risk of becoming infected with HIV as a result of sexual intercourse depends upon mainly four factors. These are: (a) Whether the sexual partner is infected; (b) the type of sexual contact involved; (c) the amount of virus present in the blood or secretions of the infected partner; and (d) the presence in either partner of other sexually transmitted diseases or genital lesions. The unit also discusses about HIV transmission risks for different types of sexual practices. These are: (1) unsafe practices with high risk of HIV transmission; (2) possibly unsafe

practices with unclear risk of HIV transmission; (3) low risk practices with some risk of HIV transmission; and (4) practices with probably no risk to HIV transmission.

In the last section of the unit, various groups vulnerable for HIV transmission through sex are discussed. These vulnerable groups of population include sex workers, homosexuals, lesbians, eunuchs, sperm donors etc.

1.8 SUGGESTED READINGS

Frumkin, Lyn and Leonard, John (1994), *Questions and Answers on AIDS*, PMIC Los Angeles.

Thomas, Gracious (1997), *Prevention of AIDS: In Search of Answers*, Shipra Publications, New Delhi.

Thomas, Sinha et al (1997), *AIDS, Social Work and Law*, Rawat Publications, New Delhi.

NACO (1999), *Country Scenario 1997-98, NACO*, New Delhi.

Thomas, Gracious (1999), *Prevention of AIDS: A Textbook,* CBCI Health Commission, New Delhi.

UNIT 2 TRANSMISSION OF HIV THROUGH BLOOD

Contents

2.0 OBJECTIVES

The aim of this unit is to create awareness and knowledge about the transmission of HIV through blood and blood products. This unit will provide information regarding various modes of transmission of HIV through blood. We will also discuss about various groups of population that are vulnerable from HIV transmission through blood. At the end of the unit some issues like blood donation, blood testing, information on blood banks etc. that has a direct relationship with HIV transmission will be discussed in detail.

After reading this unit you will be able to:

- know various modes of HIV transmission through blood;
- state various vulnerable groups of population for HIV transmission through blood;
- analyze the relationship between modes of transmission and vulnerable groups of population;
- understand various preventive measures to be adopted to checks the transmission of HIV through blood; and
- understand legal issues involved in blood donation and blood bank operations in India.

2.1 INTRODUCTION

In the previous unit we have already studied transmission of HIV through sex. In this unit we shall study transmission of HIV through blood. The magnitude of transmission through blood is very less when compared to transmission through

sex. The important aspect about transmission through blood is that this can be completely eliminated if certain precautions are followed. All these issues will be discussed in this unit.

2.2 TRANSMISSION OF HIV THROUGH BLOOD

HIV reproduces itself in the CD4 lymphocytes, which circulate in the blood and other body fluids. Blood collected for transfusion contains these lymphocytes. HIV is not only present within these cells but it is also present in serum (blood unassociated with cells). Thus introduction of blood from infected person to uninfected person will transfer the virus that is present both in the cells as well as the serum. Of all the forms of exposure to HIV, **blood transfusion** is the most effective means of transmitting the virus from person to person. No barrier of any kind exists between the infected person and the individual who receives contaminated blood directly into the blood stream.

Instruments like scalpels or suture needles, if contaminated with infected blood can transmit the infection. Similarly needles that have blood stains on them can transmit the infection. Sometimes injuries that occur with broken glass vials containing infected blood or serum can transmit the infection. The risk of infection through small cuts and abrasions that occur with contact sports e.g. wrestling, football etc. is very low.

Transmission of HIV through Blood Products

Blood that is collected from a donor can be separated into different components using a cell separator. One unit of blood will be separated into red blood cells, platelet concentrates and plasma. These components can be used as and when required.

Apart from these conventional uses, substances present in the blood i.e. antibodies are removed to produce **immunoglobulin.** These immunoglobulins are used in treatment of many medical conditions. HIV can be transmitted through these products also. Treating these products can prevent transmission.

Various Means of Transmission

A) **HIV transmission through intravenous drug use (IVDU)**

Intravenous drug use acts as a source of transmission of HIV because drug users frequently share syringes and needles to inject drugs. These instruments are not sterilised before use. Small volumes of contaminated blood remains inside previously used needles and syringes thereby providing opportunities to transmit the virus via their blood contents. In the early years of the epidemic, studies found links between HIV drug users and male homosexuals who were already infected with HIV. The overlap of these two groups facilitated in the introduction of HIV into drug using population and then to the sex partners of the drug users. Rapid increase in prevalence of HIV in drug users in major urban areas from around the world were recorded in the late 1980s and early nineties.

B) **Transmission through organ transplantation**

HIV can be transmitted through infected organs. HIV is found in the blood as well as the tissue of an infected organ. Before any organ is transplanted the donor has to be screened for HIV. In cadaver (removal of organs from brain dead patients) transplantation, the donor has to be checked. This route of transmission is very rare in practice. Since an infected person's body fluids contain HIV it is essential that screening for HIV is carried in cases of organ transplantation of any kind such as kidney, bone marrow, eyes, skin, semen etc.

Check Your Progress I

Note: Use the space provided for your answers.

1) How HIV is transmitted through blood and blood products?

.....

.....

.....

.....

.....

.....

2.3 VULNERABLE POPULATION

A) **Patients Suffering from Blood Disorders**

Patients who suffer from various blood disorders like various types of anemia, especially Thalassemia or Leukemia require multiple transfusions. We have already discussed about bleeding disorders like Hemophilia. Patients may need multiple transfusions. They are at risk to contract the infection if untested blood is used. Measures that can reduce the need for transfusion in these patients can prevent the infection from spreading.

B) **Hemophilia**

Hemophiliacs are born with an inherited bleeding disorder and are exclusively males. This disorder is determined genetically. It results in poor clotting of blood. There is an absence of a single protein that is involved in coagulation. Various forms of hemophilia exist. Hemophilia is due to deficiency of Factor VIII. It is the most common form of Hemophilia. Hemophilia B is due to deficiency of factor IX. Before the onset of universal screening of blood products HIV infection was common among hemophiliac patients. After the onset of screening new infections among hemophiliacs has decreased.

C) **Intravenous Drug Users**

Injecting drug users are potential channel for transmission of HIV. We have already discussed this mode of transmission. In India, injecting drug users have a high incidence of the infection. It is more common in the North Eastern parts of India as well as states boarding some of the neighbouring countries. The drug addicts often sell their blood to purchase drugs. Several of them are found to be professional blood donors.

D) **Professional Blood Donors**

Professional blood donors are persons who repeatedly donate blood to the blood banks for money. They are usually poor and unhealthy people. Many of them are found to be HIV carriers. Professional blood donors should be avoided at all costs. The Supreme Court of India has banned professional blood donation in the country. However, these professionals continue their profession, as there is dearth of blood donation in the country. We shall discuss more in detail about Blood Donation and Blood Banks later in this chapter. Professional Blood Donors pose a high risk for HIV transmission.

E) **Health Care Workers**

Health care workers often get injuries due to needle prick and cuts with other equipment. There are several documented cases of health care workers being infected through this route. The health care providers must be aware of the universal precautions and put them into practice.

F) **Miscellaneous**

There are certain practices through which the HIV can be transmitted through blood due to infected instruments. There are:

1) **Circumcision or Genital Mutilation**

Practices of circumcision or genital mutilations are found among some groups of people in India. A circumcision needs to be done with extra care. Using clean instruments and if a trained person does the operation the chances of the infection can be reduced. Care needs to be taken to ensure that same instrument is not used on more than one person or proper sterilization is required for each case.

2) **Tattooing, Ear or Nose Piercing**

Tattooing, ear or nose piercing is an age-old custom in India. Nose and ear piercing is very common in India. Tattooing is more common among the tribal communities. It can be seen in cities also. These procedures should be done with clean instruments. Village communities must be educated about the risks involved in such practices when the act is performed on a group of people.

3) Organ Transplantations

Patients who receive organ from donors are at a risk of getting infected. There is always a need for verifying the status of a donor before accepting any type of organ from a donor.

Check Your Progress II

Note: Use the space provided for your answers.

1) Write a brief note on professional blood donors.

.....

.....

.....

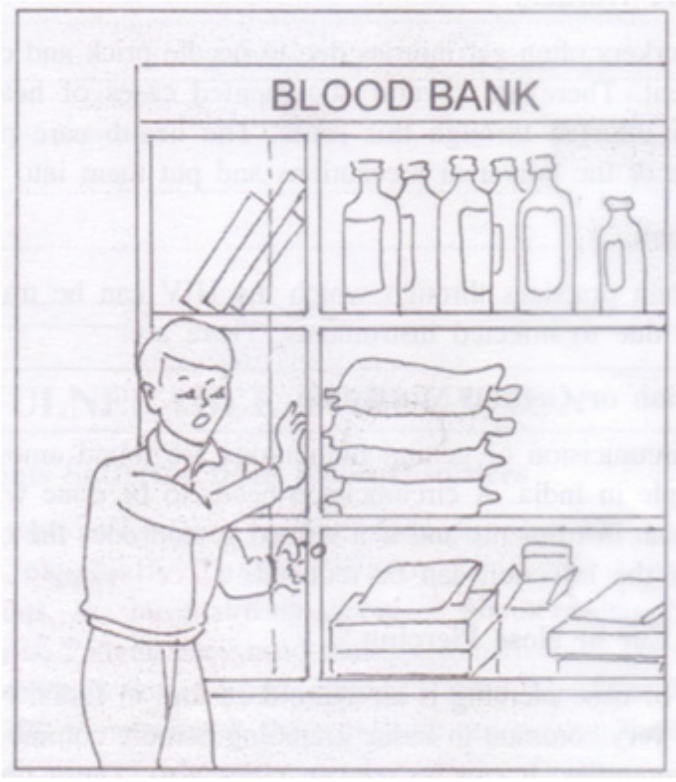
.....

.....

2.4 ISSUES RELATED TO TRANSMISSION OF HIV THROUGH BLOOD

A) **Blood Donations and Blood Banks in India**

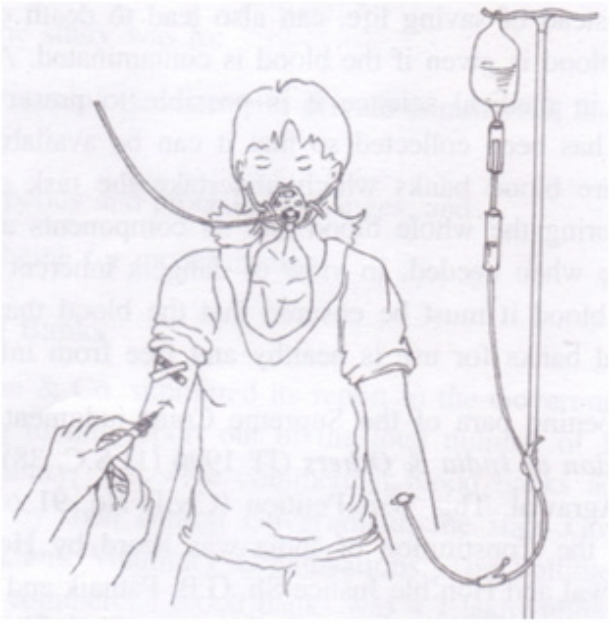
Blood donations and blood banks were started in India since 1941. During this period, the Second World War was in full swing. It became necessary to supply blood to the wounded soldiers and civilians.



Today, there are over a thousand registered blood banks all over the country. There are also several thousand illegal and unregistered blood banks in the country. A person can donate blood once in three to four months. In India demand for blood out weighs the supply hence, blood from professional donors are also encouraged by the blood banks. The Supreme Court has banned this practice since 1996.

B) **Testing Blood**

Testing of blood for HIV has been made mandatory in most of the countries. There is a law in India that makes it mandatory to test all the blood that is used for transfusion.



C) **Voluntary Blood Donation**

Voluntary blood donation should be encouraged. Volunteers are likely to be healthier and may not have high-risk behaviour that is associated with professional blood donors. The blood from a voluntary donor is likely to be of good quality.

D) **Rational Use of Blood**

Blood should be used carefully. It should be used only when it is essential. Minimum amount that is needed should be used.

E) Sterilization of Instruments

Equipments used for collection and for transfusion of blood should be properly sterilize. Health care providers need to be aware of such procedures.

Check Your Progress III

Note: Use the space provided for your answers.

1) Describe any three issues related to transmission of HIV through Blood?

.....

.....

.....

.....

.....

2.5 INFORMATION ON BLOOD BANKS

"Blood is an essential component of the body which provides sustenance to life. There can be no greater service to the humanity than to offer one's blood to save the life of other fellow human beings. At the same time blood, instead of saving life, can also lead to death of the person to whom the blood is given if the blood is contaminated. As a result of developments in medical science it is possible to preserve and store blood after it has been collected so that it can be available in case of need. There are blood banks which undertake the task of collecting, testing and storing the whole blood and its components and make the same available when needed. In view of dangers inherent in supply of contaminated blood it must be ensured that the blood that is available with the blood banks for use is healthy and free from infection."

This is the opening para of the Supreme Court judgment in ***Common Cause Vs. Union of India & Others*** (JT 1996 (1) S.C. 38) delivered by Justice S.C. Agrawal. This Writ Petition (Civil) No. 91 of 1992 under Article 32 of the Constitution of India was heard by Hon'ble Justice Sh. S.C. Agrawal and Hon'ble Justice Sh. G.B. Patnaik and the judgment was delivered on 4-1-1996. The Writ Petition was filed by Sh. H.D. Shourie on behalf of **Common Cause**, a registered Society that takes up interest litigation earnestly.

Focus Petition

The petitioners had highlighted the serious deficiencies and shortcomings in the matter of collection, storage and supply of blood through the various blood centers operating in the country. It was prayed by the petitioners to issue appropriate writs or directions to the Union of India, States and the Union Territories to ensure proper positive and concrete steps for obviating the malpractices, malfunctioning and other inadequacies of the blood banks all over the country. The union of India, the states and the Union Territories were made Respondents to the Writ Petition. The petitioners had prayed that the respondents should initiate a time bound programme and place before the Court a specific programme of action to remedy the deficiencies in the operation of the blood banks.

Blood is treated as a drug under the Drugs and Cosmetics Act, 1940, for the purpose of regulating its collection, storage and supply. In the Drugs and Cosmetics Rules, 1945, made under the 1940 Act, provisions are made for equipment and supplies required for a blood bank in Part XII-B. These provisions were inserted vide notification on 24-6-1967. In this part requirements regarding equipment, blood collection supplies, canter equipment and emergency equipment for blood donor room as well as provisions for laboratory, general suppliers, technical staff, accommodation for blood bank, label for whole blood and colour scheme for lable etc. were also made.

The Ferguson Study

In 1990 the Government of India had entrusted M/s AF Ferguson and Co., Management Consultancy Firm, with the study of blood banking system in the country.

The scope of the study was to:

- assess the status of Government, private commercial and voluntary blood banks;
- recommend policy and procedural changes; and
- prepare a scheme for modernisation

Status of Blood Banks

M/s AF Ferguson & Co. submitted its report to the Government in July 1990. According to this report out of the total number of 1018 blood banks in the country, 203 were commercial blood banks and the rest were controlled by then central Government, the state Governments, Private Hospital and Voluntary Organisations. The volume of blood collected by the commercial blood banks was 4.7 lakhs units out of the total of 19.5 lakhs units by all blood banks. It was also reported that commercial blood banks were collecting blood mostly from professional donors while the other blood banks were collecting blood mostly from the relatives of the patients or from voluntary donors.

Deficiencies

The Ferguson Report highlights various deficiencies. It was stated that:

i) Out of the total number of 1018 blood banks as many as 616 are reported to be unlicensed. There are only 201 licensed commercial blood banks; the supply of blood by licensed commercial blood banks is only about ¼ of the blood in the hospitals of the country.

ii) No medical check up is done on the blood donors (sellers); their health status is not examined. The blood trade flourishes with poor people like unemployed, rickshaw pullers, and drug addicts selling their blood. Such blood sellers suffer from various infections and their haemoglobin is lower than the prescribed level. It has been reported that there are many persons who donate blood 5/6 times in a month; poverty makes them to do so at first but later it is reported to become like an addiction, the blood seller enjoying the dizziness due to the reduced supply.

iii) It is a mandatory requirement to conduct tests on blood which is to be administered to a patient or to be issued to hospitals for transfusion. The blood so issued has to be free from **HIV (AIDS)**, viral hepatitis, malaria, venereal diseases etc. It is reported that mandatory tests which are required to be done are rarely conducted. Most of the AIDS surveillance centers are not functioning efficiently and up to 85 per cent of blood collected in the country is not screened for HIV/AIDS. Under an action plan to screen blood for AIDS 37 blood testing centers were to be set up in 29 cities, but only 11 testing centers were functioning by July 1900, and training of technicians for these centers was lagging.

iv) The blood banks presently thrive on bleeding 4000 to 5000 regular professional donors in 18-20 cities. The professional donors which include many women are reported to be victims of ill health, low hemoglobin levels and many infections, are bled at frequent intervals by the commercial blood banks.

v) Storage facilities in the blood banks are far from satisfactory. The blood banks have necessarily to possess facilities like refrigerators exclusively for storage of blood with a specified range of temperature for ensuring safety of blood. In the existing blood banks many items of equipment remain unattended for years, electricity failures are frequent, and generators are a rarity. This applies to not only to commercial blood banks but even to some of the Government hospitals. Many items of the basic equipment required for blood banks are not available and a good part of them do not have even adequate storage facilities.

vi) Many of the blood banks are located in unhygienic environment and they collect and store blood in very unhygienic conditions.

vii) In some places strong middlemen operate for the blood banks by arranging for donors. The middlemen dictate the charges to be paid and take heavy commission; the selection of donors disregards the level of health etc.

A large number of the professional donors are alcoholics or drug abusers, have indiscriminate sexual habits and are a high risk group for Hepatitis B and **HIV/ AIDS** and are unfit to donate blood.

Trained professional are generally not available in the blood banks. Most of the blood banks lack trained post-graduates at the helm; they have no donor organisers to bring voluntary donors; and many of them are manned by technical staff who do not have requisite qualifications of a Diploma in Medical Laboratory Technology. At present (2004) there are only few courses that provide post-graduate specialization in the field of blood donation and transfusion as in developed countries. The Drug Control departments, which are expected to ensure the appropriate functioning of the blood banks, do not themselves have specified and trained personnel.

In the storage of blood the basic and essential requirements of clean environments, etc. are ignored. Nexus is reported to be existing between the attending doctor of the patient and the commercial blood bank, with the former directing the patients to the latter, and the latter giving a percentage of the sale to the former.

Check Your Progress IV

Note: Use the space provided for your answers.

1) According to the Ferguson study what was the status of blood bank in the country at that time?

.....

.....

.....

.....

.....

.....

2.6 DIRECTION OF SUPREME COURT TO THE GOVERNMENT

Keeping in view of the report of the committee that was constituted by the Court and the report of the Committee of Experts set up by the Indian Red Cross Society and the programme that is being implemented by the **NACO** as well as the submissions of the learned counsel, the Court was of the view that suitable action should be taken by the Union Government as well as the Governments of the States and the Union Territories' Administration in accordance with the plan for immediate implementation as well as the plan for long-term implementation suggested by the Committee constituted by the Court.

Certain important directions as given by the Hon'ble Supreme Court or the out come of the public interest litigation can be summarized as follows:

1) The Government has to establish a National Council of Blood Transfusion as a registered society, having a vide representation from the Directorate General of Health Services, Drug Controller of India, Ministry of Finance, Indian Red Cross Society, private blood banks including Indian Association of Blood Banks, major medical and health institutions and NGOs active in the field of securing voluntary blood donations. Basic funds for the functioning of the Council shall be provided by the Government of India. The Council was also empowered to raise funds on its own.

2) The State Government and the Union Territories were to establish State Councils, to be registered as societies, with wide representation as in the National Council. Funds to be provided by the State/UT Governments with the right to raise its own funds.

3) Programmes and activities of Councils to cover entire range of services related to operation and requirements of blood donations:

   i) launching of effective motivation campaigns through utilization of all media for stimulating voluntary blood donations;

   ii) launching programmes of blood donation in educational institutions; among the labour, industry and trade;

   iii) establishments and organisations of various services including civic bodies;

   iv) training of personnel in relation to all operations of blood collection, storage and utilization and separation of blood groups and proper labeling;

   v) proper storage and transport;

   vi) quality control and archiving system;

   vii) cross matching of blood between donors and recipients;

   viii) separation and storage of components of blood; and

   ix) all the basic essentials of the blood banking.

4) The Council was to undertake training programmes for technical Personnel in related fields.

5) The Council was to establish an Institution for conducting research in collection, processing, storage, distribution of blood and its components and manufacture of the blood products and other allied fields.

6) The Council was to take steps to start special Post-Graduate courses in the above fields in various medical college / institutions

7) To facilitate collection of funds the Govt. of India was to grant 100 per cent exemption from income tax to the donations made to the Councils.

8) To ensure licensing of all blood banks which are eligible, within one year and close the operations of unlicensed banks.

9) To ensure the elimination of professional donors with in a period of two years.

10) To enforce the provisions of the Drugs and Cosmetic Act & Rules.

11) To ensure that the Drug Inspectors are duly trained in blood banking operations and posted in adequate numbers to ensure periodic checks through the country.

12) To consider the advisability of enacting a separate legislation for regulating the blood banking system. This judgment was delivered in January, 1996.

Check Your Progress V

Note: Use the space provided for your answers.

1) List the immediate action plan proposed by Indian Red Cross Society Expert Committee.

.....

.....

.....

.....

.....

.....

2.8 LET US SUM UP

In this unit, we started our discussion by describing the transmission of **HIV** through blood.

HIV reproduces in CD, which circulates in the blood and other body fluids. Blood collected for transfusion contains these lymphocytes. HIV is not only present in the cell it is also present in the serum. Thus, introducing of blood and blood products from an infected person will transmit the infection to an uninfected person. Of all forms of transmission of HIV, blood transfusion is the most efficient one.

HIV transmission occurs through blood generally when the blood is transfused, through Intravenous drug abuse, dialysis and organ transplant. There are various issues involved in the transmission of HIV through blood. These issues are also discussed in this unit.

HIV transmission through blood can be prevented at two levels. One is the personal aspect like reducing high risk behaviour like use of fresh needles. The other is the control exercised by the Government on the blood banks.

2.10 SUGGESTED READINGS

Frumkin, Lyn and Leonard John (1994), *Questions and answers on AIDS*, PMIC Los Angeles.

Thomas, Gracious (1997), *Prevention of AIDS: In search of Answers*, Shipra Publications, New Delhi.

Thomas, Sinha et. Al (1997), *AIDS, Social Work and Law*, Rawat Publications, New Delhi.

NACO (1999), *Country Scenario 1997-98, NACO*, New Delhi.

Thomas, Gracious (1999), *Prevention of AIDS: A Textbook*, CBCI Health Commission, New Delhi.

UNIT 3 MOTHER TO CHILD TRANSMISSION OF HIV

Content

3.0 OBJECTIVES

The aim of this unit is to provide awareness and knowledge related to transmission of HIV from a mother to her child. The unit also provides the present scenario about Mother to Child Transmission (MTCT) as well as discusses some of the ethical issues related to MTCT.

After reading this unit you will be able to:

- state the present scenario of mother to child transmission of HIV;
- describe various means of mother to child transmission;
- analyse the ethical issues involved with mother to child transmission; and
- discuss various methods of prevention involved in mother to child transmission of HIV.

3.1 INTRODUCTION

Women, because of their social and sexual subordination are disproportionately affected by the epidemic in many societies. The inabilities of women to control the factors at risk, place them at risk of HIV infection and are compounded by the fact that many societies define the social and cultural identity of women primarily through their role as child-bearers.

So, whenever, we discuss mother-to-child-transmission, we have to look at the problem in a broader perspective and not in a compartmentalized way. Broader perspective includes role of husband, societal pressure, norms, and values and above all her own rights over the sexual act as well as right over her body and family pressures.

3.2 EXTENT OF HIV INFECTION AMONG WOMEN OF CHILD BEARING AGE

There are millions of women of childbearing age through out the world who are HIV positive. Among these women who are pregnant, the highest rates of infection have been reported from Sub-Saharan Africa. In urban centers in Southern Africa, HIV rates among pregnant women tested anonymously at antenatal clinics was found to be between 20-30 per cent. Rates above 40 per cent to 59 per cent and even 70 per cent have been recorded in Botswana and parts of Zimbabwe. According to UNAIDS, there are very few places outside Sub-Saharan Africa in which the prevalence of HIV infection among pregnant women has reached 10 per cent.

Figures form UNAIDS also show that the risk of infection is increasing among women everywhere both in developed and developing countries alike. In a period of ten years from 1985 to 1995 the incidence increased among women in varying degrees. For example, in France, it increased from 12 per cent to 20 per cent. In Spain, it rose from 7 per cent to 19 per cent. In Brazil the proportion rose from just 1 per cent in 1984 to 25 per cent ten years later. However, with improved medication and prevention strategies, the infection rate is under control to a great extent.

Furthermore, in the worst affected countries, the virus is spreading fast among young people below the age 24 years. Studies sponsored by UNAIDS among the youth show that the incidence of HIV infection among girls is higher than among boys. In Kenya one in four girls was infected with HIV when compared to one in twenty five among boys. Similarly among the youth in Zambia the ratio is 16:1 (girls: boys) and in Uganda it is 6:1.

In 1998, one in ten of all infected was a child, and the vast majority of them acquired the virus from their infected mothers. Africa has the highest prevalence of HIV-positive children. Though Africa accounts for only 10 per cent of the world's population, 90 per cent of the world's HIV infected children are found in Africa. This is largely a consequence of high fertility rates combined with very high levels of HIV infection among women of reproductive age group. Over 5 million children below the age of 15 years have been infected with HIV since the AIDS epidemic began and more than 3.8 million of them have died of AIDS as of December, 1999.

Consequence of High Level of Infection

The effects of the epidemic among young children are serious and far-reaching. AIDS threatens to reverse years of steady progress in child survival achieved through such measures as the promotion of breast feeding, immunization and oral rehydration. UNAIDS believes that by the year 2010, AIDS may have increased mortality of children under 5 years of age by more than 100 per cent in regions most affected by the virus. In a number of countries, AIDS is now the biggest single cause of child death. The trend is already clear. In Zimbabwe the death rates among infants in their first year of life increased from 30 to 60 per thousand between 1990 and 1996. The deaths among one to five years olds, (the age group in which the bulk of child AIDS deaths are concentrated) rose even more sharply. It rose from 8 to 20 per thousand during the same period.

Implications for India

With 27 million pregnancies a year and an overall estimated 0.3 per cent prevalence rate of HIV infection among pregnant women, it is estimated that about 1,00,000 HIV infected women deliver every year. Using a conservative vertical transmission rate of 30 per cent, about 30,000 infants acquire HIV infection every year. The life span of a child infected by HIV infection is lower than that found in adults. Thus HIV infection may increase health care expenditure both in public and at family level. Increasing number of children infected by HIV has a propensity to alter the mortality rates in childhood. The effects of the epidemic among young children are serious and far reaching. AIDS threatens to reverse years of steady progress in child survival, and has already doubled infant mortality in the worst affected countries.

In India, the high HIV prevalence States coincide with those states that are doing better in terms of health indicators and development, in general. The less developed and more populated states, in the north and the central part of the country are so far classified as "low HIV prevalence States". These States reveal a variety of vulnerability factors which can fuel the spread of HIV epidemic such as wide socio-economic inequity leading to high degree migration particularly towards metropolitan cities where HIV prevalence is high among "at risk" individuals, inadequate infrastructure in health and social services, illiteracy, low women empowerment, low school enrollment limited, access to information etc. the degree of success in programmatic response by these states would determine the spread of HIV and its impact on health indicators including development in the near future. Currently, India has overall low prevalence of HIV among pregnant women in many parts of the country. The challenge for future is how to keep the prevalence of HIV infection among women low and reduce mother to child transmission.

Check Your Progress I

Note: Use the space provided for your answers.

1) Briefly describe the extent of HIV infection among children.

.....

.....

.....

.....

.....

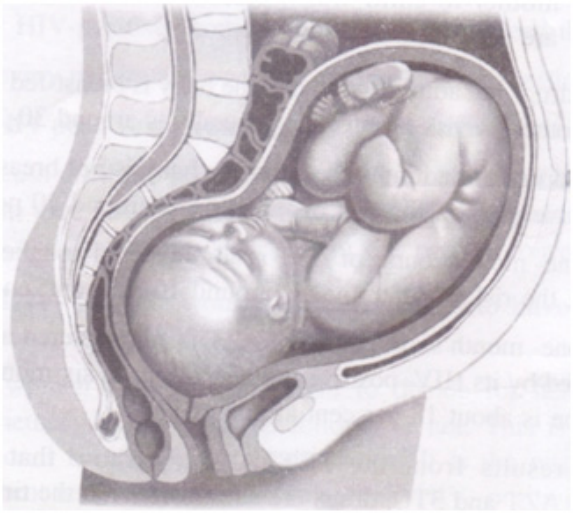
.....

3.3 WAYS OF TRANSMISSION AMONG CHILDREN

HIV can be transmitted from mother to child in three ways. It can occur in the womb, at the time of delivery and also when the child is breast-fed.

Womb

Throughout the period of pregnancy, mother is capable of infecting the foetus. Foetus receives nutrition from the mother through the placenta (before birth). When the mother has a high viral concentration in the blood, some of the virus can pass from the mother to the foetus through the placenta. It is seen throughout the period of pregnancy. A small number of foetus gets infected through this route.



At the Time of Birth

The lining of the birth canal (vagina) contains a high concentration of HIV. The baby may sustain minor cuts in the mucus membrane and in the skin during the process of birth. Hence, the baby can get infected. It has been also shown that the maximum chance of infection of the foetus occurs during the time of delivery. A significant per cent of children born to HIV mothers become infected at the time of delivery.

Breast Milk

About 14 per cent of children who are breast-fed by the HIV infected mothers will contract the infection. Hence, practices which change breast-feeding reduce HIV transmission.

Check Your Progress II

Note: Use the space provided for your answers.

1) What are the three ways of HIV transmission from mother to child?

.....

.....

.....

.....

.....

.....

3.4 THE RISKS OF MOTHER-TO-CHILD TRANSMISSION (MTCT)

The rates of mother-to-child transmission of HIV under different circumstances are as follows:

1) Where no drugs are administered and the baby is breast-fed by its HIV-positive mother the risk of infection generally is around 30-35 per cent.

2) Where no drugs are administered and the baby is not breast-fed by its HIV-positive mother, the risk of infection is around 20 per cent;

3) Where a one- month course of AZT is administered and the baby is not breast-fed, the risk of infections is around 10 per cent; and

4) Where a one- month short course of AZT is administered and the baby is breast-fed by its HIV- positive mother, for up to six months, the risk of infection is about 18 per cent at that age.

Preliminary results from the PETRA study show that when two antiretroviral, AZT and 3TC, drugs are administered at the time of labour and to mother and baby for one week following delivery, the risk of infection chance that the baby will be HIV infected at six weeks of life, with breast-feeding if it is being breast-fed by its mother is around 11 per cent. If the drugs are given for approximately one month from the 36^{th} week of pregnancy, continued in labour and given for a further week after delivery – the chances of the baby being infected or risk of infection at six weeks of life, when the baby is being breast-fed is around 9 per cent. Further follow up will show what the respective raters of infection are at 6, 12 and 18 months, if breast-feeding is maintained. This will only be known when the data from follow-up of the PETRA trail are complete. (It may be noted that all medication are to be done only on prescription by a qualified physician and not based on information given in IGNOU SIM).

Apart from these variations, there is a great amount of variation between developed and developing countries. The rate is higher in developing countries than developed countries. Evidence suggests that the risk of transmission is increased when mother has a higher viral load (this is the case when a person is newly infected with HIV or is in an advanced stage of disease) or if the baby is highly exposed to the mother's infected body fluids during birth.

The difference in risk between developing and developed countries is largely due to feeding practices: breast-feeding is more common and is usually practiced for a longer period in developing countries than in the industrialised or developing world. It is estimated that a child born uninfected to an HIV positive mother has a one in five chance of acquiring the virus from her milk if it is breast-fed. In places where breast-feeding is the norm, this route may account for more than one-third of mother-to-child transmission.

3.5 ISSUES RELATED TO MOTHER-TO- CHILD TRANSMISSION

There are various issues related to mother-to-child transmission, which are still debatable. Some of the debatable issues are:

1) Whether HIV positive women should be encouraged to have a child or not?

2) Whether HIV-positive mothers should not breast-feed their infants?

3) Should every person undergo HIV counselling and testing routinely?

4) Should HIV positive men and women marry among themselves or not?

We will discuss all these issues in detail. The purpose of the discussion here is not to give any judgment. Our aim here is to present both sides of the issue and leave the discussion to the people concerned.

1) **Should HIV- positive women be encouraged to have children or not?**

It is every woman's fundamental right to decide for herself, without coercion, whether she should have children or not. This is enshrined in the International Human Rights Conventions. It is the responsibility of the Government and health services to provide HIV- positive women and their partners with comprehensive information and education about the risks associated with child bearing as part of routine public information about HIV/AIDS. The health services should ensure that they have real choices of action and respect and support the decisions that they reach.

NACO in its policy 5.8.3 states that HIV positive women should have complete choice in making decisions regarding pregnancy and child birth. There should be no forcible abortion or even sterilisations on the grounds of HIV status of the women. Proper counselling should be given to the pregnant women for enabling her to take an appropriate decision either to go ahead with or to terminate the pregnancy.

Infant Feeding

Best practice as recommended by UNICEF and supported by NACO will be disseminated. Clear advice and support of feeding options should be given to HIV positive women. This will need appropriate training of the counselors and health care workers. Training will include breast-feeding counselling, complementary feeding, infant feeding in MTCT, and replacement feeding options. Messages will be consistent with the related programme of Reproductive and Child Health (RCH) of the department of Family Welfare. The aim of such counselling should not be just giving of information, but to empower the mother to assess the appropriateness of the alternatives to her specific situation. Every effort should be made to promote exclusive breast-feeding upto four months in HIV positive mothers followed by weaning and complete stoppage of breast-feeding at 6 months in order to restrict transmission through breast-feeding. However such mothers will be informed about risk of transmission of HIV through breast milk.

2) **Whether HIV- positive mother be told to breast-feed her baby?**

Breast-feeding has been the corner stone of child health and survival strategies for the past two decades and has played a pivotal role in reducing infant mortality rate in many countries. Even in the era of HIV/AIDS, breast-feeding remains the best possible nutrition for the great majority of babies. As against this there is another view. You may recall that the transmission of HIV through breast milk is about 14 per cent. If the mother has received prophylaxis to prevent mother to child transmission, then it is illogical to recommend breast-feeding.

There are many reasons why such advice may not necessarily be appropriate and might indeed be dangerous. The cost of infant formula supplements is often beyond the means of poor families in developing countries, even when it is widely available. Besides, many people lack easy access to the knowledge, safe clean water and fuel needed to prepare replacement feeds safely or simply have no time to prepare them. If it is used incorrectly i.e. mixed with dirty, unsafe water, a breast milk substitute may lead to infection, malnutrition and even death. Breast-feeding suppresses ovulation and delays the return of a woman's fertility. A mother who dose not breast-feed her baby loses the natural contraceptive effect and is the increased risk of getting pregnant again too soon.

In August 1997, WHO, UNICEF and UNAIDS issued a joint policy statement on HIV and infant feeding. They subsequently prepared guidelines to help national authorities, to implement the policy. These documents emphasize that it is the individual mothers right to decide how she will feed her child. Any attempt to influence her decision, no matter what the circumstances or motives, is an abuse of her human rights and freedom of choice. The responsibility of people who counsel HIV- positive women about infant feeding is to give them all the available information on the risks associated with breast-feeding. They should be educated about substitutes to breast-feeding. They also have to discuss the feasibility, pros and cons of alternative feeding methods in the light of personal circumstances. They also have to give them appropriate support for the course of action they choose.

3) **Confidential Counselling and Testing**

Whether each and every reproductive population should undergo confidential HIV counselling and testing or not is an ethical consideration. This is very much essential, as it becomes a global concern in terms of its magnitude and severity. It is very much needed for pregnant and married women and their male counterpart.

For pregnant, women to take advantage of measures to protect their off spring from HIV infection they need to know whether or not they are infected. Hence, voluntary counselling and testing services are an essential part of any programme for the prevention of mother-to-child transmission of HIV. Ideally, however, every one should have access to such services since there are clear advantages to know one's sero-status. People who know they are HIV infected are likely to be motivated to look after their health, perhaps with behaviour and life-style changes and to seek early medical attention for problems. They

can take wise decisions about sexual practices, child bearing and infant feeding and be steps to protect partners who may still be infected. And those whose test results are negative can be counselled about how to protect themselves, their partners and their children from infection.

Furthermore, voluntary counselling and testing has an important role to play in unmasking the silent epidemic and reducing the hysteria of and fear surrounding AIDS. At present UNAIDS estimates that around 90 per cent of people with HIV are unaware of their status. Efficient, widely accessible and user friendly testing services can help societies recognize and come to terms with the fact that there are many people living with HIV who show no out word signs. This in turn encourages commitment to prevention.

It is still common for women to be blamed for spreading sexually transmitted diseases, including HIV, despite the fact that very often they are infected by the husbands or partners to whom they are entirely faithful. Voluntary counselling and testing that involves the partners of the pregnant women, where this is feasible and desired, can play a vital part in challenging this pervasive prejudice.

4) **Whether HIV-positive men and women can marry among themselves or not is another debatable question?**

As far as rights of a human being is concerned, HIV-positive men and women may marry among themselves. The existing trend, shows that several infected people choose to get married and live together. The main risk factor is pertaining to their choice for having their own biological child. Morally and ethically, it may not be appropriate for an HIV positive couple to go for a biological child. There are every possibilities for the child to be born with HIV virus. Further, such children may not get a healthy environment to grow and lead a normal life as its own parents are not healthy. Such couples require appropriate counselling.

Check Your Progress III

Note: Use the space provided for your answers.

1) Explain briefly any two issues related to mother-to-child transmission?

.....

.....

.....

.....

.....

.....

3.6 PREVENTION STRATEGIES

There are three complementary strategies for preventing mother-to-child transmission of HIV. They are:

1) **The Protection of Girls and Women from HIV Infection**

This will minimize the number of women of childbearing age who are carrying the virus. This strategy is sometimes referred to as "primary prevention". It involves promoting safe and responsible sexual behaviour among couples, providing them with knowledge about HIV/AIDS and how to prevent infection. It also means providing treatment programs for sexually transmitted diseases (STDs), the presence of which increases the risk of HIV transmission as much as 6-10 fold. Steps have to be taken to deal with the cultural, legal and economic factors that make girls and women especially vulnerable to HIV infection by limiting their autonomy and power to protect themselves.

2) **Provision of HIV Counselling and Testing**

An integrated package of measures consisting of Voluntary HIV counselling and testing will enable the target population to know their HIV status well in advance. It will also enable them to adopt preventive measures. Every detection will also help victims to seek medical intervention. This is a secondary prevention measure on early detection.

3) **Antiretroviral Prophylaxis**

The provision of antiretroviral drugs for HIV-positive pregnant women (and sometimes their babies), counselling on infant feeding, and support for the feeding method(s) chosen by the mother. This package is often referred to as the antiretroviral drug strategy.

In cases where a mother knows she is HIV-positive and gives birth without refrain from breast-feeding, counting on the two-to-one chance that her baby has avoided infection in the womb or during child birth. But, if she chooses this course of action she should be made aware of the fact that she will lose the natural contraceptive effect of breast-feeding and be at increased risk of becoming pregnant unless she takes alternative precautions.

Other Prevention Methods

An infant who requires mother's milk should be given only its own mother's milk. There are hospitals in the country where human milk banks operate. Until and unless the milk collected in these milk banks are tested for HIV with the PCR, it will be risky to feed the child with such milk.

It is also the practice in some village communities and in joint families/extended families to feed infant by any of the lactating mothers if the infant's mother is unable to do so after a caesarean section. In some cases, the mother may be away at work place (farm) and other lactating mothers may breast-feed the child. In several cases, orphan infants whose mothers die during labour or soon after delivery are also breast-fed by any of the lactating and willing woman around the household village. In all such cases, one should ensure the HIV status of the woman who might breast-feed the child.

There are also possibilities of an HIV infected child infecting a woman who may breast-feed it if in case there are cuts around the nipple (breast nipple). Therefore, people should be adequately informed about the need to know the HIV status of the infants.

There are also drugs available which can reduce the chances for a foetus from getting infected. Therefore, HIV positive pregnant woman need to seek medical opinion and treatment under a qualified physician. It has been observed in several advanced countries that proper treatment can reduce the chances for foetus from getting infected form its HIV positive mother. The need of the hour is to educate the entire population about it, because support is necessary from the entire family.

Another important precaution to help an infant from being getting infected is to see that its HIV positive mother opts for a caesarean section instead of a normal delivery. A normal delivery can cause HIV transmission to the infant during its passage through the birth canal which is tight while, the baby's body is too delicate. Therefore, one should try every possible option available to help an infant from avoiding infection with HIV.

3.7 LET US SUM UP

One of the cracks and crevasses of society's inequality is vulnerability and susceptibility of women towards HIV-virus. Women because of their social and sexual subordination are disproportionately affected by the epidemic. In the next subsection we examined the extent of HIV infection. Among the women who are pregnant, the highest rates of infection have been reported for sub-Saharan Africa. This wide extension of HIV has various repercussions. AIDS threatens to reverse years of steady progress in child survival achieved through such measures as the promotion of breast-feeding, immunization and oral rehydration.

Mother-to-Child transmission occurs in three ways. These are from the womb, at the time of birth and through breast-feeding. We discussed also how these transmissions occur at various stages. In this unit we also analyzed the rates of mother-to-child transmission of HIV under the different circumstances.

There are various issues related to mother-to-child transmission, which are still debatable. Some of the debatable issue are: whether HIV positive women should be encouraged to have a child or not: if alternative feeding is available; whether each and every woman and man should undergo HIV counselling and testing or not; and whether HIV positive men and women should marry amongst themselves or not etc. At the end of the unit some of the preventive strategies were discussed very briefly.

3.8 SUGGESTED READINGS

Frumkin, Lyn and Leonard, John (1994), *Questions and Answers on AIDS*, PMIC Los Angeles.

Thomas, Gracious (1997), *Prevention of AIDS: In search of Answers*, Shipra Publications, New Delhi.

Thomas, Sinha, et. al (1997), *AIDS, Social Work and Law*, Rawat Publications, New Delhi.

NACO (1999), *Country Scenario 1997-98, NACO*, New Delhi.

Thomas, Gracious (1999), *Prevention of AIDS: A Textbook*, CBCI Health Commission, New Delhi.

UNIT 4 HIV TESTING AND ISSUES INVOLVED

Contents

4.0 OBJECTIVES

In the previous three units we have studied about the various routes of transmission of HIV from one person to another. It is however, essential that we also learn about the ways and means of finding out whether one is infected or not. Physicians across the world use certain established and approved ways of testing people to find out details about various diseases. Similarly, for HIV/AIDS too there are certain tests which will help us to identify the HIV status of a person. After studying this unit, you will able to:

- understand how HIV can detected in a human body;
- understand the various types of tests used for detecting HIV;
- know the importance of pre-test and post-test counselling; and
- know the types of testing and strategies involved in HIV testing.

4.1 INTRODUCTION

The only way to confirm whether one has HIV infection is to do an HIV test. Mere symptoms of the disease in a person alone are not enough to conclude that one is an AIDS patient. People who have exposed themselves to high risk behaviour or such situations may go for an HIV test. However, such person may have to seek the opinion of a counsellor, social worker, psychologist, physician or a family doctor.

There are various ways one can get infected. Similarly, all the body fluids also contain HIV virus. However, the test that is used to diagnose HIV infection detects the antibodies to the virus. Blood is usually used for HIV testing. It is mandatory for a hospital to seek the consent of a person for testing his/her blood for HIV. At the same time maintaining strict confidentiality regarding test result is very important because of the stigma and taboo attached to HIV/AIDS.

Let us try to learn details regarding HIV tests, testing procedure, need for pre-test and post-test counselling and testing strategies in this unit.

4.2 HIV VIRUS AND HIV TESTS

Viruses are the smallest living beings known to man. Living matter consist of two nucleic acids known as DNA (Dioxy Ribo nucleic acid) and RNA (Ribo nucleic acids). Viruses are an exception. They contain only a single nucleic acid. Human Immune Deficiency Virus (HIV) is an RNA virus. A protective coat covers the nucleic acid. It is made up of chemical substances that are called as glycoprotein/ polyprotein. This cover is called as the envelope (eve). In the case of HIV the envelope consists of glycoprotein. The HIV also contains an enzyme known as the reverse transcriptase (pol). Reverse transcriptase synthesizes DNA from RNA. The genes that control these functions are known as **gag pole** and **eve Genes.**

If you recall your biology classes, you will remember that protein synthesis takes place in the cell. DNA present in the nucleus of the cell activates RNA. RNA assembles the amino acids to form proteins. Reverse transcriptase enzyme, that is present in the HIV, produces DNA from RNA. It goes one step backward in protein synthesis i.e. DNA from RNA. Hence it is called as a Retrovirus.

Reactions of the Virus in the Body

When a micro-organism enters the body, the body recognizes the proteins present in the micro-organism as a foreign protein. This foreign protein is known as the antigen. To neutralize this protein the body produces chemical substances. These substances are known as antibodies. Antibodies interact with the antigens to form complexes and they neutralize the antigens. The body takes about four to six weeks to form the antibodies against infecting micro-organisms. The same process takes place when a person becomes infected with HIV virus.

Detection of HIV Infection

It is very difficult to grow (culture) the virus under laboratory conditions. In the laboratory the virus is grown in a suitable growth media. This process is called as viral culture. It takes about six weeks for the culture to become positive and it is costly. Hence, HIV virus is not cultured. A simple and effective test is necessary to detect the presence of HIV in the body. We use the presence of antibodies against the HIV virus to detect its existence.

Window Period

Once the virus enters the body, it starts to multiply. During this process the test does not detect the virus. The patient is highly infectious. After six to eight weeks the body produces antibodies. The tests become positive. This period when the patient has the infection and the test is negative is known as the “window period”. Similar situation may occur in a terminally ill patient, when his body cannot produce anti-bodies. The test will be negative while the patient will have the infection. The test turns out negative because it takes six weeks for the antibodies to form. In the terminal stages the immune system may be destroyed so that there are no antibodies produced by the body.

Types of Test to Detect Antibodies

To test for the antibodies, two different types of tests are used. They are the ELISA (Enzyme linked immuno sorbent assay) test and the Western Blot test.

i) **ELISA Test**

ELISA is easy to perform and it is cost effective. It is also reliable and sensitive. The basic principle of the test is to detect the antibodies against HIV Virus that are present in the blood of an infected person.

Method

Micro plates with the viral antigens are used. Serum from the patient's blood is added to the viral antigens. If the serum contains antibodies against the virus, and antigen-antibody complex will occur. An antibody to the antigen-antibody complex and a chemical are added to the test. Depending on the colour changes the reaction is reported as positive or negative.

Types of ELISA

Different types of ELISA are in use. They are based on the ways in which viral antigens are obtained. Viral antigens can be obtained by three different methods, namely, whole viral lysate, recombination DNA and by synthetic polypeptide. At present only synthetic polypeptide is available in the market.

ii) **Western Blot Test**

This test is also based on the same principle. Viral antigens are layered on to a nitro cellulose paper. Patient's serum is placed at one end of the strip. The paper is charged with electricity for 24 hours. Antibodies move along the paper and interact with the antigens. Depending upon the molecular size the antigen-antibody complexes move to different areas. These patterns are compared with the standard pattern produced by the HIV. To declare the test, as positive, antigen-antibody reactions should occur at all the three region i.e. gag, pol, and eve. If there is reaction only in one or two regions then the test is considered to have shown an indeterminate result. The test has to be repeated after six weeks.

Sensitivity and Specificity

What do sensitivity and specificity mean? Any test that is done to detect a disease does not always correctly detect the disease at all times. Similarly, it does not always rule out the disease. This is an inherent property of the test. Sometimes the test may be positive even when the person does not have the disease. This is known as a **false positive test**. Similarly, the test can be negative even when the patient does have the disease. This is known as a **false negative test**.

Sensitive Test

A sensitive test will detect all the cases that have a remote possibility of having the disease. It will detect all false positives. To use a test for screening for a disease it should be very sensitive. A sensitive test showing a negative result confirms the non-existence of the disease. Whereas a positive test result will NOT confirm the diagnosis.

Specific Test

A specific test will detect all the cases that do NOT have the disease. It will detect a high number of false negative tests. If a test, has a high specificity, than the presence of the disease is confirmed. The tests that are used to detect HIV should have a high sensitivity and high specificity. An ELISA test has a sensitivity of > 90 per cent and a specificity of > 99 per cent.

A false positive ELISA may be due to liver disease, and recent influenza vaccination. We have to be careful while interpreting a test to detect HIV.

Check Your Progress I

Note: Use the space provided for your answers.

1) What are the types of test used to detect HIV antibodies?

.....

.....

.....

.....

.....

.....

4.3 PRE-TEST AND POST-TEST COUNSELLING

Need for Counselling

Conveying a positive HIV result to an affected person is a very serious matter. As you are already aware, a positive test result is like passing a death sentence on that person. It is also like passing a moral judgment on that person. As the commonest mode of acquiring this infection is through the sexual route, morality of the affected person is very often judged. There is stigma attached to this disease in the society. Hence, the test results may upset the patient.

A patient may have varied reactions to a positive test result. He may be shocked. He may not believe the report (denial). He may become anxious about his future, become scared, depressed or angry. Sometimes these reactions can have bad consequences, so that he/she may decide to end his life or become careless and spread the disease to other persons. A patient will have different coping

mechanisms to counter the shock. He/she may like his/her family and friends to know about the disease or he/ she may like to hide the fact. Before the test is conducted the mind set of the patient has to be tuned such that he/she is able to cope up with the test result.

HIV disease can also be termed as a disease of behaviour. A person's behaviour puts him/her at risk to get infected. If the disease has to be controlled then a person's behaviour needs to be changed. To achieve all these objectives, a person has to be counselled.

1) **Pre-test counselling**

Among all the types of counselling, pre-test counselling is the most important. It helps to establish a rapport between the patient and the counselor. It also helps the counsellor to gauge the patient. It may be the only contact that a person will make with the health system and it may be the only opportunity to educate the patient about HIV. In the long run it will help the counsellor to build a rapport with the client.

Step in Pre-test Counselling

a) **Making the patient comfortable**

It is essential to establish a good contact with the patient. During this process, try to make the patient comfortable. Try to explore the patient's family, occupational, educational and social background.

b) **Reason for testing**

It is good to find the reason why that person seeks an HIV test. Many patients who are anxious will try to get the test done. It is also essential to inquire about the practices that may make the person prone to get the infection (high-risk behaviour). Inquires must be made about blood transfusions and IV drug abuse. Preliminary inquires should be made about sexual practices. Sexual practice of a person is a very private and personal matter. Unless the patient trusts the counsellor, he/she will not reveal it. These inquires should be made so that risk practices can be identified and the patient can be helped.

c) **Concepts and misconceptions**

Patient may already have some concepts of HIV/AIDS. Try to explore them. Many times they may be wrong and misleading.

d) **Clarifications about HIV and AIDS**

Tell the patient about HIV and AIDS. It is essential for them to know the differences between being HIV positive and having AIDS. It is helpful to draw a line diagram of the natural history of HIV disease. This gives them the hope, that all is not lost and that they have some years of life left which can be used productively.

It is necessary also to tell the patients about HIV and what it does to the human body. Patients may not know about the immune system. To understand the immune system, simple examples from day to day life must be used. The examples could be tailored to meet the occupation of the person. If the patient is a farmer then the example of protecting the crops can effectively be used. Ask the patient to imagine that he/she is guarding his/her field. Ask him/her as to what he/she will do if somebody tries to rob the crop or destroy the crop. Then ask the patient as to what will happen if the person becomes progressively blind, deaf and lame etc. in the process of fighting the enemy. Then tell him/her that similar thing occurs in the human body.

To explain about the HIV in the body, examples of common symptoms and common diseases can be used. A normal person will experience symptoms of fever or loose stools for a few days (3-4 days). An HIV infected person who is asymptomatic will also have the same duration of illness. When the person becomes symptomatic the duration of the disease will be longer i.e. 2-3 weeks. If the person develops AIDS, the symptoms will last for a longer time (1-2 months). Patients will have some knowledge of the symptoms of common diseases. Cough, sputum which contains blood, fever and weight loss is commonly seen in patients with pulmonary tuberculosis. You can use the patient's knowledge to illustrate tuberculosis in HIV infected patients.

e) **Health education**

Pre-test counselling may be the first and the only time when a person may come in contact with the health care system. A physician must not miss this opportunity to educate the patient about the preventive aspects of the disease.

f) **Clarify about the test**

During the pre-test counselling it is essential to tell the patient that ELISA test is a test for antibodies that are present in the body. A negative test will not rule out disease. The test has to be repeated after a few weeks. You can explain details about the window period and the need for protecting self and others from getting infected.

g) **Practicalities of the test**

A person should also be told some practical details of the test like the cost, location of the laboratory and the time taken for obtaining the result. You

have to find these details from the laboratory where you will send your patients for the test.

h) **Coping mechanisms**

As the counselling proceeds, you will be able to assess your patient better about the coping capability of the patient with bad news. This can become very valuable at the time of post-test counselling. It is also necessary to find out from the patient about the people to whom the result can be revealed.

i) **Confidentiality**

Assure the patient that the test result will be kept confidential and will not be revealed to any other person without his/her expressed consent. If the patient does not want his/her test to be revealed, then it should not be revealed to any unauthorized person. Find out the persons to whom she/he wished to reveal the test result. Very often a close family member or a friend becomes the first choice of the patient. It is always better to motivate the patient to reveal his/her status to some one close to him/her.

j) **Consent**

Ideally, after this session of counselling, a written consent should be obtained. This often does not occur in practice. A return appointment for the test result should be made. The patient should be made to understand the need for a return visit even if there are chances that the result can be negative.

Post-test counseling (Negative)

When the patient comes for the results, he/she may get a negative result. If the result is negative, then the patient has to be reminded about the window period. If the patient has some high-risk behaviour, he/she must be asked to repeat the test after six months. He/she must also be told about the ways in which he/she can reduce the risk of acquiring the infection.

While talking about the negative test result, it should be explained that the test is for antibodies. A negative test does not to rule out the disease. If there is a definite high-risk behaviour involved, the test has to be repeated.

2) **Post-Test Counselling (Positive)**

a) **Breaking the news**

Where the test is positive, the news should be broken gently to the patient after adequate counselling. You should be sure and definite about the result. Do not give false hope to the patient by saying that he/she may need another confirmatory test. Give time to react to the news. Many patients will be shocked and will take time to react. They may manifest the various psychological reactions as already mentioned. As a counsellor, you need to support the patient through all these reactions. When the person accepts the diagnosis, you have to help him/her to face life.

b) **Medical plan**

The patient may have medical problems. Try to assist him/her to seek medical help. Not all hospitals will be willing to treat HIV patients. You as his/her counsellor will have to identify those hospitals and doctors who are willing to treat HIV patients. Do you know about the facilities available in your community? The supplementary reading material will help you to identify some of the health care institutions in your state or district.

c) **Social support**

The patient may be worried about the social consequences of being infected. Every problem should be assessed and a solution should be found. Social problems may begin with the family. The patient may be afraid to tell his family. Family members may want to isolate the patient. The patient may shun other family members out of fear of infecting them. Similar fears may be faced in the work place. As you and the patient explore various possibilities you will be able to find solutions to these problems. Perhaps you may have to organise a meeting with his/her employers/colleagues or with the family to sort out these problems.

The patient may need help to organise his/her financial and legal affairs. Try to find out about various people or organisations that can help in these areas.

d) **Plan for the future**

The patient may like to make a decision as to how he/she should be cared for at the time of terminal illness (advanced directives). Help him/her to make those decisions.

e) **Reduction of high risk behaviour**

The patient needs to know the ways in which he/she can reduce high-risk behaviour. He/she will be more receptive to avoiding those behaviours if he/she knows that he/she is positive. If the patient is a drug addict, try to find facilities that will help him/her to give up drug addiction. If that is not possible, try to get clean needles and syringes for their use (needle exchange programs). If a person has multiple sex partners as a risk factor, then try to advise him/her against that practice. Patient also needs to be told about the protective effects of condoms. Patients also have to be told about the correct use of condoms.

f) **Networking**

In your area, there may be groups of HIV infected people. They may be helped to organise themselves into a support group. Try to help the patient to become a part of that group. It helps the patient to know that many like him/her have the disease and they can support one another. Patients who suffer from HIV infection often seek spiritual solace. Try to identify various spiritual organisations in your areas and try to make these organisations help your patients.

g) **Support the patient**

Assure the patient that you will always be there to help at the hour of his/her need. This calls for total commitment from your part. You may have to give him/her contact address so that he/she can contact you at the time of need. Can you do all these things in a single session? Obviously, it is not possible to do so in a single session. Post-test counselling is a process that involves many sessions.

3) **Crisis Counselling**

Patients may have acute problems that may threaten their social well being. The parents may force the patient to marry. He/she need counselling to face such a situations. Can you suggest solutions to this problem?

There are different ways of tackling this problem. He/she can inform the parents about his/her HIV positive status and its consequences. He/she may say that he/she is suffering from a serious disease and would like to avoid marriage. He/she may talk to his/her fiancée and tell him/her about the disease and marry him/her if he/she is willing. He/she may find an HIV positive patient and may marry him/her. These are some of the options that are available and being practiced. All these possible options need to be discussed. The patient should decide the best option for his/her situation. After the best option is selected, a plan should be made to implement it. If he/she decide to tell his/her parents about the disease, then he/she should inform his/her family doctor to say the same. All these details have to be worked out. The patient should report back to you and tell you about the progress that he/she is making. This type of counselling is called **crisis counselling**.

4) **Adherence Counselling**

Today there is treatment available for HIV infected persons. This treatment is known as highly active antiretroviral therapy (HAART) Combinations of three different drugs are used. These drugs may be given as individual drugs or may be formulated into a single tablet. The drugs suppress the virus improve the quality and prolong the life of HIV infected patients. These drugs have to be started at an opportune time and have to be taken life long. If these drugs are taken irregularly the virus will become drug resistant and the disease will progress faster. Resistant strains will be seen in the community. While for other chronic diseases 80 per cent adherence may prevent the progression of the disease, HIV requires more than 95 per cent adherence. Even missing a single dose in a month can be deleterious to the patient. Hence adherence is very important.

Adherence involves change in behaviour so that the patient is disciplined and conditioned to take medication. Adherence counselling should start from the time the diagnosis of HIV is made. Patients should be told about the availability of HAART, the cost of treatment and that it will be started at an appropriate time. The Government of India has set up free antiretroviral treatment (ART) centers. Find a centre in your area. Patients taking HAART must always be monitored by a physician to see the effect of the drug. Hence constant and regular attendance at medical centre is needed. All these aspects have to be stressed during the post test counselling.

Once the patient has been started on treatment, check about the drug intake during every counselling session. Enquire about the side effects. Find out of the patient has any difficulties in procuring the drug supply. Encourage the patient to continue the drug therapy.

If patients have missed their drugs, ask about the reasons for missing the drugs. Very often patients may forget to take the drug. Help them to overcome this difficulty by using pill organiser, reminders or by using other family members to remind them to take the medication. Every encounter with the patient talks about adherence.

Groups to be tested

Who are the people who need to be tested for HIV?

High risk behaviours

People, who have a history of high-risk behaviour, need to be checked. People may have multiple sex-partners. Under this category, sex workers and their customers can be included. Men who are away from their families for a long period of time like truck drivers, migrant labourers, traveling salesmen and security personnel etc. are likely to indulge in sex with unknown persons or with different partners and are at risk of contracting the disease.

Men who have sex with other men are likely to get the infection and they need to be checked for the infection.

Spouses of HIV infected patients are innocent victims of the disease. They also should be offered the test. National AIDS Control Organisation guidelines for AIDS should be followed. Some medical conditions may make the doctor think of HIV infection and an HIV test will be sought for by the doctor.

People who have received untested blood or blood products are at risk of acquiring the infection. Similarly organ recipients are at a high risk if the organs have not been tested before being transplanted.

Consent

All testing that is done should be voluntary and with informed consent.

Informed consent means that the patient will have to undergo a pre-test counselling. No test should be done without a pre-test counselling. In practice, very often it is not done. This leads to lots of difficulties for the patients as well the health care workers who subsequently have to deal with the patient. All clinical testing should be voluntary. The advantages of voluntary testing are many.

Advantages of pre-test counselling

If the patient gives an informed consent (pre-test), then we can expect that he/she, is prepared to face the test result. He/she will trust you since he/she gives the consent. He/she has control over his/her affairs. He/she will be more receptive to change his/her behaviour. Hence, the spread of the infection can be reduced to a great extent.

Check Your Progress II

Note: Use the space provided for your answers.

1) What is adherence counselling?

.....

.....

.....

.....

.....

.....

4.4 TYPES OF TESTING SITUATIONS AND STRATEGIES

Types of Testing

Various types of testing that are done include the following:

1) Voluntary testing;
2) Surveillance; and
3) Mandatory testing

1) **Voluntary Testing**

This has already been described earlier in this unit. Here the patient gives an informed consent for voluntary testing .

2) **Surveillance**

Sometimes it is essential to know the prevalence of disease in a community. This helps in planning for the health care of the community, as well as in finding effective control measures for the disease. Voluntary testing may not give true picture. A method known as ***Unlinked Anonymous*** testing is used. In this method blood that is collected in the laboratories is used. After the test that has been requested is performed, a sample of the discarded blood is used for testing for HIV. This sample will not have any patient identification on it i.e. patient's name or number will not be written on the sample. The person doing the test will not be able to identify the patient. Hence, it is called Unlinked Anonymous Test.

In the STD clinics, blood is usually collected to test for syphilis or other STDs. After the test is done, remaining sample is sent to the surveillance centers without any patient identification. This survey gives an idea about the prevalence of HIV in high-risk groups. Similar study has been done on antenatal mothers to find the extent of risk involved in the community (low risk groups). Most of the reported cases of HIV in the country are based on such surveillance.

3) **Mandatory Testing**

HIV testing that is done compulsorily without any consent is known as ***Mandatory Testing***. This method of testing is not recommended. It is against human rights and the fundamental rights of the individual. Testing against the will of the person leads to many problems. Patient\s will not come to the health care system if they know that they will be checked for HIV. The fear and stigma of the disease is enough to prevent from going to a hospital. Mandatory testing involves a huge expenditure for the health care system. It is not justified to spend huge amounts on a program that will not eradicate the disease. There is no situation that can justify doing an HIV test on a person compulsorily. Our country also follows this principle when dealing with Indian citizens. According to NACO the only condition where a HIV testing is done mandatory is in relation to requirement to armed forces. Even then it insists that the clients should be counselled.

In some countries foreigners sometime need to get an HIV test done. Mandatory testing is done on all blood banks. Only the donated blood is tested. An individual is not tested. The donor is not informed of the test. The blood that is collected is discarded. This is done because the recipient should always receive only uninfected blood.

The other situation where a mandatory testing can be done is among pregnant mothers. Now we have a definite treatment available for preventing the mother-to-child transmission. Hence, a mandatory testing will help to identify mothers who are a risk and provide them with prophylaxis. In the antenatal clinics 'opt out' technique is followed. The patient is counselled and the test is done. Only if the mother objects to testing is the test not done.

Testing Strategies

Since HIV is such a serious disease, much care should be taken to make a diagnosis. You have already learnt about the sensitivity and the specificity of the various tests. Do you remember them? Emphasis should be laid on confidentiality. Considering all these facts, the World Health Organisation (WHO) formulated a testing strategy for testing HIV. The National AIDS Control Organisation (NACO) has adopted the same guidelines for India. It makes use of the ELISA test and the Western Blot Test. Recollect these tests. Accordingly, WHO has three strategies?

Strategy I

Only a **single ELISA test** is done. This is used only for testing blood or blood products. A single positive ELISA is enough to discard the blood. The reason why this is done is to provide only safe and healthy blood to the patient who receives it. Even if there is slight doubt, the blood is rejected. The donor is not informed about the result. Usually all blood banks use a single ELISA to screen their blood stores. This testing has eliminated blood transfusions as a means of transmitting HIV.

Strategy II

In this strategy two **ELISA tests are done** if a patient manifests clinical symptoms of AIDS. A sample of blood is tested by one particular method of ELISA. If the sample is found positive, then a second ELISA is repeated using a different method. If the sample is positive even with the second test, the patient is declared as

positive. If the second test is negative it is reported as negative; some laboratories report it as indeterminate. If the test is being done for survey purposes, only strategy II is applied.

Strategy III

In this strategy three **ELISA tests are done** or **two ELISA and a Western Blot test is done**. It is done in patients who do not have any symptoms of AIDS illness. If the blood sample is positive to two ELISA tests, a Western Blot test is done. If all are positive then the patient is declared as positive. If you are working with HIV positive people, it is essential to know the type of tests that are being done in your laboratory. If the lab is not doing all the three tests, then you have to see that your patient's results are confirmed by another laboratory using a different method.

Confidentiality

Once a result is known, confidentiality has to be maintained. The lab should release all the results in a cover, which is marked as confidential. The result should not be released to friends and relatives. How does your lab release the reports? Your need to know in your locality how test results are treated by people involved in the health care system.

Certain Situations of HIV Testing

a) **Can and HIV test be done on a person before he/she is employed?**

As already stated, no mandatory testing can be done. There is no occupation in which HIV can be spread to the co-workers through working conditions. The employers cannot refuse to offer employment or terminate the workers on the basis of HIV reports. Even if the employer is paying for the test, the employer should not be given the test result. An employee gives consent for the testing.

b) **Should HIV test be made compulsory before marriage?**

In India arranged marriages are common. Many people have felt that an HIV test should be made compulsory for both the parties. Do you think it is right? It may be healthy to leave the choice to the partner whether to opt for an HIV test or not.

Check Your Progress III

Note: Use the space provided for your answers.

1) Can and HIV test be done on a person before he/she is employed?

.....

.....

.....

.....

.....

.....

4.5 LETS US SUM UP

In this unit we have gone through various issues related to HIV testing. This unit has outlined the structure of the HIV virus, reaction of the virus in the body and how to detect HIV infection. We have also studied about various HIV tests, the need for pre-test and post-test counselling and the type of HIV testing. Towards the end of the unit we also examined the strategies involved in HIV testing and briefly discussed some of the situations where a demand for conducting HIV test can be made.

4.7 SUGGESTED READINGS

Thomas, Gracious (1995), *AIDS and Family Education*, Rawat Publications, New Delhi.

Thomas, Gracious (1994), *AIDS in India: Myth and Reality*, Rawat Publications, New Delhi.

NACO (1999), *Country Scenario 1997-98*, Ministry of Health and Family Welfare, Govt. of India, New Delhi.

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

Thomas, Gracious (1997), Prevention of AIDS: In Search of Answers, Shipra Publications, New Delhi.

UNIT 5 MORAL ISSUES ON HIV TESTING

Contents

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 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

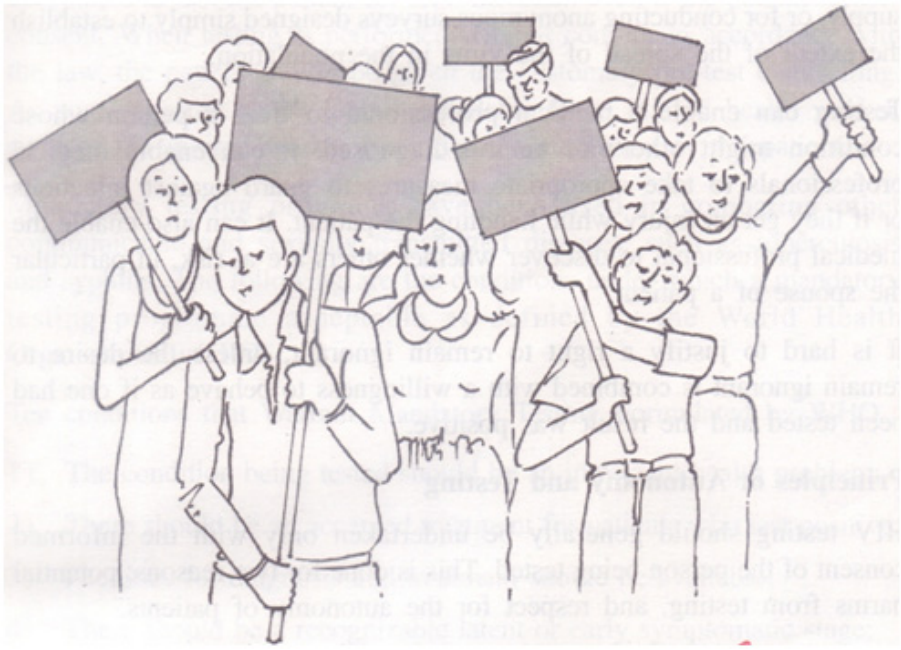
HIV/AIDS epidemic progress differently in different situations. It is driven by individual behaviour which put people at risk of infection. Their behaviour may in turn be driven by poverty, by relationship between same-sex men and women or between old and young people, or cultural and religious norms 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 or 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 intension 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 answer.

1) What are the ethical advantages of testing HIV?

.....

.....

.....

.....

.....

.....

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 additions, 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 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 human rights".

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 form 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?

.....

.....

.....

.....

.....

.....

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 encourage 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 answer.

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

.....

.....

.....

.....

.....

.....

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?

.....

.....

.....

.....

.....

.....

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.