स्वाध्याय स्वमन्थन स्वावलम्बन

# UTTAR PRADESH RAJARSHI TANDON OPEN UNIVERSITY

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Indira Gandhi National Open University

UP Rajarshi Tandon Open University

# CHFE-02
# ELECTIVE ON HIV/AIDS

First Block : HIV/AIDS AND VULNERABLE POPULATION

Second Block : HIV /AIDS EDUCATION AND CARE

Third Block : AIDS, LAW AND HUMAN RIGHTS

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# INTRODUCTION TO BLOCK 1

You are now in Block 1 of the Elective course on HIV/AIDS. This block has five units addressing HIV/AIDS issues pertaining to certain vulnerable groups in the society. Unit 1 is on 'HIV/AIDS and women'. This unit is designed to help you to understand and enumerate the socio-cultural factors that place women at risk of acquiring HIV infection. Unit 2 is on 'HIV/AIDS and children'. In this unit we discuss about children at risk of HIV infection, modes of HIV transmission among children, as well as the preventive measures to check transmission of HIV in children. Unit 3 is on 'HIV/AIDS and substance absue'. It deals with different types of drugs usually people abuse and talk about the spread of HIV/AIDS and substance abuse because of sexual activities, injecting drugs and blood donation. The unit also describes the link between HIV/AIDS, alcohol and drugs. Unit 4 is on 'STDs and their management'. This unit classifies the 'Sexually Transmitted Diseases and provides knowledge about their causes, symptoms, treatment options and prevention methods. Unit 5 is on 'HIV/AIDS and workplace'. This unit examines the issues that HIV/AIDS bring into workplace and the strategies for prevention and control of HIV/AIDS at workplace.

These five units will give you an overview of the various HIV/AIDS related issues pertaining to certain vulnerable groups as well as some of the prevention strategies to contain the spread of HIV.

# UNIT I HIV/AIDS AND WOMEN

**Contents**



## 1.0 AIMS AND OBJECTIVES

In this unit, we introduce you to the issue of HIV/AIDS and women. Women are a vulnerable group at risk of acquiring HIV infection. By the end of this unit you should be able to:

- understand and enumerate the socio-cultural factors that place women at risk of acquiring HIV infection.
- understand, compare and differentiate between HIV disease in men and women.
- describe and discuss special issues in relation to HIV/AIDS and women. such as pregnancy, breast-feeding etc; and
- enumerate the factors, which will help in empowerment of women.

## 1.1 INTRODUCTION

This is an elective course on HIV/AIDS. In the basic course on HIV/AIDS, you learnt about the basic facts on HIV/AIDS, the global and Indian scenario and the socio-ethical issues. In this section, you will learn in greater detail, the impact of HIV/AIDS on sections of the community which are vulnerable such as women and children.

You will also learn why women are more at risk of acquiring HIV infection, some of the relevant statistics, socio-cultural factors, the progression of HIV disease in women, and special issues related to women such as pregnancy and breast-feeding in the context of HIV/AIDS. There is also a section on reproductive health and empowerment of women and finally a case study. Before you start working on this unit, it is important that you go through basic facts of HIV/AIDS.

## 1.2 IMPORTANCE

There are certain groups, which are vulnerable to HIV/AIDS. Women are one such group. AIDS was first detected in the U.S.A. in 1981 among male homosexuals. Initially there were more men being infected with the AIDS virus than women, in the ratio of 10:1. but now, in the world, the number of women infected with HIV is increasing. In U.S.A, HIV/AIDS is now the third leading cause of death among women between the ages of 24 and 44 years. The burden of HIV disease among women in the developing world is even greater. Nearly all cases of HIV infections in women in the developing world have been acquired heterosexually(i.e. from man to woman).This is due to the following facts :

1) HIV infection is transmitted more effectively sexually from men to women.

2) Lack of education and illiteracy among women.

3) Cultural beliefs regarding the role of women in the family and society; and

4) Lack of economic power in the women.

All the above factors influence the relative vulnerability of women and decrease their access to means of prevention and support in the face of AIDS.

Women who are infected with HIV infection can also transmit the HIV infection to others. For health care workers dealing with care of HIV positive women, it is important to understand the psycho-social and cultural issues as they have important implications for women and related issues such as child-bearing and breast-feeding.

## 1.3 STATISTICS

The UNAIDS and WHO periodically publish statistics pertaining to the spread of HIV/AIDS. According to the latest information, in the world, there are close to 34 million people living with HIV/AIDS by the beginning of 2000. Of these 13.8 million are women. There was nearly three-fold increase in HIV disease among women from 1985 to 1995. The median age of women with AIDS is 35 years, but in India it is much younger. The greatest rate of rise has been in Africa and in the Afro-American women in the U.S.A. In these countries the rates are almost equal to that of men.

In the year 1998, 2.1 million women were newly infected with HIV disease.

900,000 women died from AIDS in 1998.

4.7 million women have died from AIDS since the beginning of the epidemic.

Women now represent 43 per cent of all people over 15 years living with HIV and AIDS. There are no indications that this equalizing trend will reverse.

Table 1.1
Regional HIV/AIDS Statistics, December 1998.

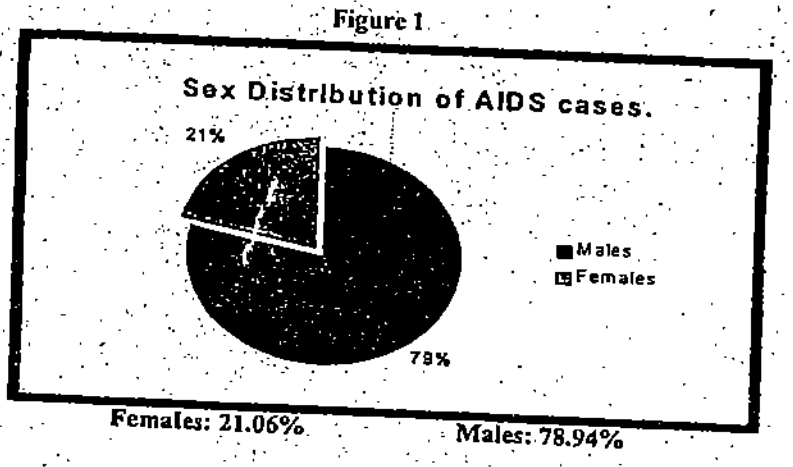
| Region | Adults & children living with HIV/AIDS | Percent of HIV positive adults who are women. |
|---|---|---|
| Sub-Saharan Africa | 22.5 million | 50% |
| North America & Middle East | 210000 | 20% |
| South & south East Asia | 6.7 million | 25% |
| East Asia & Pacific | 560000 | 15% |
| Latin America | 1.4 million | 20% |
| Caribbean | 330000 | 35% |
| Eastern Europe & Central Asia | 270000 | 20% |
| Western Europe | 500000 | 20% |
| North America | 890000 | 20% |
| Australia & New Zealand | 12000 | 5% |
| TOTAL | 33.4 million | 43% |

Source: UNAIDS/WHO: epidemic update-December 1998

In India, the exact number of women who are infected with HIV is not known but is estimated to be around one million. The male to female ratio is 4:1 in India, (i.e. 21.06 per cent of all HIV infected cases in are women).

Sex -wise distribution of AIDS cases

Figure 1




## 1.4 SOCIO-CULTURAL FACTORS

The link between powerlessness and the risk of exposure to HIV provides the key to understanding the source of women's vulnerability to HIV infections. The HIV epidemic has taken the social, economic and cultural subordination of women and translated it into a death sentence. Following are some of the factors that make an Indian woman not only more prone to HIV infection but also less likely to seek medical attention.

### *Early Sexual Intercourse*

Culturally, initiation to sexual intercourse begins several years earlier for females than for males. Many women are still in their mid-teens when they marry. Often several women get married to much older men, who are more sexually experienced. Therefore there are more chances for a female to get HIV infected from a husband who might be indulging in sexual activities outside marriage. This usually happens in the lower strata of the society.

## 1.5 HIV DISEASE IN WOMEN

*Reasons for Transmission*

The reasons for transmission of HIV disease to women are:

Worldwide promiscuity involving heterosexual intercourse is the primary risk factor for HIV infection in women.

Data also suggests that male to female transmission of HIV-I is relatively more efficient than female to male transmission.

Sexually transmitted diseases, particularly those associated with genital ulcers are strongly associated with an increased risk for HIV infection.

Non ulcerative STDs (Gonorrhea, Chlamydia, Trichomonias, and Bacterial Vaginosis) also have been associated with an increased risk of HIV transmission.

*Drug Abuse:* In Western countries, at the beginning of the AIDS epidemic, drug use was the major risk factor in women acquiring HIV. Drug use in women is associated with sharing of unsterilized needles for injecting drugs and high-risk sex behaviorus with increased number of partners.

*Contraceptives:* The inability of the woman to compel her male sexual partner about using barrier contraception such as condoms etc, places her at risk of acquiring HIV infection and other sexually transmitted diseases.

Several studies have not been able to conclusively prove or disprove the role of oral contraception or Intra-uterine devices (such as loops, copper-T etc.) as a risk factor of acquiring HIV infection. Oral contraception may thin the vaginal epithelium, making it easier for HIV transmission.

*Host factor:* If the infected partner has more advanced HIV disease, lower CD4 count and higher viral load in the semen, then there is an increased risk of HIV transmission to the uninfected partner.

Studies have also revealed that some partners in spite of being repeatedly exposed to high-risk sexual behaviour do not sero-convert and appear to be protected against infection due to immunologic responses, which has a protective effect.

*Viral factors:* Viral load and viral characteristics play a role in the risk of sexual transmission. Higher the viral load in the semen and vaginal secretions, greater the risk of transmission. Also certain sub-types of HIV-I virus may be associated with certain types of transmission, but again this has not been conclusively proved.

*Signs and Symptoms*

As in the male, the female also, once she has become infected with the AIDS virus, may not have any signs or symptoms at all. In a significant percentage of people, at the time of sero-conversion (when the antibodies are formed) there may be a flu like illness with fever, body pains, rash, headache etc. This may last for a few days to weeks and then disappear. The HIV infected person may then not have any more signs and symptoms. She may continue to do her routine work of cooking and

caring for children and submitting to her husbands needs. Her blood test may be done only when her husband or her child, has become sick. Later on, as her CD4 count begins to fall, she becomes prone to other, super-added infections called opportunistic infections.

*Opportunistic Infections*

Fungal infection of the throat and esophagus (the hollow tube that connects the mouth to the stomach) is a common opportunistic infection in women. Recurrent bacterial pneumonia and Pneumocystis carini lung infections are more common in women. Other co-infections commonly seen in HIV infected women include Cytomegalo virus, Recurrent muco-cutaneous, herpes simplex infections, muco-cutaneous candidiasis, Toxoplasmosis and Tuberculosis and Crytococcal infections.

*Gynaecological Infections*

Infections of the reproductive tract are referred to as gynecological infections. Gynecological diseases in HIV infected and non- HIV infected women are the same except for:

Genital ulcers which may be secondary to the HIV itself.

Extensive herpes simplex ulceration which may be resistant to treatment.

Vaginal infections such as Candidiasis, Trichomomaisis, bacterial Vaginosis and vaginal infections due to Syphilis, Gonorrhoea and Chlamydia.

Pelvic inflammatory diseases are more common and more aggressive in HIV infected women.

Immuno-suppression has been associated with consequences of Human Papillomma Virus (HPV) infection including cervical cancers.

HIV Associated cancers and pre-cancerous conditions in women

It is noted that HIV positive women have a higher risk of acquiring cancers, especially cancers referred to as Non-Hodgkins lymphoma and Kaposis sarcoma. Due to the loss of cell-mediated immunity in HIV infected women, they tend to develop HPV or Human Papillomma Virus infections, which are associated with pre-cancerous lesions. The common occurrence of HPV infection, often of multiple types, the rapid progression of cervical intraepithelial Neoplasia, the high rate of reoccurrence inspite of therapy and the multiple lesions, makes this an important area of concern.

**Treatment**

In HIV disease, one has to consider two regimes of treatment.

- Specific treatment for HIV disease.
- Treatment for opportunistic disease.

Drugs that are given for specific HIV disease are called anti-retroviral drugs and several drugs are available. These drugs may be given in double or triple or even as four drug combination. These drugs are very expensive and beyond the reach of the common man. They also have many side effects.

For opportunistic diseases, there is specific treatment depending on the disease, such as Tuberculosis, Candiadisis, Toxoplasmosis, Cryptococcasis and Cytomegaloiusetc.

**Disease progression and overall survival in comparision with men**

In the late eighties reports suggested a less favourable outcome for HIV infected women in comparison to men, but more recent studies have not confirmed this finding. Majority of research data suggests no difference between women and men in HIV disease progression or survival.

## 1.6 HIV DISEASE AND PREGNANCY

HIV disease has now spread from the high-risk behaviour group to the general population. This is corroborated by the fact that a significant percentage of pregnant women who are tested for HIV in the antenatal clinics are positive and this percentage is now increasing. There are several issues to be considered in the case of HIV positive mother and pregnancy and these issues are briefly enumerated below.

HIV infection does not erase women's desires and hopes for sexual bonding, intimacy and child bearing.

In India, a pregnant woman is considered to be the potential bearer of a son. Her social status improves after the birth of a son. This culturally prevalent attitude should be kept in mind when counseling the HIV positive women of child bearing age.

The pregnant HIV positive mother's chance of producing a HIV positive child is 25-30 per cent. This transmission from mother to child can occur during the pregnancy itself, or at the time of childbirth or during breast feeding. However, there is atleast 70 per cent chance of having an infant who is not infected with HIV. (For more detail, you may read Block 3 of the basic course on HIV/AIDS)

The stage of HIV infection in the pregnant mother is also important. If it is in the early stages of HIV infection, pregnancy has little (if any) effect on HIV infection. However in later stages of infection, especially if the mother has AIDS, the pregnancy can be more complicated. It is very important to help HIV positive women and their husbands assess the risks of giving birth to an infected child. They have to consider the possibility of having an infected child, or if the child is uninfected, who will care for the child in the event of their own illness or death.

It is always better to discourage a woman from opting for pregnancy if one is HIV positive. The desire to rear a child can be met by adoption or by volunteer service in an orphanage.

If the couple decide against having children, it is important to find other means of feeling socially valuable or productive and improving their sense of self-worth and purpose in life.

Counselling should help the women develop a plan of how she will care for her child, how she will cope with the possible illness of the child, how her family and community will help her, and how she expects to support and care for her child if she becomes sick and dies.

Whenever decisions about avoiding or terminating a pregnancy or about preparing for a possibly infected infant need to made, they should involve both the parents. Such couples should also discuss the matter with their religious leaders or spiritual guides.

The mother and her family may require compassionate support and psychosocial support during the pregnancy.

There should be stress on regular medical check ups and suggestion for delivery in a hospital.

**Risk factors associated with transmission**

The risk factor associated with HIV transmission from mother to child may be sub-divided as follows:

Natural and Virologic factors.

Placental factors.

Foetal factors.

Birth canal factors.

Obstetric factors.

New-born factors.

Natural and virologic factors

Frequent sexual intercourse with multiple partners during pregnancy could lead to increased risk of transmission.

Low CD4 counts in mother could lead to high risk of transmission to child.

Advanced disease stage in mother could lead to high risk of transmission to child.

Low maternal vitamin A levels could lead to high risk of transmission to child.

High viral load in pregnant mother could lead to high risk of transmission to child.

**Prevention Strategies**

Less frequent intercourse, limit the no .of partners and use of barrier contraception.

Decreased maternal viral load with anti-retroviral drugs.

Vitamin A supplementation to mother.

**Placental factors**

HIV-1 can be isolated from the placenta.

Any placental disruption could lead to higher risk of transmission and this can also happen with chorrioamionitis, cigarette-smoking or illicit drug use and sexually transmitted diseases in the mother.

**Prevention Strategies**

1. Antivetroviral therapy to prevent infection of the placenta.
2. Treatment of STDs, chorioamnionitis.
3. Stop cigarette smoking and illicit drug use.

**Foetal factors**

There are differences in the susceptibility of the foetal cells to infection by virus and this may be related to genetic factors.

**Factors during delivery**

Amount of virus in the genital tract, the infant's thin skin and mucous surface can absorb the virus during the birth process.

Swallowing of infectious maternal fluids during the delivery and labour.

Breaking of waters, any bleeding during labour and prolonged labour after rupture.

**Prevention Strategies**

Adequate treatment of genital infections during pregnancy.

Elective Caesarian section.

Viricidal cleaning of birth canal before vaginal delivery.

Preventive and therapeutic intervention

As mentioned previously the chance of the pregnant HIV positive mother producing an HIV infected baby is 25 to 30 per cent. By giving the mother an anti-retroviral drug during the pregnancy the chance of transmission can be reduced by 70 per cent to about 8 per cent. The drug most commonly used is called AZT or Azidothymidine or Zidoivudine. Sometimes two or three drug combination can also be given. The baby should also receive AZT for six weeks after birth. Recently another drug is also found to be useful in reducing the transmission from mother to child. This drug is called Nevirapine. It can be given as a single dose to the mother at the onset of labour, and to the newborn child as a single dose seventy two hours after birth. Any treatment given should be under the authentic prescription of a qualified

physician. One should never opt for any type of self medication.

**Check Your Progress II**

What are the issues that a counsellor should discuss with a HIV positive woman who wants to have a child?

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## 1.7 HIV DISEASE AND BREAST FEEDING

Transmission of HIV infection from a mother to her child can occur during breast feeding also. However, fortunately a vast number of babies breast-fed by HIV positive mothers do not become infected through breast milk. Chances of transmission during breast feeding are higher, if the woman becomes infected during the breast-feeding period and lower, among women already infected at the time of delivery. Breast-feeding is extremely crucial for child survival in our country and especially among people of the poorer socio-economic status. Breast milk provides all the essential factors that makes a baby healthy and protects it from other infections. Without breast milk many infants can die from other infections or from malnutrition. A baby's risk of dying of AIDS through breast-feeding must be balanced against its risk of dying of other causes if not breast fed.

The general recommendation is that in countries where the infant mortality rate is high, breast feeding should be encouraged among pregnant women, including those who are HIV- infected. This is because the baby's risk of getting HIV infection through breast milk is likely to be lower than its risk of death from other causes, if the child is not breast fed. Women who know they are HIV-infected and for whom bottle-feeding is an affordable option, can resort to bottle feeding rather than breast-feeding.

*Prostitution*

In India as in other counties, commercial sex workers (CSWs) are often singled out for special attention in the context of AIDS due to the multiplicity of their sexual contacts and high STD rates. Focusing on prostitution and its relationship to HIV infection has the detrimental effect of implying that women are responsible for the spread of HIV. They are viewed as transmitters for the HIV rather than as recipients of the virus. In addition it also draws away attention from male heterosexual behaviour. Nevertheless, prostitution is on the list of behaviours, which can lead to HIV infection, because of the number of and the type of sexual contacts as well as the risk behaviours of the partners. Studies indicate that CSWs in India avoid using existing health structures because of the harsh and inhuman treatment they receive at the hands of the medical staff. They are also unaware of family planning services and how to protect themselves from STDs and HIV infection. They may seek treatment from quacks to avoid facing ridicule from medical staff. From the public health point of view it is very difficult to discover, educate and counsel the large number of women who are at risk of acquiring infection through heterosexual intercourse. It is important to be non- judgmental when counselling CSWs. It becomes the goal of HIV programme to educate all women about the risk of sexually acquired AIDS, and to encourage adoption of risk reducing sexual behaviours.

Another form of prostitution which is practised in parts of Maharastra ond Karnataka is the Devadasi system, where young girls of poor families after attaining puberty are dedicated to Hindu goddesses through a religious ritual, and later on channelised into prostitution. As this form of prostitution is linked to religion, it is very difficult to abolish.

The reasons why women go into prostitution may be many. Some are forced into it because they are destitute or uneducated and have no other means of livelihood. Some others may even be forced by their husbands or sexual partners, while, several are drug dependent and need money to meet their habit. Rarely do they do it, because they want to.

**Risk Reduction**

Prostitution is found in all the states of India. Many studies have revealed that a significant number of CSWs are HIV positive. Since the advent of AIDS it is important to empower these women to protect themselves from HIV infection by risk reducing behaviour and these include:

Rehabilitation wherever that is possible.

Education and information about HIV/AIDS and other STDs.

Insisting on use of condoms by their partners to protect themselves to reduce risk factors.

Regular medical checkups to look for infection and prompt and complete treatment of all STDs.

Vocational training for alternative sources of income.

Female condom usage, so that they are not dependent on the male for their own protection. In the Indian situation, currently it is not practicable as the cost of female condoms are high and good quality condoms are not easily available.

The Sonagachi project in West Bengal is cited as an example of how CSWs can be empowered.

Many women are at the mercy of middlemen or pimps who are the link between the CSWs and the clients. Often, there are powerful men at the helm of affairs and it may be very difficult for the women to leave their jobs even if they want to.

**Drug addiction, HIV Disease and Women**

There is an epidemiological relationship between drug abuse and HIV infection. There is a tendency to high-risk behaviour under the influence of drug or alcohol. In HIV positive women, there is a significant percentage who die not from AIDS-related causes, but from drug-related causes. Thus, ensuring inclusion of HIV infected drug users and understanding drug use related issues become the key challenges to obtaining a comprehensive understanding of women affected by this epidemic.

**Rape, Incest, Lesbianism, Teenage Pregnancies and Abortions**

When a male has sexual intercourse with a woman against her wish it constitutes rape. Incest is when there is sexual relationship between members of the family (father and daughter, mother and son etc). Lesbianism means, women who have sex with women. Teenage pregnancies are girls in their teens who are unmarried and become pregnant. These specific issues become important in the context of AIDS because these groups run the risk of acquiring AIDS in addition to all the other social, physical and emotional problems that they are subjected to.

Another problem that exists in India is that of illegal abortions. These are still being practised in the case of unwed mothers and those women who are unaware or embarassed to seek proper medical facilities. It is possible that HIV positive expectant mothers may avail of these facilities to abort the foetus, but hide their own HIV status and therefore other complications may set in, as these centers do not take infection control into consideration. The counsellor must help and encourage women to avail of legal medical facilities.

**Reproductive Health**

It is important for a woman to know that their reproductive tract should be healthy and that very often women may have genital infections without even knowing that they have them. This in addition to all other

factors previously mentioned ,places them at increased risk of acquiring HIV infection.

## 1.8 WHY ARE WOMEN AT RISK?

Women are at risk of acquiring sexually transmitted infections and HIV infection because their reproductive organs are structured in such a way. Also almost 60 per cent of all sexually transmitted infections have no symptoms. Therefore even if a woman had one, she would not know it.

Women at the time of childbirth may have several problems such as prolonged labour, caesarian section or forceps delivery. As a result of these procedures, injury to the genital tract, blood loss, risk of infection and chances of ill health are common. Therefore it is important for women to take care of their reproductive health and have regular medical check ups whether they have symptoms or not.

*How are STDs transmitted?*

Through sexual contact with an infected person.

From a mother who is infected to her baby during the time of delivery.

From blood and blood products given to women.

*What are the symptoms of STDs in women*

There may be no symptoms at all.

Discharge from the vagina, which could be large in quantity, white or yellow in colour and foul smelling.

Itching or pain while passing urine.

Ulcers or blisters on vagina/vulva with or without pain.

If these infections are not treated on time then women may not be able to conceive and have children. The infection can spread from the uterus, vagina etc to surrounding areas. She is also easily prone to acquiring HIV infection from an infected partner and the infection can spread from her to her newborn child during her delivery.

The best way to prevent transmission of these sexually transmitted diseases is "safe sex" which means abstinence (not having sexual relationship at all), fidelity or mutual faithfulness between partners. Proper condom usage can reduce the risk of HIV infection to some extent especially among CSWs and their clients.

Reproductive health in women has now become an important component of total women care, and many centers have Reproductive Tract Infection (RTI) clinics which women are encouraged to visit and improve their physical and reproductive health.

***Empowerment of women*** : In the Indian situation, a woman is usually completely dependent on the male partner for food and shelter. The male partner controls the sexual interaction. The woman is at risk if her male partner has sexual relations outside marriage. She does not have the capacity or the authority to demand that she has a right to protect herself from HIV/AIDS and STDs, and therefore request her husband to be

faithful or to use a condom when indulging in sex outside marriage. Hence in a majority of cases the women become infected not through her behaviour but through that of her husband's, and once she is infected, she is at much greater risk of facing all the medical and social complications of HIV/AIDS. She is the one who is then blamed, stigmatized and discriminated against. The issue for women is clearly a survival issue. In order to survive, women will need to know that they have a choice, a choice to say no to high risk behaviours, the choice to protect themselves from infection, the choice to take care of their health if they do get infected, the choice to make decisions regarding pregnancy, and the choice to have a significant role in the marital union. This act, to make women aware of their choices to strengthen them in all areas of their work, is referred to as empowerment of women. Empowerment of women is one of the key issues in keeping a woman safe and healthy. In western countries, there are women's advocacy and rights groups, which empower women. Many of these groups are headed and run by HIV positive women themselves.

The 1970's saw the rise of a wave of NGOs known as social action groups within which women's organizations form a distinctive band. They have taken the lead in the campaigns against sexual abuse, the dowry system and violence against women. They also provide health services for women, vocational training and income generating schemes.

***Sonagachi project*** : This is a unique project and was started in 1992 in the Sonagachi area of Calcutta, West Bengal, where around 5000 commercial sex workers reside in nearly 370 brothels, apart from 1500 street based sex workers.

The project has the following objectives:

- To help modifications of sexual behaviour of sex workers and their clients so as to make their business safe.
- To enable an effective workers to sustain changed sexual behaviour
- To develop an effective strategy and guidelines for an intervention programme which can be replicated in other areas.

The basic approach of the project was based on service, respect and recognition.

Major components of the Programme

Provision of health services: basic health care services including diagnosis and treatment of STDs were started and are continuing through established clinics. 30-40 per cent of those CSWs who attended the clinic were suffering from STDs.

Information, Education & Communication (IEC): This was a good example of empowerment Sixty-five educators were selected from among the sex-workers themselves, and these highly motivated peer educators were trained for six weeks. They educate the CSWs by personal discussions, small group meetings, giving out informative handouts and flip charts.

***Condom programming*** : Condom promotion is an important activity of the project.

Expended Activities of the Project:

- Non formal education.
- Immunization programmes for children of the sex-workers.
- Exposure to various social activities.
- Formation of the multi-purpose co-operative society to encourage self-employment and impart vocational training programmes.

**Legal Training.**

***Case Study***

Rajini sat outside her thatched house and buried her head in her hands and cried in loud, wrenching sobs. She cried for her life which was now in ruins, she cried for her unborn child, she cried for the uncertain future that she now faced. Rajini was only 19 years old. She was the fifth of nine children. She had a sad childhood, living with her parents, her paternal grandparents and her eight brothers and sisters. Her parents earned their livelihood by breaking stones in quarries. She stopped attending school after the fourth standard, as she had to stay at home and look after the younger four boys and cook for them. When she was sixteen years old, she was married off to a 35 year old man who had lost his first wife 3 years before. Her married life was a living hell. Her husband had been a truck driver and an alcoholic. When he was at home from his long journeys he would spend the days lying around in a drunken state and beating her up. He never gave her any money. She already had a girl child who was 2 years old. She realized that her husband was not a healthy man and he would frequently fall sick. She borrowed money from her family and from friends and went from hospital to hospital to cure his condition. Finally they were told that he had tuberculosis, but even with treatment he was not getting better. At one hospital, a doctor told them that he had AIDS. There was no cure, the doctor said. He would die anyway. They were asked to go away from the hospital. She had taken one of her neighbors with her to the hospital. On hearing this, the neighbor ran away. On reaching her house with her husband, she found all the neighbors staring at her and then turning away their faces. She spent a lot of her energy looking after him, caring for his needs, getting him the medicines etc, and finally three months ago, he died. She was so tired. A week later, she went for a check up for her pregnancy and the doctor told her that she also had AIDS, and that her unborn child could also get it. She was illiterate, sick and deep in debt. Her future was bleak. She got up and went into the house. She closed the door, she looked at the fire burning in the *chullah* (place in kitchen where food is prepared). She looked at the bottle of kerosene nearby. She found her way out of this miserable life by self immolation.

**Check Your Progress III**

1.What do you understand by empowerment of women?

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## 1.9 LET US SUM UP

In this unit, we have described to you in detail about how women are vulnerable to HIV/AIDS. The main points that have been covered in this section include:

socio-cultural factors which influence the vulnerability of women to HIV/AIDS;

HIV disease and its progression in women;

special issues pertaining to women such as pregnancy and, breast-feeding;

positive responses to the AIDS epidemic such as empowerment of women and reproductive health; and

a case study to highlight the issues which make women prone to HIV disease.

## 1.10 KEY WORDS

| | | |
|---|---|---|
| **Homosexual** | - | Men who have sex with men. |
| **Heterosexual** | - | Men who have sex with women or vice-versa. |
| **Bisexual** | - | Men who have sex with both men and women. |
| **STDs** | - | Sexually Transmitted Diseases. |
| **Vaginal Epithelium** | - | Inner lining of the vagina. |
| **Sero-convert** | - | When antibodies to the HIV are detectable in the blood. |
| **Antenatal** | - | During pregnancy. |
| **Maternal** | - | Concerning the mother. |
| **Viricidal** | - | That which kills the virus. |
| **STIs** | - | Sexually Transmitted Infections. |
| **RTIs** | - | Reproductive Tract Infections. |
| **NGOs** | - | Non Governmental Organizations. |

## 1.11 MODEL ANSWERS

**Check Your Progress I**

1. What are the socio-cultural factors in our society that make women vulnerable to HIV infection?

The socio-cultural factors in our society that make women vulnerable to HIV infection are: Early initiation into sexual intercourse, husbands as a source of infection; lack of choice; poor access to health, education and care; blame; isolation and stigmatization of women; delay in diagnosis; dependency on husband; financial burden on society; lack of choice in pregnancy; etc.

**Check Your Progress II**

1. What are the issues that a counsellor should discuss with a HIV positive women who wants to have a child?

There are several issues to be considered in the case of a HIV positive mother and pregnancy and these issues are briefly enumerated below:

HIV infection does not erase women's desires and hopes for sexual bonding, intimacy and child bearing.

In India, a pregnant woman is considered to be the potential bearer of a son. Her social status improves after the birth of a son. This culturally prevalent attitude should be kept in mind when counselling the HIV positive women of child bearing age.

The pregnant HIV positive mother's chance of producing a HIV positive child is 25-30 per cent. The transmission from mother to child can occur during the pregnancy itself, or at the time of childbirth or during breast feeding. However, there is atleast 70 per cent chance for a child born to an HIV positive woman to be HIV free.

The stage of HIV infection in the pregnant mother is also important. If it is in the early stages of HIV infection, pregnancy has little (if any) effect on HIV infection. However in later stages of infection, especially if the mother has AIDS, the pregnancy can be more complicated. It is very important to help HIV positive women and their husbands assess the risks of giving birth to an infected child. They have to consider the possibility of having an infected child, or if the child is uninfected, the question of who will care for the child in the event of their own illness or death.

If the couple decide against having children, it is important to find other means of feeling socially valuable or productive and improving their sense of self-worth and purpose in life.

Counselling should help a woman develop a plan of how she will care for her child, how she will cope with the possible illness of the child, how her family and community will help her, and how she expects to support and care for her child if she becomes sick and dies.

Whenever decisions about avoiding or terminating a pregnancy or about preparing for a possibly infected infant need to be made, they should involve both the parents.

The mother and her family may require compassionate support and psychosocial support during the pregnancy.

**Check Your Progress III**

1. What is empowerment of women?

The desire, to make women aware of their choices to strengthen them in all areas of their work, is referred to as empowerment of women.

## 1.12 FURTHER READINGS


1. NACO-(1994). AIDS/STDS-Counselling manual
2. NACO- (1998). Country Scenario 1997-98.
3. The Medical Clinics of north America - March 1997.
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# UNIT 2 HIV/AIDS AND CHILDREN

**Contents**



## 2.0 AIMS AND OBJECTIVES

The aim of this unit is to acquaint you with the present profile of children who are suffering from HIV/AIDS disease. This will highlight the various modes of transmission of HIV to children and how it can be prevented. The unit will also discuss the various rights of these groups of children.

After studying this unit you will be able to:

- state the profile of children suffering from HIV;
- analyze the various modes of transmission of HIV among children;
- describe various preventive measures to check the transmission of HIV.
- know various rights to be provided to the children who are suffering from HIV.

## 2.1 INTRODUCTION

The mere mention of the word HIV in association with a child sounds repugnant. In the case of adults at least they have done something to contract this disease. Most children suffer from HIV disease unconsciously, involuntarily or due to circumstances. For this parents and adult members, community and society are responsible. Can any one imagine the anguish and remorse of a mother when she holds her doomed child in her arms? On the other hand there are no answers to many vital questions concerning HIV infection in children. Some of these questions are as follows:

a) What is the likelihood that an infected woman will transmit the virus to her child?

b) What factors increase the risks of transmission from mother to child?

c) Is the virus readily transmitted in breast milk?

d) Can the prognosis for infected children be improved?

e) Are there risks in immunizing infected children?

Answers to these questions are urgently needed to help stem the rising tide of HIV among very young children. In this unit an attempt has been made to analyze the various factors responsible for these happenings.

## 2.2 PROFILE OF THE CHILDREN SUFFERING FROM HIV/AIDS

It is estimated that about 4.5 million children below the age of 15 years have been infected with HIV since the beginning of AIDS epidemic to the end of 1998. On a global scale, children are becoming infected at about the rate of one child at every minute every day. In 1998, one in ten of all newly infected persons was a child and the majority of them acquired the virus from their infected mothers. Though Africa accounts for only 10 percent of the world's population, it is home to 90 percent of the world's HIV-infected children, largely as a consequence of high fertility rates combined with very high levels of HIV infections among women. However, the number of cases in India and South East Asia appears to be rising rapidly.

As far as India is concerned, an estimated 30,000, newly born babies are infected every year and the country has over 1,20,000, orphans who are infected with HIV (UNAIDS:1998). Most of the HIV cases among children are reported from Maharashtra, Tamil Nadu and among injectible drug users in the North-eastern State of Manipur. HIV affects children in many ways. Some of the known sources or situations are given below:

- Mother to child transmission: This transmission could occur in the womb, during the time of birth, and through breast-feeding.
- Children who are at risk of infection include street children, child prostitutes and devadasis.
- Institutionalized children like those who are kept at remand homes/ juvenile homes and similar institutions, where child abuse takes place are also at risk of getting infected with HIV.
- Children with diseases like Hemophilia and Thalassemia are also at risk of getting infected with HIV.
- A child can also be infected through drug addiction and due to cultural practices like circumcision, tattooing and genital mutilation.

Check Your Progress I

1. How do children get infected with HIV?

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## 2.3 MODES OF TRANSMISSION AMONG CHILDREN

Let us try to discuss some of the routes of HIV transmission among children.

**Mother-to-Child Transmission**

Mother-to-child transmission is by far the largest source of HIV infection in children below the age of fifteen years. In countries where blood for transfusion and blood products are regularly screened and where clean syringes and needles are widely available in health centers and hospitals, mother-to-child transmission is virtually the only source of infection among young children. The extremely high rates of HIV infection among women of child-bearing age in some parts of the world and increasing risk of infection among women everywhere is therefore a profound cause for worry. A child whose mother is HIV positive can be infected in three ways:

i) In the womb before birth: HIV has been detected in very early foetus and in umbilical cord blood.

ii) A baby can also be infected during delivery by the mother's infected blood or vaginal secretions. This is because during the time of birth the child's skin is very soft and thin which paves the way for the virus to get into its body.

iii) The third means of transmission from the mother to the child is from breast-feeding. Researchers now believe that the handful of documented cases where mothers did transmit HIV by breast-feeding was atypical. In each instance, the mother had received infected blood during blood transfusion immediately following birth and was therefore unusually infectious while she was breast-feeding because of high levels of virus in her blood. It is estimated that about 90 percent pregnant rural women are anaemic, requiring blood transfusions. Medical researchers estimate that the risk of

transmission via breast milk is about 30 percent for mothers who are post-natally infected. The risk is even higher for women who are infected pre-natally, which is as much as 41 percent .

It may be noted that human milk supplied to infants from milk banks operational in some of the hospitals in the country could also be a source for HIV infection, if the milk is not tested for HIV. Similarly infants should not be fed with breast milk of women whose HIV status is unknown.

**Prevention**

There are various ways and means to prevent mother-to-child transmission at various stages. Some of these prevention methods are as follows:

a) **The protection of girls and women from HIV infection:** HIV transmission can be minimized among women of childbearing age if they are provided adequate protection. This strategy is sometimes referred to as "primary prevention". It involves promoting abstinence before marriage, responsible sexual behaviour among couples, providing them with knowledge about HIV/AIDS and about how to prevent infection, and ensuring that they have the necessary personal skills and access to marital and sexual health counselling services so that they can act on their knowledge. It also means providing good quality, user-friendly prevention and treatment programmes for other sexually transmitted diseases (STDs), the presence of which increases the risk of HIV transmission to as much as from 6 to10 fold. And, crucially, it means taking steps to deal with the cultural, legal and economic factors that make girls and women vulnerable to HIV infection by protecting them from such exposures.

b) **The provision of safe/healthy and accessible family planning services:** Safe, healthy and accessible family plannning services will enable women to avoid unwanted pregnancies. The aim is to ensure informed reproductive choice. If a woman is found to be HIV positive, counselling should enable her to give up the desire for conceiving which will further cause her health to deteriorate. Besides the chances of a child being born HIV positive is 25 to 30 percent.

c) **Provision of HIV counselling, testing and treatment:** An integrated package of measures consisting of voluntary HIV counselling and testing (VCT), 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 can also minimize the chances of HIV transmission among children. This package is often referred to as the antiretroviral drug strategy.

Some HIV positive women may not take the anti-retrovrial drugs during pregnancy. Such mothers may refrain from breast feeding, counting on the chance that their babies have not been infected in the womb or during childbirth. But, if they choose this course of action they should be made aware of the fact that they will lose the natural contraceptive effect of breast feeding and be at increased risk of becoming pregnant again unless they take alternative precautions.

Among women from the poor strata of society where child survival is difficult without breast-feeding, a mother with HIV infection may be advised to breastfeed her newborn infant. This view has also been advocated by WHO.

*Caesarean Section:* An HIV positive mother should opt for a caesarean section which will reduce the chances of the child getting infected during delivery.

**Check Your Progress II**

1. What are the methods of prevention available to reduce or totally prevent mother-to-child transmission?

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## 2.4 CHILDREN AT RISK OF INFECTION

**Street Children**

India has the dubious distinction of having the highest number of street children. Most of these children are found in the big cities of the country. They earn their living through ragpicking, working in hotels, involvement in prostitution etc. This group is the most vulnerable because they do not have alternative options. The most valnerable are the girl street children. We will dwell at some length on the risks that they are exposed to. Puberty brings new stresses into young street girls' lives. These girls do not have mothers or female relatives to explain to them that menstrual periods are part of normal life, or help them cope with their anxieties. Most of them are sexually abused even before they are ten.

The street girl may not also develop a positive attitude about menstruation or her new ability to have children. Their poor nutritional status can make their menstrual cycles irregular. They may not understand why months pass in between their periods and may incorrectly conclude that they are pregnant or sick.

Avoiding an unwanted pregnancy may be a constant stress for an adolescent girl. This is especially true when viewed in the context of the high incidence of sexual abuse, rape and victimization suffered by the girls on the streets. They hardly have the emotional, physical and financial resources needed for a pregnancy or for motherhood. An

unsafe abortion, often the only option for a street girl, can cause severe health problems as well as emotional distress and in some cases death. Street girls needing abortion usually approach roadside "doctors" i.e. quacks. This further increases the risk to their reproductive health and also exposes them to other exploitative situations with unscrupulous adults who may lead them to the flesh market.

Service providers from several towns and cities report about street girls becoming pregnant and even delivering babies on the streets, with risks both to the undernourished young mother and her infant. Without having any basic means to support herself, it must be extremely difficult to keep both herself and the baby alive.

The tenderness of the age of street girls does not appear to reduce their risk of sexual abuse. Very often girl children of all age groups are sexually abused or raped. In big cities, hooligans pressurize families to vacate the shanties they occupy and very often use rape as a weapon to terrorize them.

Street girl children also indulge in drug abuse. Most of them pick up the habit unknowingly. Many of them land in brothels against their will. They have no marriage or family life. Under such circumstances, a girl child is exposed to risk factors causing HIV infection.

*Devadasis:* The devadasi system is a practice in India since ancient times, when young girls of certain sections of society were trained as skilled courtesans and were initiated into the profession through a ritual in a temple. This was to propiate the Hindu Goddess Yellamma. This practice is still prevalent in India, especially in the states of Karnataka, and Maharashtra, particularly among some of the economically weaker sections of the society. Young girls are offered to the temple by the time that they reach the age of nine or ten. The temple priests and others sexually exploit these girls even before they have their first menstruation. Many of these girl children get infected with HIV and several of them also land up in brothels or the flesh market.

**Children of Commercial Sex Workers**

While other communities in India dread the birth of a girl child and celebrate the birth of a son, the girl child of a prostitute is welcomed by her mother, the brothel keeper, and pimps as a potential source of income. The estimated six million children of prostitutes in the country have no other options than to follow the profession of their mothers. Given the present situation of HIV/AIDS in the country, many of these children of prostitutes are likely to be HIV infected either from their infected mothers or through the pimps and other customers who engage them for sex at very tender ages.

*Genital Mutilation:* Genital mutilation or circumcision of females is a phenomenon widely practised not only in Africa and the Middle East but also in Asia in the name of tradition. This practice is also prevalent among some communities in India. Genital mutilation is inflicted upon young girls of the age of about ten at the hands of ignorant traditional women at home and not in a hospital set up. Some well-to-do families

in India get it done by medical practitioners by paying them heavily. The practice usually involves the removal of clitoris and sometimes labia minora and labia majora.

Female genital mutilation has several implications. Apart from complications like infection, swelling, severe bleeding and shock; it also leads to problems in sexual activities like sexual intercourse. Initial sexual intercourse will be extremely painful and may cause severe bleeding. Any cut in the vaginal area is a potential source for acquiring the HIV virus from one's partner if the later is HIV positive. Further, neither the female nor the male partner may enjoy sexual intercourse in its real sense. Above all, the women may undergo severe pain and bleeding during childbirth.

**Prevention**

Some of the ways to prevent the spread of HIV among children at risk of infection are:

a) Strict enforcement of available legislations to protect and safeguard children from exploitation.

b) Rehabilitation of street children and children of commercial sex workers.

c) Awareness programme and education for street children and child labourers.

d) Sensitization of the general masses to enable them to see children as precious gifts of God and not as commodities to be exploited and abused.

e) Adopting measures to ban the practice of devadasi system and brothel business.

f) Adequate provisions to be made for taking care of female street children and their various needs.

**Check Your Progress III**

1. Write a brief note on devadasi system and HIV.

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## 2.5 CHILDREN SUFFERING FROM THALASSEMIA, HEMOPHILIA AND DRUG ABUSE

### Thalassemia

Thalassemia is a hereditary disease, widespread in the Mediterranean countries, Asia, and Africa. In this disease there is an abnormality in the protein part of the haemoglobin molecule. The affected red cells cannot function normally leading to anaemia. Other symptoms include enlargement of spleen and abnormalities of the bone marrow. In a number of thalassemic cases, the spleen needs to be removed when it gets enlarged and there is risk of rupture. The spleen is the scavenger of the body. It destroys the dead blood corpuscles but in cases where the spleen cannot get adequate blood, it also takes over the function of making it. This doe great harm. The body does not get good quality blood and the splee. enlarges to be able to meet the demands of the new role. Hence it starts destroying more red blood cells. The exact number of thalassemic cases in the country is not known. Every year approximately 5000 thalassemic babies are born in India. Patients with this disease are treated with repeated blood transfusions. Several patients were believed to have contracted the dreaded disease from infected blood transfusion. Twenty-one cases of HIV infection were reported from one of the hospitals in New Delhi in 1994. There are similar reports from hospitals situated in cities across the country.

### ii) Hemophilia

Hemophilia is an inherited condition, which mainly affects men. The condition involves a reduced capacity for the blood to clot due to a deficiency of factor VIII. Consequently, an otherwise minor accident can be dangerous because the person continues to bleed. Most bleeding occurs internally. The patients suffering from hemophilia are prone to HIV infection because they also require repeated transfusions of blood or use of blood products and these may be infected with HIV.

### iii) Intravenous Drug-Users

HIV is easily transmitted, when persons share infected needles. Small volumes of contaminated blood remain inside previously used needles and syringes thereby providing opportunities to transmit virus via their infected contents.

In India the entire North-eastern region and specifically the state of Manipur is threatened by the spread of HIV through intravenous drug abuse. Drug use is rampant among the millions of street children whom the Indian cities shelter.

### Prevention

Some of the methods of prevention to reduce HIV transmission through blood and blood products are given below.

1) Compulsory Testing of Blood for Transfusion

2) Testing of blood for HIV has been made mandatory in all the developed nations and some of the developing countries. In those countries, every unit of blood is tested for HIV and the governments guarantee full safety for every unit of blood. But in India and many other developing nations, the testing facilities are not adequate. There is also a dearth of trained personnel in blood banks. Therefore one should make sure that every unit of blood is screened for HIV before transfusion through ELISA, western blot or PCR test depending upon the source and time gap between donation and transfusion.

3) Professional blood donation should be avoided. In India a large number of professional blood donors have been found to be HIV infected. Therefore, accepting blood from a professional blood donor has to be discouraged. Instead, every institution and agency in the country should promote voluntary blood donation to meet the blood requirement in the country. Although the Supreme Court of India has banned professional blood donation, one should not take anything for granted in this country. One should make sure that fresh needles are used each time to collect blood from a person through ELISA, western or PCR depending upon the source and time gap between donation and transfusion.

**Compulsory Sterilization of Lab Instruments**

Heat is the most effective method for inactivating HIV. Methods for sterilization and high-level disinfection based on heat are therefore the methods of choice. Sterilization is defined as the destruction of all microbes, including bacterial spores. High level disinfection is defined as the destruction of all microbes.

Therefore equipment used for procedures that draw blood e.g. dental and clinical equipment, or instruments that pierce the skin, must be sterilized. Instruments which involve piercing of the skin by needles as in the case of tattooing, piercing of the ear/nose, acupuncture etc. if not sterilized in a proper manner, present a degree of risk of transmission of the AIDS virus.

When outside the human body, the AIDS virus has been known to be delicate and difficult to transmit. It is easily deactivated by heat (at 56 c). Chemicals such as bleach are effective sterilization agents. It is important to note that antiseptics such as Dettol are ineffective for sterilization. The details about methods of sterilization are given in Block 3 Unit 1.

## 2.6 PROGRAMME ELEMENTS FOR CHILDREN IN FAMILIES AFFECTED BY THE HIV EPIDEMIC

Many of the striking images of the HIV epidemic are found in families: a grandparent surrounded by grandchildren; adolescent-headed families; siblings and cousins bonded together; dying adults being taken care of by their children and communities. It is important to focus on such families rather than on children alone, or youth alone or adults. This

allows for an interfamilial and longitudinal analysis of the needs, skills and resources of families affected by HIV which provides a different basis for determining and ranking the required responses.

While specific programme components will vary according to the stage of disease progression, the situation, culture and resources of each country or community, five main strategic programme elements can be identified. Under each programme element, a number of programme components have been identified. These are not meant to be exhaustive nor are they operational in nature. The specific means of addressing each area may vary from one situation to another. Let us briefly examine each of these areas suggested by Elizabeth Reid (1993).

**Preparing Children for the Future**

Most parents come to know that they are HIV-infected when one of them or one of their children is clinically diagnosed with HIV-related illnesses. The earlier a parent's infection status is known, the more time he or she will have to plan for the children's future, to find another family or person who can care for and shelter them. The parent will also have more time to pass on their skills and knowledge to them, to help the children to support themselves. Knowing their infection status when they are well will help the parents prepare their children and themselves emotionally for their deaths. The longer a parent can work and the longer he or she can be helped to stay well and nurture and raise the children, the less pain and trauma the children will experience.

Components of this program element could include:

i) Access to voluntary, confidential and affordable counselling and testing for adults and the motivation to use available services.

ii) Disclosure of a child's infection to both parents through counselling.

iii) Continued employment of the HIV infected people.

iv) Simple treatment of opportunistic infections.

v) Passing on to children production-and income-generating skills.

vi) Planning children's future care.

vii) Protection of children's inheritance and other legal rights.

viii) Prevention of infection while caring for the sick.

**Assisting children whose parents have died**

Children whose parents have died of HIV-related illnesses have often also lived through the deaths of others close to them: brothers and sisters, aunts and uncles, cousins, friends and, increasingly, grandparents. Their very will to live has often been undermined. If they are to grow and develop as human beings and as members of civil society, they need love and care and the opportunity to form and maintain emotional ties with adults. Their material and psychosocial needs will have to be met; their right to remain integral members of their communities and their legal rights may be at risk and need protection. Consideration can be given to the provision of services to all children within an area

heavily affected by the epidemic rather than only to those whose parents have died of AIDS. The latter approach may lead to resentment and stigmatization of children who receive targeted assistance.

Components of this programme element could include:

i) Minimizing children's psychological and emotional trauma.

ii) Keeping survivors as integral members of their communities.

iii) Basic material needs. Direct assistance is often required by affected families.

iv) Education, training and employment creation.

v) Children's social and adolescent's development needs. To grow and develop into an adult capable of constructive social interaction, children need to be nurtured and stimulated.

vi) Children's and adolescent's sexual development needs.

**Meeting the special needs of HIV-infected children**

As with adults, most asymptomatic HIV-infected children do not know that they are infected. They continue to lead normal daily lives. Simple infection control procedures can protect all family members or institutional workers from transmission of the virus. Both mandatory and voluntary testing has been advocated to determine the HIV status of orphans. However, there are serious ethical issues involved in testing and disclosure to children. Issues which need to be determined include: Who wants to know and why? Will it benefit the child to be tested and know? How? Who should determine this and how? Can a child give informed consent to testing? Public policy needs to be drawn up in this area.

Infants and children with HIV-related illnesses may have special care needs. Meeting them is more difficult where one or both of the parents

is/are also infected or has died.

Components of this programme element could include:

i) Support to families with a sick child.

ii) Promotion of non-discrimination policies and programmes.

**Reaching children and adolescents who are vulnerable**

Among and within families affected by the HIV epidemic, there will be some children or families of children at particular risk of destitution and of HIV infection: urban families without the support of their extended families, families who for whatever reasons lack the support of their communities, children struggling to survive on the streets, children suffering sexual abuse within families, etc. For many of these young people, survival sex, sex in exchange for money, clothing, affection, shelter, food, etc., is a basic coping strategy.

Components of this programme element could include:

i) Assistance to street children.

ii) Reducing the susceptibility of young women to infection.

**Reducing the number of affected children**

This objective can be achieved by decreasing the number of adults becoming HIV-infected. Highest priority must be given to bringing about attitudinal and behavioural change and the change in community norms and values required to bring this about. Because those with less control over their own lives are at greater risk, efforts to improve the socio-economic status of the most destitute and measures to empower women are critical to reduce the spread of the virus.

## 2.7 RIGHTS OF THE CHILD SUFFERING FROM HIV/AIDS

The United Nations Convention on the Rights of the Child in the context of HIV/AIDS has spelt out principles for reducing the children's vulnerability to infection and for protecting children from discrimination because of their real or perceived HIV/AIDS status. Governments need to ensure that the best interests of the children with regards to HIV/AIDS are promoted and addressed . They can use this human rights framework:

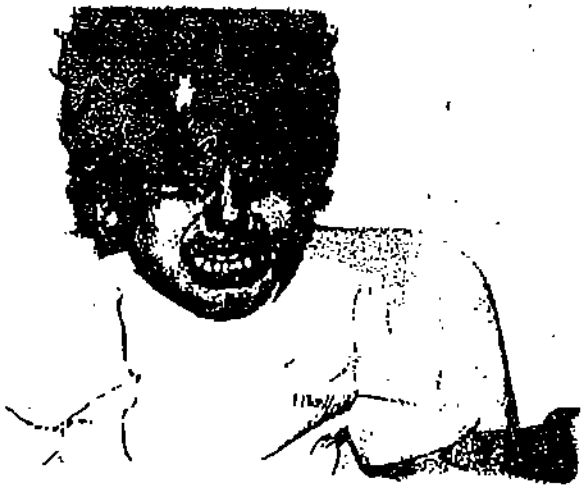
1) States should include HIV/AIDS as a disability, if disability laws exist to strengthen the protection of people living with HIV/AIDS against discrimination.

2) State the profile of children suffering from HIV.

3) Special measures to be taken by the governments to prevent and minimize the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs and harmful traditional practices.

4) Children's right to life, survival and development should be guaranteed.

5) Children's right to confidentiality and privacy in regard to their HIV status should be recognized. This includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved which should be obtained in the context of pre-test counselling. If the children's legal guardians are involved, they should pay due regard to the child's view, if the child is of an age or maturity to have such views.



6) Children should have access to social benefits, including social security and social insurance.

7) Children should have access to HIV/AIDS prevention, education and information, and to the means of prevention. Measures should be taken to remove social, cultural political and religious barriers that block children's access to these.

8) Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.

9) Children should have access to health care services and programmes and barriers to access encountered by especially vulnerable groups should be removed.

10) Children should enjoy adequate standards of living.

(*Source:* The Role of the Committee on the Rights of the Child and its Impact on HIV/AIDS: Problems and Prospects, Presentation by World Health Organization Global Programs on AIDS at "AIDS and Child Rights: The Impact on the Asia-Pacific Region", Bangkok, Thailand, 21-26 November, 1995)

**Check Your Progress IV**

What are the rights to be offered to the child suffering from HIV/AIDS according to the WHO proposal at Bangkok?

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## 2.8 LET US SUM UP

In this unit we have started our discussion stating that most children have acquired AIDS through no fault of their own. In most cases, parents or adult members of the family or societies are responsible. Today, on a global scale, children are becoming infected at about the rate of one child at every minute. As far as India is concerned, HIV infection rate is increasing very rapidly among children.

HIV affects children in many ways. If we categorize HIV infected children, then the major group will be mother to child transmission, children who are at highest risk of infection like street children, child prostitutes, devadasis etc., children with diseases like hemophilia, thalasemia, drug addicts, cultural practices like circumcision and genital mutilation. As the rate of HIV as a whole is increasing, it is found that many children are orphaned. For the development of this group of orphan children, some strategy and planning should be made.

In the last section of the unit some of the proposed rights of the HIV-infected children suggested at the Bangkok meeting by WHO have been enumerated.

## 2.9 KEY WORDS

1. **Azidothymidine (AZT) :** This is also known as zidovudine. This drug interferes with reverse transcriptase and inhibits viral replication and therefore, can retard HIV damage to the immune system. Side effects to the drug can include severe headache and anemia

2. **Hemophilia :** An inherited condition which mainly affects men. The condition involves a reduced capacity for the blood to clot due to a deficiency of Factor VIII. Consequently, an otherwise minor accident can be dangerous

because the person continues to bleed. Most bleeding occurs internally.

3. **Thalassemia :** A hereditary disease, widespread in the Mediterranean countries, Asia and Africa, in which there is an abnormality in the protein part of the hemoglobin molecule. The affected red cells can not function normally leading to anaemia. Other symptoms include enlargement of spleen and abnormalities of bone marrow. Patients with major disease are treated with repeated blood transfusion.

## 2.10 MODEL ANSWERS

**Check Your Progress I**

1. How to children get infected with HIV?

Children get infected with HIV through:

*Mother to child transmission:* This transmission could occur in the womb, during the time of birth, and through breast-feeding.

Children who are at risk of infection include street children, child prostitutes and devadasis,

Institutionalized children like those who are kept at remand homes/ juvenile homes and similar institutions where child abuse take place are also at risk of getting infected with HIV.

Children with diseases like Hemophilia and Thalassemia are also at risk of getting infected with HIV.

A child can be infected through drug addiction and due to cultural practices like circumcission, tattooing and genital mutilation.

**Check Your Progress II**

1. What are the preventive methods available to reduce or totally prevent mother-to-child transmission ?

There are various ways and means to prevent mother-to-child transmission at various stages. Some of these prevention methods are as follows:

i) **The protection of girls and women from HIV infection:** HIV transmission can be minimized among women of childbearing age if they are provided adequate protection. This strategy is sometimes referred to as "primary prevention". It involves promoting abstinence before marriage, responsible sexual behaviour among couples, providing them with knowledge about HIV/AIDS and how to prevent infection, and ensuring that they have the necessary personal skills and access to marital and sexual health counselling services so that they can act on their knowledge. It also means providing good quality, user-friendly prevention and treatment programmes for other sexually transmitted diseases (STDs), the

presence of which increases the risk of HIV transmission to as much as from 6 to10 fold. And, crucially, it means taking steps to deal with the cultural, legal and economic factors that make girls and women vulnerable to HIV infection by protecting them from such exposures.

ii) **The provision of safe/healthy and accessible family planning services:** Safe, healthy and accessible family planning services will enable women to avoid unwanted pregnancies. The aim is to ensure informed reproductive choice. If a woman is found to be HIV positive, counselling should enable her to give up the desire for conceiving which will further deteriorate her health. There is also the chance of giving birth to a child which has about 25 to 30 percent chances of being born with HIV.

iii) **Provision of HIV counselling, testing and treatment:** An integrated package of measures consisting of voluntary HIV counselling and testing (VCT), 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 can also minimize the chances of HIV transmission among children. This package is often referred to as the antiretroviral drug strategy.

Some HIV positives women may not take the antiretroviral drugs during pregnancy. Such mothers may refrain from breast feeding, counting on the chance that her baby has not been infected in the womb or during childbirth. 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 again unless she takes alternative precautions.

Among women from the poor strata of society where child survival is difficult without breast-feeding, a mother with HIV infection may be advised to breastfeed her newborn infant. This view has been advocated by WHO also

***Caesarean Section*:** An HIV positive mother should opt for a caesarean section which will reduce the chances of the child getting infected during delivery.

**Check Your Progress III**

1. Write a brief note on devadasi system and HIV.

*Devadasis:* The devadasi system is a practice in India since ancient times, in which young girls of certain sections of society were trained as skilled courtesans and were initiated into the profession through a ritual in a temple. This was to propiate the Hindu Goddess Yellamma. This practice is still prevalent in India, especially in the states of Karnataka, and Maharashtra, particularly among some of the economically weaker sections of the society. Young girls are offered to the temple by the time that they reach the age of nine or ten. The temple priests and others sexually exploit these girls even before they have their first menstruation. Many of these girl children get infected with HIV and several of them also land up in a brothel or flesh market.

**Check Your Progress IV**

1. What are some of the major rights to be offered to the child suffering from HIV/AIDS according to the WHO proposal at the Bangkok meet ?

   Some of the major rights to be offered to a child suffering from HIV/AIDS according to the WHO proposal at Bangkok meet are:

   i) States should include HIV/AIDS as a disability, if disability laws exist to strengthen the protection of people living with HIV/AIDS against discrimination.

   ii) State the profile of children suffering from HIV.

   iii) Special measures to be taken by the governments to prevent and minimize the impact of HIV/AIDS caused by trafficking, forced prostitution, sexual exploitation, inability to negotiate safe sex, sexual abuse, use of injecting drugs and harmful traditional practices.

   iv) Children's right to life, survival and development should be guaranteed.

   v) Children's right to confidentiality and privacy in regard to their HIV status should be recognized. This includes the recognition that HIV testing should be voluntary and done with the informed consent of the person involved which should be obtained in the context of pre-test counselling. If the children's legal guardians are involved, they should pay due regard to the child's view, if the child is of an age or maturity to have such views.

   vi) Children should have access to social benefits, including social security and social insurance.

   vii) Children should have access to HIV/AIDS prevention, education and information, and to the means of prevention. Measures should be taken to remove social, cultural political and religious barriers that block children's access to these.

   vii) Children should have access to HIV/AIDS prevention education and information both in school and out of school, irrespective of their HIV/AIDS status.

   viii) Children should have access to health care services and programmes and barriers to access encountered by especially vulnerable groups should be removed.

   ix) Children should enjoy adequate standards of living.

## 2.11 FURTHER READING

1. Thomas Gracious (2001). HIV Education and Prevention – Looking Beyond the Present, Shipra Pulications, New Delhi.
2. NACO (2000). Training Module for Health Workers and Supervisors on RTI/STD and HIV/AIDS Prevention and Control, NACO, New Delhi.
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# UNIT 3 HIV/AIDS RELATED INTERNATIONAL LEGISLATIONS

**Contents**



## 3:0 AIMS AND OBJECTIVES

Once you are through this unit, you should be able to:

- list the efforts made through legal provisions to address issues pertaining to HIV/AIDS across the globe,
- describe the scope and contents of legislations enacted in some of the developing and developed countries around the world on HIV/AIDS, and
- discuss the legal regulations brought in to restrict unethical practices in various settings with regard to HIV/AIDS.

## 3.1 INTRODUCTION

The advent of Human Immuno deficiciency Virus (HIV) and Acquired Immuno deficiency Syndrome (AIDS) has posed increasing dilemmas to Human society. As millions of people all over the world are affected by this epidemic, controversies are plenty concerning the origins of this disease, and the socio-economic, political and legal consequences. Issues of poverty, discrimination, draconian laws etc. make the HIV/AIDS a socio-economic, political and legal disease. In this unit, let us examine the legal provisions enacted by some of the developed and developing countries around the world.

## 3.2 DEFINITION AND EARLY LEGAL EFFORTS

Let us make an effort to define HIV related laws:

"HIV related law can be defined as that branch of the law that specifically addresses the problems, issues and challenges posed by the HIV epidemic by:

1) supporting and channelling resources for epidemiological surveillance, policy initiatives and interventions;
2) mandating interventions for healthier life styles and other preventive measures such as education, counselling, treatment and disease management;
3) establishing the rights and duties of persons with HIV/ AIDS as well as of others;
4) regulating human behaviour and laying down norms for conduct;
5) specifying the quality and use of products such as blood, semen, organs, tissue, HIV test kits and condoms; and
6) creating a supportive and enabling environment in which affected individuals and communities as well as others can mutually co-exist to enhance their quality of life." (Jauasuriya: 1995).

The early laws enacted essentially focused on notification of cases, blood safety, institutional mechanisms, education, funding and research and safety precautions. In 1983 about 12 countries like Canada, USA, Sweden, Denmark, Italy, Greece, France etc enacted HIV laws.

Developing countries started joining in only by 1984 when countries like Chile, Uruguay and Venezuela from South America enacted legislation. But most of the countries introduced legislation by 1987 when the World Health Organisation started the Special Programme on AIDS. Countries from Africa are still lagging behind and have not given priority to legislation in this regard, even though, it is the most affected continent today.

**Scope and Content**

During the 1980's the HIV laws addressed only the AIDS patients. Now, these legislation are applicable to AIDS/ HIV infection and high-risk groups, blood donors, sex workers, drug injectors, homosexuals etc. There is no universal descriptive labelling attached to HIV or AIDS. Most societies use terms like 'communicable', 'infectious', 'notifiable' diseases, 'sexually transmitted disease' or 'venereal disease' when referring to HIV/AIDS. Some legislator's use no description at all. Developments in medical technology have helped in the evolution of HIV laws. For example, the use of western blot test before a person is notified as an HIV patient is a significant legislative development.

**Key Issues in Legislation**

In the following section, let us examine some of the key issues that are subject matter of legilsation pertaining to HIV/AIDS.

1) *Regulation of Blood and Blood Products*

The main concern under area is to protect the supply of blood by requiring screening tests to be undertaken and to discourage AIDS/HIV patients as well as the high risk groups from donating blood. In the same manner restrictions are also placed on donating semen, tissues, organs etc,. Many countries like Denmark have provisions for compensation to be paid to haemophilia patients who contract HIV infection from donated blood. In most of the US courts blood is considered as a 'service' and not a 'product', thus, there is no strict liability for contaminated blood. Most of the developed countries have centres that provide confidential test reports on the HIV status of persons who want to find out the same.

2) *Regulations Imposed on Certain Behaviour*

These measures are mostly concentrated on high risk groups like sex workers. In Austria, they have to undergo periodic tests and the licences of those found having HIV virus are cancelled. However, most of the countries have no provision to register commercial sex workers nor is there any legal requirement to do compulsory medical examination. Some countries have banned massage parlours and bath houses while others require distribution of condoms at hotels, bars and restaurants etc.

The criminal laws of many countries make it an offence to intentionally or through negligence to cause or spread infectious diseases. Some laws declare it an offence punishable with imprisonment to expose a person to AIDS or knowingly transmit AIDS. A US law makes it an offence for a commercial sex worker to solicit after testing HIV positive.

3) *Screening*

The debate whether screening should be mandatory or voluntary still continues. Some states in the USA have compulsory screening for certain categories of population including marriage applicants, pregnant women, new borns, hospital patients, mentally ill or retarded patients, prisoners, commercial sex workers, intravenous drug users and sex offenders. Several countries have categories that include foreigners. The 1990 USSR Regulations on medical testing for detection of HIV has listed several categories. Some of them are:

1) Donors of blood, blood plasma, and other biological fluids and tissues, on the occasion of each donation
2) Soviet citizens returning from abroad after more than three months stay
3) Foreigners who have come to the USSR for any purpose, within ten days of their arrival. Those having certificates recognised by the USSR to the same effect are exempted
4) Soviet citizens going abroad to countries where such certificate is required
5) Soviet citizens and foreigners who had sexual contact with AIDS patients or with carriers of the virus and have been identified
6) Patients with certain clinical symptoms

7) Patients with suspected or confirmed diagnosis of certain sickness
8) Children born of HIV-infected mothers
9) Patients receiving blood transfusions or blood products
10) Pregnant women upon admission to maternity unit, when an AIDS test result is not available
11) Pregnant women undergoing examination for abortion
12) Children admitted to intensive care, cancer, chest, and haematology units
13) People suffering from sexually transmitted diseases applying for medical care
14) Medical personnel working with the virus or treating the AIDS patients
15) People in the risk groups: drug abusers and addicts, homosexuals and bisexuals and those engaged in prostitution
16) People in risk groups placed in solitary confinement or in corrective labour establishments etc, upon admission and release
17) People with no fixed abode and engaged in vagrancy

More than fifty countries require one or more of the following categories of foreigners to be tested on arrival or submit a certificate to the effect of their non HIV status. Some of the persons are:

1) Applicants for work permits
2) Applicants for residence permits
3) Applicants for naturalization
4) Immigrants
5) Tourists
6) Refugees
7) National returning to country
8) Foreign students
9) Cabaret artists
10) Foreign defence contractors
11) Nationals who are pilots or marine crew members
12) Returning national who are seamen or entertainers
13) Truck drivers who cross national frontiers
14) Visitors coming frequently
15) Foreigners wishing to marry nationals, and
16) Persons who have developed clinical symptoms

4) *Reporting and Contact Tracing*

Most of the countries with HIV legislation require notification of AIDS cases. Contact tracing is a public health strategy used for the traditional

sexually transmitted diseases. Many states in the USA have classified AIDS as a sexually transmitted disease and thus, made the contact tracing applicable to AIDS as well. Some legislation provide for tracing the sexual contacts of the AIDS patients and seropositive persons. Hungary requires sexual partners of such persons to be placed under epidemiological surveillance.

5) *Detention, Isolation and Quarantine*

Many countries use measures to curtail the mobility of the AIDS patients and to submit them to tests, examination and treatment. Some countries even have steps to identify their sexual partners. All these are coercive measures curtailing individual freedoms. These options are available to them as AIDS has been classified under the communicable, infectious, notifiable, or sexually transmitted diseases category. Some of the States of the U.S., and China provide for quarantine and isolation. In Cuba, AIDS patients are send to sanatoriums. It is now being realised that such strong measures are counter productive, but countries with such laws are not repealing the same in any hurry.

6) *Restrictions*

Certain groups like the homosexuals, bisexuals and sex workers and even some nationalities and ethnic groups are being discriminated against by linking AIDS to their promiscuous conduct. Ignorance and fear have played havoc by having children with HIV/AIDS being debarred from schools, workers being dismissed and tenants being evicted. Confidentiality has assumed a very important role in reporting, screening, discrimination etc. The failure to guarantee confidentiality of the HIV status has resulted in violation of privacy and many other related rights of the patients. Some of the discriminatory practises imposed on the HIV patients include the following:

— Restrictions on the movement of persons across national frontiers;

— Restrictions on freedom on internal travel due to compulsory hospitalisation or other reason such as quarantine or isolation;

— Restrictions on sexual behaviour;

— Restrictions on donation of blood, semen, breast-milk or organs;

— Restrictions on freedom of occupation; and

— Other forms of restrictions like marriage contracts.

7) *Role of Criminal Law*

In some countries like Australia, Korea and Singapore, it is a criminal offence for a person who is aware of his HIV status to have sex with another unless the fact is disclosed and the other person has voluntarily accepted the risk. Courts in the USA have convicted persons who have transmitted the virus. Criminal sanctions are provided in respect of blood, semen, organs donations when the donor is HIV positive. The sex industry also has attracted criminal sanctions on activities like soliciting, pimping, maintaining brothels etc. Under a law in the Australian state of Victoria, the brothe owner must provide free supply of condoms and

water based lubricants to the clients and the sex workers. The brothel owner is also under obligation to provide written information, in many languages, on sexually transmitted diseases.

8) *Access to Needles and Syringes*

Some countries provide for a system of exchanging new needles for those already used. Travellers to high risk areas are advised to carry their own supply of needles and syringes as they may not be available. But in some countries these would be a serious offence under their drugs laws while others prescribe compulsory treatment of drug users.

9) *Education and Counselling*

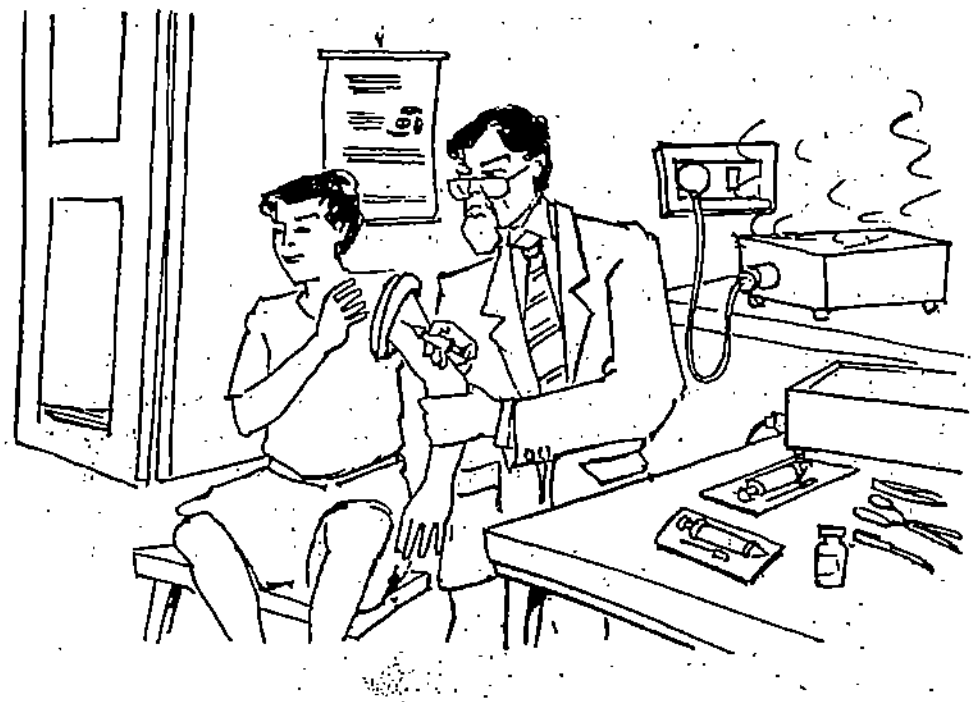
Education and counselling have been accorded priority in many countries. Some States of the USA have made mandatory AIDS education programmes stressing the need for sexual abstinence outside marriage. There are also countries that do not allow public advertisement of condoms. Some countries have made pre/post testing counselling mandatory to minimize the psychological trauma of HIV positive finding.

10) *Treatment, Services and Research*

The 1990 USSR laws make drugs available to HIV/AIDS patients. In the USA law promotes research in AIDS related treatments and services. Some states have made medical, mental health, social, housing, testing and financial services available to AIDS patients and their families.

11) *Pharmaceutical Laws and Clinical Trails*

Clinical trails have brought in sharp focus on legal and ethical issues. Few developing countries control clinical trails. Though the US Food and Drug Administration has been quick to adapt procedures governing the investigational use of new drugs, it is still not clear how drug regulatory authorities can best respond to the research based industry.



Transmission of AIDS through blood or blood products have been greatly eliminated/minimized due to the legal requirements for screening blood, semen, organs etc. at the time of donation/transfer at least in developing countries. The symbolic effect of legislation through the discussions and debates have made their impact on the behaviour and attitudes and sensitized the public to some extent. Improved mechanics of collecting, screening and storing blood and use of good quality condoms have effectively slowed down the spread of HIV virus. What once was simply a question of tracking down HIV infection, law now has to regulate human behaviour with respect to the rights of the individuals, whether infected or not. HIV is no more a virus alone. Today, it challenges the ways we regulate inter-personal relationships. HIV law once dealt with notification, isolation, quarantine or other restrictions that are applicable to other communicable diseases. Today, it is more concerned with social, economical, cultural, ethical, legal and human rights environment that regulates human behaviour. Experience of the epidemic has demonstrated everyone's vulnerability. Social prejudices, unequal power relations as well as the unjust laws have added to this plight. Under the circumstances, the HIV law should address itself to those aspects of development that affect the quality of life of the individual and the society.

**Check Your Progress I**

1) Define the HIV law?

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2) What do you understand by regulation of blood and blood products and screening?

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3) Who are the people who are normally asked to undergo HIV tests?

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## 3.3 HIV LAW IN EUROPE DURING THE 1980's

Having discussed details about some of the key issues regarding HIV and legal implications, let us now examine the laws enacted or in place in respect of HIV/AIDS in Europe during the 1980's.

In 1983, legislative activity on HIV/AIDS started in Europe. The Swedish National Board of Health and Welfare issued regulations to survey suspected and confirmed cases of AIDS in order to provide the information needed to determine whether preventive measures are required. France was the first one to draw attention to the possibility of HIV transmission through blood transfusion. Soon the member states of the Council of Europe were advised to provide all blood donors information on AIDS, so that 'those in risk groups will refrain from donating. The 1983 Declaration on AIDS adopted by the Parliamentary Assembly of the Council of Europe affirmed 'unshakable attachment to the principle that each individual is entitled to have his privacy respected and to self-determination in sexual matters.' Earlier in 1981, it had noted its concern on the issue of discrimination against homosexuals raised through inaccurate media campaigns linking AIDS to homosexuality. During 1983, both Austria and Greece had made precautionary reccomendations addressed to health and laboratory personnel.

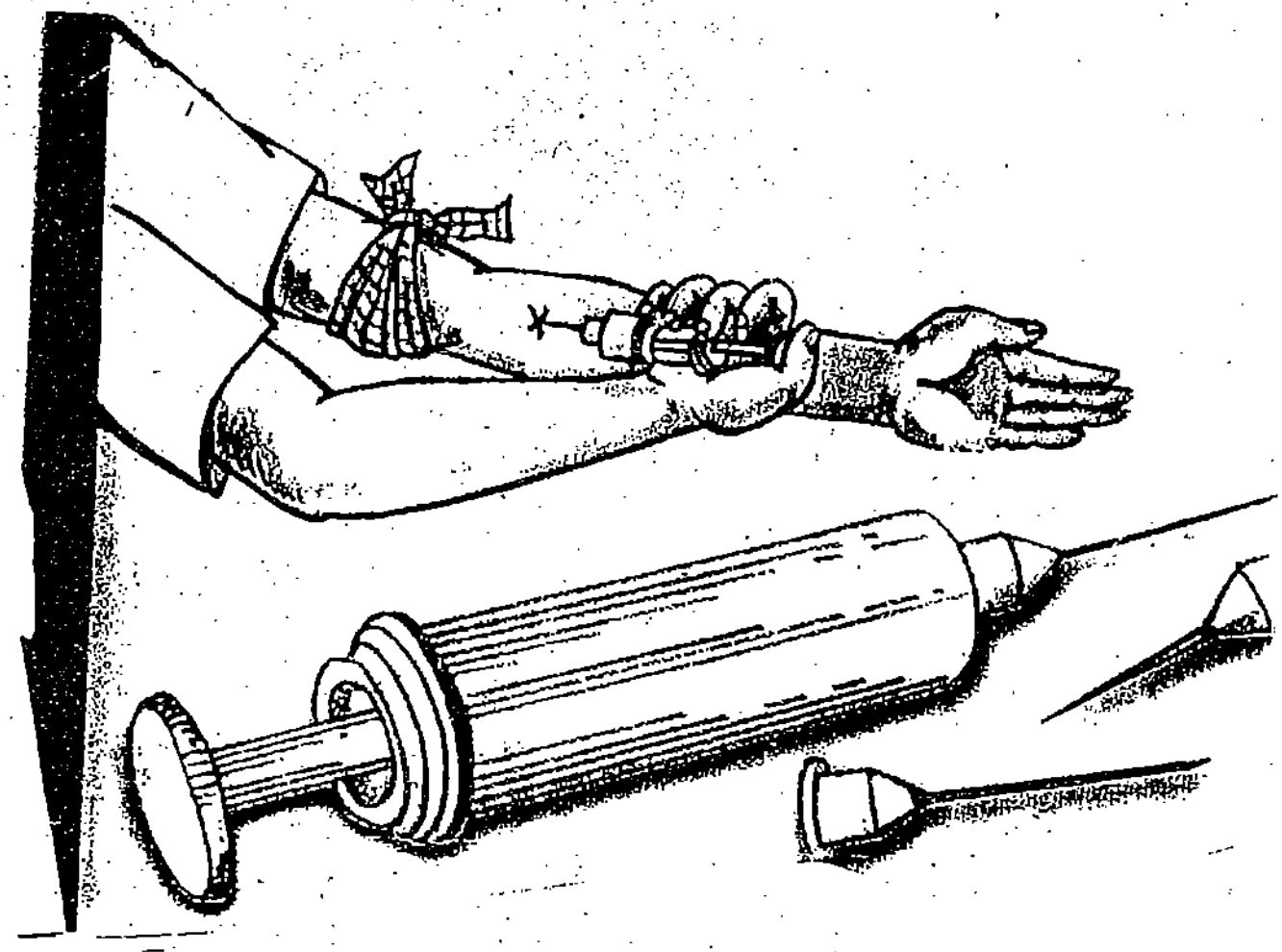
### Austria

Austria was the first country in Europe to enact a comprehensive statute on AIDS. This AIDS Law had the provisions for the following aspects:

1) Notification of AIDS cases and deaths from AIDS
2) Preservation of confidentiality
3) Prohibition on AIDS-infected persons engaging in prostitution.
4) Screening of prostitutes

you would have even said, "as if those who do not abuse substance never get HIV". If you have reacted in any of these ways, it shows you have started thinking about substance abuse very deeply.

We will try in this section to find out the connection between substance abuse and prostitution. Addiction has close connection with lewd thinking and action. Though we may not be justified in making a sweeping statement, it is a known fact that alcohol provokes sexual desire . With all the problems that are likely to be created in an alcoholic's home and the bad company an alcoholic will have, it is natural that an alcoholic indulges in multi-partner sex. It has already been mentioned in the previous sections that having multi-partner sex is responsible for the spread of HIV. We have also established that with the compulsive desire, an addict makes money just to keep his habit going. Selling one's body is the easiest way for a drug addict to earn money for the procurement of drugs. Many of the women in prostitution are in the habit of taking drugs. Drug abusers, especially women, do not hesitate to take up prostitution as they need a lot of money to keep their habit going. If they are in the habit of injecting drugs they are more vulnerable to contracting HIV. Even within a group of drug abusers, there is a possibility for having multi-partner sex and this also leads to the spread of HIV. So a substance abuser, whether male or female has more chances of contracting HIV/AIDS.



## 3.7 INJECTING DRUGS AND HIV/AIDS

We discussed the various ways in which drugs are usually taken. Do you remember them? Oral intake (drinking, chewing and swallowing), smoking, injecting and sniffing or snorting are the ways in which drugs are taken. Of these, injecting the drug has a very close link with the spread of HIV/AIDS. Before establishing the link between injecting drugs and HIV/AIDS, we should know some basic facts about the habit of injecting drugs and the drugs usually injected. A question that you may raise is why do some people go for injecting? It is the hardcore drugs that are used for injecting. There are three ways in which drugs are injected. Some inject it under the skin ('skin popping') while some go in for intramuscular injection (injecting deep into the muscles). Intravenous intake (mainlining) or injecting directly into the vein is the third method of injecting. Morphine, codeine, heroin, methadone, methaqualone, tranquilizers like benzodiazepines, cocaine, amphetamines etc. are the drugs that are usually injected. People indulge in injecting drugs for different kinds of experiences with substances.

But little do the drug abusers realize the risk involved in injecting drugs. As you are aware, usually substance abusers take drugs in company. When people sit in a group and take drugs, usually the same needle is used to prick different persons. In the previous sections we saw that drug addicts are more prone to contract HIV/AIDS either because of their multi-partner sexual behaviour or because of the close link between prostitution and substance abuse. Now in a group of substance abusers using the method of injecting the drug, if one person is HIV positive, the other members of the group who share the same needle are at a greater risk of getting HIV. Remember, even if the drug abusers are aware of the risk involved in sharing the needle, they won't have the patience to sterilize the needle every time or change it as substance abusers are usually in a desperate hurry to inject the drug. In states like Manipur,the HIV prevalence rate is very high among substance abusers who inject drugs.

A case study presented in the book *Broadening the Front and NGO Responses to HIV and AIDS in India* is worth presenting here as it shows the close link between substance injecting and HIV/AIDS.

**Case Study**

A few years ago Abdul and I used to live together, and we would share our money to buy drugs. Then Abdul went to stay at SAHARA, and had an HIV test, which turned out to be positive. I was very worried about myself, because I had shared equipment with Abdul. I went to SHARAN for advice. A counsellor took me to a nearby teashop and I told him I wanted to get the HIV test done.

I decided that I would join SAHARA for rehabilitation if my result was negative, but if it was positive I would keep on injecting because I didnot care about the future. The counsellor explained a few things about AIDS, and the test. He also explained why sharing injecting equipment is risky, and what one can do to make it safe, like cleaning

the needle with household bleach. I said I would rather use the money on heroin. One shot of heroin costs 12 rupees and a bottle of bleach costs 10 to 15 rupees.

A couple of days later the counsellor took me to a clinic for the test. We had to wait for an hour and a half to have my blood taken. It was very hard for me because a social worker there knew me and kept asking me personal questions, until the counsellor asked him to leave me alone.

It took almost two weeks to get my test result. The counsellor from SHARAN took me to a quiet place and told me that I had tested positive. I thought I had AIDS. But the counsellor told me that I would not fall sick with AIDS for a long time if I led a healthy life. I asked him if I could change my blood if I stopped using drugs, but the counsellor told me that I didn't get the virus through heroin, but through another person's blood.

I decided to come and live at SAHARA, and Abdul and I now share a room. A few days ago I met another old friend, Salman. He's a drug user and he's shared equipment with me. I started thinking about other members of our group—Sameer and Mohammed for example. They've also shared equipment with Abdul and me. But how can I tell them that we have HIV?

## 3.8 LINK BETWEEN SUBSTANCE ABUSE AND HIV/AIDS AND THE WAY OUT

We have seen in the previous sections that there is a close link between substance abuse and the spread of HIV/AIDS. This link is true not only of India but worldwide. Now that this link has been established we should be in a position to suggest ways out of this predicament that are effective and practical. Though what we suggest here may not be exhaustive and may not be applicable to all parts of the world and all sections of the society, the suggestions may be useful.

*Motivating the youth:* The youth should be motivated to keep off drugs. Conscientization, awareness programmes, using the media, including lessons on the evils of substance abuse are some of the ways through which we can motivate the youth. The youth should be equipped in such a way that they will never experiment with drugs and they will boldly say "NO TO DRUGS".

*Encouraging voluntary blood donation:* The youth should be told that blood donation will not do any harm to our health. If there are voluntary blood donors with clean habits and good sexual morality, passing on HIV through blood donation can be avoided.

*Enacting and implementing laws:* Strict laws and severe punishments may deter a person to some extent from becoming an addict. In India drug trading is a serious offence and strict vigil and implementation of the laws will prevent drug trade to a very great extent. Conscientisation

programmes as suggested above, along with implementing the law will do a good job in supply and demand reduction.

*Health care to substance abusers and compulsory testing of blood and blood donors:* Care should be given to substance abusers in such a way that neither do they get HIV/AIDS nor are they allowed to infect others. When supply and demand reduction tactics fail, in some parts of India and also in the Western world, methods like needle exchange are adopted.

## 3.9 LET US SUM UP

In this unit we have tried to study what substance abuse is and its connections with the spread of HIV/AIDS. We looked at the different ways in which they are taken. We also tried to look at the life of an addict and discussed the link between substance abuse, blood donation and HIV/AIDS, the link between substance abuse and prostitution and also the link between injecting drugs and HIV/AIDS. An attempt was also made to suggest ways by which we can fight against substance abuse with a view to curtail the spread of HIV/AIDS.

**Check Your Progress II**

1. Can you suggest at least four ways of finding a way out to reduce HIV infection through substance abuase?

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## 3.10 MODEL ANSWERS

**Check Your Progress I**

1. According to WHO definition, when does a person become an addict?

According to the definition of WHO a person becomes an addict when:

1) He has the compulsive desire to continue to take the drug.
2) He is willing to get it by any method .
3) He increases the dose in such a way that he becomes psychologically and physically dependent on its effect.
4) If the physical or mental faculties or both are affected due to taking the drug, the person may be termed as an addict.

2. How would you categorize the commonly abused drugs?

The commonly abused druigs can be categorized as:

- Depressants

- Stimulants
- Hallucinogens and
- Narcotics.

3. What are the four major methods of taking drugs?

There are many ways in which the drug abusers consume drugs or substances. The very common way is oral intake, that is drinking or swallowing. Alcohol is usually drunk and opium is swallowed. Smoking is another way of taking drugs. For example cannabis or ganja is usually smoked. Drugs like heroin and cocaine are sniffed or sent through the nostrils.

This is called inhalation Another method is intake with needles or injecting the drug. Drug injection is the method that has a close link with the spread of HIV/AIDS. This will be discussed in depth in the following sections. The table below gives information about the different types of drugs and how they are taken.

**Check Your Progress II**

1. Can you suggest at least four ways of finding a way out to reduce HIV infection through substance abuse?

*Motivating the youth:* The youth should be motivated to keep off drugs. Conscientization, awareness programmes, using the media, including lessons on the evils of substance abuse are some of the ways through which we can motivate the youth. The youth should be equipped in such a way that they will never experiment with drugs and they will boldly say "NO TO DRUGS".

*Encouraging voluntary blood donation:* The youth should be told that blood donation will not do any harm to our health. If there are voluntary blood donors with clean habits and good sexual morality, passing on HIV through blood donation can be avoided.

*Enacting and implementing laws:* Strict laws and severe punishments may deter a person to some extent from becoming an addict. In India drug trading is a serious offence and strict vigil and implementation of the laws will prevent drug trade to a very great extent. Conscientisation programmes as suggested above, along with implementing the law will do a good job in supply and demand reduction.

*Health care to substance abusers and compulsory testing of blood and blood donors:* Care should be given to substance abusers in such a way that neither do they get HIV/AIDS nor are they allowed to infect others. When supply and demand reduction tactics fail, in some parts of India and also in the Western world, methods like needle exchange are adopted.

## 3.11 KEY WORDS

**Commercial Sex Worker:** Prostitute

**HIV:** Human Immunodeficiency Virus that causes AIDS.

**Multi-partner Sex:** Having sex with more than one partner.

**NIMHANS:** National Institute of Mental Health and Neurological Science.

**Professional Blood Donor:** One who frequently gives his blood for money.

**Withdrawal Symptoms:** Problems, especially physical, an addict develops when he suspends taking drugs.

## 3.12 FURTHER READING

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# UNIT 4 STDs AND THEIR MANAGEMENT

**Contents**



## 4.0 AIMS AND OBJECTIVES

In this unit you will learn about Sexually Transmitted Diseases (STDs) and its importance in the context of HIV/AIDS. By the end of this unit you should be able to:

- understand the link between STDs and HIV infection.
- classify and know the causes, symptoms, treatment and prevention of Sexually Transmitted Diseases.
- understand the efforts of the Government to reduce the impact of HIV/AIDS and STDs.

## 4.1 INTRODUCTION

There is an important link between STDs and HIV infection. One cannot properly understand one without adequate knowledge of the other. One can worsen the other. Controlling one disease can help controlling the other. Therefore, in a course on HIV/AIDS, it is always essential to have a comprehensive section on STDs. Before starting on this unit it is important to revise the Basic Course on HIV/AIDS. BLOCK -I- unit - III, Block - II, unit - I and from the Basic course on Family Education, Block - III, unit - I and II.

## 4.2 DEFINITION AND MEANING

STD stands for Sexually Transmitted Diseases. Earlier, STDs were known as venereal diseases or VD. STDs are diseases which are communicable and are transmitted by an infected man or woman to his/

her partner during sexual intercourse. For this reason they are called Sexually Transmitted Diseases.

A person becomes infected with STDs when he or she has:

1) Vaginal sexual intercourse or

2) Anal sexual intercourse or

3) Oral sex with an infected person.

The vagina, penis, rectum and mouth are the sources from which the STD germs can invade the body.

**Statistics**

India has a high incidence of STDs with annual incidence rate of 5 per cent. Thus on an average 40 million new cases are reported every year. An established 3 - 4 percent of the total population is suspected to be having STDs.

**History of STDs**

Prostitution is one of the oldest institutions of the Human Society. As every coin has two sides, this old practice too has two aspects and the behaviour pattern and the price one has to pay for it in terms of the risks attached to such practices- i.e the STDs. STDs have been in existence for centuries. Syphilis, one of the best known STDs before AIDS came into the picture, took away lives of thousands of people during the first decade of the 20th century. Later, Gonorrhea became known, as another common STD. Fortunately, with the discovery of penicillin, both these STDs could be treated. Since then more than twenty STDs have now been identified and they affect millions of men, women and even children every year.

**Misconceptions**

There are many misconceptions prevalent in India regarding sexually transmitted diseases. It is important to know about these misconceptions.

**Regarding STD Transmission**

Lack of genital hygiene, for example—visiting dirty toilets, using unclean underclothing etc., causes STDs.

'Excessive Heat' caused through eating spicy food or drinking alcohol or through constitutional or occupational reasons leads to STDs.

Non-sexual contact with an infected person, eg. touch, sharing objects, sharing the same toilet etc. causes STDs.

**Regarding STD Prevention**

The only way to prevent STDs is to avoid CSWs or wash the genital area with one's own urine, water, soda or lime juice.

**Regarding STD Treatment**

- Home remedies are believed to be adequate for STD treatment.

- Sexual intercourse with a child, a virgin or an animal is said to cure STDs.

## 4.3 IMPORTANCE OF STDS

Why are STDs Important?

STDs are important for many reasons, which include:

- Millions of men, women and children are infected with STDs each year. India provides a vast playground for the rapid spread of STDs. The main cause for this spread is ignorance.
- Many STDs show early symptoms, which then disappear without treatment, but the germs continue to remain in the body, causing damage to different parts of the body. Anyone with an STD may look and feel healthy but can still keep infecting others. Very often, the infected people do not inform their sexual partners.
- STDs can occur again and again in the same individual because the human body cannot build immunity against them and there is no vaccination for them.
- These diseases can have serious consequences on those suffering from them .They can cause blindness, sterility and even death.
- Some of the STDs produce ulcers on the genitalia. These STDs which produce ulcers are collectively called genital ulcer disease or GUDs. These GUDs are associated with an increased risk of HIV transmission. A woman is more likely to be infected by a HIV positive person with GUD than one without GUD. Similarly if a woman is HIV positive and has GUD, she is more likely to pass on the infection.
- STDs can cause profound problems in women. STDs in women can occur without any symptoms. These STDs can then spread into the uterus and the fallopian tubes and cause pelvic inflammatory disease, which can be quite painful. As a result of this, the tubes can get blocked and the woman may not be able to produce children (sterility). In other instances, a tubal pregnancy can occur and sometimes this can be fatal.
- Another important problem, which STDs can cause in women, is cancer, especially of the cervix, which is the lower portion of the uterus. One of the STDs, namely, Human Papilloma Virus (HPV) can result in genital warts and also leads to cancers.
- Untreated STDs can cause several complications in adults and these include liver problems, heart problems and brain problems.
- If a women has untreated STD and she is pregnant, then it can cause problems in the new born child such as conjunctivitis (inflammation in the eyes), blindness or pneumonia. Sometimes these children may be born with defects in their organs and therefore are permanently disabled.
- Health Education and counselling to STD patients is an important

component for the prevention and control of STDs. Those who are at risk of acquiring STDs are also at risk of acquiring HIV infection.

- It is important that a person with STD should complete the full course of treatment, even if he feels better. Incomplete treatment may lead to chronic infection, with potential, serious, long-term, consequences. It is important for the patients to return for further treatment also, if he is not feeling improved with the first treatment.

**Importance of STDs in relation to HIV/AIDS**

The relationship between STD and HIV infection is manifold.

- First of all STD and HIV infection are associated with the same risk behaviours, that is sexual intercourse with multiple partners. Thus the same measures that prevent STD also prevent sexual transmission of HIV infection.
- The presence of STD has been found to facilitate the acquisition and transmission of HIV infection. It is believed that for those STDs associated with genital ulcer disease such as syphilis, chancroid and herpes, the risk of HIV transmission increases ten-fold.
- For those STDs associated with discharge such as Gonorrhea, Chlamydia and Trichomoniasis the risk of HIV disease is four-fold. Thus early diagnosis and the treatment of STD can contribute significantly to a reduction in HIV transmission.
- Other routes of transmission for HIV and STDs are also similar. In addition to sexual transmission, HIV/AIDS can also be transmitted through blood, blood products, donated organs or tissue, and ffom mother to newborn infant.
- Many of the measures for preventing the sexual transmission of both HIV infection and STDs are the same. Therefore STD clinical services are important access points for persons at high risk for both HIV and STD, not only for diagnosis and treatment but also for education for prevention.

Increasing evidence suggests that there is increased severity of manifestations of STDs and reduced response to conventional therapeutic regencies in HIV infected persons.

Trends in STD incidence can be used as indicators of changes in social behaviour. It is easier to monitor trends in STD reduction than the spread of HIV.

## 4.4 STDs AND TREATMENT OPTIONS

Let us now try to understand some of the common STDs, their signs and symptoms and treatment options.

**Syphilis**

Syphilis is the oldest of the STDs, and was discovered centuries ago. It is caused by a bacterium called Treponema Pallidum. The course of Syphilis can be divided into four stages:

i) Primary stage.

ii) Secondary stage.

iii) Latent stage.

iv) Tertiary stage.

A person who is infected can pass on the disease to others during the first two stages and during latent stage if he or she does not get treatment. These three stages usually last one to two years. However, the tertiary stage, which can occur several years after the primary stage can cause serious problems of the brain, heart and blood vessels and can even cause death.

Syphilis is one of the most dangerous STDs. It is transmitted almost always by sexual contact, but can be spread also by contact with broken skin. One can get syphilis if one has sexual intercourse with someone who has an active infection. People who are at risk of acquiring syphilis are those who have sexual relations with an infected partner of those who have multiple partners and those who have a history of STDs.

*Symptoms*


The first symptom of primary syphilis is a sore called chancre. This may appear within one week to three months after exposure, but generally appears within two to six weeks. It is ordinarily painless. It usually occurs on the penis, the vulva, the vagina, the cervix, the tongue, lips or other parts of the body.

It disappears within a few weeks with or without treatment. If it is not treated at this stage, it may progress on to the other three stages.

*Secondary stage*

This occurs from 3 to 6 weeks after the chancre appears. It is marked by a reddish, skin rash, which may occur all over the body or only in a few areas such as the palms of the hands or soles of the feet. It usually heals within several weeks or months. Other symptoms include fever, tiredness, headache, sore throat, as well as patchy hair loss and swollen lymph glands throughout the body. The signs of secondary syphilis may come and go over the next one or two years.

*Latent Stage*

The latent stage may continue for many years after the secondary stage. The organism is dormant in the body and does not produce any symtoms, but the titers in the blood are positive.

In about two-third of the cases, the latent stage continues for the rest of the patient's life without the development of any clinical lesion, but at the time of death, there may be clinical signs of syphilis if a post-mortem is done.

*Tertiary Syphilis*

If syphilis is not treated during the primary, secondary or latent stage it can progress on to late syphilis which causes chronic destructive changes in the brain, heart, bones, liver, stomach, eyes or other tissues. The skin, mucous membranes and other organs may develop rubbery tumors called gummas.

*Blood Test For Syphilis*

These tests are refered to as reagin tests and the most common test is the VDRL test (Venereal Disease Research Laboratory test). They are not very specific. This test becomes positive within 7 to 14 days after appearance of the syphilitic chancre. It is almost always positive in the secondary and recurrent stages and in the early latent stage. It may be positive in a majority of cases in the late latent stage also, but in cases of late tertiary syphilis where heart and brain are involved, it may be negative in a proportion of cases. The specific tests are called the Treponema tests.

*Treatment and Prevention*

Syphilis is usually treated with the antibiotic, penicillin, administered by injection. Patients allergic to penicillin can be treated with other antibiotics. Within 24 hours of starting treatment, a person can no longer transmit syphilis. Normally, in all stages of syphilis, proper treatment will cure the disease. However, in tertiary syphilis, damage has already been done to the body organs and these cannot be reversed. If not treated, a pregnant woman with active syphilis may pass the infection to her unborn child. The only sure and safe method to prevent getting infected with syphilis is abstinence before marriage and fidelity within married life.

Testing and treatment early in pregnancy is the best way to prevent syphilis in infants and should be a routine part of prenatal care.

*Complication of Untreated Syphilis*

Approximately 3 to 7 percent of persons with untreated syphilis develop Neurosyphilis. Some persons with Neurosyphilis never develop any symptoms, while, others may have headache, stiff neck and fever due to inflammation of the lining of the brain. Some people may have convulsions (fits). Some others may have the symptoms of stroke with resulting numbness, weakness or visual complaints. The duration from time of infection up to development of neurosyphilis may take up to 20 years. Untreated syphilis can also affect the spine and cause what is called Tabes Dorsalis which can give rise to excruciating pains. Untreated syphilis can also affect the heart and cause syphilitic aortitis and involve the valves at the base of the aorta. Aorta is the largest blood vessel in the body. Sometimes parts of this vessel can become thin-walled and bloated like a balloon. This is referred to as Aneurysm of the aorta and is a serious complication of untreated syphilis.

*Treatment and Prevention*

As mentioned earlier the drug of choice is penicillin. Both long and short acting forms are available. All sex partners within the previous three months should also be treated. Doxycycline or Tetracycline can also be given. In HIV positive persons syphilis may cause increased risk of brain complications. There is also a higher risk of treatment failure.

**Chancroid**

Chancroid is another fairly common STD. It is very common among men who have frequent contact with commercial sex workers. Its importance also lies in the fact, that it is one of the genital ulcer diseases that is associated with an increased risk of transmission of HIV disease.

*Symptoms*

The disease is caused by a bacterium called H. Ducreyi. It usually occurs within seven days of exposure. There are open and painful sores on the genitalia accompanied by swollen tender lymph nodes in the groin. In women there can be painful urination, painful defecation, painful intercourse, rectal bleeding and vaginal discharge.

*Treatment and prevention*

Successful treatment for chancroid cures the infection, resolves the clinical symptoms and prevents transmission to others. In severe cases, scarring may result. Drugs usually advised include Azithromycin, Ceftriaxore, and Ciprofloxacin. Ciprofloxacin should not be given to pregnant and lactating mothers. Sex partners of patients with chancroid should also be treated irrespective of whether they have symptoms, or if they had sexual contact within the previous ten- twelve days. No adverse effects of the chancroid on pregnancy outcome or on the foetus have been reported. However pregnant mothers should not receive Azithromycin or Ciprofloxacin.

All patients with chancroid should be tested for HIV disease, since they require longer courses of therapy. The disease is generally more severe

in HIV positive individuals and the healing is slower. Treatment failures can occur in certain cases.

**Granuloma Inguinale**

This is an STD which occurs in tropical areas such as India, Papua New Guinea, Central Australia and Southern Africa.

*Symptoms*

It is caused by a gram-negative bacterium called calymmato bacterium granulomatis. This causes painless, one or more beefy red open sores that slowly enlarge. They bleed easily to touch. There is no associated lympadenopathy. They usually appear within seven days of exposure but may take as long as 3 months also. A secondary bacterial infection may occur on top of this one or it may co- exist with other STDs.

*Prevention and treatment*

Drugs usually given are Septran, Doxycycline, Ciprofloxacin or Erythromycin for a minimum period of three weeks for all four drugs. Recurrence can occur 6-18 months later inspite of effective initial therapy. Patients should be followed regularly till all signs and symptoms have been resolved. Sex partners who report history of sexual contact during 60 days preceding onset of infection should also be treated.
treated.

**Genital Herpes**

It is an STD. It is caused by a virus, contagious and affects millions of people each year. The virus is called the Herpes Simplex virus or HSV. HSV are of two types -1 and 2. Both viruses cause diseases.

*Symptoms*

The early symptoms of the disease occur within 2 to 30 days of exposure and may last on a average 2 to 3 weeks. There is an itching or burning sensation, pain in the legs, buttocks or genital area. Vaginal discharge may also occur. The sores appear around the vaginal area, penis, oral opening, buttocks as well as thighs. The sores appear as small red lumps, which may develop into blisters or painful open sores. There may also be fever, headache, muscle aches, painful urination, vaginal discharge and swollen glands in the vaginal area. The virus reactivates from time to time and remains in certain nerve cells of the body for life.

*Treatment and prevention*

The most commonly used anti-viral is called Acyclovir. It should be taken within 24 hours of onset of the symptoms. However, Acyclovir is not a cure for Herpes, but if taken regularly, the drug interferes with the virus' ability to reproduce itself. The treatment is usually given for 7-10 days. It may be extended if healing is incomplete. Counselling is an important aspect of managing patients who have genital herpes. Many patients benefit learning about the chronic aspects of the disease after the acute illness subsides. Counselling of these patients should include:

otential for recurrent episodes, asymptomatic viral shedding and sexual ransmission.

atients should abstain from sexual activity when lesions are present. ex outside marriage should be discouraged.

exual transmission of HSV can occur even if the patients have no ymptoms or no sores. This is more common for HSV-2 than HSV-1 ıfection and those who have infection for less than 12 months.

regnant women with genital herpes can spread the infection to their ewborn children at birth. Children can develop inflammation of the rain, rashes and eye problems. There can be death also.

atients having a first episode of infection should be told that taking pisodic anti-viral therapy can shorten the duration of illness. ontinuous therapy can ameliorate or prevent recurrent outbreaks. recautionary measures include:

) Keep the infected area dry and clean to prevent secondary infections.

) Avoid touching sores with the hands. Hands should be washed after contact with sores.

**onorrhea**

onorrhea is one of the most commonly reported sexually transmitted iseases. In addition to infecting the genitalia, it can also affect the hroat and the rectum if there has been oral or anal intercourse. It can lso be passed from an infected mother to her newborn child during the ime of delivery.

*ypmtoms*

onorrhea is caused by a bacterium called Neisseria Gonorrhea. It grows nd multiplies quickly in moist, warm areas of the body such as the ervix, urethra, rectum etc. From the cervix, it can spread to the uterus nd the fallopian tubes also, resulting in inflammation of all these pelvic rgans and causing pelvic inflammatory disease. All cases of Gonorrhea nay not necessarily develop symptoms, but when they do, usually appear within 2 to 20 days after exposure (sexual contact) with an infected artner. Men usually have severe burning on passing urine and white lischarge from urethra. A smear may reveal the Gonococcus or it may e cultured from the discharge. In women, many may have no symptoms t all or mild symptoms. Others may have burning on passing urine or n abnormal vaginal discharge. The other symptoms include severe bdominal pain, bleeding between menstrual periods, vomiting or pain. ymptoms of rectal infection include discharge, anal itching and ometimes painful, bowel moments.

*reatment and prevention*

sually amoxicillin, quinolones, and tetracyclines may be given for the reatment of Gonorrhea. Gonorrhea may occur in combination with hlamydia, so physicians prescribe a combination of antibiotics to treat oth diseases. It is important to complete the full course of medication

and return for the follow up. All sex partners of a person with gonorrhea should be treated even if they do not have symptoms of the infection. If Gonorrhea is not treated, the bacteria can spread to the blood stream and infect the joints, heart valves and the brain. Constant awareness and precautions are necessary, because a person who has once contracted the disease does not become immune. The infection can recur.

**Chlamydia**

Chlamydia is yet another common STD prevalent among both men and women. Very often it occurs in conjunction with gonorrhea. In many cases, the infection does not produce any symptoms at all. In women, complications of chlamydia infection include pelvic inflammatory disease, ectopic pregnancy and infertility. It can affect newborn children at the time of birth if the mother is infected. In these newborns it can cause infection in the eye, throat, urethra and rectum. It can also cause pneumonia in children from the age of 1 to 3 months.

*Symptoms*

Chlamydia is caused by a bacterium called Chlamydia trachomatis. The transmission occurs during the sexual contact either vaginal or oral or anal. Symptoms usually occur 1 to 3 weeks after exposure and include abnormal genital discharge and pain on passing urine. Half the patients may have no symptoms at all. In men there may be swelling and pain in the scrotal area which is a sign of epididymitis. It can also cause inflamed rectum, conjuctivitis and throat infection.

*Treatment and prevention*

The drug usually given for this infection include Doxycycline, Azithromycin or erthyromycin. They should be given for atleast 7-10 days. Azithromycin may be given as a single dose..Of course, these drugs should be given only under the treatment of a physician. Pregnant women should not take tetracycline and should opt for erythromycin. Women should get themselves examined for Chlamydia before conceiving, as this infection can cause tubular pregnancy. All sex partners should also be treated.

Since both Gonorrhea and chlamydial infection co-exist, routine dual therapy without testing for Chlamydia is recommended. This has resulted in decrease in the prevalence of chlamydial infections.

**Bacterial Vaginosis**

This is an STD that is caused by a variety of bacterial organisms that replace the Lactobacillus in the vagina. Although it occurs in women who have multiple sex partners ,it can also occur in those who are sexually not active. The most important symptoms is the presence of an abnormal, white discharge from the vagina which has a fishy odour. The treatment is with metronidazole or clindamycin cream for seven days. Bacterial vaginosis during pregnancy has adverse outcomes, i.e. premature rupture of the waters, preterm labour and preterm birth.

## Trichomoniasis

This is another STD that often develops without any symptoms. A protozoan called Trichomonas Vaginalis causes it. Symptoms occur usually within 4-20 days of exposure. In women there may be a yellow green or grayish, malodorous vaginal discharge and painful urination. Irritation and itching of the female genital area and lower abdominal pain can also occur. Men may not have any symptoms, but can transmit the infection. It is therefore recommended that both partners be treated simultaneously for this infection. The drug of the choice is Metranidazole, either as a single dose or for seven days. Patients taking this drug should avoid alcohol as it can cause nausea and vomiting. HIV positive people should receive the same regimen as HIV negative people.

## Vulvovaginal Candidiasis

This is not necessarily a disease contracted through sexual intercourse and can occur in various other conditions such as pregnancy, diabetes mellitus, use of drugs (steroids, oral contraceptives; drugs for cancer etc.) use of sprays etc. It is caused by a fungal organism called Candida Albicans.

The common symptoms include itching, burning and irritation of the vagina and a curdy white discharge. The treatment consists of anti, fungal creams or tablets, which are inserted intra vaginally for 1,3 or 7 days. Single dose of oral antifungal tablets may also be taken. As this is not acquired through sexual intercourse, treatment of sex partners is generally not recommended except for those women with recurrent vulvo vaginal Candidiasis. Studies have revealed an increase in this infection in HIV positive women, but the treatment advocated is the same.

## Pubic lice

Pubic lice are parasites which often spread by sexual contacts. These tiny insects are visible to the naked eye. They are pinhead size, oval in shape and appear reddish-brown when full with the blood of the host. The eggs of the lice are called nits, which can be seen clinging to the pubic hair. The main symptoms are itching and by this the lice can spread to the other parts of the body. Creams, lotions and shampoos are available to kill the lice. The bedding and clothing should be de-contaminated as re-infection can occur. All sex partners should also be treated. HIV positive people should receive the same treatment as HIV negative people.

## Scabies

Scabies is usually transmitted through sexual contact. However, it is also transmitted through contacts with sheets, towels, furnitures etc. The scabies mite is called Sarcoptes Scabeii, and causes intense itching. In addition to affecting the genital area, it can also affect the hands between the fingers, wrists, elbows and lower abdomen. After the exposure, it usually takes about a month or more to develop skin reaction. However during this period one can pass on the infection to another person. The entire family needs to be treated simultaneously to eradicate this infection. Bedding and clothing should also be de-contaminated at the

same time. Many solutions and ointments are available for treatment.

HIV infected patients who develop scabies, are at risk for Norwegian scabies, a disseminated skin infection. Such patients should be managed under consultation with an expert in the field.

**Hepatitis**

Hepatitis is basically an inflammation of the liver and manifests as jaundice. In many cases, hepatitis are caused by viruses and these viruses are named from A to E. Vaccines are available for prevention of Hepatitis A and Hepatitis B. If vaccines become available for HIV disease and Herpes simplex viruses then possibly immunization will become one of the routes to prevent STDs.

**Hepatitis A**

Hepatitis A is caused by infection with the hepatitis A virus (HAV). The most common mode of transmission is faecal-oral, ie either by person to person contact in households or through sexual partners, particularly in homosexual and bisexual men. At acute infection, the virus is present initially in the blood, and so it can be transmitted through needles as well, especially among injecting drug users. HAV infection is self-limited and does not result in chronic liver disease. Treatment is supportive, (Rest, high carbohydrate diet etc). No medications that might cause liver damage should be given.

*Prevention and Treatment*

i) Maintenance of good personal hygiene.

ii) Health education messages that this disease can spread by oro-anal routes.

iii) Two types of vaccination are available; the immunoglobin, which provides protection for six months and is generally used for household and sexual contacts. The second vaccine provides long-term protection.

**Hepatitis B**

Hepatitis B is a common STD. In the United States, sexual transmission has accounted for 30-60 per cent of Hepatitis B infections in the last 10 years. This disease can spread by:

- Having sexual intercourse with an infected person.
- Through needles.
- Mother to child transmission at birth.
- Blood transfusions
- Personal contact with an infected person. Blood, semen and saliva are the major sources of infection.

The importance of Hepatitis-B infection lies in the fact that a percentage of this group can develop acute fulminant disease, chronic liver disease or cancer of the liver. This disease can also be transmitted from mother to child at birth or by personal contact during the first five years of life.

Supportive and symptomatic care is the mainstay of therapy. Alpha-2 interferon has been 40 per cent successful in eliminating chronic HBV infection and so also the drug lamivudine.

*Prevention*

Hepatitis B vaccination is the most effective means of preventing infection. Other measures of prevention include:

- Routine screening of all pregnant mothers.
- Routine vaccination of all newborns.
- Vaccination of older children.
- Vaccination of persons who report a history of STDs.

HBV infection in HIV infected persons is more likely to lead to chronic HBV infection. HIV infection can also impair the response to hepatitis B vaccine. Revaccination with three more doses should be considered for those who do not respond initially.

*Vaccination*

Both the immunoglobulin for short-term protection (contacts) and the vaccine are available.

**Lymphogranuloma Venereum**

It is caused by certain strains of C. Trachomatis. It causes painful inguinal lymphadenopathy that is usually one-sided. Others may cause involvement of the rectum and can result in fistulas and strictures.

*Prevention and Treatment*

Doxycycline or erythromycin for a period of 3 weeks should be given. Sex partners should be treated within 30 days of onset of infection in the affected person. Again treatment might have to be prolonged in HIV-positive individuals.

**Cytomegalovirus infection**

Cytomegalovirus (CMV) is a member of the herpes virus family. It is found in various body fluids. It can spread by sexual contact as well as by other forms of physical touch. Once infected it remains in the body like the herpes virus. Infected mother can pass on the CMV to their babies before birth. Such a baby may suffer from mental retardation, blindness, and deafness and even epilepsy. Such a baby can also infect others, as it will have CMV in its saliva and urine.

**Human Papillomavirus Infection (HPV)**

HPV is one of STDS that can affect men and women. There are over 60 types of HPV, but only certain types can cause STD (6,11, 16,18, 31,33 and 35). This disease is characterized by the presence of warts (Cauliflower like growths which vary from a tiny size to very large ones) on the genitalia, as well as on the mouth or anus if one has

indulged in anal or oral intercourse. The importance of these warts lies in the fact that these HPV types are associated with the development of cancer. Removal of these warts doesn't remove the risk of cancer. Applications of certain resins, surgical cryotherapy etc. can remove the warts, but these treatment modalities are not curative. Examination of sex partners is not necessary. Patients with HIV disease may not respond to any treatment as well as those without any recurrences are more common.

**Pelvic Inflammatory Disease or PID**

This is an infection which affects women. This happens when infection spreads from the lower reproductive tract i.e. vagina and cervix to the upper reproductive tract i.e. uterus, ovaries and fallopian tubes. Sexually transmitted organisms, especially N. Gonorrhea and C.trachomatics are responsible in most cases, but others that generally reside in the vagina can also cause disease, if left untreated. It can lead to tubal pregnancy, primary infertility or acute emergency.

*Symptoms*

It has been found that sexually active teenagers are more likely to develop PID than older women. Those who have more sexual partners, IUD insertion, induced abortions etc. are more at risk of developing PID. The symptoms can vary from asymptomatic to abnormal symptoms, acute and severe. The patients may have irregular menstrual bleeding, pain on intercourse, abnormal vaginal discharge, pain and tenderness in the lower abdomen, high temperatures, severe abdomen pain etc. Hospitalization is required if the pain is acute and severe or if the patient is pregnant or has high fever with vomiting or has not responded to oral medication. In these cases, intra-venous antibiotics have to be given.

*Treatment and prevention*

Oral antibiotics such as Metranidozole and Doxycyline are given. In hospital, second or third generation cephalosporins, fluroquinolones etc. are given. Antibiotics may have to be continued for two weeks.

Patients who have received treatment should follow it up regularly. Sex partners of these women should be examined and treated as asymptomatic infection in them can cause recurrent infection in the women. The patient should receive drugs, which will cover both gonorrhea and chlamydia. Pregnant women with PID have a high risk of death, foetal death or early delivery and they should be hospitalized and treated.

HIV positive women with PID tend to have more severe symptoms than HIV negative women, but respond equally well to the standard drugs. Sometimes they require very aggressive treatment especially if the CD4 count is low.

**Check Your Progress I**

1. Define STDs

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2. List the names of common STDs

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## 4.5 PREVENTION OF STDs

The prevention and control of STDs is based on five major concepts:

- Education of those at risk on ways to reduce the risk of STDs.
- Detection of asymptomatically infected persons and persons unlikely to seek treatment.
- Effective diagnosis and treatment of infected persons.
- Evaluation, treatment and counselling of sex partners of those who are infected.
- Pre-exposure vaccination of persons at risk for vaccine preventable STDs.

*Prevention measures*

It is important to take a good sexual history from the person and identify the risk factors for STDs. This then, provides an opportunity to deliver prevention measures. Counselling skills are important. These messages should be tailored to the patient. Other prevention measures include

getting both partners tested for STDs, using of condoms by prostitutes and their clients, etc. Those on drugs, must enroll or continue in a drug treatment programme. Do not use unsterile equipment. Obtain clean needles etc. for those STDs which can be prevented using vaccines.

## Government Response

*STD Control Programme in India*

The importance of treatment and control of STD in relation to HIV infection was recognized by NACO. After taking over the STD control programme, NACO made it an integral component of AIDS control policy. Suitable strategies were devised for the control and prevention of STD as a priority in the overall planning to control the spread of HIV infection.

*Objectives of the STD Control Programme*

The STD control component of the National AIDS control programme has two major objectives.

- Reduce STD cases and thereby control HIV transmission by minimizing the risk factor.
- Prevent the short-term as well as long-term morbidity and mortality due to STD.

In order to accomplish these objectives, the following strategies have been incorporated in the strategic plan for the prevention and control of AIDS in India.

### Strategies

The broad strategies for controlling STD, as outlined in the strategic plan for the prevention and control of AIDS in India as the following:

- Adequate and effective programme management.
- Prevention of the transmission of STD/HIV infection through IEC and promotion of safer sexual behaviour by the use of condoms.
- Adequate and comprehensive case management including diagnosis, treatment, individual counselling, partner notification and screening for other diseases.
- Increasing access to health care for STD by strengthening existing facilities and structures and creating new facilities where ever necessary.
- Early diagnosis and treatment of mostly asymptomatic infections through case finding and screening.

The following major actions have been taken along the lines suggested in the strategies :

a) Training of health care workers in both public and private sectors in comprehensive STD case management.

b) Development of appropriate laboratory services for the diagnosis of STD.

c) Conduct of microbiological, socio-behavioural and operation research.

d) Surveillance to follow the epidemiological situation, monitor and evaluate the on-going STD control programme.

**Organization of Training Programmes**

- 5 regional STD referral centres upgraded to conduct training, research, supervision and monitoring.
- All the districts have been provided facilities for the management of STD control programme.
- 18,558 Medical officers from various states trained in STD case management through syndromic case management.
- 132 new STD clinics along with the existing 372 clinics, upgraded to function as referral centers of primary health care facilities.
- More than 10,000 private health care providers trained in STD case management by Indian Medical Association (IMA) in collaboration with NACO.
- Guidelines for syndromic management and treatment of STD revised and updated.
- Training module on STD surveillance prepared and finalized for training AIDS/STD programme officers.

*Laboratory Services*

Laboratory services in the five regional STD referral centers and in the STD clinics in medical colleges and districts as well as taluka hospitals have been upgraded.

*Surveillance*

Guidelines on STD surveillance based on syndromic approach as well as etiological diagnosis have been developed for district down to health centres for implementation in a phased manner.

**Check Your Progress II**

1 What are the five major concepts in the prevention of STDS?

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## 4.6 LET US SUM UP

This unit dealt with STDs and their management. The main points discussed were the link between STDs and HIV infection; the misconceptions of STDs, knowledge of STDs such as symptoms, treatment and prevention, and the Governmental responses to the management of STDs.

## 4.7 KEY WORDS

| | | |
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| **Urethritis** | - | Inflammation of the male or female urethra. |
| **Mucous membranes** | - | Lining on the inside of the mouth, vagina, rectum, etc. |
| **Aortitis** | - | inflammation of the aorta, which is the largest blood vessel in the body. |
| **Ectopic pregancy** | - | when the pregnancy occurs in a part other than the uterus such as tube/ ovary. |
| **Infertility** | - | Inability to reproduce. |
| **Epidydymitis** | - | A tubal connection from the testes which becomes inflammed. |
| **Conjuctivities** | - | Inflammation of the inside of the eyelids. |
| **Homosexual** | - | Men who have sex with men. |
| **Bisexual** | - | Men who have sex with both men and women. |
| **IUD** | - | Intra uterine device, such as copper - T or loop to prevent contraception. |

## 4.8 MODEL ANSWERS

**Check Your Progress I**

1 Define STDs

STDs are diseases which are communicable diseases and are transmitted by an infected man or woman to his or her partner during sexual intercourse. For this reason they are called sexually transmitted diseases

2 List the names of common STDs.

The common STDs are as follows:

Syphilis

Chancroid

Granuloma inguinale

Genital Herpes

Gonorrhonea

Chlamydia

Bacterial Vaginosis

Trichomoniasis

Vulovovaginal Candidiases

Pediculosis pubis

Scabies

Hepatitis - A

Hepatitis - B

Lymphograholoma Venereum

Cytomegalovirus

HIV Infection

**Check Your Progress II**

1) What are the five major concepts in the prevention of STDs?

The prevention and control of STDs is based on five major concepts:

1) Education of those at risk on ways to reduce the risk of STDs.
2) Detection of asymptomatically infected persons and persons unlikely to seek treatment.
3) Effective diagnosis and treatment of infected persons.
4) Evaluation, treatment and counselling of sex partners of those who are infected.
5) Pre-exposure vaccination of persons at risk for vaccine preventable STDs

## 4.9 FURTHER READING


1) NACO (2000). HIV/AIDS/STD Counselling and Training Manual, NACO, New Delhi.
2) Gracious Thomas, N.P. Sinha, Johnson Thomas K (1997). AIDS, Social Work and Law, Rawat Publications, New Delhi.
3) NACO (2000), Country Scenario, 1997-98 NACO, New Delhi.
4) "Clinical Guidelines for Management of STDS" - MMWR, - January, 1998.
5) NACO (2000), Training Module for Health Workers and Supervision on RTI/STD and HIV/AIDS Prevention and Control, NACO, New Delhi.

# UNIT 5 HIV/AIDS AND THE WORK PLACE

**Contents**



## 5.0 AIMS AND OBJECTIVES

The purpose of this unit is to provide you with an understanding of the various issues related to HIV and the workplace. After reading this unit, you should be able to:

- learn the factors that make workplace vulnerable to HIV infection.
- understand the issues that HIV/AIDS brings into the workplace.
- describe the various social, ethical, and legal issues related to HIV/AIDS and workplace.
- learn how these issues can be addressed.
- know the strategies for prevention of HIV/AIDS in the workplace and have a basic understanding about workplace policy on HIV/AIDS.
- understand the initiatives in India for HIV/AIDS prevention in workplace.

## 5.1 INTRODUCTION

You have already learnt about various issues related to HIV/AIDS, from the Basic course on HIV/AIDS. In this unit, we are taking you through specific issues related to HIV/AIDS and workplace so that you will be able to understand the need for proper policy on HIV/AIDS at the workplace.

An understanding of HIV/AIDS and the workplace will strengthen the capacity to deal effectively with the problem of HIV and AIDS at the local, national and international levels. It provides an opportunity to re-examine the workplace environment and how the workplace has an impact on the lives of the people and their behaviour. It also provides an opportunity to re-examine:

- Working relationships in a way that promote human rights and dignity.
- Ensures freedom from discrimination and stigmatization .
- Improves working practices and procedures.

This review has got implications for the people infected with HIV and their working conditions by way of creating an atmosphere conducive to caring for and promoting the health of all workers.

The present unit elaborately discusses the ways of promoting healthy atmosphere in the workplace conducive to caring for and promoting the health of all workers. Its main focus is on the organised sectors of workplace.

## 5.2 HIV AND WORKPLACE

In order for people to live they need to work and earn money. The work place creates an environment for the people to interact with many others. Most of the active period of one's life is spent at the workplace .Thus the workplace plays a central role in the lives of people. Hence, there has been a growing concern about HIV/AIDS at the workplace. The effect of HIV will reduce the productivity of the working population. More children and elderly people will have to be supported by a smaller active labour force. This epidemic has started attacking skilled labourers and professional workers in many industries. This will result in labour shortage in the near future, which will lower production ,which in turn will affect the economy. Thus our wealth and prosperity are under a gigantic threat.

In the light of this concern, workers and organisations around the world have been trying to explore the opportunity to decide what is the best approach to promoting health in the workplace, ameliorating discrimination and maintaining status and dignity - (Pragetter and Prior, 1987; Sad, 1987; Prince, 1993; Joshi, 1997; Thomas et al, 1997 as explained in Saxena, P. & Sharma, S.D).

According to the World Health Organisation (WHO ,1998) report "approximately 90 per cent of the 5-10 million HIV infected persons worldwide are in the economically productive age group. Obviously HIV/AIDS has an enormous potential impact at the workplace". A recent global report indicates that the majority of new infections are in young people between the age of 15 and 24, sometimes younger (UNAIDS, 1997). In India, although surveillance is patchy, all indications are that there are four million people living with HIV. India is reported to be the second country with the largest number of HIV infected people in the world after South Africa.

As the pandemic gathers momentum, its effects at the workplace are felt more accurately, especially in the Developing Nations (Engel, 1996; Bay and Oppenheimer 1986; Li, 1992; Williams and Roy,1993;New Zealand All Foundation 1994; Red Cross and Red Crescent societies,1996, as explained in Saxena,P and Sharma S.D).

**Vulnerability at the Workplace**

Migration is a major risk factor with regard to HIV infection. According to the Ministry of Labour, Govt. of India, in 1996, there were about 180 million migrant workers in India, most of whom are either single or living apart from their wives and families. At any given time, they comprise 30-40 per cent of the population of large cities, where they also account for much of the clientele of the "red-light" areas (Sreedhar,J and Colaco, A 1996, 5).

Rapid industrialisation coupled with unemployment, results in attracting thousands of young people to big cities in search of jobs. Most of the migrants to the cities and industrial areas are either unmarried or staying away from the family. They are also unskilled or semi-skilled labourers. Life in cities give them more freedom and privacy and many a time they indulge in multipartner sex and drug abuse.

HIV/AIDS is predominantly a sexually transmitted disease (STD). It mainly afflicts people in the sexually active age group. Being the productive members in the community, major corporations can expect to find atleast a few HIV infected persons among their staff. The reason as to why only a very few problems related to HIV/AIDS have emerged till date in the workplace in India may be attributed to many of them being still asymptomatic, besides keeping their HIV status confidential. However, as the latency period advances, opportunistic infection would gradually develop and as the number of such persons increases, the impact at the workplace will naturally become more obvious.

Therefore, pertinent issues need to be considered with regard to the HIV infected workers. These include:

i) the fitness to work during the so-called incubation period and adjustments in the duties of the workers who turn out to be HIV/AIDS patients.

ii) implementation of adequate precautions in the workplace to reduce risk of transmission of HIV during accidental exposure such as deep penetrating injuries from hollow injection needles with an AIDS patient as the source.

iii) mandatory HIV antibody testing of employees without their informed consent and counselling, which is an infringement of their civil rights. Besides,it is not the solution because it does not,guarantee that they will not acquire the infection following a negative ELISA test.

**Workplace and HIV/AIDS in U.S.A—Some facts**

- One in 300 Americans is affected with HIV.

- AIDS is the second leading cause of death among U.S adults in the age group 25-44 years.
- More than half of the U.S workplace population is 25-44 years old, the largest age group at risk.
- Two-thirds of large businesses have employees with HIV or AIDS.
- One in 10 small businesses have employees with HIV infection or AIDS.

The workplace varies in its nature based on various factors such as whether it is organised/unorganised, the attitude of the management towards the employees, numerical strength of the employees, the type of job involved, role of employee's union etc. Vulnerability to HIV infection and the impact of HIV/AIDS will also vary based on the same factors. For example, the organised sector, which usually give permanent employment to its employees will have more difficulties in adjusting to the challenges of HIV/AIDS. Whereas in the unorganised sector, the workers may not get any benefit from their employers and their families will also be immediately affected with the HIV infection of any family member.

**Check Your Progress I**

1. What are some of the pertinent issues to be considered with regard to HIV Infected workers?

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## 5.3 ISSUES THAT HIV/AIDS BRINGS TO THE WORKPLACE

Infection with the human immuno-deficiency virus and the acquired immunodeficiency syndrome represent an urgent world-wide problem with broad social, cultural, economic, political, ethical and legal dimensions and impact. We will now analyse these issues in detail.

**Cost of HIV/AIDS at the Workplace**

As a business issue, HIV/AIDS continues to make an impact. Companies have felt the loss of tremendous talent since the epidemic began. AIDS has become the second leading killer of adults in their prime working years in Europe. Co-workers have grieved the loss of many colleagues, family members and friends. Unwarranted fear and ignorance of the disease have caused discrimination and disrupted work and employee productivity at a time when the competitive global market place demands nothing less than total efficiency and outstanding performance.

There are various issues related to HIV and AIDS that can have a direct

or indirect impact on the productivity of the workers in any workplace. These are:

*a) HIV absenteeism*

HIV affects the most productive age. Due to physical, psychological and social reasons, a HIV positive person shows reluctance to report for work. This increases the level of absenteeism, thus reducing the productivity of the entire organisation.

*b) AIDS absenteeism*

An employee who has developed AIDS, has a lot of physical problems and frequently becomes sick. He may not be fit enough to perform his duties and hence may abstain from work. This results in a long-term deficiency of manpower. Hence AIDS absenteeism can turn out to be a severe problem with respect to an industry.

*c) Labour Turnover*

HIV affects not only the physical health of a person but also his psychological state. He avoids persons and situations and thus shows reluctance to report for work. It is not clear whether external labour flows will add to or subtract from the total working population. In some cases the most able and internationally most mobile labour could leave a country. There is also the possibility that a country could attract migrants, thus revealing some of its labour shortages, especially of skilled and professional workers.

*d) Productivity*

HIV affects the most productive age group. Due to physical, psychological and social reasons, a HIV positive person shows reluctance to report for work once s/he comes to know about his/her HIV status. This increases the level of absenteeism and thus reduces the productivity of the person as well as the organisation.

New recruitment has to be made to stabilise the loss in human resource, which is an extra burden for an organisation. The training of new recruits has to be done. Thus, the organisation will have to handle two issues: turnover of its experienced and skilled employees and the training of new recruits who may need some time to adjust to the new situation and to learn the work.

*e) Administration and Recruitment*

New recruitment has to be made to stabilise the manpower loss. There may be additional financial loss. This is an extra burden for the organisation. The work of the organisation is thus highly affected. Thus the business cost of HIV / AIDS in an industrial set up is very high.

*f) Training*

As a result of new recruitment, on the job training has to be imparted to the workers which proves to be an economic burden to the employer. This also involves a lot of time and resources.

*g) Employment benefits*

The liability on the part of the employer will increase when the employer has to give all benefits to the employee who is infected with HIV, since, sooner or later, the person is going to develop symptoms of AIDS. The monetary liability due to the death of an employee to his/her family will be very high. When there are more infections and number of deaths due to AIDS, the employer will have to spend a huge amount on the employment benefits like paying back the provident fund. The insurance companies will have to pay back huge amounts due to premature death of persons. Most of the companies will have to give employment to the next kin of the employee on the basis of provision of died-in-harness.

*h) Health Care and Discrimination*

The current state of health in India, where epidemics are recurring phenomena, calls for urgent introspection and action. Despite the fact that the Indian Government evolved a Health Policy as far back as 1983, health care services have been deteriorating and do not meet people's expectations .Thus, they turn to private health care which is not regulated by any statute or laws unlike the public health care sector. According to the National Sample Survey conducted by the National Council for Applied Economic Research, sixty to eighty percent of health care is sought in the private sector for which households contribute four to six percent of their total income. This fact speaks volumes about the inadequacies of the public/government run health care institutions. With the numbers of HIV infections on the rise daily, there will arise a pressing and urgent need for the private health care infrastructure to provide treatment for people living with HIV/AIDS. As of today, very few private hospitals are willing to admit and treat people living with HIV/AIDS.

For people living with HIV/AIDS, the health care setting is the most conspicuous environment for HIV/AIDS - related discrimination. The denial of services vis-a-vis care and support represents one of the most immediate and pressing concerns of people living with HIV/AIDS. There are innumerable instances of discrimination against people living with HIV/AIDS viz. refusal of doctors to touch patients during routine medical examination, delays in treatment, breach of confidentiality, mandatory or routine testing without informed consent, wrapping dead bodies of HIV positive people in plastic sheets etc. In case workers are detected as HIV positive, they cannot just be removed from the rolls. Medical care has to be given to them and as you are already aware, the cost of reducing the effect of HIV/AIDS on the health of the individual is very high. More than that AIDS related symptoms can cause several health problems for the individuals infected with HIV. For example, in India, where 50-60 per cent of the population are already carriers of the Tuberculosis Bacillus (T.B), the HIV epidemic is likely to lead to a dramatic increase in active TB cases (Sreedhar, Jaya and Colaco, Anthony, 1996; 5). This will result in huge amount of expenses from the part of the employer on taking care of the health issues of the employees. Since most of the companies have a limited health care

delivery system, it will be a burden on the public health system to provide care to the AIDS patients.

Studies indicate that the risk of exposure from an HIV -positive patient to health care workers is fairly negligible and can be successfully mitigated by observing universal precautions and Post Exposure Prophylaxis (PEP).

**Social Issues Related to HIV and Workplace**

*a) Denial*

A common misconception is that HIV is someone else's problem. It is a disease of selected groups commonly referred to as "high risk groups", ie., promiscuous people, intravenous drug users, foreigners. This ignores the evidence that the greatest single mode of transmission of HIV is heterosexual activities outside marriage. The virus does not put groups at risk. People practising unsafe behaviour put themselves at risk.

Statistics demonstrate that the virus is already spreading at an alarming rate in Asia. Continued beliefs that HIV only affects a selected population is dangerous allowing large sectors of society to feel protected from the epidemic thus blocking the understanding of the necessity to develop effective intervention strategies.

*b) Fear*

Over fifteen years into the epidemic and still the most common response to the subject of AIDS is fear. Misinformation, misconceptions and dread of the unknown heighten the anxiety felt by those who have their first encounter with a person with AIDS, or someone known to have HIV disease. Fear is best handled by allowing people to express their concerns openly. Acknowledgment of their feelings and discussion about them helps to dissipate the fear.

*c) Discrimination*

Fear often leads to discrimination against people who have HIV. Loss of jobs, friends, and homes are not uncommon occurrences. Mistaken beliefs that casual contacts can spread the virus have led to the isolation and loss of dignity and respect to which people infected with the virus often become subject. Presenting medically correct facts and discussing the misconception that cause fear will reduce the discrimination that results from it.

*d) Confidentiality*

A person's medical history is confidential. Revelation of items such as a person's HIV status can lead to the consequences of his/her being stigmatized and subjected to discrimination. HIV is still associated with discrimination due to misconceptions of how the virus is transmitted. Cases of people losing their jobs, homes and families have occurred after disclosure that they are infected with the HIV virus. The medical facts regarding transmission of the virus clearly prove that ordinary workplace behaviour and interaction does not lead to the spread of infection. To

reduce disruption in the workplace and protect the injected individual, privacy about his/her status is required. United Nations policy states, "confidentiality regarding all medical information, including HIV/AIDS status, must be maintained".

**Applicants for employment**

Persons infected with HIV, who do not have an employment, generally will have to face discrimination from the time pre -employment tests are conducted. Some companies screen blood for HIV as part of the assessment of fitness to work. Screening of this kind includes direct methods (HIV testing), indirect methods (Assessment of risk behaviour) and questions about HIV tests already taken. Pre employment HIV/AIDS screening for insurance or other purposes raises serious concerns about discrimination and merits further close scrutiny. First of all, there is no guarantee that the person will not have HIV even if he/she is tested negative for once due to the fact that he/she needs to be tested again and again at intervals of about three months, to ascertain whether he/she is in the 'window period'. Secondly, when it is known that HIV will not spread through casual contacts in the context of work, it is highly discriminatory to deny employment to a person infected with HIV. The fact that the person infected with HIV can be productive, in many cases, for many years, denying the opportunity to him/her, is also discriminatory. At the same time, there is no guarantee that the person will not get infected with HIV after joining the organisation, or for that matter, the existing employees do not have HIV. Thirdly, it is highly unethical to screen the blood of a person without his consent. This is endorsed by national and international bodies.

**The case of Amol**

Amol began working as a casual labourer of a large corporation in Mumbai in 1986. He had always hoped to be taken on as a permanent employee, which would give him and his family financial security.

In 1994 he was interviewed for a permanent post, and to his delight was informed that he had been selected, subject to the results of a medical test. But his joy was short-lived. The Personnel Manager informed him that he would not be appointed after all, because he had tested HIV positive the previous year, when he applied for a different job in the same company.

Amol was shocked and amazed to learn that he had been tested for HIV without his knowledge, and wrote to the Executive Director of the company to ask for an explanation. His letter went unanswered, so he approached Dr. Subhash Salunke, Director of Health Services for the State of Maharashtra, who wrote to the company pointing out that it was government policy not to discriminate against HIV positive people at work, as long as they could fulfill their duties.

The Lawyer's Collective then filled a petition on behalf of Amol in the Bombay High Court, requesting that he be allowed to appeal against the company's decision, without having to reveal his identity in the course of

suppression of identity , enabling Amol to sue the corporation under a pseudonym.

The company, for its part, has declared that its policies do not allow it to employ HIV people on a permanent basis. Amol no longer works for the company.

Amol's case is the first of its kind in India. As far as the State of Maharashtra is concerned, the case has paved the way for people with HIV to seek justice in a court of law without revealing their identity.

*Courtesy:* Jaya Shreedhar and Anthony Colaco, 'Broadening the Front: NGO responses to HIV/AIDS in India,' Action AID in Association with the British Council and the UNDP, 1996.

**Persons in Employment**

Persons in employment usually undergo screening while applying for promotion or as part of routine testing by the organisation. A lot of issues related to testing while a person is in service are being debated such as:

*Informed consent*

Most of the time, the testing is done without consent from the employee, which is against the national policy on HIV testing. Very often, blood samples are taken in the name of routine checkup.

*Confidentiality*

Confidentiality regarding all medical information including HIV status is supposed to be maintained by the employer even if the test is done with the consent of an individual which often does not happen. Most of the time rumours spread and the infected person often gets harassed by the employers as well as the co-workers. Very often, the test is associated with loss of job for the HIV positive person.

*Informing the employer*

There should be no obligation for the employee to inform the employer regarding his or her HIV/AIDS status.

*Legal Issues related to HIV/AIDS and Work Place*

The Universal Declaration of Human Rights (Article 25) upholds the right to a standard of living adequate for the health and the well-being of individuals and their families. Article 12.1 of the International Covention on Economic, Social, and Cultural Rights recognizes the right to the enjoyment of the highest attainable standard of physical and mental health. In terms of HIV, this means that people living with HIV or who are at risk of contracting HIV can safely seek information, voluntary testing, counselling and medical care.

By law, State health care institution /providers are obliged to provide medical treatment to all persons in emergency and non- emergency situations. They cannot discriminate on the basis of HIV status. Fundamental rights are not available against the private sector. Private sector may refuse to provide medical treatment except in the case of a

medical emergency. In the case of an emergency, the private health sector will have to provide medical services for people living with AIDS.

*a) Human Rights and HIV*

The reason why human rights are so important in the context of HIV arises from the fact that many of the people who have been and will be most affected by the epidemic are people who are already in a socially disadvantaged position. The people who remain vulnerable are those who are denied the means of protecting themselves against HIV because of economic need, for example, or powerlessness to control the basis upon which their sexual relationship takes place. Many factors come into play here. These are poverty, geographical isolation, inadequate health care and health education, and cultural values that compel certain practices that expose some members of the community to the risk of HIV transmission. The fact that those now most at risk of HIV infections are those who are already socially and economically vulnerable means that the need to incorporate human rights concerns into HIV policy is essential.

*b) The Law & HIV*

The law has an important impact on how the HIV epidemic is experienced in any country. This became evident very early on in the epidemic because many of the people affected, such as sex workers, gay men and drug users, were already the target of punitive legal provisions. Creating a supportive legal environment can involve both positive and negative legal interventions. The laws that we do not need are the laws which discriminate against people with HIV, which distance them from their communities and which makes it less likely that these people will share in the common interest to reduce the effects of epidemics.

*c) Ethics and Law*

Ethics and laws have become common in the context of HIV policy. This is done for obvious reasons because the ethical dilemmas that arise are invariably played out in legal terms. Nonetheless, the blurring of the distinction between law and ethics can sometimes obscure the fact that tensions may exist between ethical imperatives and legal obligations. It is therefore worth considering the interaction between law, ethics and HIV.

**Check Your Progress II**

1 List some of the social issues related to HIV/AIDS in the work place.

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## 5.4 ADDRESSING ISSUES OF HIV/AIDS AT THE WORKPLACE

The disruption in the workplace caused by the fear of HIV can be minimised by providing an HIV education and support system to all employees and by establishing HIV related personnel policies well in advance of any problems. However, only a comprehensive educational programme supported by top management will encourage employees to comply.

Successful workplace education programmes have approached executives first to help them develop an understanding of the basic facts regarding HIV. This knowledge can be used to develop appropriate policy measures that will maintain a high level of worker productivity, ensure the rights and dignity of all, clarify legal issues and create an atmosphere conducive to caring for and promoting the health of all workers.

A workplace education programme meeting the needs of all workers must be developed. Each programme must be tailored to the particular audience and company. Union representatives or worker spokespersons can be involved in the design of the educational programme. Logistical decisions regarding who, where, how and when this programme should be undertaken must be determined both to meet the objectives of the programme and to create the minimum disruption in the workplace.

**Planning HIV/AIDS education programme**

The first step in addressing the issues is acknowledging the need for an HIV/AIDS education programme. This needs to be followed up by contacts with professional groups who can assist in the development of that programme. In some countries, local health departments or national AIDS committees may have material to assist in this process. The WHO has several publications that may be relevant. In other countries, local non-government agencies may be the strongest ally.

**Steps for planning HIV / AIDS Education programme**

- Approach management and then, take the steps necessary to get support from the chief executive officer and senior management.
- Compile information on HIV/AIDS and on what other organisations similar to yours have done.
- Identify a leader who can champion the cause for an HIV/AIDS education programme. If there is more than one person who is well suited for the opportunity, then develop a team.
- Encourage team work.
- Educate yourself on this issue so that you can educate others.
- Gather information about resources and use them as needed. There are a number of excellent providers of HIV education programmes for workplaces.
- Plan your budget including the cost of materials (brochures, videos, flyers, reprints etc).

- Plan to train managers and supervisors so that they are knowledgeable about HIV/AIDS.
- Develop a marketing communications plan with a message that you intend to send and communicate the basic information needed to avoid potential confusion around the issue.
- Plan to hold employee sessions to explain organisation's HIV/AIDS workplace policy, information on how HIV/AIDS is transmitted, prevention methods, company benefits available to employees afflicted with the disease, confidentiality requirements etc.

**Advocacy**

Though the legal position is clear that public sector health care institution/providers cannot refuse medical care for people living with HIV/AIDS, people living with HIV/AIDS encounter much discrimination vis-a-vis their access to health care. There is an urgent need for advocacy with the health care sector in order to improve the quality of health care available to HIV positive people. Lawyers Collective HIV/AIDS Unit, in a participatory process with health care workers, AIDS Unit and people living with HIV/AIDS have developed draft protocols on patient management relating to health care services for those affected by HIV/AIDS. The protocols have been developed with a view to improving the access and quality of health care services available to people living with HIV/AIDS whilst respecting the rights of health care workers.

## 5.5 WORKPLACE POLICY ON HIV/AIDS

**Policy**

Every company should have in place a policy that addresses how communicable diseases should be handled in the workplace. The policy is an important first step. It sets the tone for communicating information about HIV as a workplace and productivity issue. Policy statements should be educational in tone and provide guidance for employees in terms of procedures and resources. However, companies do need a policy that deals with treatment of employees who are HIV positive.

The policy can be quite extensive or stated in a few simple paragraphs. The agency culture and management attitude will determine the length and extensiveness of the policy. Managers and supervisors should be involved in developing the policy. If this is not possible, they should be given the policy prior to other employees to become familiar with it so they may address employees' concerns.

When writing the policy, many issues need to be considered. The workplace policy should spell out how the company will treat and protect employees' confidentiality regarding HIV. As a social worker, you are keenly aware of the importance of confidentiality for clients. The same care and compassion should be extended to your workers with confidential issues. One way this point is illustrated is the manner in which healthcare claims are filed in your company. Many employees in

large companies file claims with their human resource department. This means that any claims for reimbursement identify the presenting problem on the claim form or the medical bill. When these claims are turned in, the company personnel handling them know the diagnosis of the employee. Many employees, might feel awkward and embarrassing in this situation but it certainly affects employees living with HIV. The workplace policy should address this problem. A solution would be a recommendation to management to contract out the claims process to an external business.

The policy will also need to address the company's nondiscrimination policy related to HIV infection. The policy will need to address employee education and where to go for help within the company. As with many work assignments, if time and energy are invested initially, the implementation and effectiveness phases will be much smoother. After the policy is written, it is important that it not be filed and forgotten. The policy should be posted in a common area so that it becomes a part of everyday work life.

**Policy development and implementation**

Policy development and implementation is a dynamic process, not a static event. Therefore, HIV/AIDS workplace policies should be–

- communicated to all concerned
- continually reviewed in the light of epidemiological and other scientific information
- monitored for their successful implementation
- evaluated for effectiveness

**Policy components**

HIV/AIDS screening as part of the assessment of fitness to work is unnecessary and should not be required. Some of the suggested policy components are listed below:

*a) HIV/AIDS screening*

HIV/AIDS screening, whether direct, indirect or through questions about tests already taken, should not be required.

*b) Confidentiality*

Confidentiality regarding all medical information, including HIV/AIDS status, must be maintained.

*c) Informing the employer*

There should be no obligation for the employee to inform the employer regarding his or her HIV/AIDS status.

*Protection of employee*

Persons in the workplace affected by, or perceived to be affected by HIV/AIDS, must be protected from stigmatisation and discrimination by co-workers, unions, employers or clients. Information and education are

essential to maintain the climate of mutual understanding necessary to ensure this protection.

*e) Access to services for employees*

Employees and their families should have access to information and educational programmes on HIV/AIDS as well as to relevant counselling and appropriate referral.

*f) Benefits*

HIV infected employees should not be discriminated against, and should have access to and receive standard social security benefits and occupationally related benefits.

*g) Reasonable changes in working arrangements*

HIV infection by itself is not associated with any limitation in fitness to work. If fitness to work is impaired by HIV related illness, reasonable alternative working arrangements should be made.

*h) Continuation of employment*

HIV infection is not a cause for termination of employment. As with many other illnesses, persons with HIV related illnesses should be able to work as long as they are medically fit for available, appropriate work.

*i) First aid*

In any situation requiring first aid in the workplace, precautions need to be taken to reduce the risk of transmitting bloodborne infections, including hepatitis B. These standard precautions will be equally effective against HIV transmission.

## 5.6 NGO AND CORPORATE SECTOR INTIATIVES IN INDIA FOR PREVENTION OF HIV/AIDS IN THE WORKPLACE

As the epidemic spreads at an increasing rate, many Non Governmental Organisations (NGOs) and Corporate companies have realized the importance of developing preventive programs. Many have targeted the workplace as an appropriate setting for their efforts. Training modules, videos, peer training programs and written materials have been developed to assist in comprehensive workplace intervention programs. A business /NGO collaboration is a strong deterrent to the spread of HIV.

In India, a number of Corporate Houses have initiated programmes for prevention of HIV/AIDS in the workplace. The Confederation of Indian Industries (CII) has developed certain modules on HIV/AIDS Prevention and Care. They also have training and communication materials and modules that are being extensively used by their member Industries.

An NGO, after providing basic education about the medical facts and societal realities of HIV, can help management prepare workplace policies that will guide the company's response to questions and

concerns about HIV. An NGO can also be asked to prepare management to deal with HIV related issues that are likely to arise in the workplace. Then, in conjunction with management it can draw up the most effective and efficient method of providing training to line workers. If necessary, the NGO can offer ongoing support in the form of pre-and post-test conselling, individual sessions/ training of trainers; others can offer legal guidance, support for condom distribution, family counselling or education and an opportunity to allow people openly to discuss sexuality.

**The need to collaborate**

India must address the crisis of AIDS. Each day the number of infected persons is growing. All efforts must be made to curb the rate of infection. AIDS cannot be stopped by any one sector of society. Only through alliances and partnerships which maximise available human and material resources can we hope to control the epidemic.

Non-governmental organisations have a front-line role to play in responses to the HIV epidemic. In some developing countries, NGOs have already developed new community-based forms of care, counselling and support for people with HIV and their families. NGOs are also involved in educating communities about HIV and AIDS.

Among India's greatest assets are its many non-governmental organisations (NGOs) involved in promoting health, development, education and social welfare. The social reform movements which began to challenge feudalism in the late 19th century were followed, in the 1920s and 30s, by the independence movement inspired by Mahatma Gandhi and his philosophy of self-reliance, non-violence and non-discrimination. In the 1950s and 60s a new generation of Gandhian-inspired NGOs arose, often in response to emergencies such as droughts and floods; many continued to work with communities on health and development programmes.

**Check Your Progress III**

1. List the steps for planning HIV/AIDS education programme.

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## 5.7 LET US SUM UP

We have already seen how the workers are vulnerable to HIV/AIDS infection and what the various social, economic and legal issues related to HIV/AIDS and workplace are.

We have also described the importance of HIV/AIDS education and the need for HIV/AIDS policy in the workplace. The components of workplace policy on HIV/AIDS is also described in detail in the present

## 5.8 KEY WORDS

1. **Absenteeism:** Keeping away from workplace; not attending office for duty.

2. **Denial:** A person infected with HIV refuse to accept the fact that he/she is infected with HIV. Not accepting one's HIV status because of stigmatization.

## 5.9 MODEL ANSWERS

**Check Your Progress I**

1. What are some of the pertinent issues to be considered with regard to HIV infected workers?

   Pertinent issues needed to be considered with regard to the HIV infected workers include:

- the fitness to work during the so-called incubation period and adjustments in the duties of the workers who turn out to be HIV/ AIDS patients.
- implementation of adequate precautions in the workplace to reduce
- risk of transmission of HIV during accidental exposure such as deep penetrating injuries from hollow injection needles with an AIDS patient as the source.
- mandatory HIV antibody testing of employees without their informed consent and counselling, which is an infringement of their civil rights. Testing is not the solution because it does not guarantee they will not acquire the infection following a negative ELISA test.

**Check Your Progress II**

1. List some of the social issues related to HIV /AIDS in the workplace are:

- Denial
- Fear
- Discrimination
- Confidentiality
- Applications for employment requiring medical certificate

**Check Your Progress III**

1. List the steps for planning an HIV/AIDS education programme:

   Steps for planning an HIV / AIDS Education programme are:

- Approach management and then, take the steps necessary to get support from the chief executive officer and senior management.
- Compile information on HIV / AIDS and on what other organisations similar to yours have done.

- Identify a leader who can champion the cause for an HIV / AIDS education programme. If there is more than one person who is well suited for the opportunity, then develop a team.
- Encourage team work.
- Educate yourself on this issue so that you can educate others.
- Gather information about resources and use them as needed. There are a number of excellent providers of HIV education programmes for workplaces.
- Plan your budget including the cost of materials (brochures, videos, flyers, reprints etc.)
- Plan to train managers and supervisors so that they are knowledgeable about HIV/AIDS.
- Develop a marketing communications plan with the message that you intend to send and communicate the basic information needed to avoid potential confusion around the issue and efforts.
- Plan to hold employee sessions to explain organisation's HIV / AIDS workplace policy, information on how HIV/AIDS is transmitted, prevention methods, company benefits available to employees afflicted with the disease, confidentiality requirements etc.

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# CHFE - 02
# ELECTIVE ON HIV/AIDS

Block

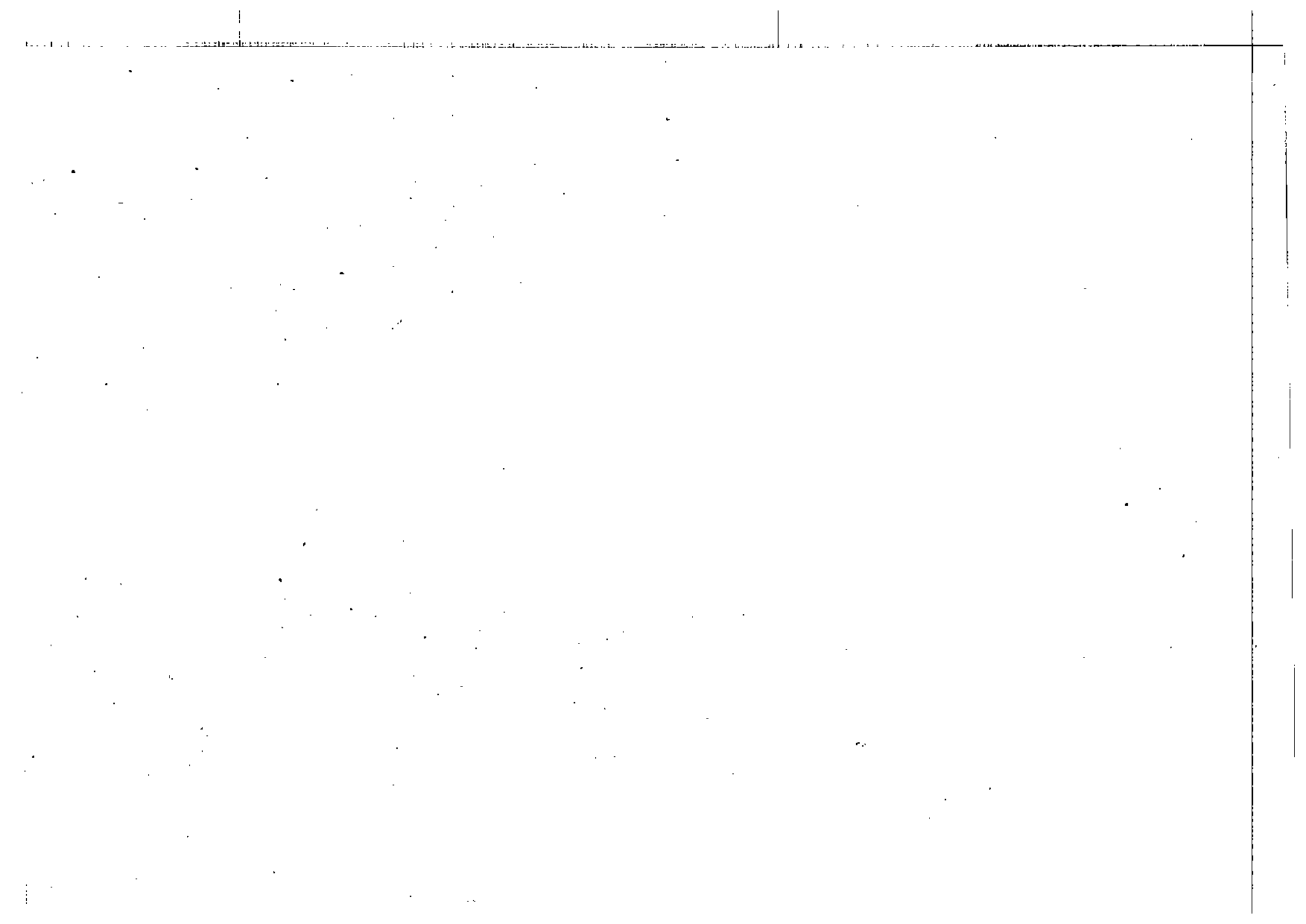
# 2

## HIV/AIDS EDUCATION AND CARE

# INTRODUCTION TO BLOCK 2

Block 2 is on 'HIV/AIDS Education and Care'. This Block will provide you with basic information about the care of the dying and the need of education for behaviour modification. There are four units in this Block. Unit 1 deals with 'HIV/AIDS and its implications for individual, family and community'. The implication of HIV/AIDS on the individual has been presented under headings of physical, psychological, spiritual and social concerns. Care is also taken to explain how these concerns should be addressed and overcome. Unit 2 on 'Care of the dying' describes the meaning of death, how to care for those who are dying of HIV/AIDS and the mechanisms for coping with loss. Unit 3 explains 'HIV/AIDS education and behaviour modification'. Apart from listing the goals of HIV/AIDS education, this unit also describes the principles and the steps for effective HIV/AIDS education. Unit 4 describes 'Palliative Care'. It has provided the differences between HIV/AIDS palliative care and traditional palliative care. The objective of this unit is to provide knowledge of simple treatment measures to make the patient comfortable.

The units presented in this Block provide very useful information and knowledge on crucial issues like care of the dying and palliative care which will go a long way in guiding health care workers as well as those invovled in home nursing of HIV/AIDS patients. The units on HIV/AIDS education and behaviour modification will be very useful for everyone concerned about the HIV/AIDS pandemic.



# UNIT 1 HIV/AIDS AND IT'S IMPLICATION FOR INDIVIDUAL, FAMILY AND COMMUNITY

**Contents**



## 1.0 AIMS AND OBJECTIVES

In this unit you will learn about implications of HIV/AIDS for an individual, his family and on the community. This unit is prepared in a story form. By the end of this unit, you should be able to:

- list the implications of HIV/AIDS on the individual under the sub headings of physical, psychological, spiritual and social concerns,
- know the implications of HIV/AIDS on the family and the community, and
- understand the ways by which these concerns should be addressed and overcome.

## 1.1 INTRODUCTION

In this chapter, you will learn in greater detail the impact of HIV/AIDS on the life of an individual, on his family and in the community where he lives. To some extent, you will also understand how the ignorance of friends and family can worsen the situation for the individual. You will understand how educating everyone about this disease will lessen the impact of this disease not only on the individual in particular but also on society as a whole.

## 1.2 WHY HIV/AIDS IS DIFFERENT FROM OTHER DISEASES

One of the crucial factors about HIV/AIDS is that it is different from most other diseases and consequently requires a radically different and a broader responses, one which goes beyond the health sector. The various factors which make it different from other diseases are:

- HIV occurs through specific risk behaviours that are within the realm of private life - i.e. extra-marital sexual intercourse, which is intimate and private and not open to public debate.
- HIV selectively affects two groups — the young adults and the very poor. Eighty to Ninety per cent of those affected are young adults at the prime of their productive and reproductive lives.
- HIV/AIDS retains a long period of invisibility, AIDS appearing many years later. However, the danger is that during this period most are unaware that they are infected and continue to spread the disease.

The prognosis for HIV/AIDS is bleak. Currently there is no vaccine and no medical cure. Treatment options are very expensive. HIV/AIDS is essentially an incurable and fatal disease as at present.

HIV/AIDS aggravates existing health problems like tuberculosis, hepatitis, enteric fever etc.

HIV/AIDS destabilizes society because of the fear, blame and stigma attached to it. It threatens basic human rights and invades the right to privacy and human dignity.

The scale of the epidemic is vast and almost every country is involved compared to other infectious diseases.

The epidemic's less visible and visible consequences, constitute an urgent and massive threat to development i.e. deteriorating child survival, reduced life expectancy, increasing number of orphans, and loss of the most productive section of the population.

## 1.3 IMPLICATION OF HIV/AIDS FOR THE INDIVIDUAL

**Story**

Devaiah was 24 years old. He received a call from a friend to say that blood was needed urgently for another friend of theirs. So, Devaiah went to the hospital and donated blood. Three days later, his friend came to him, took him to a corner and told him his blood has been thrown away as he had AIDS. Devaiah had heard of AIDS, he knew that there was no cure for it. He could not believe it. He was only 24 years old. Would he die soon? He was so afraid. He was so anxious. He did not know what to do. What could he tell his pregnant wife? He had married two years ago and till this moment, his life had been on even keel; and now, he had no control over his life. He wanted to go and buy insecticide from

the local shop and consume it, so that he could die. He felt so frightened, so anxious, so tense, and so helpless. He thought of his sisters, his old parents, his wife and he controlled himself. He must calm down, he thought, he must control himself, he must think carefully, about the next step.....

## Concerns of the Individual

The concern of an individual suffering from HIV/AIDS can be divided into:

- Physical concerns,
- Psychological concerns,
- Social concerns, and
- Spiritual concerns,

### Physical concerns

A person who is HIV positive may not have any symptoms at all. He may look and feel quite healthy. It is only having his blood-tested for HIV that he comes to know that he is HIV positive. This state may last for many years (5-10 years and even more) and the person may continue to do his routine work and continue with his life as usual. However, as the immune system becomes weaker, he begins to develop signs and symptoms the disease. There may be episodes of fever on and off. White, curdy plaques may develop in the mouth and on the tongue. He begins to feel weak and tired. There can be pain in the muscles. He develops opportunistic infections and there may be several infections going on at the same time. He begins to lose weight. He becomes extremely thin, sick, emaciated, and ultimately succumbs to the opportunistic diseases.

### Psychological concerns

When a person is diagnosed to be HIV positive, he will have several emotional reactions and these includes;

*Fear:* There is fear of death of the unknown, of losing everything.

*Anxiety:* There is anxiety for himself, his future, and the future of the dependents. He is anxious about his health and about the response of society.

*Guilt:* He feels guilty about his infection, and also for infecting others. He feels guilty about being a burden on his loved ones.

*Denial:* It is a protective defense mechanism characterized by a refusal to acknowledge any thoughts, feelings or concerns about a difficult or painful situation.

*Anger:* There may be anger at the powerlessness and hopelessness that accompanies an incurable illness and at the negative reaction of the family, friends and society. The patient as a result, may become abusive, aggressive and non-cooperative.

*Depression:* This stems from the patient living his guilt and anger towards himself. There will be sorrow, helplessness, emptiness and despondence.

*Shock:* Feeling of impending catastrophe. There is no time, it cannot be happening. The patient may collaps.

*Grief*: There may be intense grief at having brougth so much trauma into a family. Griel at loss of life; grief at having HIV positive children.

All of these emotions can occur one at a time or all together. In addition, there may be so many other emotions. There may be a lack of self-esteem, feeling of unworthiness, a desire to attempt suicide. These feelings may worsen as the disease progresses, because of associated deterioration in physical appearance.

**Social concerns**

Here, the issue of confidentiality becomes very important. At the present time as there is much stigmatization and rejection associated with the disease and if the knowledge that a person is HIV positive becomes public, it could have disastrous consequences. Hence, it is important that confidentiality is maintained. The person living with AIDS (PLWA) also has considerable tension about informing this to his or her spouse and the rest of the family. These social concerns have to be taken care of within families. There is conflict between the wish to confide and to receive emotional and practical support and the wish to protect others from distress, particularly children or frail parents. A conspiracy of silence is a source of tension. It blocks discussion of the future and preparation for parting. If it is not resolved, the bereaved often experiences much regret. There should, however, be respect for the right of privacy. Issues related to life insurance, assets, will etc., may have to be taken care of and will require the help and support of the care giv

**Spiritual concerns**

'Spiritual' relates to values, and to a person's reach for meaning and purpose in life. It also refers to experiences and relationships, which transcend sensory phenomena.

The spiritual dimension holds together the physical, psychological and social dimensions. For those nearing the end of life, there is commonly an increase or renewed need for:

- Affirmation and acceptance
- Forgiveness and reconciliation, and
- The discovery of meaning and direction.

Most patients dying from AIDS are in need of spiritual help and are seeking answers. Often, they think about their suffering and pain, why they were chosen to acquire this affliction and so on. Is there a God? Why is God allowing me to suffer like this? What is the meaning of life? What will death be like? Is there life after death? etc.

*Crisis counselling:* Identifying and validating client's ability to cope with past life crisis, assisting with concrete problem solving, encouraging client's active and positive participation in current situation, increasing awareness of options, encouraging expression of feelings within counselling session, mobilizing support network, providing client with appropriate referrals.

*Substance Abuse Treatment:* Providing referral for abuse treatment if client is experiencing negative consequences from his or her use of alcohol and/or drugs.

*Encouragement of client's active participation to increase sense of empowerment:* Learning more about the illness, changing health behaviours, helping others, increasing involvement with spiritual and religious practices.

*Skills Training:* Problem solving, coping skills, stress management.

*Mobilize Social Support:* Facilitating contact with other people.

*Advocacy:* To intervene on behalf of client who is unable to do so on his or her own, for example, financial assistance, basic living concerns, medical and treatment issues. These interventions have been explained in greater detail in other Units. Professionals must provide all these services. These are the various ways by which an individual who is HIV positive may be supported and through these interventions the impact on his personal life may be reduced.

**Check Your Progress 1**

Why is AIDS different from other diseases?

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2 What are the individual interventions that a care giver can provide to lessen the impact of AIDS on a person?

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## 1.4 IMPLICATION OF HIV/AIDS FOR THE FAMILY

**Story**

One of Devaiah's main concerns was how to tell his family and whether who was pregnant with their first child, and how it would harm her when she would know about this. He had to get his three sisters married. He was the only earning member in his family and was also taking care of his old parents. Was it safe for all of them to live together in one house as he was doing? What about his unborn child? All these doubts and fears were torturing his mind. He could not eat or sleep; he did not know what to do. He was walking along the road, his mind deep in thought and fear. Suddenly, he saw a big hoarding by the side of the road. The hoarding mentioned an AIDS helpline run by an organization called ASHA Foundation through the telephone and said that they maintained confidentiality. He jotted down the number and when time permitted and he was alone, he went to the nearly telephone booth and placed the call.

The counsellor at the other end of the line was concerned and helpful. He seemed to care and talked to Devaiah at length. Devaiah called the counsellor many times over the phone in the next few weeks and expressed all his doubts and fears. He talked about his family and his wife and her pregnancy. Finally, he had established a good rapport with the counsellor and fixed up a meeting face to face with him. He looked forward to the meeting. Devaiah was happy after his meeting with the counsellor. The counsellor spoke to him at great length and clarified all his doubts. He spoke to him about living positively with AIDS, about how to look after himself. He was willing to help him to inform his family. He told him that his wife also needed to be checked for the disease, and that if she was positive she needed to take specific medication during her pregnancy, which would help in reducing the risk of the newborn child from being infected. He advised him to have a full medical check up with a doctor who looked after people with HIV/AIDS. He told him that he looked healthy and probably had many years of useful life ahead of him. He told him all about HIV/AIDS and what it means.

The best part was that ,the counsellor, was patient and kind and non-judgmental, compassionate and professional. He did not force his opinions on him, but suggested to him all the options that were available. For the first time in months, Devaiah felt at peace with himself. After an appointment was fixed, he went to the doctor also who took details of his history. The doctor examined him and also asked him

to get some blood tests done. At the end of the examination the doctor assured him that physically he was well and in good health. He also clarified Devaiah's doubts and advised him on precautions to be taken. The doctor also assured him that he was always available and ready to treat him if the need arose and to return regularly for check-up. Devaiah felt relieved after the visit. He felt that he was no longer alone.

### Concerns of the family

When an individual in the family becomes HIV positive and his family comes to know about it, the concerns in the family are considerable.

Many families because of ignorance immediately tend to reject the individual and stigmatize him.

They feel that the person has brought a bad name to the family. They are hurt and they show their hurt and anger. They assume that he got the disease through sex, and sex is a taboo topic in our country.

Another major concern of the family is that by living with a person who is HIV positive, they also will get the infection. The fear of death from this disease is so great that they advise or force the HIV positive person to leave the house and live separately or put him in an institution that cares for HIV positive people.

Families also tend to reject the wife of the man, especially if he is recently married. In many instances, the wife is blamed as the primary cause for the misfortunes that have befallen the family. They consider her a curse. They blame her for his illness, though in a majority of cases, the opposite is (i.e the wife gets the disease from her husband).

Even in families that are supportive, the fear of losing the loved one, even though he is HIV positive is real. In many instances, the person is young and the only earning member in the family. The family worries about how they will cope with the loss, the emotional and physical loss of a loved one.

They worry about how the family will survive without regular source of income after the death of the HIV positive individual. They also worry about who will care for them and for the widowed wife and orphaned children.

They worry about looking after him at home when he is ill. They worry that hospitals will not look after him and so if they keep him at home, they need to care for him. They don't know how to do that.

In India, many families are completely isolated from the support systems that are available. Very often, the family is completely isolated in society itself and the family has to cope with several factors at one time andthat of dealing with a life threatening illness at home and stigmatization and rejection by society.

### How Can We Help?

There are many ways in which professionals can help in reviewing the fears of the family and assisting them to go through the difficult period

of "adjusting to and accepting the life threatening illness of a loved one up to the time of his death".

The professionals need to remember a few key rules before getting involved with a particular family. They need to remember that they are there to play a supportive and professional role to help this family in need. They should provide all information necessary to help the family make informed decisions in various matters. They should ease the burden of the family without taking the burdens on themselves or becoming the main pivot in the family. Professionals can alleviate the concerns of the families in various ways:

- Providing helpline and counselling centres. In these situation, the affected persons can use these helplines or approach these counselling centres where help is provided. The person is educated about the disease that he has and how he should care for himself, the problems that he may face in the future and how he can cope with them.
- The support system at home and work should be evaluated.
- If the situation seems right then the person should be encouraged to inform his family members. Unlike the western countries, the family support system in India is very strong. In many instances, the family are very supportive, once they are educated about the disease. Often, the HIV positive person requests the help of counsellor in informing his wife and other family members. The counsellor can help to ease the situation and clarify doubts and questions then and there.
- The counsellor can encourage the patient that, though he is HIV positive he can continue to have many years of healthy life ahead of him and he can plan the future and prepare for the future for the family.
- He can encourage the person to bring his wife and children for testing. If the wife is HIV negative then he can advise on how the wife should be protected. If the wife is HIV positive and pregnant, then the counsellor can advise on medication for the mother during pregnancy so that the risk of the child getting infected is reduced and refer her to a doctor for the needful.
- The children of the couple need to be tested depending on their ages and the likelihood of their being infected. If a child is infected, then the parents can be helped to cope with this additional trauma. The child can be followed up regularly by a medical team.
- If any of the children of an HIV positive couple are negative, then their future should be planned for. They would have to consider a future in which their parents may no longer be there to care for them. Support systems within the family and outside have to be assessed and suitable arrangements made.
- As an HIV positive person progresses on to AIDS he becomes more and more sick. Decisions will have to be made as to whether the person would like to be looked after at home or in a hospice. If at home, then the family members have to be assessed as to who would be able to look after him. They would have to be taught about how

to look after him. They have to be advised as to what precautions they as a family have to take in looking after him.

- If a person has property, then arrangements have to be made as how this property has to be handled after his death. The patient may want to make a will. Legal advice may have to be sought.
- If the situation so permits, then the impending death of the HIV positive person has to be discussed with him and the family, the requirements that need to be made after the death, funeral arrangements that are necessary etc.

The counsellor/doctor, over all, has a crucial role to play, because he can help ease the situation and help the family make decisions during critical phases.

The family interventions therefore are:

*Education:* Educate the family about the disease, transmission. What to expect in terms of the course of the illness and emotional response.

*Assistance to family:* Clarifying doubts about the disease, stigma, reactions to disclosure of the diagnosis and risk factor(s), fears of contagion, reactions to anticipated death of the family member and other losses, shame, impulse to reject, giving everyone opportunity to share their viewpoint etc.

*Conflict medication:* Alliance with supportive family member, establishing common ground, mediating conflicts.

*Modelling positive interaction:* Diffusing fear about contagion by acting as a role model for family members when interacting with the person with AIDS.

*Modelling family support:* Helping maximize support for family members within the family and from friends and community members where possible.

*Encouraging family members to take action:* Finding out more about the disease, and by helping others.

*Supporting the spouse of partner:* Validating their concern about their own risk of HIV infection, reinforcement for behaviour change, exploration of satisfying and safe forms of sexual contact and intimacy.

*Grief counselling:* Talking directly about reactions to the losses already experienced and /or anticipated, talking directly about death and dying, helping the family take care of practical matter (provision for children, legal matters, finances), assisting the family in addressing unresolved emotional and relationship issues.

**Check Your Progress II**

1) What are the ways in which a care-giver can intervene to support th family of a HIV positive person?

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## 1.5 IMPLICATIONS OF HIV / AIDS FOR THE COMMUNITY

A general fear of AIDS as an unknown phenomenon easily ends up with society condemning those already infected. There could be rejection of the individual and family from lack of awareness on the part of the community. By marginalising and isolating those infected or at risk of infection it would practically drive the disease underground, thus making effective health education and prevention all the more difficult.

**Story**

Devaiah was now a calmer person. He had someone whom he could confide in, to help him in decision making. His wife was already receiving tablets so that their child had less chance of getting infected. Since his family had been educated about the disease, the situation at home was not too bad. They continued to live, and eat as before. His family was supportive. His mother cried many times but overall was coping well. His three sisters were also all right. The eldest one was working in a garment factory. The second one was undergoing a typing and shorthand course, and the third one was still at school. He worried about their future and their marriage.

Devaiah was returning home deep in thought. As he reached the road, leading to his village, he saw a group of people (all men) standing under a tree and talking in whispers. When they saw him, they moved away and went about their own work. Devaiah was frightened. He thought about what he had heard – how in another village, the villagers had beaten up an HIV positive person and almost killed him. The police had to be called in to help the man and take him to a hospital. The man ran away from the hospital and disappeared. He was worried about the reaction of his village. He even suspected his friend who first told him that his blood had been thrown away. He thought his friend must have spread the information to others in the community. That night while he

was sleeping, he heard some noise and woke up. He saw at a distance, few people standing furtively. They were throwing stones at his house. After some time they went away. The next day Devaiah went to his counsellor and told him about what had happened. He expressed his fear. He was afraid that he and his family would be banished from their village. That afternoon a team of four people came to the village and conducted awareness programmes on HIV/AIDS in the local language. They showed slides and made it very interesting. Many of the villagers asked questions. Many of them realized that they were at risk of acquiring HIV/AIDS. Many of them had indulged in high-risk behaviour themselves and thought that they may already be positive. Many felt that they should get themselves checked for HIV/AIDS.

**Concerns of the community**

The cultural attitude towards health varies from place to place. In a study in Bombay it was seen that slum dwellers are well informed about disease and their treatment, but not about the need for early intervention to keep the problem in check. Women's health is also traditionally neglected. Generally sex related problems are treated by the traditional system of medicine. The perceived causes of illness or ill health are often of two types - supernatural causes and physical causes. Under the category of supernatural causes, various categories of causes can be included like breach of taboos, wrath of god and goddesses, sorcery, evil eye, etc. Sexually transmitted diseases and leprosy are believed to be the result of certain undesirable behaviour. Physical causes include excessive heat or cold, wrong combination of food and impurity of blood etc.

In the case of HIV/AIDS, infection may be viewed as being caused by supernatural factors and treatment may be approached from that angle especially for example in the case of repeated and unexplained fevers

and diarrhoeas. Beliefs related to food intake and impurity of blood, may also affect people's approach to prevention, diagnosis and clinical services in relation to AIDS. This needs to be addressed in educational programmes in relation to HIV/AIDS.

Skin piercing and unsterile injections may be another method by which HIV/AIDS spreads in the general community. Prescriptions for injections are often sought after. Skin piercing is used for decorative and ritualistic purposes - especially among women and tribal groups.

The role of health care belonging to alternative systems of medicine as well as traditional health and quacks needs to be examined in the context of their contribution to health care, especially in the context of HIV/AIDS.

Certain kinds of socio-political environments marginalize weaker groups. It increases their vulnerability to HIV infection. These include women in general, commercial sex workers in particular, and migrant labour, street children, homosexuals, intravenous drug users etc.

The main concern of a community in the context of HIV/AIDS would be:

- Spread of the disease from one individual to the rest of them in the community.
- Ostracisation of the community itself from the rest of the world.
- Impact of such ostracisation on their social and economic lives.
- If a large number in their community were HIV positive, how it would affect them as a community.

**How Can We Help?**

Counselling and health education are very important components of community care services. The most important ways in which we can help are:

*Education:* Counselling complements health education but serves a different purpose for the many people who may not believe that they themselves are directly threatened, who find it hard to change risk behaviour or who are unable to apply general information to their own specific circumstances. Education helps in making the community become aware and understand the disease. They realize that this is not a disease which spreads through casual contact and therefore, are unlikely to get it through that route.

Counselling is essential in helping people to:

- Understand the consequences for themselves and others of their risk behaviour
- Define their potential for changing risk behaviour to protect both their own health and the well being of others, and
- Find and use the personal and social resources necessary for starting and maintaining behavioural change or managing illness.

- Access facilities for voluntary testing with pre and post test counselling.

*Group interventions:* Any intervention, which facilitates interactions among people with HIV/AIDS, will help to decrease rejection and stigma while providing education, social support and role models, for coping with the illness. Peer groups can be focussed or targeted to a specific audience.

In addition to specific measures for HIV/AIDS, general education to the community is also essential. In addition to knowledge about HIV/AIDS, they should also be taught about general health measures to be taken, maintenance of good hygiene, sterile methods for skin piercing etc.

Much importance must be given to women. Women should be taught how to protect themselves from HIV/AIDS. They should have "well women clinics" where they can be checked out for reproductive tract infections, cancer etc,. They should be given adequate knowledge about HIV/AIDS. Commercial sex workers should be encouraged to insist that their clients use condoms and they should be treated for sexually transmitted infections too.

The marginalized groups also should be educated and taught how to practice safe behaviour.

**Check Your Progress III**

What are the concerns of the community in the context of HIV/AIDS?

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## 1.6 LET US SUM UP

This unit dealt with the impact of HIV/AIDS on the individual, family and community. The main points to be remembered are that:

- HIV/AIDS can have profound impact on an individual, as it is a fatal disease.
- Counselling and professional care giving can go a long way to help an individual cope with this disease and lessen the impact on his life.
- Families can be supportive, if their combined doubts and fears are clarified.

## 1.7 KEY WORDS

**PLWA** : People living with AIDS

**Transmission** : The spread of infectious Pathogers from one person to another.

**Community** : People living in a specific locality including its inhabitants.

**Counselling** : The process of assisting and guiding clients, especially by a trained person on a professional basis, to resolve especially personal, social or psychological problems and difficulties.

- Education and health care of this community is and will continue to be an important consideration to lessen the impact of this disease in society.

## 1.8 MODEL ANSWERS

**Check Your Progress 1**

1 Why is AIDS different from other diseases?

The various factors which make AIDS different from other diseases are:

- HIV occurs through specific risk behaviours that are within the realm of private life - i.e. Sex outside marriage, which is intimate and private and not open to public debate.
- HIV selectively affects two groups - the young adults and the very poor. (Eighty to Ninety) 80-90% per cent of those affected are young adults at the prime of their productive and reproductive lives.
- HIV/AIDS retains a long period of invisibility, AIDS appearing many years later. However, the danger is that during this period most are unaware that they are infected and continue to spread the disease.
- The prognosis for HIV/AIDS is bleak at present. There is no vaccine and no medical cure. Treatment options are very expensive. HIV/AIDS is essentially an incurable and fatal disease.
- HIV/AIDS aggravates existing health problems like Tuberculosis, hepatitis, enteric fever etc.
- HIV/AIDS destabilizes society because of the fear, blame and stigma attached to it. It threatens basic human rights and invades the right to privacy and human dignity.
- The scale of the epidemic is vast and almost every country is involved compared to other infectious diseases.
- The epidemic is less visible and visible consequences, constitutes an urgent and massive threat to development i.e deteriorating child survival, reduced life expectancy, increasing number of orphans, and loss of the most productive section of the population.

2 What are the individual interventions that a care giver can provide to lessen the impact of AIDS on a person?

There are several counselling interventions for people living with HIV/AIDS. These individual interventions include:

- Education about HIV/AIDS
- Individual counselling
- Provision of support
- Assistance with disclosure of diagnosis
- Grief intervention
- Substance abuse treatment
- Encouragement of clients active participation to increase sense of empowerment
- Skills training
- Mobilize social support
- Advocacy.

**Check Your Progress II**

What are the ways in which a care-giver can intervene to support the family of a HIV positive person?

The family interventions are:

- Education
- Assistance to family
- Conflict mediation
- Modelling positive interaction
- Modelling family support
- Encouraging family members to take action
- Supporting the spouse or partner
- Grief counselling

**Check Your Progress 3**

What are the concerns of the community in the context of HIV/AIDS?

The main concerns of a community in the context of HIV/AIDS would be:

- Spread of the disease from one individual to the rest of them in the community.
- Ostracisation of the community itself from the rest of the world.
- Impact of such ostracisation on their social and economic lives.
- If a large number in their community were HIV positive, how it would affect them as a community.

## 1.9 FURTHER READINGS

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# UNIT 2 CARE OF THE DYING

**Contents**



## 2.0 AIMS AND OBJECTIVES

In this section, you will learn about caring for people who are dying from HIV/AIDS, and how to cope with the aspects of chronic loss. By the end of this unit, you should be able to:

- Describe the meaning of death.
- How to care for those who are dying from HIV/AIDS.
- The mechanisms for coping with loss.

## 2.1 INTRODUCTION

The following paragraph is taken from a book by well known author and expresses fully the purpose of this unit and its relevance to HIV/AIDS:

> 'I have learnt that dying does not have to be agonizing. Physical suffering can always be alleviated. People need not die alone. Many times the calm, caring presence of another can soothe the dying person's anguish. I think, it is realistic to hope for a future in which nobody has to die alone and nobody has to die with his pain untreated. I have learnt from my patients and their families a surprising truth about dying. This stage of life holds remarkable possibilities. Despite the arduous nature of the experience, when people are relatively comfortable and know that they are not going to be abandoned, they frequently find ways to strengthen bonds with people they love and to create profound meaning in their final passage. ('Ira Byock from the book-'Dying well-the prospect for growth at the end of life').

## 2.2 FACTORS RELEVANT TO DYING IN THE CONTEXT OF HIV/AIDS

As we all know, more than half of the people living with HIV/AIDS are in the age group of 15-25 years. Once, they are diagnosed with HIV disease, they begin to face the possibility of death, especially in the underdeveloped and developing countries where treatment is prohibitively expensive.

Dying in the context of HIV/AIDS have several relavant factors:

- Many of them are in the prime of their lives and relatively healthy, when they are diagnosed to be HIV positive.
- Many of them may be the only earning members of their families and have to face the reality of not only their own deaths, but also worry about the future of their wives, parents and their children.
- They are filled with emotions such as shock, fear, worry, guilt and anxiety.
- They are very uncertain about the nature of their deaths and their ability to face it.
- They are subjected to ridicule and rejection by society, because society assumes that they have acquired the disease through immoral behaviour, even if that may not be the case at all.
- They may lose their jobs and identity.
- In many cases, where sexual orientation was kept 'under wraps' it may now become public and add to a further impetus for isolation and stigmatization.
- There may be loss of confidence, depression, loneliness and suicidal thinking.
- The person may be under tremendous pressure from self, friends, family and society.
- He/she has to cope with the impact his/her disease which will have on the members of the family - emotionally, socially and financially.

Taking the above factors into context, HIV/AIDS is the one disease in which care of the dying becomes important because every one of the above aspects have to be considered and settled, so that the person can have a peaceful and uneventful death.

A point will come during the process of treatment of HIV/AIDS when nothing more can be done to effectively treat the opportunistic infections, or completely relieve the symptoms that they cause. At this stage, the infections or illness have progressed beyond what medicines can cure. At this point, the goal of all care (medical, nursing, religious and psychological) is to keep the person as comfortable as possible and to maintain their dignity till their death and in death.

## What is death?

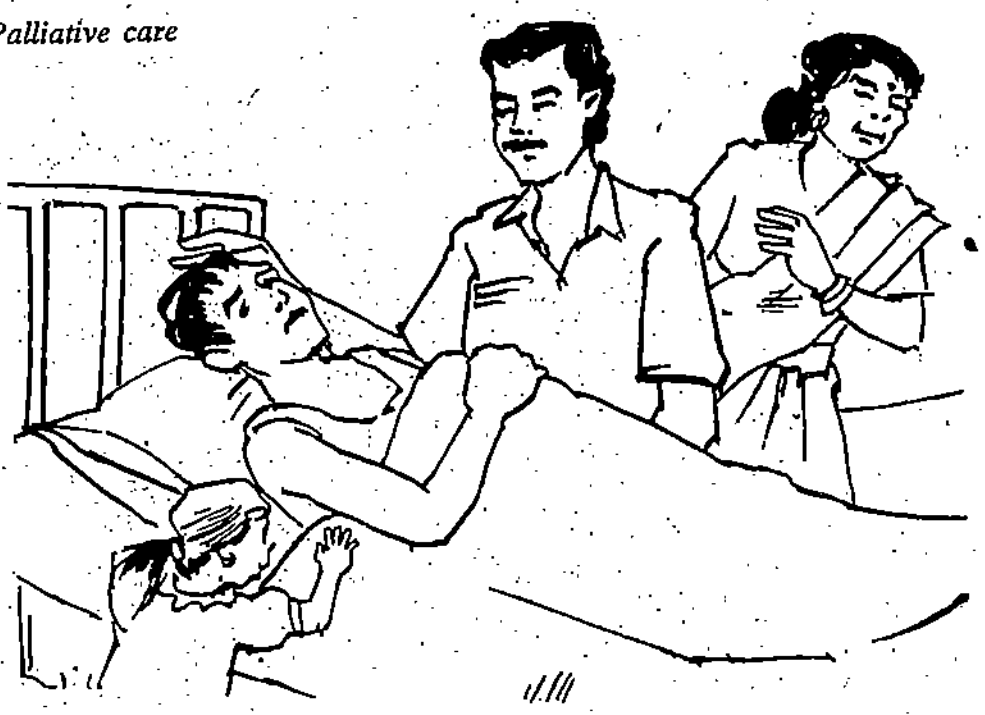
Death may be defined as:

1) The complete and irreversible cessation of circulatory and respiratory function, or
2) The complete and irreversible cessation of all brain function including the brain stem. Such a person will not have a pulse or heart beat, there will be no spontaneous breathing; and there will be no response to external stimulation.

### Physical aspects of death

A person who has died will be completely still. The eyes may be open or closed, and if open will stare blankly. There will be no response of the eyes to touching them, or clapping or to light. There will be no pulse or heart beat. There will be no breathing and the chest will not rise or fall with each breath, but will be motionless. The hands and legs will be limp and lifeless and flops down on lifting them and releasing. On lifting the neck, the head falls back. After a few hours, a condition referred to as rigor mortis sets in and the limbs and body becomes stiff and cannot be easily positioned.

*Palliative care*



Palliative care is derived from a Latin word 'pallium', meaning a cloak or cover. Thus, in palliative care, symptoms are 'cloaked' to promote patient comfort. Palliative care developed as a reaction to the attitude spoken or unspoken, that there is nothing more that can be done. This left the patient and the family with a sense of abandonment, hopelessness and despair. This is not true. There is always something that can be done. Even there are times when the carer feels that there is nothing more that he or she can offer. At such times, it helps to remember:

- Slowly, I learn about the importance of powerlessness.

- I experience it in my own life and I live with it in my work.
- The secret is not to be afraid of it-not to run away.
- The dying know we are not God.
- All they ask is that we do not desert them.

Palliative care is the active, total care of patients and their families by a professional team at a time, when the patient's diseases are no longer responsive to curative treatment and life expectancy is relatively short. It responds to physical, psychological, social, spiritual needs and extends if necessary, to support in bereavement. The goal of palliative care is to provide support and care for patients in the last phases of the disease so that they can live as fully and comfortably as possible. There is a complete section on palliative care in Block-2, Unit - 3 and palliative care with regard to HIV/AIDS is dealt with in that section.

**Check Your Progress 1**

1. What is death?

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2. What is palliative care?

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## 2.3 CARE OF THE DYING

Before reading this section, it is important to look at the section on "Common symptoms in HIV/ AIDS and Their Relief Measures" in the unit on palliative care.

The medical profession most commonly approaches dying as if it were solely a problematic medical event. End-of-life care is unlike elective surgery, fracture management, treatment of the flu; surgery for acute appendicitis or even a heart attack, from which one is expected to survive. For the terminally ill patient, life cannot be simply put on hold, while treatment is endured.

Dying is more than a set of problems to be solved. The nature of dying is not medical, it is experimental. Dying is fundamentally a personal experience, not a set of medical problems to be solved.

**When does this time of caring for the dying begin?**

It is often difficult to decide when the focus on medical treatment should stop and care for the dying should begin. The change in care may begin, for example:

- When medical treatment is not available or is no longer effective.
- When the person says he or she is ready to die and really does appear to be very sick.
- This is clearly different from someone who is depressed for a time and who must be encouraged not to give up.
- When the body's vital organs begin to fail.

**Where can you provide care for someone who is dying?**

Care for the dying can be provided in a hospital or in the home. Most people prefer or are forced by circumstances, to remain at home. However, some people may not want to actually die in their homes. They may want to stay at home until the last moment but either because of their own or family's wishes they may want to go to the hospital to die. If this is the case, a plan for transporting them will need to be thought out.

**What are the goals of caring for someone who is dying?**

- Keeping them comfortable and protecting them from problems that can make them feel worse.
- Helping them to be as independent as possible.
- Assisting them in grieving for, and coping with, the continuing losses they experience (physical losses, financial losses, etc.).
- Helping them and their families to prepare for death; this may include making a will, tending to relationships in the family or the community, and arranging for the transfer of responsibilities.
- Keeping them within the community and family groups for as long as possible: family members can bring them into this part of their lives even when it seems they are too ill to or enjoy or understand what is going on.

**What can we do to help meet this goal?**

- If the person is in constant pain, make sure that pain medication is

available and given in regular doses. It should not be taken just when the pain is really bad.

- Use relaxation techniques, such as encouraging deep breathing, or giving back rubs or body massages. Continue basic physical care to keep the person clean and dry and prevent skin problems, and stiffness of joints.
- Encourage communication within the family and community. People with AIDS and those they love need to feel that they are not outside the love and life of their community. Help them use this time as a chance to heal old wounds and to make peace with each other. This will help to increase the comfort and acceptance of the whole family.
- Provide physical contact by touching, holding hands and hugging.
- Provide or arrange for counselling if desired, for e.g.: from religious representatives. They can be very helpful for spiritual counselling.
- Allow the sick person independence.
- Accept the person's own decisions such as a refusal to eat or get up, or even a demand to get up when you think that resting would be better for them. Respect requests, for example, regarding not wanting to see visitors. Ask them what they are feeling. Listen and allow the person to talk about how they feel. Accept the person's feelings of anger, fear, grief and other emotions.
- Prepare for death
- Talk about death if the person wishes to. Many people feel that it is not good to talk about the fact that someone is going to die, as if mentioning death is a wish for death. But by discussing death openly, those around are helping the dying person to prepare for death. It may take great courage to talk about it but it can be a big help for the person to feel that their concerns are heard, that their wishes will be followed and that they are not alone. To avoid talking about death is a form of denial.

One of the most common worries is for the future of the children in a family. People may fear that their children will be hungry or lack money for school fees after they have died. Begin planning with relatives, friends or orphan programmes for future of the children. It will ease such worries if the person knows that suitable arrangements have already been made. The person may be worried about being in pain as he or she nears death. Knowing what it will be like can lessen the fear. If the person asks, describe what might happen, such as difficulty in breathing, or passing in and out of consciousness. If pain medications are available, reassure the person that they will be used in order to prevent unnecessary pain. The person may be worried about what will happen after they die. The anxiety can be lessened by helping them to write a will, by planning and writing down details such as funeral arrangements and discussing spiritual beliefs, perhaps with a representative of the person's religion.

**What precautions should the family take with the body of someone who has died of AIDS?**

Immediately after the death of the person, you need to follow the same rules in dealing with the body as you did when helping the person through his illness. Hands should be protected when cleaning and laying out the body, particularly if there are body fluids such as diarrhoea or blood. The hands should then be washed with soap and water. Wounds on hands or arms should be covered with a plaster or bandage.

Shortly after the person has died, the virus will also die. HIV can only live and reproduce inside a living person. Therefore, you do not need to worry about special precautions during the funeral itself. The person can be either buried or cremated according to local custom.

**How can you help the family after the death?**

There are a few things to be done before the body is moved. One has to respect the wish of the person as to particular spiritual or religious rituals and funeral and memorial service arrangements she/he wished to follow. Caring for the body can be a very important task for some people.

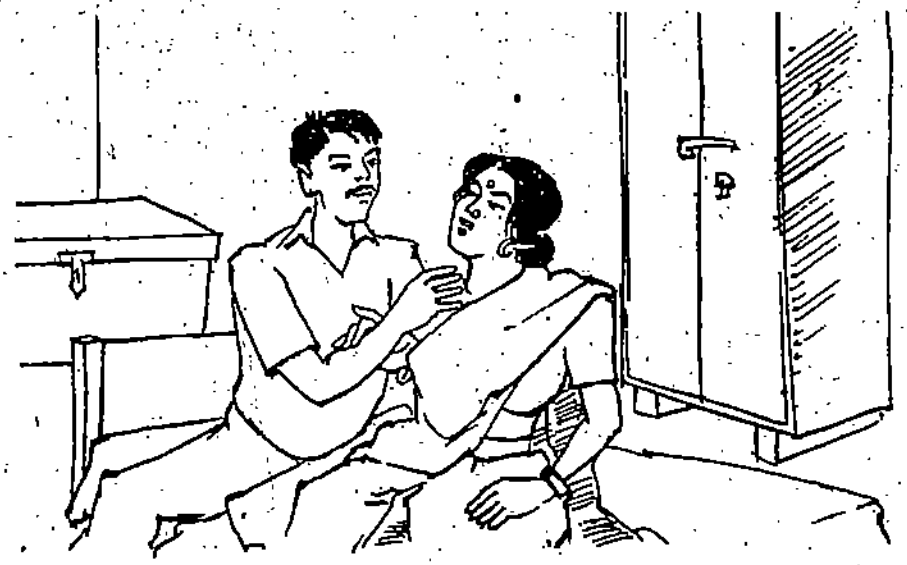
*What to do?*

If the head is raised, lower it so that body remains almost flat. Keep a pillow under the head and gently straighten out the body.

If the eyes remain open, close them gently. If the mouth is opened, you can insert a rolled up towel under the chin which will help close the mouth and have the body look as peaceful as possible.

After the doctor officially declares the person dead and before the funeral attendants arrive, the body can be bathed and dressed. Family or friends usually know what dress the person would favour.

Take time to say goodbye properly. Some people tend to forget in the flurry of activity and may later feel that they neglected the person. The best time would be after the body is dressed and ready to be taken out of the house. There is usually no privacy once the body is taken out of the house.



Immediately after a person has died, the family may need help to grieve or arrange practical matters. You can offer this by listening to them. You can also assist them with the funeral arrangements in accordance with the customs and regulations of the area in which they live. Again, it may be appropriate for the instructions to be written down, so that nothing is forgotten.

The death may continue to cause practical difficulties for the family. This is particularly true if planning for the death was not done properly. Also, the family and loved ones will continue to grieve for many months. Any care or practical help you can give during this time can be useful. Setting aside time to visit and asking how they are doing will help them to think of life beyond this painful time. It will be very useful to help the family in obtaining a death certificate from local administration.

*On the family's role in care for the dying*

Family derives its meaning from processes involving qualities of belonging, mutuality and responsibility. Family is defined by the relationship of love and belonging. The dying process affects each member of the person's family. Families also deserve the care of a professional in the process of losing a loved one and deserving bereavement. Yet, families often benefit deeply from providing care Those who are willing deserve skilled support enabling them to love and honour the person departing in a physical and emotional way.

*On the community's role in care for the dying*

Like family, community is defined by a collective sense of belonging, mutuality and shared responsibility. First, as dying is part of the life of an individual and is part of the life and history of a family, caring for those who are dying is a part of the ongoing life of the community. It is important to ensure that people are visited, that their stories are heard, and that they may know that they are valued. The community can bear witness to their lives, their frustrations, defeats and triumphs and bear witness to their passing.

*On dying well*

Dying well can be thought of as a subjective personal experience, which embodies a sense of meaning, and purpose and a sense of completion, at times, even fulfillment. People can change in remarkable ways even as they die. They do not become someone else, but somehow more themselves, often more accepting and forgiving of themselves and more loving towards themselves and with others.

**Check Your Progress II**

1. What are the goals of caring for someone who is dying?

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## 2.4 ROLE OF THE CARE GIVER

The care giver should have some basic medical knowledge of AIDS. There are some opportunistic diseases from which a person may recover and others from which one may rapidly deteriorate, with loss of one function after another occurring daily to weekly. Therefore, time is of the essence. Thus, the social worker or care giver needs to know the following:

- What care will be needed.
- What natural supports does the family have i.e. people to help with hands on care, sitting with the patient, doing the cooking, washing, shopping, etc.
- Are the family members aware of the AIDS diagnosis? Do they need education, including precautions that need to be taken.
- What formal supports are available? Visiting nurse, doctor, etc. nearby hospitals or nursing homes etc.
- What are the patient's resources?

The care giver needs to be aware that in addition to the issue of loss of life for the patient there may be a multitude of other losses over a period of time. These may include:

- Loss of ability to work which could lead to a decrease in the standard of living
- Loss of self-esteem
- Loss of energy
- Loss of familiar body image.
- Loss of eyesight etc.

Keeping the above facts in mind and after one has established rapport, some of the questions that need to be asked include the following:

- What things need particular attention?
- What resources are there?
- Does he want to die at home?
- What should be done with the body?
- Is there any unfinished business that needs to be attended to?
- Is there anyone who wants to make peace with?
- What are the spiritual beliefs?

**Suggested action steps**

Let the patient be the guide. Explore gently what would be intolerable for him. If there is clinical depression, would a small dose of medication improve the quality of his life. Reassurance is an important aspect. Try and make him understand that he is important to the care giver.

In addition to interaction between the patient and the care giver, there should be interaction between the care giver and other providers. Areas that could be evaluated at this time include:

- Physical needs
- Emotional needs
- Spiritual needs
- Social needs
- Legal needs
- Medical needs etc.

**Spiritual aspects of death**

'Palliative care' integrates psychological, social and spiritual aspects of care so that patient may come to terms with own death as fully and constructively as they can.

Spirituality relates to values (ultimate issues and life principles) and to a person's search for meaning and purpose in life. It also refers to experiences and relationship, which transcend sensory phenomena.

Religion is shared framework of theistic beliefs and rituals, which give expression to spiritual concerns.

The spiritual dimension may also be viewed as the integrating component, holding together physical, psychological and social dimensions.

For those nearing the end of life, there is commonly an increased or renewed need for, affirmation and acceptance.

Forgiveness and reconciliation.

The discovery of meaning and directions.

Death is not the ultimate tragedy of life. The ultimate tragedy is depersonalization, e.g. Dying in an alien and sterile area. Separation from the spiritual nourishment of a fellow human being. Hopelessness and despair. Whether apparent or not, most patients are in need of spiritual help and are seeking answers to the following questions.

- Meaning of suffering and pain. Why do I to suffer? Why has this happened to me?
- **Value systems** - What value is there in money, material possessions and social position? What is valuable in my life?
- **Quests about God** - Is there a God? Why does God allow me to suffer like this?

- **The meaning of life** - What is the meaning of life in a time of serious illness? What is the point of it all? What is my relations with God?
- **Guilt feelings** - I have done many wrong things. How can they corrected? How can I be forgiven?
- **Life after death** - Is there life after death? How can I believe i life after death? What is it like?

**Religious and cultural needs**

The religions that are generally practised in this country include:

- Hinduism
- Islam
- Christianity
- Sikhism
- Buddhism

**Hinduism**

Hinduism dates back to about 2500.BC. Many Gods and Goddesses worshipped. The temple is the place of worship. The main festivals the Hindus are Diwali, Dussehra, Janmmashtami, Holi, Ram Navam etc. Worship may be done at home also. Beliefs include transmigrati of the soul with an indefinite number of reincarnations until the attainment of Nirvana or fusion with the supreme being. A Pandit is called in to perform the last rites. Cremation is usual. In some hosp a temple is also provided for those who wish to worship.

**Islam**

Islam is the Arabic word for submission, surrender, obedience. Mohammed is the prophet sent by God. The Quran is the Holy Boo the Muslims. The five pillars of Islam are:

- There is only one God
- Prayer five times a day
- Almsgiving
- Fasting
- Pilgrimage to Mecca

Friday is the Holy Day. The main festivals are Idu'l Fitr, Milad-Un-Nabi, Muharram etc. The mosque is the place of worship. When dy the Quran is read and the Muslim articles of faith are whispered to bring peace to the soul. The head should be turned to the right. Cremation is prohibited and coffins are not allowed. The families ar close-knit and there are many visitors.

and strength is given in many ways particularly through the Bible, prayers and sacraments. Many hospitals have a chapel and many patients value its peace and quietness. The main festivals of Christians include Christmas, Good Friday, Easter, etc. At the time of death a funeral service is held at home or in the Church and a memorial service later. After death the body is buried in a cemetery.

**Sikhism**

This religion was founded in the 15th century AD. The main festivals are Guru Nanak's birthday, Guru Gobind Singh's birthday, Guru Ravidas's birthday etc. the way of salvation is through a good life of kindness to others and concern for family and society. Their Holy Book is the Guru Granth Sahib. During death, the relevant scriptures are read. Cremation is favoured.

**Buddhism**

Buddhism came into existence in the sixth century B.C. Buddha is revered as an example of a way of life. Helping people is fundamental to the Buddhist ideal. The main festival is Buddha Purnima. A dying Buddhist may wish to maintain clarity of thought till the end. Cremation is usual. White is the colour of mourning.

**Bereavement counselling**

Blessed are they that mourn for they shall be made strong. Bereavement or grief is not only an emotional experience suffered by the family and friends of the dead person, but it is also a physical, intellectual, social and spiritual experience. By grieving, the bereaved person adjusts to the loss and the meaning of that loss in their life.

**Common Reactions to Grief**

*Physical:* sighing, self-neglect, sleep disturbances, weakness, fatigue etc.

*Emotional:* numbness, sadness, despair, confusion, yearning, guilt, anger, helplessness etc.

*Behavioural:* disorientation, pre-occupied, forgetful, crying, withdrawal etc.

**Phases of grief**

*Shock, numbness and disbelief:* Initially, bereaved people may feel detached from reality. The reality of death may not have penetrated awareness.

*Separation and pain:* The absence of the dead person is everywhere palpable. The home may be full of painful reminders. There is intense yearning. Searching for the dead person is common.

*Despair:* Despair sets in when one realizes that the dead person will not return. There is anger, guilt, anxiety, restlessness, etc.

*Acceptance:* Bereaved people may be intellectually aware of the finality of the loss long before their emotions let them accept the truth.

Gradually, despair gives way to acceptance of the loss.

*Resolution and re-organization:* As old patterns of life are given up, new patterns without the dead person are adopted and the bereaved person enters the phase of resolution and re-organization. Eventually, they are able to reinvest in the world.

**Tasks of mourning**

The process of grief has also been described as a series of tasks to be completed by the bereaved in order to move on:

- Accept the reality of the loss.
- Experience the pain of grief.
- Adjust to an environment where the dead person is missing.
- Withdraw emotional energy and reinvest in other activities.
- By encouraging the bereaved to work through the tasks of mourning, it is possible to facilitate the process of grief.

There are also five tasks to complete mourning. They are referred to as the five Rs. and include:

- Recognising
- Reacting
- Recollecting
- Relinquishing
- Readjusting

This means to recognize the loss, react to the separation, recollect and re-experience the relationship, relinquish the old attachments and readjust to the new world in which the loved one is absent.

**Dimensions of the loss**

This model focuses on how the loss affects all the dimensions of life, i.e. the identity, emotional, spiritual, practical, physical aspects and the lifestyle of the bereaved person. Has the person's role changed within the family and the community, e.g. by taking on the deceased person's role as father or mother in the family, being a widow instead of a wife in the community etc.

**Dual process**

Most people cope after bereavement by fluctuating between confronting grief and avoiding grief. These are described as loss-oriented and restoration oriented behaviour. The first focuses on the loss and the emotional reactions to it and the other encompasses a degree of suppression, distraction and taking time off from grief. Thus, a person may appear to be coping well one day and full of grief the next. Thus, people may oscillate between the two ways of coping.

## Risk assessment in bereavement

People vary in their response to bereavement. Most people work through their grief with the help of family and friends. The grief may be immediate or delayed, brief or unending, severe or mild. It may be associated with health risks, physical or mental. The mode of death and the nature of the relationship between the deceased and the bereaved, the support from family and friends, concurrent life events, previous losses, and the medical history are factors that are important in assessing how the bereaved person will cope with the loss. The most important factor in favour of a good outcome is a supportive family or friend who is there as long as he or she is needed.

## Care for the care-giver

Care givers are probably people who are good at their work and not afraid of a challenge. They are people who are trained to help, to fix and to cure. And then they meet in growing numbers the people living with HIV infection. They meet people, who are just like them, and they work with them and fight with them and they pray for them and they watch them lose. They watch them losing their vision, their mobility, their jobs, their children. They watch them losing bladder and bowel control. They watch them losing their lives.

And indeed, they have not been trained for this. They have not been trained to lose so many battles with so many people who are just like them and so they feel helpless. They are overworked and overloaded and yet, they don't seem to be making much of a difference in the world. And nobody has told them about death. Nobody has told them about grief. Nobody has told them that they will grieve. Nobody has told them how to grieve or what to expect.

## What is disenfranchised grief?

This is a condition that is common among professional care givers whose loss is often not recognized or validated by friends, colleagues or family. It is a notion that grief is not theirs to have. It belongs to families and loved ones of the deceased. Grief may be considered as disenfranchised when the relationship between professional care giver and the patient is not recognized, the loss is not recognized or the griever is not recognized. As professionals they have no right to grieve or to get involved. And yet, if they fail to experience this pain, then experts say, "anything that continually allows the person to avoid or suppress this pain can be expected to prolong the course of mourning." Sooner or later, some of those who avoid all conscious grieving break down, usually, with some form of depression. Regular and ongoing attention to the emotional needs of the care givers can do much to alleviate the onset of symptoms of burnout.

Therefore, AIDS service organizations must have a greater sensitivity to the needs of grieving caregivers. In AIDS we are dealing with chronic loss, that is, ongoing loss. Studies have revealed that people who undergo chronic loss may experience depression, helplessness, sorrow, numbing, panic attacks, sleeplessness, fears of developing HIV infection, etc. This

may lead to symptoms of burnout, or post traumatic stress syndrome. The other factors that contribute to this syndrome are:

- Failure of medical cure for the patient
- Repeated exposure to death of known people
- Emotional conflicts
- Absorption of anger of relatives and families
- Role blurring
- Personal idealism

**What is the response to this problem?**

There are a range of strategies that have, over a period of time, evolved to cope with this problem. They include pre-requisites for self care which are:

- Love
- Self-esteem
- Imagination
- Flexibility
- Humour
- Compassion
- A capacity to accept and correct mistakes
- A mind ready to take challenges.

It is important to:

- Work as a team.
- Have good resources and support services.
- Self realistic goals.
- Have adequate off-duty/food/rest.
- Take time for recreation and spiritual refreshment.

The key to long term survival for HIV care givers are:

- Learn about grief through reading in-service training; and give yourself permission to grieve and attend a care givers support group.

**Check Your Progress III**

1. What are the five R's in relation to the tasks of mourning?

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## 2.5 LET US SUM UP

This unit dealt with care of the dying in the context of HIV and AIDS. The main points we discussed are: care of dying is as important as care of the living; the caregiver has an important role to play in the care of the dying; the care giver is the link between the patient, the family and the society and community; the care giver has needs too and should be prepared to work in a field that encompasses death and pain.

## 2.6 KEY WORDS

**Circulatory:** the heart, the blood vessels and the blood flowing through them.

**Respiratory:** the trachea and branches, the lungs and the movement of the breathing.

**Brain stem:** the lower portion of the brain which has the control centre for the circulatory, respiratory system etc.

**Bereavement:** The process undergone by relatives in the aftermath of death.

## 2.7 MODEL ANSWERS

**Check Your Progress I**

1 What is death?

Death may be defined as:

The complete and irreversible cessation of circulatory and respiratory function *or*

The complete and irreversible cessation of all brain function including the brain stem. Such a person will not have a pulse or heart beat; there will be no spontaneous breathing, and there will be no response to external stimulation.

2 What is palliative care?

Palliative care is the active, total care of patients and their families by a professional team at a time, when the patient's diseases are no longer responsive to curative treatment and life expectancy is relatively short. It responds to physical, psychological, social spiritual needs and extends if necessary to support in bereavement. The goal

of palliative care is to provide support and care for patients in the last phases of the disease so that they can live as fully and comfortably as possible.

**Check Your Progress II**

1. What are the goals of caring for someone who is dying?

- Keeping them comfortable and protecting them from problems that can make them feel worse.
- Helping them to be as independent as possible.
- Assisting them in grieving for, and coping with, the continuing losses they experience (physical losses, financial losses, etc.)
- Helping them and their families prepare for death; this may include making a will, tending to relationships in the family or the community, and arranging for the transfer of responsibilities.
- Keeping them within the community and family groups for as long as possible: family members can bring them into this part of their lives even when it seems they are too ill to or enjoy or understand what is going on.

**Check Your Progress III**

1. What are the five R's in the task of mourning?

The five tasks to complete mourning include:

- Recognising
- Reacting
- Recollecting
- Relinquishing
- Readjusting.

This means to recognize the loss, react to the separation, recollect and re-experience the relationship, relinquish the old attachments and readjust to the New World in which the loved one is absent.

## 2.8 FURTHER READINGS

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# UNIT 3 HIV / AIDS EDUCATION AND BEHAVIOUR MODIFICATION

**Contents**



## 3.0 AIMS AND OBJECTIVES

This unit deals with education and behaviour modification in the context of HIV/AIDS. By the end of this unit you should be able to:

- list the goals of HIV/AIDS education,
- describe the principles of HIV/AIDS education: do's and don'ts,
- discuss the steps for effective HIV/AIDS education, and
- explain the strategies for implementation of an AIDS control programme.

## 3.1 INTRODUCTION

You have already gone through the basic courses on HIV/AIDS and Family education. From this, you can understd the importance and need for AIDS education. In this unit you will study the goals of HIV/AIDS education. You will look at the attitudes reflected through them, the communication methods, the impact of how these messages are conveyed and the situation of the recipients of that education which makes them ignore it or act upon it.

## 3.2 GOALS OF HIV/AIDS EDUCATION

The goals of HIV/AIDS education include:

- Providing correct information to the lay public about the new disease syndrome called HIV/AIDS, so that HIV positive persons are dealt with by society in humane and caring manner.
- Maintaining the attitude of people not engaging in high risk behaviour to continue to maintain that behaviour.
- Motivating behaviour change in those engaging in high risk behaviour such as sex outside marriage, IV drug abuse etc., which are likely to transmit HIV.
- Providing planners, administrators and service providers with correct information, so that they can perform their duties effectively and in the best interests of HIV/AIDS control.

Experience shows that information alone will not have a significant impact on the spread of HIV infection. Social conditions, material inputs and services must allow for action in accordance with it. For instance, information about symptoms and modes of transmission may make individuals fear that they have an STD or HIV/AIDS, but social stigma and poor access to health services would hinder them from seeking treatment. Similarly, the psychological condition of unemployed youth may make them easy prey to temptations offered by drug peddlers even if they are aware of the dangers involved. Social values and peer pressure can help to some extent by supporting refusal but the danger will remain as long as the drug mafia continues unchecked and the condition of unemployment creates a fertile ground for them. The goals of AIDS education can therefore, be fulfilled only when:

- It is complemented by effective action in the other related spheres.
- Leads to capacity building for actions conducive to AIDS control.

**Check Your Progress I**

Answer the following questions:

1. What are the basic goals of AIDS education ?

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## 3.3 SOME DOS AND DON'TS OF HIV/AIDS EDUCATION

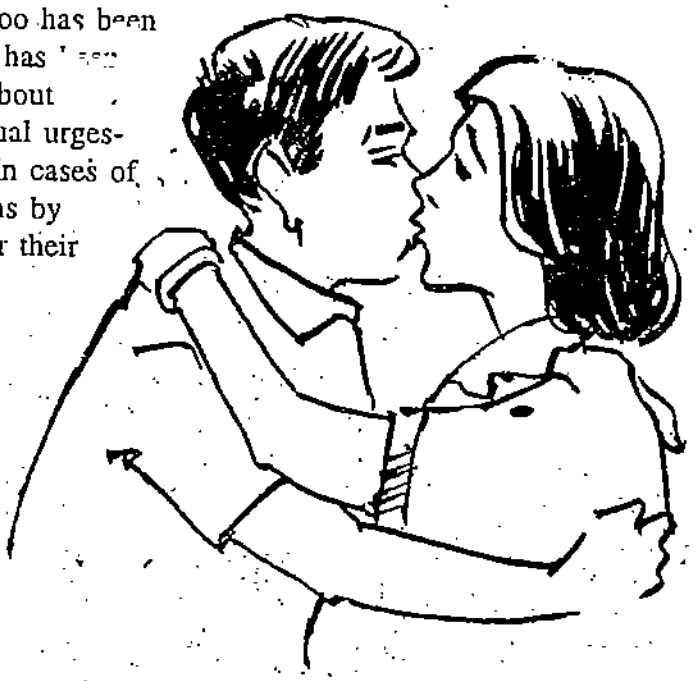
Lessons learnt from communication approaches early on in the HIV/AIDS epidemic across the world must be considered before any further HIV/AIDS communication is undertaken. These include the following.

*Fear Campaigns are Counter-productive*

In many countries of the developed and developing world, fear campaigns were initiated with the reasoning that people would be shocked into behavioural change. However, studies showed contrary results. Since individuals at low risk became irrationally panic-stricken and those at high risk turned away from the messages, this approach did not fulfill the goals. It was found that such messages may provide short-term improvements in some situations but the behavioural change was generally not sustained for long and reversion to earlier (risky) behaviours often occurred. Fear generated by the projected numbers of HIV infected and AIDS cases by the international agencies to draw the national policy-makers' attention to the problem of HIV/AIDS also proved counter-productive. This led to a panic-stricken response and not a rational, well thought out control programme suited to local context. So later, much of the counter- productive efforts of the AIDS control activities had to be undone. The fear generated also conveyed itself to the medical professionals who too responded irrationally and unethically by refusing to treat HIV positive persons.

*Significance of Images of Women, Gender Relationships and Sexuality*

Images of the submissive, passive female and the aggressive macho-male pervade attitudes towards sexuality. These attitudes reflect the difference in status between men and women. The controls have always been more stringent on women than on men. Female sexual desires have been represented as evil and, therefore, to be controlled even through coercion. Women's virginity before marriage has been considered all-important and any extra-marital relationship is considered sinful. Male sexuality too has been condemned but society has been much more indulgent about fulfillment of male sexual urges- they have been liberal in cases of violation of social norms by men, even allowing for their institutionalization. Prostitution is one such institution. It has been viewed as an institution necessary for fulfilling the male sexual needs and protecting the majority of women as well as allowing their marriages to go on undisturbed.



This view of women's complete virginity on one side and commercial sexual exploitation on the other has undermined the emotional and mutually supportive dimensions of man-woman relationship. It allows for many forms of exploitation of women both within the home and outside it. The woman's weaker position in the power equation of the relationship does not, permit the societal situation to be checked by individuals within their specific relationships.

Propagating ideas of individual sexual freedom and sexual rights of both men and women without empowerment of women in other spheres of life only strengthens the existing exploitation. It further commodifies sex more blatantly and creates a space for greater sexual irresponsibility by men, thereby increasing chances of spread of HIV. Therefore, there is a need for public questioning of the stereo-images about sexuality, particularly, in the context of various dimensions of gender relations. However, the debate must be within the framework of responsibility and mutuality, so that the new attitudes developed towards sexuality minimize exploitation of women and the spread of HIV.

*A Non-Stigmatizing, Non-Discriminatory Attitude is Essential*

The focus on certain socially marginalised groups as 'high risk groups' for HIV/AIDS (i.e. Truck drivers, homosexual men, commercial sex workers and IV- drug users) has stigmatized HIV positivity and AIDS when in fact the HIV can be found in many other pockets of society (e.g. in clients who infect sex-workers) and in the population in general (e.g. when transmitted by medical interventions). This has led to discrimination against HIV positive persons to the extent that they have been turned out of jobs, been forced to leave their places of residence and suffer social isolation. This creates their suffering even while they are not suffering from any physical illness (i.e. when they have not become AIDS cases) and adds to the suffering of those who are ill. The social discrimination and the suffering of individuals also puts the population at greater risk as it makes the HIV positive persons hide their serological status. It makes others deny any risk to themselves, and thus, adds to spread of HIV. Therefore, a non-stigmatising, non-discriminatory attitude must be developed for protection of the individual, the social group and the population as a whole.

*Moralising Messages have Little Effectiveness*

AIDS education messages which preach behaviour change to those engaging in activities likely to transmit HIV (such as preaching monogamy to those undertaking multiple partner sex or preaching about the negative consequences of drug abuse to those engaging in intravenous drug use) are seldom effective in inducing the desired behaviour changes. Making other optional behaviours attractive, ensuring the required material base, access to the necessary services and a psychological environment with social and peer group support for the required behaviour change, are all essential contributors. For instance, besides telling youth using intra-venous drugs about the risk of getting infected with HIV/AIDS, they must be helped to overcome the need for the addiction by giving them a meaning in life. Once they decide to give

it up, they need constant support to actually enable them to do so.

*Social Values supporting Responsible Behaviours must be Strengthened*

It has been effectively shown that social value frames and cultural norms support specific kinds of behaviour patterns. For instance, among certain tribes sexual experimentation is permitted between young, unmarried boys and girls, but if a girl becomes pregnant the boy must marry her. The finding in studies in the American population that the more religious persons become sexually active at a later age and tend to be monogamous more often than the less religious, irrespective of which religion they practice, also demonstrates the role of social values in determining behaviour patterns. When individualism colours the predominant world view (as it does in modern industrialized societies) and consumerism is a way of life, achieving pleasures of the physical senses becomes a prominent aim in life and the means to achieve this aim is viewed as a commodity. Social relationships then become low priority and socially responsible behaviours both at individual and societal levels are found to decrease. In such an environment, sexual relationships too tend to lack mutual responsibility that is essential for people to adopt safe sex practices. Thus, large-scale impact can be made on sexual behaviour patterns through HIV/AIDS education only if it is supportive of, and supported by, societal structures (both economic and cultural) conducive to non-transmitting behaviour.

Keeping all these issues in mind, guidelines which can assist in avoiding some of the mistakes of the past, indicate that messages should:

- Be consistent and accurate.
- Be positive and aim to help people protect themselves and help those already infected to live productive and socially beneficial lives. They should contribute to creating a conducive environment in the long-term.
- Be linked to service delivery. For example, information and counselling centres must be available to help people gain knowledge about the spread of infection and methods of prevention, and to counsel those in need. If condoms are being promoted, affordable, good quality condoms must be available in the area. STD treatment services should also be made easily accessible.
- Offer options. For example, when dealing with difficult-to-change behaviour patterns such as drug use, it is helpful and more effective to provide the individual with options for action. For example, 'your chances of getting HIV/AIDS are high if you inject drugs, so don't inject: if you can't avoid injecting, don't share needles; if you can't avoid sharing, at least clean the needles before sharing. Such behaviour options also apply to sexual transmission. For example, your chances of contracting HIV/ STDs increase if you have multiple sexual partners; so abstain from sex or stick to one uninfected partner; or practise safer sex such as condom use for every sexual encounter outside marriage'.

**Check Your Progress II**

1. What are the major guidelines which can assist in avoiding some of the mistakes of the past in an HIV/AIDS education campaign?

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## 3.4 BASIC STEPS FOR EFFECTIVE HIV/AIDS EDUCATION

The steps which need to be taken for an effective HIV/AIDS education programme are planning, preparatory activities like materials development, undertaking the planned HIV/AIDS education activities, monitoring and evaluation.

### Planning

The first step has to be a review of the current situation including a through assessment of the programme's information, Education and Communication (IEC) needs and existing IEC activities. Based on this the second step would be identification of target audiences, formulation of achievable objectives, and identification of activities to be carried out on as well as potential partners for implementation.

### Situation analysis

The organisational structure and manpower available for HIV/AIDS prevention should be analysed, while communication and outreach networks, both within the government as well as among NGOs, should be assessed for use in HIV/AIDS educational activities.

Another task in situational analysis is examination of existing epidemiological, cultural and behavioural data and exploration of the existing situation from a number of points of view, including:

- past/present preventive action and their effectiveness;
- the extent of spread of HIV in different groups and areas;
- assessment of vulnerable populations; and
- any information relating to particular groups of interest such as demographic data, social structure, the status of women and literacy levels.

Every effort must be made to fully utilize existing data from studies in various fields, particularly, including those in sociology, social anthropology, psychology, and fields related to health education. However, when looking for information related to sexual practices, it may be necessary to conduct new studies using qualitative approaches such as 'focus group discussions'.

Studies can be carried out to fill gaps in information on the following subjects:

- Who is at risk;
- Existing transmitting behaviours and what are the desirable changes;
- Factors which might facilitate or inhibit desirable behaviours
- Who are the influencers for different groups;
- Access to media, and media habits (viewing/listening/reading); and
- Access to and use of health services.

In addition, the following issues must be kept in mind while planning IEC programmes:

- Those discussed under 1.3.
- Difficulty in talking about sex and sexuality and the need to address these issues through advocacy and education offered in a non-threatening and culturally acceptable way;
- The need to protect and promote confidentiality with respect to persons with high-risk behaviour and those with HIV infection or AIDS.

**Establishing Programme Objectives**

Based upon the transmitting behaviour patterns in the population, the overall HIV/AIDS control activities and the goals of HIV/AIDS education, the programme would have to set its own objectives. These could be in terms of the different needs among different sections of the population and the desired outcomes for each.

**Developing AIDS Education strategies**

Strategies would have to be evolved in order to meet the objectives most effectively. This must be done keeping in view the existing context as delineated by the situational analysis. Different strategies would be needed for the varied social groups and the objectives of HIV/AIDS education for each. Also, the relationship between the different groups and the influence of HIV/AIDS education for one or the other must be considered. For instance, while emphasizing on the use of sterilized needles among a groups of IV drug users, the impact of this message on others vulnerable to drug abuse but not yet engaging in such activity must be assessed. While targeting HIV/AIDS education at a specific group, care should be taken that it does not become counter-productive for other sections of the population.

## Implementation

Preparation of HIV/AIDS education messages, materials and manpower mobilization is the first step; their utilization in interaction with the population is the next.

Data and inputs from target groups can be used to determine the messages, and the medium and channels conveying them (such as radio, television, posters, interpersonal approaches, traditional media) to each segment of the audience. This is the culmination of the conceptualization, analysis and planning exercise. Targeted IEC research, including an analysis of existing data, and a knowledge of the target group, plays an important role in selecting and defining the message, format, presentation, medium etc., for each identified target group. At the design stage, the exact types of media, the channels for communication and the style should be determined. A balance between passive (e.g. posters, print or video) and interactive media must be created. In many cases, folk media such as puppetry, drama and story telling can be used quite effectively to support interpersonal communication and should be actively considered as part of the overall IEC plan.

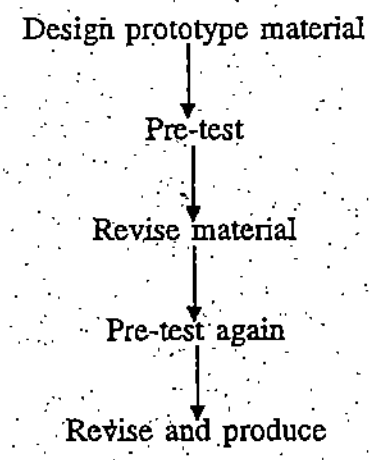
Development of draft materials is based on decisions about messages, media and channels to be used for delivery to each target group. Materials may consist of radio/TV spots, booklets, posters, handouts or hoardings; but these are not all. IEC also involves tools for use in interpersonal communication. It must be kept in mind that materials are a support tool for activities that lead to the achievement of goals and objectives. IEC materials alone will not produce behavioural changes.

Pre-testing of materials is one of the most important steps in materials development. Pre-testing allows the evaluation of messages and materials with regard to acceptability and potential impact before large amounts of resources are used in production and distribution. Although it adds to the cost and time of producing materials, it prevents wastage of resources by ensuring that materials are effective.

Once a draft materials are developed, they are carefully reviewed with groups selected from the specific target audience. For example, a television spot providing general information on HIV/AIDS should be tested with samples from the general public using a rough story board or outline of the pictures and text, before even beginning to film the spot. This process should continue once the rough film has been shot. In this way, planners can be assured that, as much as possible, the spot will convey the information desired as effectively as possible. Pre-testing should take place with every material from television spots to more specific outreach materials being developed for non-literate audiences. Pre-testing is cost-effective in the long run.

A summary of the steps to be followed in materials development is shown below:

**Materials design steps**




Determining affordability and cost-effectiveness is important, as resources are always scarce. In this context, it would be well to judiciously and selectively use expensive media such as film and TV. The glamour of these media often results in an overemphasis on their use, even though the cost of production and dissemination is extremely high. On the other hand, traditional media (including puppetry, traditional theatre, and songs), interpersonal communication (through conversations and with help of tools such as flip-charts and flash cards) are often neglected, though they are generally very cost-effective. Special efforts must, therefore, be made to use traditional media wherever they are more suitable.

Planning effective ways to make sure that materials reach their target audiences is as important as producing effective materials. It is often the case that good quality materials never reach those who need them or who could most effectively use them. Planning a distribution strategy and setting up a distribution network at the beginning is important. Using materials to support IEC activities, through mass media or for interpersonal communication requires knowing how to use them effectively. Instructions and suggestions for use must be supplied along with the materials.

Providing information to several persons within the community through an interactive process can lead to developing locally suited strategies for HIV/AIDS control and education. This requires a conscious effort to keep the HIV/AIDS education process a two-way affair and not merely a passing down of information. Peer educators (e.g. youth of the area trained to provide HIV/AIDS education and support behaviour change, ex-addicts as educators for IV- drug users and CSWs for other CSWs in their area) have been found to be the backbone of several effective HIV/AIDS education programmes. The effectiveness of these programmes is greater when they allow the peer educators to inform the content and strategy of the AIDS control effort.

**Monitoring and Evaluation**

Monitoring and evaluation provide inputs:

- For guiding and improving programme implementation;

- For appropriate redefinition or fine-tuning of messages and materials;
- For reworking objectives/goals and for the overall IEC approach.

Monitoring can be defined as the ongoing process of collecting and analysing information about implementation of the programme. It allows managers to follow the progress of planned activities, identify problems, give feedback to staff and solve problems before they cause delays. Monitoring can answer questions such as:

- Have relevant health care workers and others received training.?
- Are the appropriate services in place?
- Have the IEC materials been distributed to those they are intended for?
- Are the IEC materials being utilized?
- Are the IEC materials appropriate?

Aspects such as the target groups interest in the material, comprehension of it, reaction to the format, language and characters used (if any), and visual appeal (where relevant) are crucial to the whole exercise.

Evaluation is the process of collecting and analysing information at regular intervals about the effectiveness and impact of either particular parts of the programme or the programme as a whole. A variety of different evaluation methods is possible depending on programme needs. Regardless of method, planning for evaluation, including development of programme indicators and planning for information collection, should take place at the beginning of the programmes to ensure that essential data will be available when needed. Collection of appropriate baseline data is essential if an evaluation of impact is to take place.

Impact is measured against the programme objectives. Baseline data will be needed, and methods for collecting the information need to be spelled out so that the amount of change can be assessed. Evaluation should include (i) impact assessment and (ii) process evaluation. At a given point in time, evaluation can answer such quantifiable, impact-related questions such as:

- What proportion of the general population who are sexually active report that they are practising monogamy?
- Has the incidence of STDs declined?
- Is access to condoms and information on their correct use increasing?
- What proportion of health workers are providing health education?
- What proportion of CSWs report the correct and consistent use of condoms by clients?
- What proportion of the general population can cite at least two acceptable ways to protect themselves from HIV infection?
- What proportion of women who have been advised on the risks of HIV infection and pregnancy at antenatal clinics can cite two risk factors for HIV infection?

Evaluation can also be designed to help a programme manager understand why a programme is where it is. Did certain types of activities have bigger impacts than others? What types of problems occurred? How can such problems be solved or prevented in the future? Periodic programme reviews provide more qualitative or descriptive information on the status of the programme.

Check Your Progress III

What do you understand by monitoring and evaluation?

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## 3.5 EDUCATION FOR PREVENTING HETEROSEXUAL TRANSMISSION OF HIV

Let us now see how we can apply the general principles of HIV/AIDS education to the specific case of heterosexual transmission in India. A situational analysis of India has to form the basis of the exercise. We begin with a brief sociological understanding of heterosexual activity and its social patterning.

### The Sociology of Sexuality

In the Basic Course on HIV/AIDS (Block 3) you read about the social construction of sexual behaviour patterns. The following discussion should be read as a continuation of that.

Sexuality can be variously perceived as a necessity for procreation, as an expression of caring, sharing and bonding between two individuals, as a means of deriving emotional and physical pleasure from transient relationships, as a means of sublimation and spiritual transcendence, as means of displaying power, punishing adversaries and so on. All strands, i.e. those giving primary to one or the other view, exist in all societies at all times but the relative proportion of persons subscribing to different views change with changes in societal values and social conditions. Social control, self-restraint and the degree to which society values these, determine the dominant pattern of sexual behaviour in a society. India had Kamasutra and Khajuraho, socially accepted forms of prostitution (such as devadasis and courtesans), and polygamy. On the other hand, the majority in all classes placed a high value on faithful, stable

relationships within marriage. Of course, there was greater space and tolerance for expression of male sexual desires outside a monogamous relationship than for women. As a norm, extra-marital and pre-marital relationships have been socially disapproved of even among those sections of society where such social mores are less rigid.

With India's shift from a predominantly agricultural, low subsistence and low consumption economy and a community based social structure, to an industrially developing nation with urbanization, migration and the breakdown of rural economies and communities, there have been shifts in social values and world views. The degree and nature of this impact has been varied across different sections. The weakening of earlier forms of social and community controls have allowed greater individual freedom, releasing the stifling controls on men and women. While most males by and large experience this autonomy, for women it is primarily the upper and middle classes who can claim it to some extent. Indications from different sources of data are that conditions of women of many sections may have relatively worsened. High consumption life-styles have spread to a larger proportion, raised aspirations of others and increased the consumption gap between the top and bottom sections. Along with the increasing value placed on material consumption, there has also been an increase in perception of sexuality as a commodity to be consumed for pleasure. The gap between material aspirations and socio-economic status has led to distortions such as the spread of corruption, rise of the mafia, dowry deaths etc. Similarly, there has been a rise in desires for sexual pleasures and consumption. But, given the nature of gender relationships, the pattern of family relationship and the level of living conditions including housing, it is not possible for the majority to fulfill them through socially legitimate relationships. This, together with the loosening of community ties with no concomitant replacement by any other form of social control, with a decline in values of self-restraint and in shared norms for respecting other's rights, has led to a rise in sexual assaults on women and even the girl child. These gross perversions of sexuality of men are indicative of the less visible shifts in social behaviour in our society. Increasing prostitution reveals the increasing demand for commercial sex. Pre-and extra-marital relationships are thus, likely to be on the rise, and some surveys do indicate high levels in different sections. All these changes are most conducive to the spread of HIV/AIDS in women.

However, when we compare the scene with information available on sexual norms and behaviour in other societies, we still seem to be 'conservative' and the sexual restraint maintained is of a higher order. Whether it be the industrialized West, the African situation or closer home, Thailand, the social sanction against transient multi-partner relationships is much more. The impact of this is evident in the levels of HIV infection in these respective areas. Refer to the table 3.1 for details regarding behaviour pattern of married persons.

Table 3.1

Behaviour Pattern of Married Persons (Adults)

| S. No. | Country | Norms and Definition of Marriage | Extra-Marital Sexual Experience (ems) | % Going to CSWs |
|---|---|---|---|---|
| 1 | 2 | 3 | 4 | 5 |
| 1. | India | Marriage almost universal and as a life long stable relationship with disapproval of other partners. Greater freedom for males | M 15-30% (Ever engaged in ems in lifetime) F 5-10% | M 3-20% |
| 2. | U.S.A. | Serial monogamy (high pre-marital partner change + low marriage rate + high divorce rate) Only 58% adults Married | M 37% (Married & unmarried adults reporting 2 or more sex partners in the past 5 years) F 26% | |
| 3. | Thailand | Marriage almost universal and as a life long relationship but with high extra-marital sexual activity. | M 77% (Ever engaged in ems in lifetime) | M 50% (Going to CSW often a group acvitity) |
| 4. | Sub-Saharan Africa | Multiple patterns - Lifelong stable monogamy + polygyny + short-term stable relationship. (WHO-GPA definition of Marriage-relationship lasting for one year or likely to last for one year. | M 8-47% (Multiple partners in previous one year) | |

**Source:** Vishwa Deepak (1998) : Leigh B.C. et al.

Thus, among Indians the sexual norms are still to abide by the life-long rule of monogamy, while in the US, parts of Europe, Africa and some parts of Asia, the norms has become change of partners. Among those with sex outside marriage, the number of partners and the network within the group appears to be less than in the other countries.

## 3.6 IMPLICATIONS FOR STRATEGY FOR AN HIV/AIDS CONTROL PROGRAMME

### A General Population Perspective

These differences are epidemiologically extremely significant. Even statistical epidemiological models for generating projections of the future of the epidemic have used the following factors as those which influence extent of sexual spread of HIV (Isham 1988, May & Anderson 1987, Schalfe 1990):

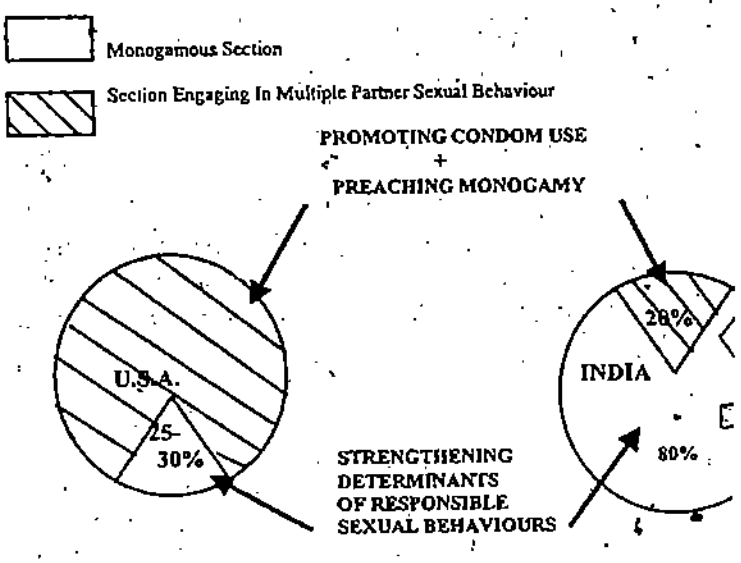
- The average number of partners per unit time
- The average rate of acquiring new partners
- The distribution of partner change in the population

The pattern of partner choice and interaction between members of different sexual behaviour groups interaction e.g. between those who visit CSWs and their other partners.

The epidemiological significance of this difference in sexual norms i corroborated by the data on prevalence of AIDS in the different cour (UNAIDS & WHO, 1997). Though the real difference will be less th this data depicts because of the incomplete reporting of HIV/AIDS c the margin of difference between the Indian and other rates is too m to be explained by differences in reporting systems alone.

This is not to say that AIDS is not a public health problem in India that it may need a different kind of intervention to minimize the spr of AIDS. Twenty per cent of young males engaging in activities that can transmit HIV is epidemiologically significant. Also important is the level of resort to CSWs in some pockets e.g. among migrant worke Chennai and college students in Mumbai (ICRW, 1997); the levels prevalence of extra-marital sex (10-30% by different studies), and th high level of STDs (about 1-3 per cent of VDRL positivity for syph and a prevalence of 0.5 per cent of HIV infection in the populatio addition, current changes in social structures, economy and culture increasing globalization are likely to be giving a thrust towards behaviour change from safe to risky behaviours.

With such significant differences in behavioural norms, can we hav common approach to controlling the epidemic across the globe, wh in the US, in Africa, in Thailand or in India? In the US (and Euro countries) where sexual activity outside marriage and with changing partners is the norm or is socially accepted, it is logical to make promotion of condom use the primary measure for prevention. In countries like India where it is not the norm in most social groups engaged in by a minority, but changes are occurring in society suc the majority norms are likely to be transferred and risky behaviour adopted more often, the primary prevention strategy must certainly designed differently. It must have a double-pronged approach, simultaneously giving consideration to both the 75 per cent and th per cent.



The strategic approach should be one which considers all the three parts of sexual behaviour patterns influencing the epidemiology of HIV/AIDS in India, the prevailing levels of monogamous relationships, the extent and nature of sexual activity outside marriage, and the nature of changes currently occurring in sexual behaviours. It would develop a comprehensive view to the problem by examining:

- The conversion of members from one group to the other i.e. from "monogamous to multi-partner" and vice-versa,
- The interaction among the two groups
- The impact of measures targeted at one group on the other e.g. of condom promotion on the monogamous,
- The factors allowing the monogamous to continue in that group and the factors making them shift to the other group,
- Devising measures to strengthen the positive factors which maintain monogamy e.g. community and family ties
- Devising measures to counter the negative factors e.g. provision of better housing living and working conditions to migrant labour so that whole families can migrate instead of just the earning male, countering the commodification of sex by generating a social perspective about gender relationships.
- Devising targeted interventions for the high-risk behaviour pockets, using the understanding of prevailing relationship between the monogamous and high risk group perceptions to elicit a positive response, e.g. giving importance to the romance and emotional dimension of a monogamous relationship. At the same time, it has to be ensured that these interventions do not act negatively on the majority group (e.g. as by the IEC messages discussed later)

**More Specific Considerations**

With the overall consideration being to identify and strengthen the positive tendencies in the social context, some specific issues must necessarily be addressed. These include the following:

- Different practices and their meaning for diverse social groups
- While a generalised analysis has been made for "sexual behaviour patterns in India" it needs to be clearly recognised that there is great diversity in social norms within Indian society for example, between rural and urban populations, between different caste groups, tribal and non-tribal groups, between different tribal groups. These differences are important to identify so as to examine the existing factors that can be harnessed to promote and plan HIV/AIDS control activities for the diverse groups appropriately.

**Responsible Sexuality, not Merely 'Safe Sex'**

In such a cultural context, 'safe sex' is that which is socially legitimate. The use of terms like 'safe sex' and 'safer sex' shifts the image of the relationship from one with social responsibility implicit in it to merely a biological 'safety' through use of a condom. Such messages strengthen

the negative changes. HIV/AIDS education or sex-education messages must consciously emphasize the social and emotional dimensions of sexual relationships in addition to the physiological.

### Role of Mass Media

Films, advertisements and other such mass media have been promoting the commodification of sex in recent years. In this age of liberalisation and globalisation, both material consumerism and sex consumerism are being promoted as an on slaught on our culture. One negative example of AIDS "education" is given here, as a concrete illustration of the issues involved.


Only a firm mind can prevent AIDS.
It's true.
Let's say a modern young woman has decided she doesn't mind going to bed with a man she likes.
Nothing wrong with that.
She asks him to wear a condom.
He acts surprised. He fusses.
He gets angry.
He says it robs him of his pleasure.
He tries emotional blackmail.
Rather than let it get unpleasant she gives in.
He gets his way.
She gets AIDS.
Don't let it happen to you. Only a condom can stop AIDS during Sex.
So keep your mind firm — insist he wears a condom.
Don't give in with an 'OK, never mind.'
Because weak minds spread AIDS.
Never forget that.

AIDS
Weak minds spread it.

Source : Times of India, Feb. 4, 1994

This advertisement, put out in public interest by a group of industries in a leading newspaper, is a stark illustration of very creatively and sensitively made but highly counter-productive AIDS communication material. It has been widely acclaimed, having received the annual award of the Advertising Guild of India and international advertising agencies. Analyzing it, certain issues emerge:

- It addresses itself to less than one per cent of the Indian population the english newspaper reading women.
- Among them it identifies the 'modern' young girls with short hair and jeans as the one most suited to depict the persons at risk.

Therefore, even among the small group addressed, the majority of the english-speaking working women or house-wives, will not identify themselves with the person in the advertisement. Another instance of 'the other', and so the majority will view HIV/AIDS as something that can happen to 'her' not to 'me'.

The 'man she likes' certainly does not include the husband and therefore does not convey the need for condom use in the husband-wife situation, by far the commonest form of sexual relationship.

Even for the girls/women at whom it is specifically targeted, and to whom, it will effectively communicate the message of condom use for safety, it is counter-productive. It reinforces in the minds of males and popular image of the 'modern' young girl who is easily 'available' and game for 'loose pleasure trips' thus promoting further their harassment, molestation and sexual assault.

For the young, middle and lower middle class girls aspiring to be a part of the 'modern' jet-set, it conveys what, "to be modern" means—wearing jeans, cutting one's hair short, and being open to pre-or extra marital sex without necessarily having gained "strength of mind" or an equal footing in the power equation with men. She will feel obliged to give in to sexual advances even when she does not feel the urge, just to prove her "modernness". This will make her more vulnerable to exploitation in a situation where she will encounter a hostile social environment and will not have the psychological, social and material supports to protect herself. There is some evidence of such girls coming into the prostitution market to acquire the money needed to attain the jet-set life-style. The cases of young college girls forced into nude modeling for magazines like "Fantasy" (against which court cases are in progress) highlight this dimension further.

This advertisement puts the onus for spread of HIV/AIDS on the woman who is portrayed as of weak mind. A counterpart advertisement addressed to males had a similar photograph of a young male but a different text. It only spoke of having information about HIV/AIDS mode of spread and therefore, the need for condom use. The slogan instead of 'Weak Minds Spread AIDS' was 'Know It to Avoid It'. Thus, she is the 'spreader' and he has to 'avoid it'.

While this may be an advertisement promoting liberation of women from morality shackles, it is counter-productive for their liberation from social discrimination and for HIV/AIDS prevention. It is clearly propagating cultural changes that will be more conducive for expansion of a market for consumer goods and for the spread of HIV/AIDS.

In an attempt to produce HIV/AIDS education messages that are non-discriminatory and not based on the conventional sense of morality, we have witnessed IEC material (Information, Education, and

Communication Material) that has furthered this trend. Promoting irresponsible sexual behaviour among women is not non-discriminatory in our socio-cultural context. It is a cultural onslaught and one that increases the violation of rights of majority of women and is counter-productive for HIV/AIDS control. On the other hand, promotion of the value of self-control by males is conducive to both. Not preaching about this, but creating an environment where the romance and pleasure of a stable, mutually supportive man-woman relationship is found attractive and sought after can take us a long way in this direction.

**Targeted Interventions**

HIV/AIDS education and behaviour change interventions targeted at specific groups at higher risk of getting infected by HIV is an important component of any HIV/AIDS intervention programme. The groups at high risk may differ from city to city and area to area. It is important for each national or district-level programme to evaluate the risk determinants and identify the population that may be at high risk of infection, so that appropriate strategies to reach such population can be developed on a priority basis.

Messages and delivery channels must be tailored for the specific target group. Consideration needs to be given to cultural appropriateness and available infrastructures. The development of messages should take place after assessment of the current knowledge, attitudes, behaviour and practices in relation to sexuality and HIV/AIDS/STDs.

**Check Your Progress IV**

Do you feel that HIV/AIDS education is an important component in targeted interventions? Describe.

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## 3.7 LET US SUM UP

In this unit on HIV/AIDS education and behaviour modification, we have discussed certain specific aspects regarding HIV/AIDS education in the context of the experiences gained from sensitisation programmes launched across the globe. In the process, we have learned the goals of HIV/AIDS education, some of the Dos and Don'ts of HIV/AIDS

education, education for preventing hetero-sexual transmission and the implications for strategy on HIV/AIDS control programme. The illustration pointing out the role of media, especially in the context of advertisement is an eye opener to everyone involved in the HIV/AIDS prevention and control programme across the country.

## 3.8 KEY WORDS

**Prevention** : A measure to contain a widespread disease in the community or population group.

**Risk Group** : A group of individual sharing a common behaviour or characteristic placing them at a risk of HIV infection that is higher than the general population.

**Monogamous** : Where the two people confine their sexual activity, exclusively within their relationship.

## 3.9 MOEDEL ANSWERS

**Check Your Progress I**

1. What are the basic goals of AIDS education?

The goals of HIV/AIDS education include:

- Providing correct information to the lay public about the new disease syndrome called HIV/AIDS so that HIV positive persons are dealt with by society in humane and caring manner.
- Maintaining the attitude of people not engaging in high risk behaviour to continue to maintain that behaviour.
- Motivating behaviour change in those engaging in high risk behaviour such sex outside marriage, IV drug abuse etc., which are likely to transmit HIV.
- Providing planners, administrators and service providers with correct information so that they can perform their duties effectively and in the best interests of HIV/AIDS control.

**Check Your Progress II**

What are the major guidelines which can assist in avoiding some of the mistakes of the past in an HIV/AIDS education campaign?

Keeping all the issues in mind, guidelines which can assist in avoiding some of the mistakes of the past, indicate that messages should :

- Be consistent and accurate.
- Be positive and aim to help people protect themselves and help those already infected to live productive and socially beneficial lives. They should contribute to creating a conducive environment in the long-term.
- Be linked to service delivery. For example, information and counselling centres must be available to help people gain knowledge about the spread of infection and methods of prevention, and to counsel those in need. If condoms are being promoted, affordable, good quality condoms must be available in the area. STD treatment services should also be made easily accessible.
- Offer options. For example, when dealing with difficult-to-change behaviour patterns such as drug use, it is helpful and more effective to provide the individual with options for action. For example, your chances of getting HIV/AIDS are high if you inject drugs, so don't inject: if you can't avoid injecting, don't share needles; if you can't avoid sharing, at least clean the needles before sharing. Such behaviour options also apply to sexual transmission. For example, your chances of contracting HIV/ STDs increase if you have multiple sexual partners; so abstain from sex or stick to one uninfected partner; or practise safer sex such as condom use for every sexual encounter outside marriage.

**Check Your Progress III**

1. What do you understand by monitoring and evaluation ?

Monitoring can be defined as the ongoing pro s of collecting and analysing information about implementation of the programme. It allows managers to follow the progress of planned activities, identify problems, give feedback to staff and solve problems before they cause delays. Monitoring can answer questions such as:

- Have relevant health care workers and others received training?
- Are the appropriate services in place?
- Have the IEC materials been distributed to those they are intended for?
- Are the IEC materials being utilised?
- Are the IEC materials appropriate?

Aspects such as the target groups interest in the material, comprehension of it, reaction to the format, language and characters used (if any), and visual appeal (where relevant) are crucial to the whole exercise.

Evaluation is the process of collecting and analysing information at regular intervals about the effectiveness and impact of either particular parts of the programme or the programme as a whole. A variety of different evaluation methods is possible depending on programme needs.

Regardless of method, planning for evaluation, including development of programme indicators and planning for information collection, should take place at the beginning of the programmes to ensure that essential data will be available when needed. Collection of appropriate baseline data is essential if an evaluation of impact is to take place.

**Check Your Progress IV**

1 Do you feel that HIV/AIDS education is an important component in any targeted intervention? Describe.

HIV/AIDS education and behaviour change interventions targeted at specific groups at higher risk of getting infected by HIV is an important component of any HIV/AIDS intervention programme. The groups at high risk may differ from city to city and area to area. It is important for each national or district-level programme to evaluate the risk determinants and identify the populations that may be at high risk of infection so that appropriate strategies to reach such populations can be developed on a priority basis.

Messages and delivery channels must be tailored for the specific target group. Consideration needs to be given to cultural appropriateness and available infrastructures. The development of messages should take place after assessment of the current knowledge, attitudes, behaviour and practices in relation to sexuality and HIV/AIDS/STDs.

## 3.10 FURTHER READINGS

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# UNIT 4 PALLIATIVE CARE

**Contents**



## 4.0 AIMS AND OBJECTIVES

The purpose of this unit is to provide you with an understanding about the concept of palliative care, and how this care caters to the physical and mental concerns of a person with HIV/AIDS ,as well as his deterioration over a period of time, till the time of his death .By the end of this unit, you should be able to:

- describe the term 'palliative care'
- understand the differences between HIV/AIDS palliative care and traditional palliative care,
- have knowledge of pain management in AIDS palliative care,
- have knowledge of simple treatment measures to make the patient comfortable.

## 4.1 INTRODUCTION

You have learnt about the implications of HIV/AIDS on the individual, family and community and about the care of the dying from previous units. This section deals with the palliative care for people living with HIV/AIDS.

There are people living with HIV in every part of India, from every walk of life. They are living as best as they can, faced not only by illness but also by emotional stress, economic crisis and most of all social stigmas and discrimination. The general fatigue, fevers and diahorrea, the wasting away of their bodies; the sudden onslaught of many different illnesses can leave once. A healthy person feeling so weak, unable to walk or breathe or do anything that they did usually. These people are often shunned and hounded out of their own homes and neighbourhood by family, in-laws, neighbours and friends. They are even denied basic health care. Even in death, they are not spared. Their bodies are at times discarded and families are denied the privilege of

performing the last rites. The much-feared death often creeps in silently and unpredictably leaving families and friends devastated.

Our society seems unable to cope with a situation that apparently challenges their moral values.One wonders where all the warmth and hospitality have gone when they deal with people living with HIV/AIDS (PLWHA), who, more than anyone else, need an empathic, caring community around them. We perceive ourselves as sympathetic, gentle and tolerant yet, we fail to reach out to and hold the hands of those in need. We need a society which will act together to bring about a change in the lives of PLWHA and their families so as to allow them to live a better quality of life.

Individuals who face a life threatening or terminal illness need to have access to services that provide personal care, symptom control, emotional support, financial and legal planning and nutritional care. The enormous gap between the need and the available services particularly in India is startling.

In major cities and towns, such services may be purchased at a small cost but in smaller towns and villages, professional care is scarce. Hence, PLWHA migrate to larger towns or cities. Newer surroundings offer limited access to their usual recreational activities and significantly curtails interaction with supportive groups of persons; friends or family, however, small it may have been.

## 4.2. HIV AND PALLIATIVE CARE

The goal of Palliative care is relief from pain and suffering in advanced disease, spiritual support and psychological or emotional support to the patient. In the context of HIV, good palliative care often include active treatment and the palliative care team may work along with a primary care physician.

At first, the domain palliative care, in India was restricted by a narrow perspective developed in patients dying of cancer- a model based on withholding disease specific treatment and providing simple hospice-based terminal care. Of late, palliative care has been extended to taking up a key role in the management of patients with advanced AIDS. It works with active treatment and has increasing importance as symptoms increase. Palliative care is provided in very few centres across the country. YRG CARE at Chennai, Tamil Nadu and Snehadhaan in Bangalore are two such centres which provide palliation to the patients without any fear or discomfort. The concept of palliative care is presently being introduced in several teaching institutes and hospitals, clinics as well as in homes. Designated Palliative care services are provided flexibly to meet the needs of the patient rather than according to one specific mode of service delivery and it is frequently provided on a consultative basis to assist the basic primary care team, General Practitioner (GP), community nurse or hospital staff in providing, continuum of care for the patients.



GP

At first, palliative care had little to offer to patients with advanced HIV disease. The incidences of new infections are on the rise still, making palliative care for HIV/AIDS different from other terminal illnesses. Palliative care includes disease-specific antimicrobial/antiviral and other non-HIV treatment when appropriate, largely because this is often the best way to relieve symptoms. For a major number of PLHA, costs of HIV Antiretroviral Therapy (ART) are costly and thus, GPs and HIV related organizations recognise the need for palliative care. It is important to remember the unit on care of the dying after this section as care of the dying and it's aftermath is also an important component of palliative care in AIDS.

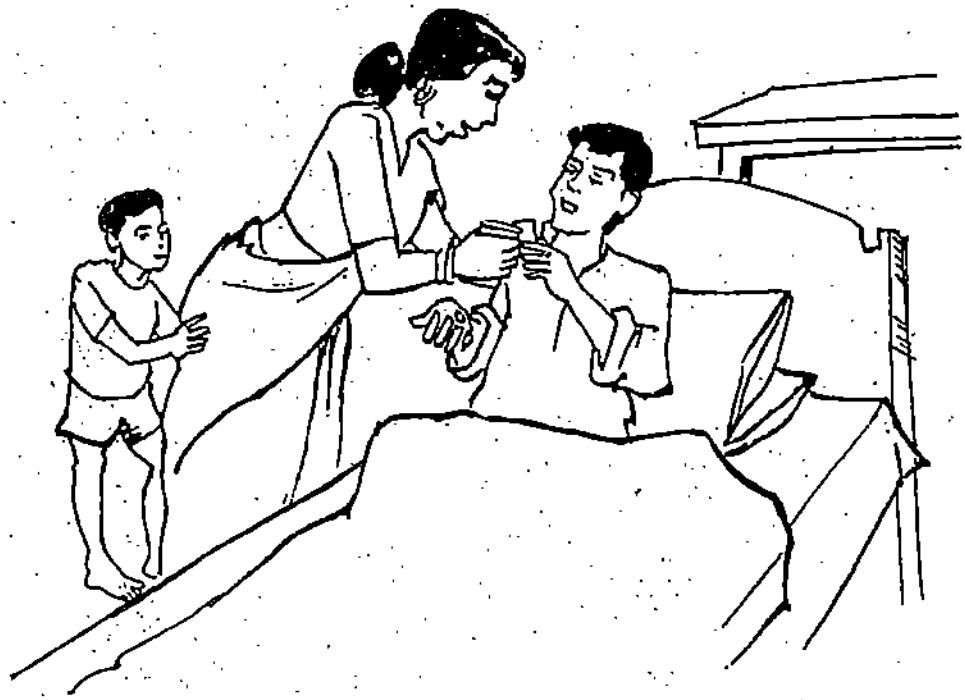

Table 4.1

**Differences Between HIV Palliative Care and Traditional Palliative care**

| S. No. | Traditional palliative care | AIDS palliative care |
|---|---|---|
| 1 | 2 | 3 |
| 1. | Care only for cancer patients | Care for AIDS patients |
| 2 | Mainly older age group | Mainly younger age group |
| 3 | Not much variation in disease patterns | Wide variation of disease patterns |
| 4 | Predictable Terminal Phase | Unpredictable terminal phase |
| 5. | Less drugs require | Several drugs required at same time |
| 6. | Less incidence of psychological Sx. | More psychological sx. And dementia. |
| 7. | Less substance abuse | More substance abuse |
| 8. | Pain management most important | Control of many Sx. Including pain. |

The philosophy of contemporary palliative care is to shift the focus of care away from the disease and prolong survival towards meeting patient's needs and improving their qualities of life. Palliative care doctors can assist GPs and HIV specialists in:

- making an assessment of the patho-physiology of symptoms;
- managing palliative therapeutics;

- clinical decision making in advanced disease;
- identifying the psychological, social and spiritual components of suffering;
- breaking bad news to patients and families;
- liaisoning between hospital and home care; and managing the terminal phase.

### Check list for regular examination

In the basic course on HIV/AIDS, you would have already learnt about opportunistic infections and their manifestations. However, as part of palliative care, it is important to know what and where the problem could be if the patient complains of particular symtoms and how best to ease this problem. Table 4.2 briefly describes this.

Table 4.2

Check List for Regular Examination

| S. No. | Symptoms | Important conditions to consider |
|---|---|---|
| 1 | 2 | 3. |
| 1. | Localised weakness | Cerebral space-occupying lesion, cytomegalovirus polyradiculopathy |
| 2. | Numbness | Peripheral neuropathy, drug toxicity |
| 3. | Abdominal pain | Gastritis/oesophagitis, acalculous cholecystitis, colitis, intrabdominal malignancy, enteric pathogens |
| 4. | Skin rash | Folliculitis, Norwegian scabies, molluscum contagiosum, Kaposi's sarcoma |
| 5. | Difficulty swallowing | Oral/oesophageal candidiasis or ulceration |
| 6. | Cough | PCP, bacterial infection, tuberculosis, pulmonary Kaposi's sarcoma |
| 7. | Change in mental state | Toxoplasmosis, cryptococcocis, progressive multifocal leukoencephalopathy, dementia, cerebral lymphoma |
| 8. | Change in vision | Cytomegalovirus retinitis, papilloedema (cryptococcus, lymphoma) |
| 9. | Diarrhoea | Enteric pathogens, cytomegalovirus, cryptosporidium |

For identifying some of these infections, special laboratory techniques are required.

The information given in table 4.2 will be useful for health care providers, particularly, doctors and nurses.

It helps to perceive a person with HIV/AIDS as living with the disease, rather than dying of it. Many people living with HIV are challenging society's perception that HIV is a death sentence. They are coming out in the public, announcing their HIV status openly without any shame, guilt or hostility. Self help groups and support groups are emerging all over the country to make society acknowledge their existence and to support those in need. It is no longer US and THEM but US' only is the positive replacement.

**Check Your Progress I**

1. What are the differences between HIV palliative care and traditional palliative care?

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## 4.3 DEFINITION OF PALLIATIVE CARE

Palliative care is a philosophy of care, is the combination of active and complementary therapies intended to comfort and support individuals and families who are living with life threatening illness. During periods of illness and bereavement, palliative care strives to meet physical, psychological, social and spiritual expectations and needs, while remaining sensitive to personal, cultural and religious values, beliefs and practice. Palliative care may be combined with therapies aimed at reducing or curing the illness or it may be the total focus of care.

Palliative care is planned and delivered through the collaborative efforts of an inter disciplinary team including the individual, family and care givers. It should be available to the individual and his/her family at any time through the illness phases and bereavement.

While many care givers may be able to deliver some of the therapies that provide comfort and support, the services of a specialised palliative care programme may be required as the degree of distress, discomfort and dysfunction increases.

HIV/AIDS has challenged palliative care. The complex dynamics of the disease process, the treatments, the social circumstances, including stigmatisation, have all brought new dimensions to the provision of palliative care. Most care programmes/services did not respond quickly to meet the needs of persons living with HIV/AIDS. Over the last few years, a few specialised programmes have been developed. Snehadhaan, Bangalore, YRG CARE, Chennai, and Missionaries of Charity centres are a few to name that attends to the individual and his/her family without any hesitation. There are still large gaps in the palliative care resources available to persons living with HIV/AIDS in India.

While symptom control and support may be needed prior to knowing the diagnosis, disease-specific therapies are likely to play an important role soon afterwards. As the degree of disease, distress, discomfort and

dysfunction waxes and wanes over time, there is a varying need for.

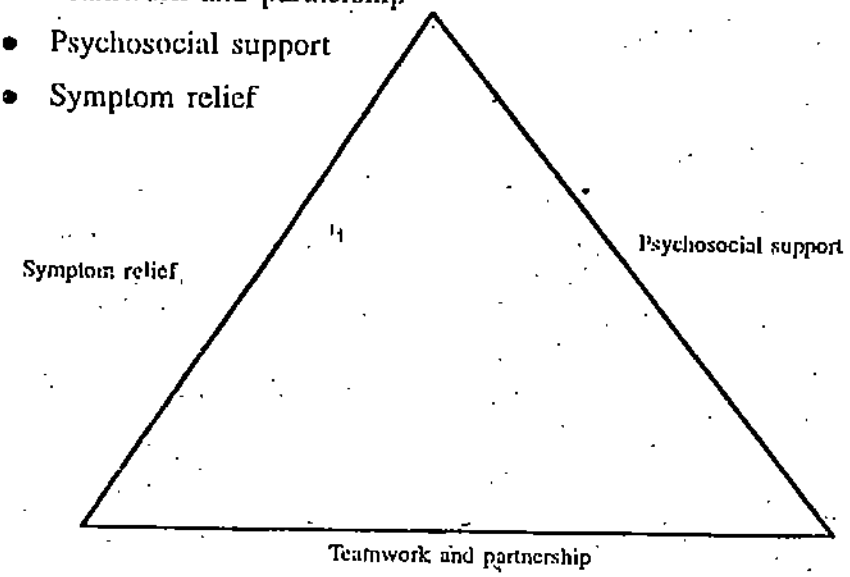
Disease-specific therapy (anti-retrovirals, anti-microbials, chemotherapy and surgery).

Therapy focused on providing comfort, including symptom control, and psychosocial support.

During the last days of a person's life, therapies that provide comfort and support are usually more important, though, disease-specific therapies may continue until death, i.e. for e.g. anti-retrovirals, anti-microbials for cytomegalovirus (CMV) etc.

**Three essential components of palliative care are ;**

- Teamwork and partnership
- Psychosocial support
- Symptom relief




**Teamwork and Partnership**

Palliative care is best administered by a group of people working as a team. In practice, some of the following will be involved:

- Doctors and nurses
- Physiotherapist ,occupational therapists and others
- Social worker, counsellors etc.
- Chaplain, priest, spiritual comforters etc.
- Volunteers.

Because, there is an overlap of roles, co-ordination is an important component of teamwork..Conflict can erupt from time to time and the challenge is to handle conflicts constructively and creatively.

*Partnership:* The essence of palliative care is partnership between the caring team, the patient and family. Partnership requires mutual respect and this is manifested by:

-Courtesy in behaviour

-Politeness in speech

—Being honest

—Listening and explaining

—Agreeing on priorities and goals

—Discussing treatment options

—Accepting treatment refusal

**Psycho-social Support**

Addressing the psycho-social needs of persons living with HIV/AIDS requires that care givers adhere to the principles of palliative care which include:

- Providing open communication
- Respecting the individual
- Nurturing unconditional positive regard
- Involving significant others
- Developing the support network

In order to provide excellent palliative care, the care giver must have underlying respect and understanding for the individual living with HIV/AIDS. Needs and interventions should be discussed with the person living with HIV/AIDS along with the care givers and must include issues of concern to the individual and his/her family and friends as well.

Psycho-social aspects of care include,

- Communication-breaking bad news.
- Strategies for coping with uncertainity.
- Psychological aspects of terminal illness.
- Care of the relatives,spiritual care, religious needs etc.
- Bereavement.

The aims of communication are are to reduce uncertainity, enhance relationships,and give the patient and family a direction in which to move. It includes active listening, asking questions and avoid distancing.

In breaking bad news, it is important to remember, never lie to a patient,and avoid thoughtless candour.The doctor-patient relationship is founded on trust. It is fostered by honesty but poisoned by deceit. The strategies for coping with uncertainities really depends on how long the doctor thinks the patient has to live. Coping strategies include:

- A rolling horizon
- Hope for the best but plan for the worst
- Reaching anniversaries
- Living one day at a time.

Remember that if a patient is deteriotating month by month s/he is likely to live for months, if s/he is deteriorating week by week s/he is

likely to live for weeks and if s/he is deteriorating day by day s/he is likely to live for days.

Regarding the other aspects of psycho-social care, kindly refer to the units on 'care of the dying' and 'implications of HIV/AIDS on individual, family and community'

**Symptom Relief**

*Pain:* Pain is common in HIV/AIDS. It is progressive, occurring in patients at different stages of infection especially, in hospitalized patients and ambulatory AIDS patients. Pain may be caused by the disease or a side effect of treatment, or due to debility or an unrelated condition. In relieving pain, it is essential to identify the cause and treat it specifically, if possible, as the best form of palliation is direct treatment.

Some common examples include peripheral neuropathy, headache, abdominal pain due to enteric pathogens, malignancies and; perianal pain due to herpes simplex, and ulcers in the mouth. Pain in patients with advanced disease is not simply a sensory event but a multi-dimensional phenomenon with cognitive, psychological and socio-cultural components, each of which has to be addressed for optimal pain control.

Often, pain is an underrated and under-treated problem in patients with advanced HIV disease.

***Management of Pain***

The goal of palliative care is to relieve the patient from acute and chronic pain even if it means dosing the patient with round-the-clock analgesics.

Aggressive treatment of pain is required in the later stages or terminal phase of the infection.It is important to reassure the patient and family at all times. The underlying pathology must be diagnosed and treated as soon as possible. Oral medications are recommended before initiating parenteral drugs if possible.Treat associated conditions like nausea, constipation, depression and insomnia.

Make use of complementary treatment for e.g. warm compressors, radiotherapy, regional/local anesthesia.

Three step model for pain treatment of HIV disease

**Step I *Mild Pain***

Use nonopioid analgesic medications as recommended (dosage and frequency) by the GP. E.g. Paracetomol, Ibuprofen, Acetaminophen etc.

**Step II *Moderate Pain***

If the above drugs fail to relieve, a weak opioid can be used in addition to the nonopoid. E.g. Codeine, Propoxyphene.

**Step III *Severe Pain***

When the above combination is no longer effective, a strong opioid may be used, e.g. Morphine, Methadone, Pethidine. All type of medication should be carried out under the direction of a qualified physicia

**Check Your Progress II**

1. Illustrate with the help of a diagram the three essential components of palliative care.

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## 4.4 COMMON SYMPTOMS AND THEIR RELIEF MEASURES

**Fever and chills**

In AIDS, the patient's metabolic rate is increased to fight infections, thus, raising the body's temperature. Prolonged fevers exhaust the body, requiring food and drink to replenish the depleted energy.

- Keep the room well ventilated.
- Record the temperature at regular intervals, if very high, sponge out the patient's body with tepid water.
- Fevers may last a few hours to a few days. If the patient is shivering, cover with extra blankets, which can be removed when the fever goes down.
- When fever breaks, the patient may sweat profusely. Change the wet clothes and bed linen so that the patient's skin is dry.
- Ask the doctor to prescribe an antipyretic to bring down the fever.

**Nausea and Vomiting**

The pressure on the stomach may cause nausea from blocked intestine or from a sensitive stomach or constipation, anxiety, etc.

- A washcloth soaked in cool water on the forehead and slow deep breathing exercises may help to alleviate nausea.
- Avoid keeping the stomach empty for long intervals, offer frequent small meals, attractively preserved.
- Give cold foods or foods at room temperature.
- Avoid liquids with the meals, give them an hour before/after the meals.
- Avoid sweet, spicy, greasy or strong smelling foods.
- Make the patient sit up for atleast half an hour after eating/drinking.
- Anti-emetics may need to be given orally at least 30 minutes before feeding. If that does not work, then medication may need to be given either by injection or rectally.
- Keep a clean kidney tray or a bowl handy at all times.
- Keep patient's on his side to prevent him choking on his own vomitus.
- Wipe patient's face clean during and after each episode of vomiting.
- Make a patient rinse out the mouth with water to which a teaspoon of salt has been added. This will not only remove the taste of vomitus but will also cleanse the mouth of the acids and enzymes of the stomach which would otherwise irritate it.
- Make sure that the patient does not become dehydrated or malnourished because of frequent vomiting. Give frequent small portions of clear liquids such as water, juices, coconut water, soups, rice or barley water. etc. through a straw so that the patient can drink it sip by sip.
- Avoid giving alcohol, coffee, tea, chocolates and sugar.

**Diarrhoea**

Watery stools may stem from intestinal infections, stress or ingestion of strong drugs. It comprises the body's ability to absorb nutrients leading to dehydration.

- Keep a clean bedpan/commode handy at all times.
- After each bowel movement, clean the patient thoroughly with warm water, dry well and apply vaseline to prevent skin breakdown.
- Sometimes, the diarrhoea may be foul smelling. Be sensitive to the patient's embarrassment, do not make a big issue of it. Just use room refreshers.
- Give the patient lots of fluids. To compensate for the loss of electrolytes, give a quarter glassful of oral dehydration liquid with/ without lemon juice several times a day.
- Do not give alcohol, coffee, tea, colas, chocolate, sugar and milk.
- Do not give spicy and greasy foods.
- Give foods, which are low in roughage and easily digestible, do not

give raw fruits and vegetables.

- Since potassium is lost in diarrhea, supplementing the food with banana, potato (without skin), broccoli, avocado, etc. may be a good idea.
- For medicines, always consult the doctor.

**Wasting**

PLWHA usually lose up to 20 per cent of their body weight, leading to repeated infection and progressive deterioration. The patent may show a general lack of interest in food and loss of appetite as he/she deals with fatigue and depression.

- Give foods enriched with extra energy.
- Give foods of the patient's choice, on demand.
- Give small and frequent meals, attractively presented.

**Constipation**

Tuberculosis of the intestinal tract, long-term use of narcotics, lack of activity, weakness, poor diet, low fluid intake or stress may cause blockage of bowel movement. Constipation can be very painful and embarrassing and may cause nausea and a decreased appetite. The best way to deal with constipation is to prevent it.

- Encourage the patient to exercise, even if only in bed.
- Gradually increase the roughage in the diet by adding whole grain cereals (wheat, legumes, vegetables, fruits and their juices (esp.prunes) to the diet.
- Add more liquids to the diet, especially, a hot drink such as tea, coffee or milk in the morning to start the bowel movement.

If all this fails, the doctor can prescribe a laxative in the form of a pill, syrup or suppository. Sometimes, the patient may be too weak and may not respond to any of these. In that case, the doctor might prescribe an enema. A simple soap-water may induce bowel movement.

**Acidity and heartburn**

As a side effect of medicines

- Encourage the patients to chew the food well.
- Avoid smoking.
- Make the patient sit up atleast an hour after eating or drinking.
- Avoid alcohol, coffee, tea, chocolates and sugar.
- Avoid spicy and greasy foods.
- Ask the doctor to prescribe some antacid etc.

**Shortness of Breath**

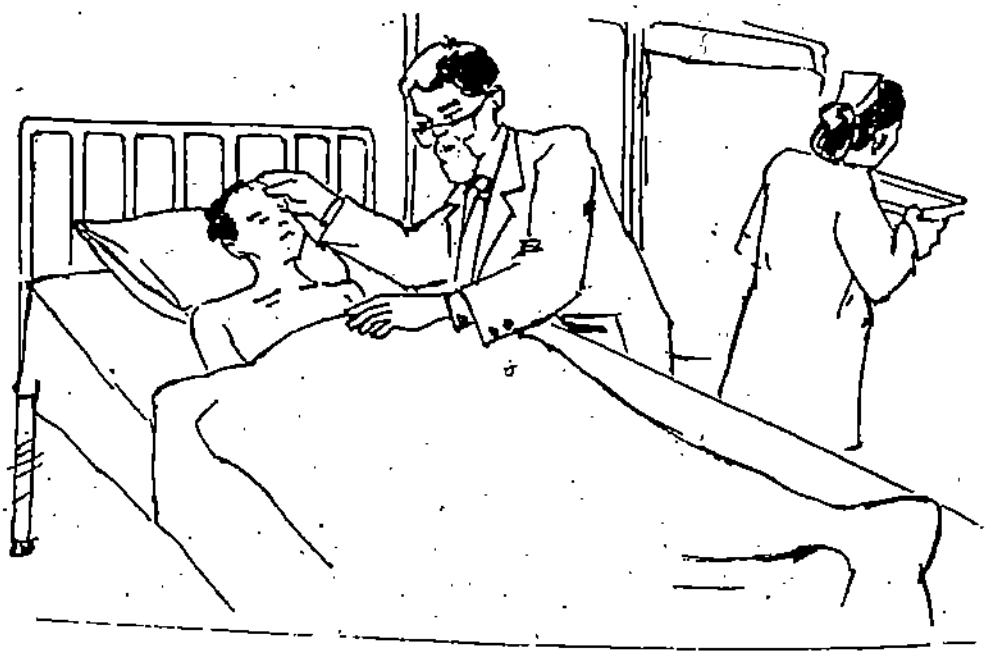
Breathlessness can occur with illness like pnemocystis carinii pneumonia

(PCP), other pnemonias, lung tumors, excess secretion (fluid) in the lungs, asthma, weakness, anxiety.

- Let the patient rest in a well-ventilated room, in their most comfortable position, supported by pillows if required. With the arms raised for maximum lung expansion and breathe deeply (inhaling through the nose and exhaling through the mouth), before and after every activity including eating.

If the problem persists, ask the doctor for medication.

**Insomnia**



Because of physical, psychological and spiritual problems, the patients may have difficulty in sleeping. Sometimes, the patient may sleep throughout the day and stay awake all night thus causing stress to the care giver.

- Do not force the patient to sleep as per your wishes.
- Let him/her relax, read, listen to music or watch television if s/he so desires.
- Make a proper time schedule for sleep.
- Closer to the evening, relieve patient of all physical discomfort and keep the physical activity low and relaxed.
- You could listen/talk about all concerns.
- Give the patient a hot sponge /bath/body massage to relax.
- Avoid caffeinated drinks.
- Warm milk works as a good sedative.

As the last option, the doctor could advice certain medication to reduce restlessness, confusion and agitation, which are causing the insomnia.

## Skin Care

The skin is the first line of defence against injury and infection. When it is weakened, irritated or broken, bedsores can develop. Patients, who are bedridden and not able to control their bladder or bowel movement, are prone to bedsores. Bedsores are caused by a part of the pressing continuously against a hard surface. The blood circulation in the bony parts of a skinny body constantly pressed against a hard bed or chair, is cut off thereby killing the cells in that area of the skin. This dead skin then peels off exposing the tissue underneath. The commonest sites for bedsores are back, hips and shoulders. The first sign of a bedsore is redness and burning of the skin.

- Relieve the pressure by changing the position of the patient, providing water bed or water pillow.
- Massage around the red portion with a light cream, lotion or moisturizer to stimulate blood circulation.
- If the redness persists, keep the pressure off this site ad apply a simple protective dressing (while petroleum jelly, ghee, malai or any soothing cream wi h gauze) which should be changed twice/thrice a day.
- In extreme cases, the skin can break down exposing muscle and bone. These sores are very painful and require complex wound dressing with acriflavin and glycerol.
- The dressing should always be kept clean and dry and done once a day, after a through wash with potassium pennanganate or hydrogen peroxide.
- Prevention is the key to managing bedsores.

## Mouth and Throat Sores

Thrush (a side effect of medication or dehydration) makes eating painful and may make the patient nauseous. Oral hygiene may increase the patient's ability and desire to eat/drink.

- Encourage the patient to brush the teeth atleast twice a day.
- If brushing is too painful, then rinsing the mouth several times a day will suffice.
- If the patient is too sick to take care of oral hygiene, then care giver will have to do it for them.
- Use a soft brush. Be gentle but thorough.
- Take care not to wet the patient's clothes by keeping a towel under the chin. Use a kidney tray for the spittle.
- Try and make the patient sit up or lie on their side to swish the water in the mouth and spill it out.
- If the patient is unconscious, clean his/her mouth with a cotton swab dipped in rinsing solution or glycerine. If he/she bites down on the swab, do not pull it out. Wait for the mouth to relax and then remove the swab.

- Read the instructions carefully, especially, on the rinsing solution - whether it is for swallowing or spitting out. (Homemade-rinsing solution - 1 cup of water mixed with 1 tablespoon of baking soda or salt).
- To prevent discomfort during eating, apply a topical solution before feeding.
- Drinking liquids through a thick straw or sucking at room temperature.
- Give soft foods; which can be swallowed easily.
- Avoid alcohol, salty, spicy, rough and acidic foods.
- Give more water, coconut water and juices (non acidic ones like carrot, avocado).
- Give more liquid food like very fresh yogurt, fruity milk shakes, smoothies, ice cream, etc.

**Personal Hygiene**

Understand that the patient has managed to take care of his/her personal hygiene all their life; be sensitive to their need for privacy, in order to help them retain their dignity.

- A full bath may not be required everyday, but it is necessary to keep the eyes, mouth and genital areas clean.
- If the patient is mobile and strong enough, he/she should be encouraged to go to the bathroom and clean up thoroughly.
- Keep a stool for them to sit on, so that they don't get tired.
- Keep soap, oil, towel, fresh clothes etc. handy so that you don't need to leave the patient alone in the bathroom.
- If the patient has any wound, wrap it well with plastic to keep it from getting wet during bathing; if the dress does get wet, change it.
- Select a family member with whom the patient is most comfortable, for giving assistance in personal hygiene.
- If you are giving the patient bath, be careful not to rub against any fragile skin or lesions.
- When giving sponge bath in bed, keep the room warm and free from draft and clean small areas of the body at a time while keeping the rest of the body covered so that the patient does not get chilled. Change the water as and when necessary, especially, after cleaning the genital areas, dry well. Apply moisturizer; give a back rub for better blood circulation.
- Wash patient's eyes with water only. If there is a dried discharge from the eyes, often it with a cloth soaked in warm water or moisturistur or oil and only then pry it off.
- Encourage the patient to wear their spectacles or hearing aids. These are important for general orientation and self esteem.

If at the end of it all, there is a problem, ask your doctor for advice.

To date, there is no cure for HIV/AIDS in Ayurveda, Homoeotherapy or any other line of medication. There is no point in wasting money on an AIDS cure. Instead, try to assuage the symptoms with alternate therapies such as distraction, massage, relaxation, acupuncture, skin stimulation, yoga, etc.

*Nutrition:* A well balanced diet of clean, germ free food can be one of the healthiest ways of preventing several infections, there by maintaining good body weight and consequent strength. But, this is easier said than done. There is one major problem in the care of a patient; they may not feel like eating/drinking; the quality/quantity of food/drinks that you think are nutritionally correct.

- Provide the patient with food, wholesome, nutritious and hygienically prepared food.
- Consider the likes/dislikes of the patient and work the menu around them.
- Give the food in small quantities at frequent intervals.
- Present the food attractively to make it appetizing.
- Remember a pleasant atmosphere is conductive to a healthy appetite.
- When feeding a patient, don't shovel food down their throat; give small spoonfuls.
- Try to maintain the patient's body weight according to the standard weight chart.

**Recommendations For Safe Eating**

When a person is infected with HIV, his immunity is weakened ,leading to easy infections from air, food and water. Therefore, it is important for the patient to:

- Wash hands frequently with soap and water.
- Drink boiled water only.
- Wash all vegetables and fruits before use.
- Avoid alcohol, tobacco and cigarettes.
- Reduce oil, salt and spice.
- Avoid eating outside food.
- Eat freshly prepared foods.
- Avoid uncooked foods.

**Check Your Progress III**

1 What are the three model steps for pain relief in HIV treatment?

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2. What are the recommendations for safe eating?

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## 4.5 LET US SUM UP

In this unit, you studied about the concept of palliative care, it's essential components, and the management of pain and relief of simple symtoms in terminal AIDS disease. Remember that this unit cannot be studied in isolation . It is better understood when studied along with the Basic Course on HIV/AIDS Block-2 Units1 and 2.

## 4.6 KEY WORDS

| | | |
|---|---|---|
| Palliative | : | Anything used to alleviate pain. |
| Antiviral | : | Effective against viruses |
| Continuum | : | Anything seen as having a continuous, not discrete, structure |
| Terminall | : | Ending in death or the last stage of fatal disease. |

## 4.7 FURTHER READINGS

Grame Stewart; (Edited : 1997), Managing HIV, Edited

Palliative Care - A Comprehensive Guide for the Care of Persons with HIV Disease (1995) Mount Sinai Hospital, Casey House Hospice, Toronto, Canada.

Robert Twycross. Introducing Palliative Care

## 4.8 MODEL ANSWERS

**Check Your Progress 1**

1. What are the differences between HIV palliative care and traditional palliative care?

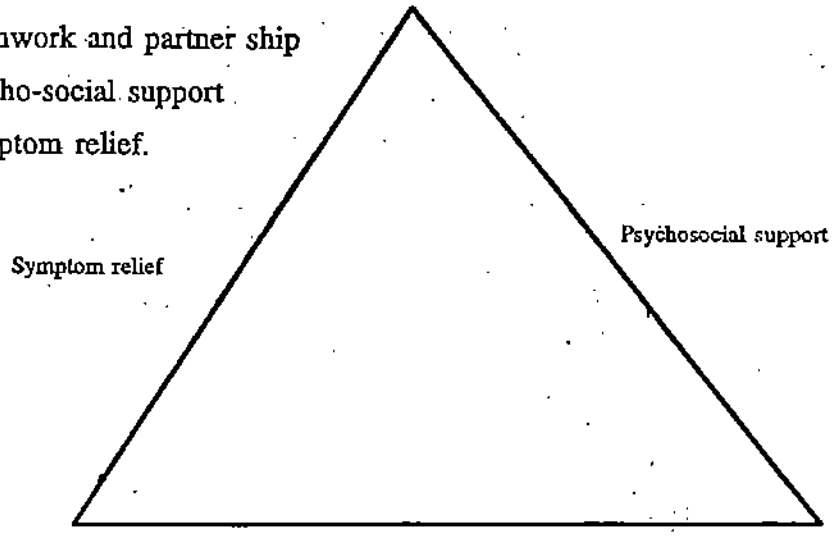
| S. No. | Traditional palliative care | AIDS palliative care |
|---|---|---|
| 1 | 2 | 3 |
| 1. | Care only for cancer patients | Care for AIDS patients |
| 2. | Mainly older age group | Mainly younger age group |
| 3. | Not much variation in disease patterns | Wide variation of disease patterns |
| 4. | Predictable terminal phase | Unpredictable terminal phase |
| 5. | Less drugs require | Several drugs required at same time |
| 6. | Less incidence of psychological Sx. | More psychological sx. And dementia. |
| 7. | Less substance abuse | More substance abuse |
| 8. | Pain management most important | Control of many Sx. Including pain. |

## Check Your Progress II

1. Illustrate with the help of a diagram the three essential components of palliative care.

The three essential components of palliative care are:

- Teamwork and partner ship
- Psycho-social support
- Symptom relief.




## Check Your Progress III

1. What are the three model steps for pain relief in HIV treatment?

Three step model for pain treatment of HIV disease are

*Step I* Mild Pain

Use nonopioid analgesic medications as recommended (dosage and frequency) by the GP.

E.g. Paracetomol, Ibuprofen, Acetaminophen

*Step II* Moderate Pain

If the above drugs fail to relieve, a weak opioid can be used in addition to the nonopoid.

E.g. Codeine, Propoxyphene

When the above combination is no longer effective, a strong opioid may be used with the recommendation of a qualified physician.

E.g. Morphine, Methadone, Pethidine

2. What are the recommendations for safe eating ?

Recommendations for safe eating are as follows:

- When a person is infected with HIV, his immunity is weakened leading to easy infections from air, food and water. Therefore, it is important to:
- Wash hands with soap and water.
- Drink boiled water only.
- Wash all vegetables and fruits before use.
- Avoid alcohol, Tobacco and cigarettes.
- Reduce oil, salt and spice.
- Avoid eating outside food.
- Eat freshly prepared foods.
- Avoid uncooked foods.

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# CHFE - 02
# ELECTIVE ON HIV/AIDS

Block

# 3

## AIDS, LAW AND HUMAN RIGHTS

# INTRODUCTION TO BLOCK 3

Welcome to the third block of the elective course on HIV/AIDS. In the previous two blocks we have seen various vulnerable groups of population as well as the aspects covering HIV/AIDS education and care. In this block we shall discuss about various legislation and their implications. There are three units in this block. Unit 1 is on 'AIDS and Law'. This unit describes the basic aspects of law, constitutional safeguards ad their limitations and lists the laws which the HIV/AIDS patients can use in various situations. Unit 2 desribes 'Rights of people living with 'HIV/ AIDS'. This unit speaks about the legal response to HIV/AIDS in India and abroad, the judicial response to HIV/AIDS in India and the legal rights of the HIV/AIDS patients in India. Unit 3 explains 'HIV//AIDS' related international legislations.' In this unit the efforts made through legal provisions to address issues pertaining to HIV/AIDS across the globe and the scope and contents of legislation enacted in some of the developing and developed countries around the world on HIV/AIDS have been described.

The three units of this Block provide basic understanding about the legal aspects associated with HIV/AIDS within and outside the country. The information contained in this Block will provide guidelines to people involved in HIV/AIDS related work to help their beneficiaries to seek justice as and when denied.

# UNIT 1 HIV/ AIDS AND LAW

**Contents**



## 1.0 AIMS AND OBJECTIVES

After studying this unit, you should be able to:

- describe the basic aspects of law,
- explain the Fundamental Rights, Constitutional Safeguards and their limitations, and,
- list laws which the HIV/AIDS patients can use in various situations to get justice.

## 1.1 INTRODUCTION

In the previous blocks on HIV/AIDS, we discussed several issues pertaining to HIV/AIDS, how it spreads, how to prevent it, the so-called vulnerable groups and the need for care and education. In this Block, let us examine some of the important legal aspects concerning HIV/AIDS at the national and international levels.

In this unit, we shall discuss HIV/AIDS and Law keeping in view the Indian constitution and existing judicial provisions.

The hardships faced by the AIDS patients are innumerable. Social isolation, lack of diagnostic and treatment facilities, lack of counselling and rehabilitation centres, harassment from family members and the police, scarce medical care, sense of shame and accusing fingers, treatment as if the patients are criminals etc. are some of the painful situations faced by the AIDS patients in their daily lives. It is this background that we can create better legal awareness about AIDS. Thevery

search for the ultimate truth behind AIDS by two scientists, luc Montagnier and Robert Gallo, had involved them in fierce legal battle as to who had identified the virus first. This just shows the role law can play in the whole business.

## 1.2 WHAT IS LAW?

There are many definitions, but none of them is complete. In general it is the written and unwritten body of rules, largely derived from customs and formal enactments which are recognised as binding among those persons who constitute a community or state, so that they will be imposed upon and forced among those persons by appropriate sanctions. (L.B Curzon, Dictionary of Law) Law is to be enforced or there will be lawlessness. Every civilized society has rule of law and is bound by a constitution.

**Indian Constitution and its Preamble**

The Indian Constitution is the product of research and deliberations and not of political revolution. The objects behind our Constitution can be found in the preamble of the constitution. After the 1976 Amendment, the preamble of our Constitution reads as follows:

WE THE PEOPLE OF INDIA, having solemnly resolved to constitute India into a SOVEREIGN, SOCIALIST, SECULAR, DEMOCRATIC, REPUBLIC, and to secure to all its citizens:

- JUSTICE, social, economic and political;
- LIBERTY of thought, expression, belief, faith and worship;
- EQUALITY of status and of opportunity; and to promote among them all;
- FRATERNITY assuring the dignity of the individual and the unity and integrity of the Nation;

In our Constituent Assembly, this twenty sixth day of November, 1949, do hereby adopt, enact and give to ourselves this Constitution.

A democracy cannot function unless there are some minimal rights essential for a free and civilised existence are assured to every member of the community. Thus liberty is guaranteed to all the citizens of the country. Ours is not only a political democracy it is also a social democracy. Dr. Ambedkar, in his concluding speech to the Constituent Assembly stated that "Political democracy cannot last unless there lies at the base of it social democracy. What does social democracy mean? It means a way of life which recognizes liberty, equality and fraternity which are not to be treated as separate items in a trinity. They form a union of trinity in the sense that to divorce one from the other is to defeat the very purpose of democracy. Liberty cannot be divorced from equality, equality cannot be divorced from liberty. Nor can liberty and equality be divorced from fraternity."

AIDS and Law are very much rooted in the society in the same manner as the economy of the nation. They all affect the human resources. HIV/AIDS affects mostly people from the most productive age group, i.e; those between 15 and 45. Estimates show that more than 70% of the AIDS affected persons come from this group. Thus, it has it's toll on the national economy as well. We need medicines and hospital facilities and they in turn need money for all these. Most of the AIDS patients cannot afford the treatment nor do we have necessary medicines in India. To import medicines would mean foreign exchange and our financial policies. Law comes in as the regulator. Like health care is provided by the hospitals, doctors etc, social care is provided by the administration of justice.

The HIV virus responsible for the spread of AIDS does not discriminate between women or men or children in its spread or impact. The epidemic is strongly bound to the social and cultural values and economic relations within the communities. It is also related to the interaction between the individuals. Social inequalities facilitate the spread of the virus. Those who are socially, economically and sexually vulnerable have to bear the (harshest) impact of the epidemic. Women are disproportionately affected by the virus due to their social and sexual subordination. Sexual relations are such that women are unable to protect themselves against the sexually-transmitted HIV infection. More than 70 per cent of all the cases of infection all over the world occur through sexual activities.

"As wives and sex workers, women are at risk of sexual transmission. As mothers, women must deal with the implications of HIV infection for unborn children. As mothers, aunts, sisters, grand mothers and daughters, women will have to care for the children orphaned by the epidemic. As carers, women bear the burden of caring for sick and dying partners, children, relatives and neighbours and attempting to hold the family unit together in the face of sickness and death. On all these counts, women are disproportionately affected by the epidemic."(Elizabeth Reid).

**Human Rights and HIV/AIDS**

It is an acknowledged fact that those most affected by the epidemic come from socially and economically disadvantaged groups. The global burden of HIV infection in the years to come will be in the developing countries. Inequalities of gender, race and wealth are emerging in the demography of infection. In no time the global risk factor for HIV, infection will not be sexual activity but social and economic dependency.

"Since HIV infection is preventable, people who have access to information and appropriate preventive measures and have the means to implement these measures will in future be able to protect themselves from infection. The people who remain vulnerable are those who are denied the means of protecting themselves against HIV because of economic need or powerlessness to control the basis upon which their sexual relationships take place. Many factors come into play here, including poverty, geographical isolation, inadequate health care and health education, and cultural practices that expose some members of the community to the risk of HIV transmission." (Julie Hamblin).

There is now a special need to respect the rights of the people with HIV, drug users, gay men and sex workers etc. Right to knowledge; freedom from discrimination; access to health care, education and economic independence etc. need to be understood from this background.

## 1.3 FUNDAMENTAL RIGHTS AND CONSTITUTIONAL SAFEGUARDS

All written constitutions include a code of fundamental rights and the judiciary is the guardian of individual rights every where. How these rights can be used by the AIDS patients is further explained in the portion dealing with Constitutional Provisions and AIDS.

The Fundamental Rights under the Indian Constitution are exhaustively enumerated in Part III of the Constitution and any expansion of the same rest on judicial interpretation. This does not mean that there are no other rights available to the citizens. Limitations imposed upon the state by other provisions of the constitution also confer rights to the individuals. Both these rights are (justifiable) but only in case of the violation of the fundamental rights has one the right to move the Supreme Court under Article 32 of the Constitution.

Under some constitutions fundamental rights are immune from constitutional amendments, thereby meaning that these rights have a special sanctity but this principle has been rejected by the Indian Constitution.

All the fundamental rights can be repealed or amended by a special majority in the Parliament.

Originally, Indian Constitution provides for seven group of fundamental rights. They are as follows:

i) Right to equality

ii) Right to particular freedoms

iii) Right against exploitation

iv) Right to freedom of religion

v) Cultural and educational rights

vi) Right to property

vii) Right to constitutional remedies

Of these, the right to property was removed by the 44th Amendment in 1978. The right not to be deprived of one's property save by authority of law is no longer a fundamental right and one cannot approach the Supreme Court under Article 32 of the Constitution.

Some of the fundamental rights are granted only to the citizens, namely, protection from discrimination on grounds of religion, caste, sex etc., equality of opportunity, freedoms of speech, assembly etc., as well as the cultural and educational rights.

The other fundamental rights like equality before law and equal protection of the laws, protection of life and personal liberty, rights against exploitation etc. are available to any person on the soil of India, including foreigners.

**Articles on Fundamental Rights**

Let us briefly examine the provisions or safeguards enshrined in some of the Articles relating to Fundamental Rights.

Article 14 provides that- "The state shall not deny to any person equality before the law or the equal protection of laws within the territory of India".

Equality before law means that no one is above law of the land and that every person, whatever his status, is subject to the ordinary law and courts. However, the President and the Governors of States are not answerable to the courts under certain situations. Equal protection before law means the right to equal treatment in similar circumstances, both in the privileges and liabilities imposed by law. However, the legislature can make reasonable classification to merit differential treatment. But this classification should not be arbitrary.

Article 15 provides that "(1) The state shall not discriminate against any citizen on grounds only of religion, race, caste, sex, place of birth or any of them. (2) No citizen shall on grounds only of religion, race, caste, sex, place of birth or any of them be subject to any disability, liability, restriction or condition with regard to (a) access to shops, public restaurants, hotels and places of public entertainment; or (b) the use of wells, tanks, bathing ghats, roads and places of public resort maintained wholly or partly out of state funds or dedicated to the use of general public. (3) Nothing in this article shall prevent the state from making any special provision for women and children. (4) Nothing in this article or in clause (2) of article 29 shall prevent the state from making any special provision for the advancement of any socially and educationally backward classes of citizens or the Scheduled Castes and the Scheduled Tribes."

Article 16 provides that- "(1) There shall be equality of opportunity for all citizens in matters relating to employment or appointment to any office under the state. (2) No citizen shall on grounds only of religion, race, caste, sex, descent, place of birth or any of them, be ineligible for any office under the state."

Article 17 provides that- " 'Untouchability' is abolished and its practice in any form is forbidden. The enforcement of any disability arising out of untouchabiliity shall be an offence punishable in accordance with law."

Together with Article 18 which abolishes titles, this article tries to ensure social equality. Protection of Civil Rights Act, 1955 prescribes punishment for this offence. The word 'untouchability' is not defined in the Constitution or in the above Act. It is assumed that this word has a well known connotation of social practices which looks down upon certain classes only on the ground of their birth.

Article 21 provides that- "No person shall be deprived of his life or personal liberty except according to the procedure established by law."

Life and liberty of a person is sought to be ensured by a two-fold guarantee under Articles 21 and 22 of the Constitution by providing that no person will be deprived of his liberty except according to law and by laying down specific safeguards against arbitrary arrest or detention. The executive cannot interfere with the liberty of citizens unless the same is justified and supported by law. Personal freedom is secured by the judicial writ of *habeas corpus*. Through this, an arrested person may be brought before a court, have the grounds of his detention examined, and regain his freedom if the court finds no justification for his detention.

The expression 'personal liberty' in Article 21 is very wide covering a variety of rights, some of which have been included in Article 19. Thus, any law which seeks to deprive a person his liberty must not be arbitrary, unfair or unreasonable.

Article 32 provides for constitutional remedies for enforcement of fundamental rights. "(1) The right to move the Supreme Court by appropriate proceedings for the enforcement of the rights conferred by this Part is guaranteed. (2) The Supreme Court shall have power to issue directions or orders or writs, including writs in the nature of **habeas corpus, mandamus, prohibition, quo warranto and certiorari,** whichever may be appropriate for the enforcement of any of the rights conferred by this part.

Article 32 is the cornerstone of the constitution. This Article provides a guaranteed remedy for the enforcement of the rights in Part III. This remedial right itself is a fundamental right being included in this part and the Supreme Court is the constituted protector and guarantor of fundamental rights. The sole object of this article is the enforcement of fundamental rights.

**Scope of the Writ Powers**

*Habeas Corpus:* A writ of **habeas corpus** is in the nature of an order calling upon the person who has detained another to produce the latter before the court in order to let it know on what ground he has been confined and set him free if there is no legal justification for the imprisonment. The Latin term *habeas corpus* means to have a body. Article 21 provides for personal liberty and if the executive has arrested and detained any person with out authority of any law, then the Supreme Court or the High Courts may issue the writ of habeas corpus against the authority and order release of the person under detention. This writ is not issued against private individuals but only against the state.

*Mandamus: Mandamus* literally means a command. It commands the person to perform some public or quasi-public legal duty which he has refused to perform. *Mandamus* will not be issued unless the petitioner has a legal right to the performance of a legal duty.

This writ will lie against officers of the state or against the government itself as well as the inferior courts or judicial bodies when they refuse to

perform their duties. Apart from enforcing fundamental rights, this writ is used to enforce performance of a statutory duties of public officers. It can be used to compel courts or tribunals to exercise its jurisdiction.

*Prohibition:* The writ of Prohibition is issued by the Supreme Court or the High courts to an inferior court forbidding the latter to continue proceedings therein in excess of its jurisdiction or not to usurp jurisdictions which it does not have. This writ differs from the writ of *mandamus* in the sense that *mandamus* commands an activity while *prohibition* commands inactivity. *Mandamus* is available against judicial and administrative authorities, while Prohibition and *Certiorari* are available only against judicial or quasi-judicial authorities. Where excess of jurisdiction is apparent on the face of the proceedings, a writ of Prohibition is a right. This writ is available during the pendency of a proceeding and before the order is made while the writ of *Certiorari* will come into picture after the order has been made.

*Certiorari:* Both *Certiorari* and Prohibition are issued against courts or tribunals exercising judicial or quasi-judicial powers. *Certiorari* is issued to quash an order while Prohibition is to prohibit it from making the *ultra vires* decision. The object of both is to secure that the jurisdiction of an inferior court or tribunal is properly exercised and it does not usurp the jurisdiction which it does not possess. A tribunal may be said to act without jurisdiction when it is not properly constituted or the subject matter of enquiry is beyond the scope of the tribunal. Where the tribunal has assumed jurisdiction on the basis of a wrong decision of facts or it has violated the principles of natural justice and its decision has been obtained by fraud or corruption etc, it can be said to act with out jurisdiction.

*Quo Warranto: Quo Warranto* is a proceeding whereby the court enquires into the legality of the claim which a party asserts to a public office and to expel him if the claim is not well founded. To issue a *writ of quo warranto* the claim must be to a public office created by the constitution or a statute, the office must be a substantive one and there must be a contravention of the constitution or the statute in appointing that person. The basic principle behind this writ is that the public has an interest to see that an unlawful claimant does not usurp a public office.

**The Limitations on the Enforcement of the Fundamental Rights**

The Parliament has power to modify the application of the fundamental rights to the members of the Armed Forces to ensure proper discipline and efficiency. In the same manner when martial law is enforced in some territory, persons in the service of the state are indenified for any act done in enforcing the same.

Fundamental Rights will remain suspended while a proclamation of emergency under Article 352 of the constitution is made by the President of India. During the emergency period the state shall be freed from the imitations imposed by Article 19. In effect the legislature and the executive will be free to make any law or take any action even if such law or action is in direct violation of the freedoms guaranteed under

Article 19 of the Constitution. Article 19 will revive as soon as the Proclamation of Emergency ends.The citizens will have no remedy against any violations of their freedoms during the Emergency period.

The President may also issue a further Order suspending the right to move the courts to enforce any of the fundamental rights while proclaiming the emergency under Article 359. This right to move the courts will be revived once the emergency is over or the order is revoked earlier by the President. However, this order of the President is not final and such order has to be approved by the Parliament.

**Check Your Progress I**

1. What do you understand by law?

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2. List the seven groups of Fundamental Rights originally given in Indian Constitution.

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## 1.4 CONSTITUTIONAL PROVISIONS AND AIDS

The provisions that are relevant to the AIDS situation in India are found in Part III and IV dealing with Fundamental Rights and Directive Principles of State Policy respectively. The above study on the provisions of the fundamental rights guaranteed by Indian Constitution will be of help as we proceed in our study on the rights of the HIV/AIDS patients.

Public health and sanitation, hospitals and dispensaries fall in the state list. Population control and family planning, medical education, adulteration of food stuffs and other goods, drugs and poisons, registration of births and deaths, mental deficiency etc. are in the concurrent list. The Union Ministry for Health and Family Welfare plays a vital role in the national efforts for primary health care and prevention and control of diseases.

Since Articles 14 to 18 guarantee us equality before and equal protection of the laws, any law that isolates AIDS patients denying them treatment on any grounds, can be challenged before the Supreme Court or the High Courts. In the same manner, if any government hospitals or dispensaries refuse to admit or treat AIDS patients, of course without a good reason, the same can be challenged as violations of the Fundamental Rights. However, under Article 14, the authorities can open up separate AIDS treatment centres as this would only be reasonable classification.

The 1989 AIDS Prevention Bill was full of inequalities and discrimination. It could have been also an attack on the human dignity of the AIDS patients, thus, violating Article 21 of Indian Constitution.

As seen earlier, Article 19 guarantees certain freedoms. There are also other freedoms that are enforceable though not listed under Article 19. They are right to travel, right to privacy, right to receive such higher or professional education, right to human dignity, right to speedy trial, to information etc. Under this provision, we can approach the courts seeking correct information and scientific data regarding the health care and other facilities available to the HIV/AIDS patients. Right to information on medical care is one of the freedoms that can be used to help the HIV/AIDS patients.

Under Article 21, which guarantees life and personal liberty, medical care is a fundamental right. In a Supreme Court case it was laid down that there is 'an obligation upon the state to preserve the life of every person by offering immediate medical care to every patient.' Any act that endangers life can be and should be challenged in the Courts. Refusal to treat HIV/AIDS patients by the doctors or the nurses thus will be in violation of the fundamental right of the patient. There is an urgent need to spread information regarding HIV/AIDS universally as this dreaded plague is waiting to strike at any one at any time. Under this article we can force the state to go on an information offensive to prevent HIV/AIDS assuming national calamity proportions.

We have seen the right to constitutional remedies under Article 32 of the Constitution. Generally speaking only the aggrieved can approach the courts but with the arrival of the Public Interest Litigation (PIL) any public spirited person or social activist or voluntary organizations can approach the courts to redress griviences of individuals or class of people who are disadvantaged due to their poverty, lack of education or other handicaps. In a PIL (Rakesh vs State of Bihar) the Supreme Court appointed a Committee of Experts to study the issue of the Mismanagement of a mental hospital in Bihar. The Bhopal Gas Disaster, the

Narmada Dam case etc. are examples of this right utilized by public spirited persons. Action under this Article should be resorted to whenever the rights of HIV/AIDS patients rights as citizens are violated.

## 1.5 LAWS THAT CAN BE USED BY HIV/AIDS PATIENTS

Criminal Procedure Code or the Cr. P.C lays down the procedures in a criminal case. The part relevant for HIV/AIDS comes under Chapter XB, Public Nuisances sections 133 to 143. Any unlawful obstructions or nuisance at any public place or at any way or channel which is or may be used by the public are to be dealt by the Magistrates. The conduct of any trade or occupation or keeping goods which is dangerous to the health or physical comfort of the community is also barred. Obstructions in hospital or blood banks compounds, corridors, stairways or wards etc, are public nuisances that comes under this chapter.

Another useful provision deals with compensation to victims. Section 357 of the Cr.P.C provides for compensation to victims of crimes. This compensation can be ordered after the conviction of the offender. Thus, public nuisance, annoyance and obstruction or inconvenience to life can be overcome if the legal provisions are properly resorted to. If these laws are used, then blood banks operating with out proper licence, recycling of used syringes, needles and blades , hospitals flouting safety and sterilisation norms etc. can be stopped. Haircutting saloons and beauty parlours are where there are limited chances for HIV/AIDS spreading and it can be effectively controlled if the provisions on public nuisance are used.

**Law of Torts**

Tort is a civil wrong independent of contract. Liability in Tort arises from breach of a duty primarily fixed by law which is generally towards others. For example, there is no separate contract between a member of a municipality that all the municipal areas will be kept clean by the municipality. Still the municipality which taxes people is duty bound to provide civic amenities. So is the case of a hospital and a patient stating that there will be no negligence on the part of the hospital. The hospital is bound to show due diligence in treating the patient.

In Laxman B. Joshi Vs. T.B. Godbole (AIR 1969, SC 128) the Supreme Court held that a doctor holds himself as possessed of skill and knowledge required for the purpose; when consulted he owes his patient certain duties, viz, a duty of care in deciding whether to undertake the case, a duty of care in deciding what treatment to give and a duty of care in administration of that treatment. A breach of any of these duties will give rise to an action for negligence against them.

**Other Laws that can be used by HIV Patients**

There are many laws under which justice can be sought by an HIV/AIDS patient. Some of these are:

- The Consumer Protection Act, 1986
- The Indian Medical Council Act, 1956
- The Indian Medical Council Rules, 1957
- The Code of Medical Ethics, 1956
- The Dentists (Code of Ethics) Regulations, 1976
- The Pharmacy Council of India Regulations, 1952
- The Pre-natal Diagnostic Techniques (Regulation and Prevention of Misuse) Act, 1994
- The Transplantation of Human Organs Act, 1994
- The Epidemic Diseases Act, 1897
- The Protection of Human Rights Act,1993
- The Drugs and Cosmetics Act, 1940
- The Medical Termination of Pregnancy Act, 1971
- The Mental Health Act, 1987
- The Pharmacy Act, 1948
- The Maternity Benefit Act, 1961
- The Narcotic Drugs and Psychotropic Substances Act, 1985
- The Environmental Protection Act, 1986
- The Hazardous Waste Rules, 1989
- The Infant Milk Substitutes, Feeding Bottles and Infant Foods (Regulation of production, Supply and Distribution) Act, 1992
- The Monopolies and Restrictive Trade Practices Act, 1969
- The Dentists Act, 1948
- The Drug (Control) Act, 1950
- The Drugs and Magic Remedies (Objectionable) Advertisement Act, 1954
- The Homeopathy Central Council Act, 1973
- The India Medical Degrees Act, 1916
- The Lepers Act,
- The Indian Lunacy Act,
- The Medicinal and Toilet Preparation Act,
- The Personal Injuries (Emergency Provisions) Act,

Thus, if any person dispensing medical service violates any of the provisions of the above Acts, Rules etc. can be sued for compensation under the laws of torts in addition to the remedies provided in the respective laws. Law of torts can also be used to discipline unethical or greedy practitioners of medicine. The government hospitals that do not care for the patients or those private hospitals or doctors offering free, but faulty medi-care will also come under the law of torts.

**Consumer Protection Act, 1986.**

Today, we have a well developed medical jurisprudence. Damages can be sought for unethical, deficient or negligent medicare. Medical negligence can be brought before the courts for damages under the Consumer Protection Act, 1986. This Act can also be used to fight AIDS. The blood banks, governmental or private, can be taken to task if they are operating without proper precautions. If they operate without licence they can be closed down by the orders of a Consumer Forum. If contaminated blood is supplied, the amount paid can be got refunded along with compensation. In the same manner, tattooing, faulty blood testing, side effects from medicines, misleading medical or para medical publications or teachings, etc. are all actionable under law. Though the Consumer Protection Act is time saving and needs no advocate, the compensation awarded is often absolutely meagre making the whole effort actually worthless.

*The Code of Medical Ethics*

The decline in noble profession of medical care is unbelievable. Commercialisation has taken its toll. Unnecessary operations, medication and other treatments are the order of the day. One cannot complain also when we look at the premium the MBBS aspirants pay to get their admission to the medical courses. For most the race to recoup the money invested in the studies starts the moment registration is granted by the Medical Council. For example, the code demands that not he exaggerate nor minimize the gravity of a patient's condition. But the money minting medical business would not perm him to abide by such rules. Lodging complaints to the respective Cou ils can strengthen one's case in the courts of law.

However, one should not look at the courts or the judiciary as the answer to all problems in relation to HIV/AIDS. There is no single remedy to

any social malady. Of course, the judiciary should be approached at every occasion where it is needed. Our courts are over-burdened and the delay in delivering judgements are a major set back to the whole system.

## 1.6 A LEGAL POLICY ON HIV/AIDS

The fear generated by the HIV epidemic has not helped the cause of HIV patients. Sex workers, gay men and drug users who are the first one to be infected by HIV are already targets of punitive legal provisions. Some suggestions made by Julie Hamblin in a UNDP paper 'People living with HIV: The Law, Ethics and Discrimination' are apt in summing up this Unit. The four points that should guide the legal policy framers are:

1) *A protective and supportive legal framework*

The law can and must be used to establish a protective and supportive framework for people affected by the epidemic and not a punitive one.

- The element of collaboration and mutual support that emphasises the community of interest between the infected and the uninfected and between government and individuals.
- Creating a supportive legal environment can involve both negative and positive legal interventions.

The negative interventions arise from the need for absence of law in some contexts. The laws we do not need are the laws which discriminate against the people with HIV, which distance them from their communities and which make it less likely that these people will share in the common interest to reduce the effects of the epidemic. Examples of such laws are:

— Laws that make homosexuality a criminal offence

— Offences relating to drug use and prostitution that have the effect of making it harder to reach drug users and sex workers with HIV.

— Laws restricting the availability of condoms and needles and syringes

— Censorship and broadcasting laws that restrict the dissemination of safe sex information

— Laws that permit HIV testing without consent or the detention of people with HIV

— Immigration and travel laws that restrict the movement of people with HIV between countries

These laws should have no place in a sensitive and sensible response to the epidemic and need to be replaced

Then there are positive legal intervention that can actively promote the supportive environment. These legal interventions include:

— Human rights laws that give legal effect to rights such as the right to

privacy, the right to protection against unlawful search and seizure and rights to protection against unlawful detention

— Anti-discrimination laws that will provide redress in the event of discrimination in employment, housing, access to health care etc., against people with HIV or their family or friends

— Legal provisions that protect the confidentiality of a person's with HIV status

— Laws compelling a person's consent to be given before HIV testing is undertaken.

— Laws that encourage appropriate workplace practices, eg. infection control procedures and HIV education for employees.

The thrust of this approach to legal policy on HIV must be to use law not as a weapon but as a protective instrument that respects the worth of all individuals and reinforces co-operative efforts to deal with the effects of the epidemic.

2) *Ethics and Law*

It has become common to talk about law and ethics in the context of HIV policy. This is done for obvious reasons because the ethical dilemmas that arise are invariably played out in legal terms. Nonetheless, the blurring of the distinction between law and ethics can sometimes obscure the fact that tensions may exist between ethical imperatives and legal obligations. It is therefore worthwhile considering the interaction between law, ethics and HIV.

Existing legal principles may be inadequate to mediate all the different interests involved and may lead to inappropriate and anomalous results. The potential inadequacy of existing law provides us with an opportunity, because many of the legal issues thrown up by the HIV epidemic are new, and the development of new legal principles and solutions will be required. There is therefore, an opportunity to direct the law in the way we want it to go , that is, to have ethics drive law reform and not the other way around. If one takes the case of whether to disclose a man's HIV status to his spouse, for example, the legal principles governing this decision may well be uncertain and any judge called upon to decide the case will almost certainly be least equipped to arrive at an informed view. Therefore, there is a real possibility that careful and informed ethical debate can guide the direction of the evolution of law in this area. Appropriate ethical guidelines may even mean that the law will not need to become directly involved and such guidelines will assist in shaping the law in the best way possible.

3) *The Law as an Instrument of Behaviour Change*

The notion that law can be used actively as an instrument to bring about changes in personal behaviour needs to be explored. In order to understand this point, it is necessary to appreciate the complex interdependence between the law and the society within which it operates. While the law is a product of prevailing social and cultural

values with in any community, it can also be instrumental in defining, reinforcing and, in some cases, actively promoting certain values and practices. By either condoning or outlawing certain values, the law can be powerful instrument for shaping or reinforcing these behaviours or values.

Where poverty and economic dependency lead to vulnerability, laws that address these issues, for example, through changes to land ownership or credit regulation, may assist other efforts to change the behaviours that spread HIV. Where women are unable to protect themselves against the virus because of their unequal position within the relationship, or in communities, laws such as those dealing with rape within marriage and the age of marriage or sexual consent, which uphold the independent rights of women, may increase the options for women in the context of the epidemic.

4) ***Mobilize the Lawyers***

We have to find ways to mobilize lawyers to take up these issues. We need to have lawyers who are prepared to argue for appropriate law reforms on HIV, to give legal advice to people affected by the epidemic and to take test cases to court where necessary. Only by having an informed group of lawyers we can ensure that the legal issues associated with the epidemic will be tackled properly.

**Check Your Progress II**

1. What are the laws that can be effetively used by AIDS patients?

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2. What do you understand by AIDS and law?

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## 1.7 LET US SUM UP

Through this unit, we looked through certain fundamentals on what is law, rule of law, Indian Constitution and its preamble, Human Rights and AIDS Law and Fundamental Rights etc. We went into some detail detail about the various fundamental rights granted by the constitution and the writ powers of the courts. We also studied the constitutional and penal provisions that affect the rights of the HIV patients and some of the laws that support and sustain the rights of them.

## 1.8 KEY WORDS

1) *Habeas corpus* produce the body; to produce the person illegally detained
2) *Mandamus* a command; order to do something that should have been done
3) *Certiorari* an order to quash an order passed by a lower court.
4) *Quo warranto* by what authority; enquiring into the legality of a claim
5) *Justiciable* enforcable through courts intervention.

## 1.9 MODEL ANSWERS

**Check Your Progress 1**

1. What do you understand by law?

Law is the "written and unwritten body of rules, largely derived from customs and formal enactments which are recognised as binding among those persons who constitute a community or state, so that they will be imposed upon and forced among those persons by appropriate sanctions." (L.B Curzon, Dictionary of Law).

2. List seven groups of fundamental rights originally given in Indian Constitution.
   i) Right to equality.
   ii) Right to particular freedoms.
   iii) Right against exploitation.

iv) Right to freedom of religion.

v) Cultural and educational rights.

vi) Right to property.

vii) Right to constitutional remedies.

**Check Your Progress II**

1. What are the laws that can be effectively used by AIDS patients?

The Consumer Protection Act, 1986

The Indian Medical Council Act, 1956

The Indian Medical Council Rules, 1957

The Code of Medical Ethics, 1956

The Dentists (Code of Ethics) Regulations, 1976

The Pharmacy Council of India Regulations, 1952

The Pre-natal Diagnostic Techniques (Regulation and Prevention of Misuse) Act, 1994

The Transplantation of Human Organs Act, 1994

The Epidemic Diseases Act, 1897

The Protection of Human Rights Act,1993

The Drugs and Cosmetics Act, 1940

The Medical Termination of Pregnancy Act, 1971

The Mental Health Act, 1987

The Pharmacy Act, 1948

The Maternity Benefit Act, 1961

The Narcotic Drugs and Psychotropic Substances Act, 1985

The Environmental Protection Act, 1986

The Hazardous Waste Rules, 1989

The Infant Milk Substitutes, Feeding Bottles and Infant Foods (Regulation of production, Supply and Distribution) Act, 1992

The Monopolies and Restrictive Trade Practices Act, 1969

The Dentists Act, 1948

The Drug (Control) Act, 1950

The Drugs and Magic Remedies (Objectionable) Advertisement Act, 1954

The Homeopathy Central Council Act, 1973

The India Medical Degrees Act, 1916

The Lepers Act

The Indian Lunacy Act

The Medicinal and Toilet Preparation Act

The Personal Injuries (Emergency Provisions) Act

2. What do you understand by AIDS and law?

Law in the context of AIDS is to be used to establish a protective and supportive framework for people affected by the epidemic. Creating a supportive legal environment can involve both negative and positive legal interventions.The law we do not need are the laws which discriminate against the people with HIV. There are positive legal intervention that can actively promote the supportive environment, including

—Human rights laws that give legal effect to rights such as the right to privacy, the right to protection against unlawful search and seizure and rights to protection against unlawful detention.

—Anti-discrimination laws that will provide redress in the event of discrimination in employment, housing, access to health care etc., against people with HIV or their family or friends.

—Legal provisions that protect the confidentiality of a person's HIV status.

—Laws compelling a person's consent to be given before HIV testing is undertaken.

—Laws that encourage appropriate workplace practices, e.g., Infection control procedure and HIV education for employees.

## 1.10 FURTHER READINGS

1. Gracious Thomas, et.al (1997). AIDS, Law and Social Work, Rawat Publications, New Delhi
2. P.D. Mathew (1998). AIDS and Law, Indian Social Institute, New Delhi
3. UNDP (1993). Law, Ethics and HIV. Proceedings of the UNDP inter country Consultation, CEBU, Philippines.

# UNIT 2 RIGHTS OF PEOPLE LIVING WITH HIV/AIDS

**Contents**



## 2.0 AIMS AND OBJECTIVES

HIV/AIDS is generally transmitted through having sex with someone infected with the virus, through injection or transfusion of contaminated blood, by sharing needles / syringes etc for drugs, or from an infected mother to her foetus during pregnancy or possibly during delivery.

Since the disease is not curable at present, it has to be viewed with utmost seriousness.

After studying this unit, you should be able to:

- describe the legal response to HIV/AIDS in India and abroad.
- excplain the judicial response to HIV/AIDS in India.
- list the legal rights of the HIV/AIDS patients in India, and
- understand the issues raised by the International Conference in Law, Humanity and Public Policy in Delhi.

## 2.1 INTRODUCTION

From the previous blocks and course on HIV/AIDS, we understood that misinformation and ignorance have made AIDS the most fearsome threat to the public health system every where. AIDS is not a single disease, but rather a complex of symptoms caused by infections primarily due to disruptions of the immune system in the body by an underlying viral infection. With no vaccine available as of date to stop the HIV infection, prevention is the only answer. An effective public health policy to combat AIDS will also depend on the recognition of the human rights of

the persons affected by it as well. Thus, public health laws need to be enacted to prevent the further spread of the dreaded virus and in the meanwhile protect the human rights and dignity of the persons already affected by AIDS. Legislation alone does not guarantee answers to the challenges thrown up by the epidemic. Persons affected by AIDS need to be adequately helped financially. Public information, education and human laws to tackle the legal issues associated with HIV/AIDS are urgently needed.

## 2.2 LEGAL RESPONSE TO AIDS BY THE WORLD COMMUNITY

Most of the countries in the world have adopted HIV/AIDS related legislations. Some perceive AIDS as a disease and look at the victims with sympathy while others view it as a catastrophe. Many feel that AIDS is caused by sinful and irresponsible behaviour. Establishment of a national AIDS Committee, public health surveillance, national AIDS strategy, specific control measures, reducing the impact of HIV/AIDS etc. are some of the main components of the AIDS prevention and control legislations everywhere. The issue has been approached from three angles: coercive penal, facilitative pragmatic, and compensatory rehabilitative. Every country making laws to face AIDS has been influenced by one of these approaches and the enforcement of laws are influenced by the perceptions on the background of the disease.

HIV/AIDS is variously classified as a communicable/ viral/ infectious, contagious/occupational or sexually transmitted disease. There is no uniformity in the classification on AIDS. The trends available in the laws related to AIDS are in the field of classification, compulsory notification which makes it obligatory to report the AIDS cases to authorities, protection of confidentiality about the infected persons, compulsory HIV testing on specific population categories, eg. foreigners, high risk groups meaning therby commercial sex workers, drug addicts, professional blood donors, homo-sexuals etc. The other category is the access to information and education about the disease itself.

It is very necessary to have laws to prevent discrimination against those found to be HIV positive as they too have rights to enjoy the same fundamental and human rights as those not affected. Of course those infected should have an additional responsibility to contain further transmission of the disease. Adoption of anti-discrimination legislation, acceptance of the human rights of affected persons by the United States of America, USSR, France, and several other countries have had positive impact in preventing the spread of AIDS.

Denmark has laws offering compensation to infected haemophiliacs while France, Italy, Ukraine and Switzerland have laws giving compensation to health workers infected by HIV while working among the infected persons. Switzerland in fact offers compensation to the victims of AIDS. If the infected person dies before receiving the full benefit then the persons who incurred the costs as a result of his death may be compensated. France, Spain, Belgium, Philipines and Uganda have

established nodal AIDS control agencies to frame uniform policies for their countries. Uganda even has a scheme for the welfare of bereaved orphans to find a drug for the cure of the AIDS.

Many countries have made legal provisions to ensure supply of clean blood. They are Algeria, Lebanon, France, Italy, Mali, Switzerland, Costa Rica, South Africa, Philipines and the Council of Europe. Various regulations include:

- Compulsory testing of blood and blood products
- Lebanese law requires all sero positive units to be destroyed and all sero positive blood donors to be excluded.
- Swiss law provides that it should be ensured that donors can be identified at all times.
- Italian law lays down "human blood and its derivation should not constitute a source of financial gain; they shall be distributed free of charge to the recipient and shall be exclusive of any accessory charges or taxes".

Ukraine has enacted welfare provisions to protect the rights of the health care workers. They include incentive based on option; rigorous sanctions against professional negligence; liberal provisions to compensate for occupational disabilities of health workers; compulsory state insurance; allowance like extra payment, extra annual vacation and early retirement with pension for infected health workers; and permission to medical personnel to refuse to provide treatment if protective coverings is not provided to them.

An obligation to notify to prescribed authorities continue to be the most preferred method of surveillance. Danish law requires the report to be made in a manner where the HIV person's sex, age, place of residence, and to the extent possible, his risk behaviour remain anonymous. French law also prescribes anonymity countries like, Singapore, Argentina, China, Tunisia, Ukraine and Vietnam have laws that endorse confidentiality norms along with situations in which the can be over-rules. Vietnam seeks confidentiality only when the test was voluntarily undertaken.

**Check Your Progress I**

1. What are some of the major legal provisions included in the laws enacted by various governments to ensure supply of clean blood?

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## 2.3 INDIAN RESPONSE TO AIDS

Section 421 of the Bombay Municipal Corporation Act, requires every medical practitioner who treats or becomes aware of the existence of any dangerous disease to give information of the same to the Executive Health Officer.

Under the Epidemic Corporation Act, Section 2 provides for special powers to be given to state government officers to take such measures including prescribing temporary regulations to be observed by the public or any class of persons to prevent the outbreak and spread of any such epidemic disease.

The Carriage of Passengers Suffering from Infectious or Contagious Diseases Rules 1990, provides that the railway administration shall not carry persons suffering from certain infectious or contagious diseases except in accordance with the conditions laid down in these rules. The diseases so listed are the following:

| | | | |
|---|---|---|---|
| a) | Cerebro-Spinal meningitis | b) | Cholera |
| c) | Chicken-pox | d) | Diphtheria |
| e) | Leprosy | f) | Measels |
| g) | Mumps | h) | AIDS |
| i) | Scarlet fever | j) | Typhus fever |
| k) | Typhoid fever, and | l) | Whooping cough |

Any person suffering from any of the above diseases shall not enter or remain in a railway carriage or travel in a train without the permission of the Station Master or other authorised persons. Once such permission is given, the railway is to arrange for the patient to be separated from fellow passengers.

The Drugs and Cosmetics Rules, 1993 has the following provision to prevent the spread of AIDS through blood transfusion: Rule H of the Part XIIB (1993, GSR 28 (E) provides that "every licencee of a Blood Bank shall get samples of every blood tested for freedom from HIV ant bodies either from such laboratories specified for the purpose by the central government or in his own laboratory. The result of testing shall be recorded on the label of the container also."

The Delhi Artificial Insemination Human Act, 1995 too has safeguards against the HIV virus. Section 10(1) reads as follows: "The semen bank before accepting the semen for artificial insemination shall test the donor for presence of HIV 1 and 2 antibodies by using a highly sensitive ELISA Kit and if found negative, only then, the donor shall be allowed to donate."

*Explanation:* The expression 'HIV' 1 and 2, ELISA Kit or ELISA Test and 'HIV' used in this section or in other sections of this Act denote respectively 'Human Immune Deficiency Virus Type 1 and Type 2', 'Enzyme Linked Immune Sorbent Kit or Enzyme Linked Immune Sorbent Assay Test' and 'Human Immune Deficiency Virus.'

10(2). "The donor shall be screened for HIV surface antigen and if found negative, only then, the donor shall be allowed to donate."

Section 11 is as follows: "The donated semen shall be stored either by cryo preservation of liquid nitrogen freezing or any other safe method for a period of minimum of three months in order to exclude window period of HIV 1 and 2 infection in the donor."

Section 12 is as follows: "At the end of three months, a second ELISA Test shall, by the same method, be performed on the donor."

Section 14 provides that "the qualified medical practitioner or government hospital or the semen bank performing artificial insemination, as the case may be, shall-

(a) test the recipient for 'HIV 1 and 2' and sexually transmitted diseases before performing artificial insemination.

(b) seek the written consent of the recipient for using the semen on the basis of only one ELISA test being negative where facilities for cyro-preservation and liquid nitrogen for semen are not available."

**Criminal Laws Applicable to HIV Patients**

Under Section 269 of the IPC, performance of a negligent act likely to spread infection of a disease dangerous to life is an offence punishable with imprisonment for a term up to six months or with fine. To punish a person under this section it must be proved that he acted unlawfully or negligently.

If an HIV infected person, after he was tested positive, indulges in sex without taking the precaution of using contraceptives, it can be said that he is liable to punishment under Section 269 IPC. This offence can be considered very serious, if the act is done intentionally without just cause or reason. For this act, imprisonment up to 2 years or with fine is provided under Section 270 of the IPC.

A blood-bank, which negligently supplies blood containing HIV, can be punished under Sections 269 and 270 of the IPC. Even section 304-A of the IPC, which deals with killing of a person by negligent act, can be invoked against a blood bank if the blood supplied results in death of a person due to HIV infection. For an offence under section 304-A, two years imprisonment or fine is awarded as punishment.

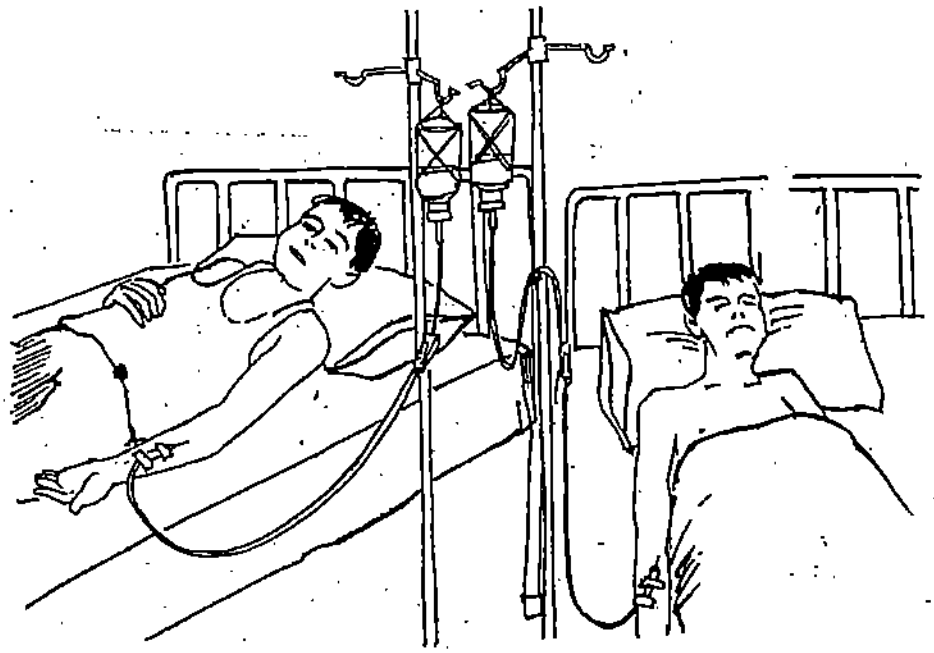
**AIDS (Prevention Bill), 1989**

In 1989, AIDS (Prevention Bill), 1989 was introduced in the Rajya Sabha. This was introduced in the parliament without adequate public debate. In fact, it sounded more like a hysterical response to the challenge posed by the HIV virus than a considered and studied answer to the threat. It basically resembled the Indian Leprosy Act, 1898 and the provisions treated the patient or the victim of the HIV virus as criminals and who needed to be removed from the public. The proposed Bill gave Government authorities sweeping powers to infringe upon the liberties of private citizens without any rational link to the objective of treating

infected individuals or of checking the spread of HIV/AIDS.

The focal point of the Bill was based on the concept of high risk groups. This in turn condemned and isolated the patient rather than educating, protecting or treating him for the dreaded disease victim of. The principle of having one's consent in doing anything that affects a person was given a go by in the provisions proposed in the bill. Even worse was the provision that the health authorities were not obliged to provide information about the nature or the consequence of the tests conducted on the patients or the high risk groups.

There was no provision for confidentiality in the Bill. The HIV status of the person was open to unwarranted disclosure. There was also nothing to prevent the health authorities from abusing or misusing the information availed against the affected person. The designated authorities could act on the basis of information furnished by doctors or anyone else. In fact any one could report to the authorities that some one is infected by HIV and thus, get him into trouble.



The Bill had nothing on how to control the spread of HIV through contaminated blood, blood products and contaminated hypodermic needles. The Bill also did not hold the hospitals, blood banks and pharmaceutical companies manufacturing blood products responsible for the spread of HIV/AIDS through their negligence and failings. The Bill put the entire burden of preventing HIV/AIDS on the individuals and professional blood donors.

In fact the Bill violated the principles of medical ethics. The Bill heavily relied on the isolation theory. The Bil. was formulated on the basis of the discredited Goa Public Health Act, 1987. It completely overlooked the scientific facts and other developments about HIV/AIDS. The real threat from the punitive measures such as isolation, quarantine and incarceration etc., proposed by the Bill was that the disease would be sent underground, defeating the very purpose of the Bill, i.e. stopping

the spread of the virus. The absence of confidentiality about testing would make it a herculian task to get one undergo the tests.

No MP opposed the Bill. In 1990 a group of social activists made a representation for the withdrawal of the Bill. Finally, it was allowed to lapse as serious protests by voluntary organisations started to pour in.

**Judicial response to AIDS in India**

Let us now examine some of the judicial responses to HIV/AIDS in India with special reference to Goa High Court and Goan Government policy.

a) **Goa Public Health Act**

In 1987, the Goa Public Health Act was amended to incorporate measures to prevent AIDS by amending clause (vii) of section 53 (1) of the Act. AIDS was treated as a contagious disease. Under the added clause it became mandatory for authorities to isolate persons found to be HIV carriers through the serological tests. Clause (viii) provides that an HIV patient should be provided with separate materials, equipments, etc. which should not be used by other persons. Clause (x) provides that linen, mattresses, etc. used by diseased AIDS patients should be immediately destroyed by burning. What is very disturbing about the amendments is that there were no opportunities given to the patient to show that he has been conclusively determined positive or he has been wrongly so determined or that there was no need for isolation.

(b) **Goa Government's Policy**

The Government of Goa adopted a policy under which any foreign national found to be HIV-positive should be isolated at the AIDS centre and therafter deported to his parent country. In case if he was an Indian national from another state then he should be sent back to his place residence or work. If the person is Goan, then he may not be interned. he would be allowed to go to his residence or work place on the condition that he visits the nearest Primary Health Centre for follow up. A special card will be given to him and a laminated card with a photo of the person shall be kept for record. In case, he fails to report to the Health Centre, then he is liable to be isolated.

(c) **Goa High Court**

Smt. Lucy R. D'Souza filed a Writ Petition in the Bombay High Court (Panjim Bench) challenging the constitutional validity of section 53 of the Goa Public Health (Amendment) Act, 1987. This section provides for:

— Compulsory collection of blood for investigation of AIDS by Public Health Officer on the grounds of reasonable suspicion that a person is suffering from AIDS,

— Isolation of a person found to be positive for AIDS by serological tests, and

— Precaution to be taken in case of patient suffering from AIDS.

The petition challenged the provision on the grounds that:

—Provision for isolation is based on wrong scientific material foundation

—Object sought to be achieved by isolation is nullified by the provision

—Discretion to isolate is unguided and uncontrolled, and

—Provision for isolation is procedurally unjust in the absence of the right of hearing.

The High Court was not convinced by the arguments placed before it by the petitioner. It upheld the constitutional validity of the section as reasonable and not violative of either Articles 14 or 19(1) or 21 of the Constitution. The Division Bench comprising of Mr. V.A Mehta and Mr. G.F Couto (JJ) upheld the Goa government's order providing for isolation of AIDS patients for 3 months. The Division Bench accepted that "isolation was an invasion upon the liberty of a person" yet "in matters like this individual's right has to be balanced against public interest." It further held that isolation would protect an AIDS patient from himself in case he becomes "desperate and loses all hopes of survival". Finally, the Judges felt that with the rising number of AIDS cases all over the world the current preventive measures had failed to check the spread of AIDS and hence, segregation was necessary.

(d) **Madras High Court**

The Tamil Nadu government had ordered the continued detention of four women who were undergoing sentence under the Immoral Traffic (Prevention) Act, 1986, on the ground that they were HIV positive. Mr. Shyamala Nataraj, a journalist, filed a writ petition in Madras High Court seeking the release of these women. The High Court ordered the release of the women in July, 1990.

Box : 1

AIDS Bhedbhav Virodhi Andolan (ABVA), an association established in 1988 to work for the cause of AIDS patients, filed a Writ Petition in 1994 in the High Court of Delhi to prevent AIDS among the prisoners. The ABVA challenged the constitutional validity of sections 377 of the India Penal Code and sought a direction to the Respondents (against whom a petition is filed) to take appropriate measures to prevent the spread of AIDS and isolation of certain groups or individuals infected with HIV positive. The respondents in the writ petition were: (1) The Union of India, (2) Delhi Administration, (3) The District and Sessions Judge, Tis Hazari, (4) Inspector General of Prisons, Tihar Jail, Delhi, (5) Superintendent of Tihar Jail, Delhi, (6) National AIDS Control Organisation (NACO).

What prompted the petitioners was the statement of the then Inspector General of Prisons, Tihar Jail, that condoms will not be supplied to the prisoners because it would mean encouraging homosexuality which is a criminal offence under section 377 of the Penal Code. The petitioners feared that the government own National AIDS Programme will not be implemented by not supplying condoms to prisoners. They also feared

that those suspected to be homosexual might be segregated or prosecuted.

The ABVA wanted the Court to declare section 377 of the IPC as unconstitutional and sought direction for the implementation of the NACO's programme. The petitioners sought to restrain the respondents from isolating prisoners with certain sexual orientation or those suffering from AIDS and to make immediately available condoms and disposable syringes at the dispensary in Tihar Jail. They also wanted the court to direct the jail authorities to regularly consult the NACO and direct an independent citizens' enquiry committee to look into the health of the prisoners and sanitary conditions in the Jail.

Though the matter was admitted in February,1995, till date no judgement has been passed in the case.

Box : 2

(Common Cause Vs. Union of India & Others. 1996)

A Voluntary organisation called Common Cause filed a Public Interest Litigation in the Supreme Court of India in March, 1992, about the malfunctioning of the blood banks, against the Union of India through the Ministry of Health. It had made the Drug Controller of India and the Departments of Health of all the State Governments in India. The complete text of the judgement in the Blood Bank case, with comments is available in the Supplementary Reading Material.

Common Cause filed the writ petition under Article 32 of the Constitution as the petitioner felt the laxity in licensing and monitoring of the blood banks to be violating the fundamental right to life guaranteed under Article 21. The Supreme Court admitted the matter in March, 1992, and issued show-cause notices to the Government of India and all the State Governments.

Common Cause prayed for a writ of *Mandamus* or other appropriate directions to the authorities to adopt appropriate measures to ensure proper licensing and effective monitoring of the blood banks operating all over the country in strict compliance of the rules under the Drugs and Cosmetics Act, 1940. It also sought an action plan or rather a specific performance of action from the governments aimed at overcoming the deficiencies in the operation of the blood banks.

After extensive hearing of all the parties and governments the Supreme Court passed a judgement giving an extensive list of steps to be taken by the authorities. The full text of the Blood Bank case is given as a separate unit in the Supplementary Reading Material

**Check Your Progress II**

1. What are the provisions available with Drugs and Cosmetics Rules, 1993 to prevent the spread of AIDS through blood transfusion?

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2. Briefly highlight the Goa Government's policy on HIV infected.

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## 2.4 RIGHTS OF AN HIV PATIENT

Anyone associated with HIV/AIDS needs to know the basic rights of an HIV/AIDS patient when so many atrocities are committed against them, particularly in India. Let us examine some of these legal rights available to them in India.

An HIV person has a right to privacy. There is no legal definition of privacy. 'But it is understood as the right to be left alone', or as that area of a person's life, which, in any given circumstances, a reasonable person with an understanding of the legitimate needs of the community would think it wrong to invade.' The right to privacy is an aspect of the right to live with human dignity. This right is affirmed by Article 12 of the Universal Declaration of Human Rights, Article 17 of the International Covenant on Civil and Political Rights and Article 21 of Indian Constitution.

Article 21 of the Constitution, which guarantees the right to life and personal liberty to every one, is available to the HIV patients also. Under

this, the HIV patients have a fundamental right to adequate treatment provided by the government. The state also has a duty under Article 47 of the Constitution (under the Directive Principles of the State Policy) to improve public health services. It is now a human rights issue that AIDS patients or those tested HIV positive cannot be refused treatment. The World Health Organisation (WHO) has also issued guidelines to this effect. Stern action is recommended against those who refuse to treat AIDS patients. Refusal by medical professionals to treat, investigate or operate upon persons with HIV/AIDS will be treated as professional misconduct. In case of violation of medical ethics, inquiry and action can be demanded by the Medical Council.

A patient or his legal heir is entitled to file a suit for compensation in case of injury or death suffered due to negligence or unskilled treatment by the medical personnel. A doctor can be prosecuted under section 304-A of the IPC (causing death through negligence), it will be on the complainant to prove the negligence.

**Legal Strategy Required for an AIDS Law**

We need an AIDS law based on integrating the victim and a constructive movement to stop the spread of the disease. We need a comprehensive legislation in the form of an AIDS Prevention and Rehabilitation of Victims Act. PD Mathew, in 'AIDS and Law' has aptly summed up the legal strategy for enacting AIDS laws in India.

It must

1. Harmonise state laws with the National Policy on HIV/AIDS;
2. Regulate public health standards for sex workers;
3. Provide privacy and redress against discrimination in their work place;
4. Abandon the policy of compulsory testing for HIV of specific groups;
5. Promote ethical values related to sex;
6. Frame laws on HIV/AIDS based on up to date scientific knowledge of the disease, its cause and effects;
7. Supplement and complement the medico-social strategy to fight the disease;
8. Replace punitive approach with preventive and rehabilitative approach;
9. Frame laws in conformity with the human rights jurisprudence;
10. Protect individual communities from life threatening infections such as HIV/AIDS;
11. Recognise the basic needs of the AIDS patients and protect them from unjust and inhuman discrimination;
12. Encourage people to voluntarily testing for HIV;
13. Advocate education for prevent ;



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14. Protect confidentiality and privacy of those infected with HIV/AIDS;
15. Create a well equipped communication system and a centralised information service on HIV/AIDS;
16. Give tax relief to persons and organisations who support and serve those infected with HIV/AIDS; and
17. Establish a central agency to co-ordinate the efforts of those working to prevent HIV/AIDS.
18. Identify priority areas for HIV legal policies."

Some of the Legal provisions that must be included in the AIDS Law are listed below:

1. means to check the spread of AIDS;
2. emphasising the dignity and rights of the AIDS patients;
3. encouraging voluntary testing among the people;
4. setting up AIDS surveillance clinics;
5. prohibiting the isolation of AIDS victims;
6. maintaining the secrecy about the identity of the patient;
7. not making any discrimination by the state on the ground of an individual's HIV status in matters of employment, education and travel, etc;
8. regulating the services to the patients by medical personnel;
9. the insuring of medical personnel working among HIV positive persons or AIDS patients;
10. punishing for breach of confidentiality about the identity of the HIV positive / AIDS persons;
11. mandatory screening of HIV in manufacture of blood related products;
12. providing facilities for confidential testing, security and rehabilitation of the victim;
13. compulsory testing of blood when donated;
14. severe punishment to intravenous drug users for sharing needles and other drug equipments with other users;
15. disciplinary action against health care workers and other medical personnel for not providing adequate care to patients suffering from HIV/AIDS.
16. declaring AIDS patients or HIV positive patients as disabled and thereby entitling them for special protection;
17. ensuring of education of the masses on AIDS by the state;
18. punishment to HIV positive/ AIDS patients for sexual contact with another or donating blood, organs or transfer of body fluids such as semen, blood, vaginal secretion, tissues after knowing that he is infected with HIV positive virus;

19. special care of special children born out of HIV positive mothers; and

20. persuading persons engaged in sex work to undergo test for HIV voluntarily.

## 2.5 RECOMMENDATIONS OF INTERNATIONAL CONFERENCE ON LAW, HUMANITY AND PUBLIC POLICY

An International Conference aimed at addressing the issue of law and humanity and public policy was held in New Delhi, in December 1995. It was organized by Indian Law Institute under the auspices of the Ministry of Health and Family Welfare with the cooperation of the UNDP and the WHO. It emphasised the need for a concerted approach to the legal issue presented by HIV/AIDS which would not only protect the society against the spread of the infection, but also respect the dignity and fundamental human rights of those who are infected or who are suspected of being infected and their families and associates.

**Guidelines and Strategies to Combat HIV/AIDS**

Some of the principles accepted by the Conference as a guide to developing laws and strategies to help combat the spread of HIV/AIDS are the following:

1. All laws and policies on HIV/AIDS should be based upon scientific data, and not upon presumptions, prejudice and stereotypes;
2. In combating HIV/AIDS, it is essential and urgent to adopt a global approach. This calls for a model global AIDS law which chalks out action at the local, national and international level;
3. The approach should respect and protect the human rights of all persons at risk of HIV/AIDS and discrimination on the ground of HIV/AIDS. It is recognized that one of the most effective strategies for changing behaviour and ensuring against the spread of HIV infection lies in the protection of the rights of at risk.
4. Laws should be made for prevention of HIV and for protection of persons affected by HIV/AIDS. These should be effective and enforceable.
5. Law makers who have a special responsibility in responding to HIV/AIDS, must work in an interdisciplinary way with health care workers, Government and non-governmental organizations, representatives of vulnerable groups, people living with HIV/AIDS and citizens in general who must be well informed about how HIV/AIDS is transmitted and of how the infection from the same can be prevented; and
6. The importance of moral, spiritual and religious values in response to the HIV/AIDS epidemic should be emphasized.

## Objectives of HIV-related Laws

The Conference also listed certain objectives of law related to HIV/AIDS. Some of them are listed below:

1. To protect human rights and empower individuals so that by their cooperation, the spread of the HIV infection is contained;
2. To promote voluntary behaviour which will protect the health of individuals, families and children throughout the world;
3. To prevent coercive and punitive action against a person who has demonstrated or is suspected of HIV infection or AIDS;
4. To protect society and to promote a sense of responsibility in the face of an epidemic which poses serious threat;
5. In securing the foregoing goals, the law should facilitate the provision of access to information about HIV/AIDS prevention, to health care services relevant to HIV/AIDS and to legal services to uphold and protect the rights of the individuals.
6. While effective laws in the context of HIV/AIDS must be just and always consistent with fundamental human rights, their ultimate objective must be to protect the individual as well as the society;
7. Respect for fundamental rights must be ensured including the right to privacy and freedom from discrimination; and
8. To provide for the allocation of adequate resources for prevention, care and anti-discrimination efforts including support for government and non-governmental organisations, and network of people living with HIV/AIDS.

## Priorities in Legislative Action

The Conference proposed certain terms for priority attention in legislative action in every country. They are:

1. Legislation to ensure the safety of the supply of blood so that blood products, organs and tissues are accurately and safely tested before use and provision must be made for legal liability in the event of blood, which is provided, (to abeneficiary) is found to be contaminated with HIV;
2. Introduction of anti-discrimination, equal opportunity, privacy and confidentiality legislation designed to provide effective protection for persons living with HIV/ AIDS or suspected to be living with HIV/ AIDS and effective remedies for such persons;
3. Removal of restrictions on the dissemination of full and accurate information and education about prevention of HIV infection and on the availability and quality of condoms and sterile injections;
4. Appropriate legislative protection for women in the context of marriage where their status increases their vulnerability to infection or to socio-economic impact of HIV/AIDS;
5. Initiating schemes for the provisions of sterile needles/ syringes to

prevent the further spread of HIV/AIDS amongst drug injecting persons;

6. Appropriate legislative action be taken to repeal those provisions of the penal code of all countries which are contrary to modern day concepts of human dignity and human rights;
7. Forbidding discrimination in employment, education, housing, health care, social security, travel, marital and reproductive rights and other privilages of people;
8. Reforms in the laws relating to commercial sex workers, viz: removal of criminal stigma which interferes with imparting education to commercial sex workers and their clients and provide the sex workers with alternative forms of employment so that they can protect themselves and thereby protect their society from further spread of HIV/AIDS.

**Priorities in Executive Action**

The Conference considered the following areas of action by the executive to be of highest priority from the legal point of view:

1. Prohibition of compulsory testing and screening of HIV/AIDS;
2. Prohibition of isolation, segregation and quarantine ;
3. Protection of confidentiality and privacy of people living with HIV/ AIDS;
4. Promotion of education on human rights, particularly the human rights of those living with HIV/AIDS infection; and
5. Establishment of ethical review committee to ensure ethics in the provision of health care and in HIV related research.

**Priorities for the Judiciary**

The Conference also had suggestions for the Judiciary:

1. Familiarising members of the judiciary with HIV/AIDS, the fair and timely application of statutory and common laws and the urgent need for an informed approach to the spread of virus and its impact upon the legal system;
2. Prompt and sympathetic disposal of cases involving issues connected with HIV/AIDS; and
3. Judges should play a leading role in proposing and suggesting reforms of the law to ensure that the law responds in an effective and just way to HIV/AIDS.

**Check Your Progress III**

1) List any three priorities in Legislative Action.

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2) What are the priorities suggested for the Judiciary during the conference?

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## 2.6 LET US SUM UP

In this unit, you have seen the legal response to AIDS, how various Acts treat the disease, what are the provisions of the Penal Code applicable to the HIV patients, Indian legal response in the form of the AIDS (Prohibition Bill) 1989, etc. We also had a review of the judicial response in the form of Smt. Lucy R D' Souza case. AIDS Bhedbhav Virodhi Andolan case and the Blood Bank case. After seeing the provisions protecting the rights of the AIDS patients we have also had extensive guidelines, suggestions, strategies, priorities etc. needed for an all round preparation to tackle the HIV/AIDS epidemic from the legislature, executive and the judiciary as well as general public.

## 2.7 KEY WORDS

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|---|---|
| **Legal/judicial response:** | The manner in which the laws as well as the courts in the country react to situations |
| **IPC (Indian Penal Code):** | Statement of offences and punishments provided for the same in India |
| **Enforceable Laws :** | Laws that are to be put into practice |
| **Coercive Action:** | Forcing someone against own will |

## 2.8 MODEL ANSWERS

**Check Your Progress I**

1) What are some of the major legal provisions included in the laws enacted by various governments to ensure supply of clean blood?

Many countries have made legal provisions to ensure supply of clean blood. They are Algeria, Lebanon, France, Italy, Mali, Switzerland, Costa Rica, South Africa, Philipines and the Council of Europe. Various regulations include:

— Compulsory testing of blood and blood products.

— Lebanese law requires all sero positive units to be destroyed and all sero positive blood donors to be excluded.

— Swiss law provides that it should be ensured that donors can be identified at all times.

— Italian law lays down "human blood and its derivation should not constitute a source of financial gain; they shall be distributed free of charge to the recipient and shall be exclusive of any accessory charges or taxes".

**Check Your Progress II**

1) What are the provisions available in the Drugs and Cosmetics Rules 1993, to prevent the spread of AIDS through blood transfusion?

The Drugs and Cosmetics Rules, 1993, has the following provision to prevent the spread of AIDS through blood transfusion. Rule H of the Part XIIB (1993, GSR 28 (E) provides that "Every licensee of a Blood Bank shall get samples of every blood tested for freedom from HIV anti-bodies either from such laboratories specified for the purpose by the central government or in his own laboratory. The result of testing shall be recorded on the label of the container also."

2) Briefly highlight the Goa Government's policy on the HIV infected.

The Government of Goa adopted a policy under which any foreign national found to be HIV-positive should be isolated at the AIDS center and therafter deported to his parent country. In case, if he is an Indian national from another state then he should be send back to his place of residence or work. If the person is Goan, then he may not be interned, he would be allowed to go to his residence or work place on the condition that he visits the nearest Primary Health Center for follow up. A special card will be given to him and a laminated card with photo of the person shall be kept for record. In case, he fails to report to the Health Center, then he is liable to be isolated.

**Check Your Progress III**

1) List any three priorities in Legislative Action.

a) Legislation to ensure the safety of the supply of blood so that blood products, organs and tissues are accurately and safely tested before use and provision must be made for legal liability

b) Introduction of anti-discrimination, equal opportunity, privacy and confidentiality legislation.

c) Removal of restrictions on the dissemination of full and accurate information and education about prevention of HIV infection and on the availability and quality of condoms and sterile injections;

2) What are the priorities suggested for the Judiciary during the Conference?

a) Familiarising members of the judiciary with HIV/AIDS situation, timely application of the laws and an informed approach to the spread of the virus,

b) Prompt and sympathetic disposal of HIV related cases, and

c) Proposing reforms in law to respond effectively to HIV/AIDS.

## 2.9 FURTHER READINGS

1) P.D. Mathew (1998). AIDS and Law, Indian Social Institute, New Delhi.

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

# UNIT 3 HIV/AIDS AND SUBSTANCE ABUSE

Contents



## 3.0 AIMS AND OBJECTIVES

The aim of the unit is to:

- inform you that there is a connection between substance abuse and the spread of HIV/AIDS.
- introduce to you different types of drugs that are abused and how drugs are taken.
- show you the link between the spread of HIV/AIDS and substance abuse because of a) sexual activities b) injecting drugs c) blood donation.

When you finish reading this unit, you will have a basic idea about substance abuse and the different substances of abuse.

You will further know that there is a close link between substance abuse and the spread of HIV/AIDS.

The unit establishes the link between substance abuse, prostitution and blood donation.

This unit shows how injecting drugs also serves as the reason for the spread of HIV/AIDS.

The unit also suggests ways by which one can fight against drug abuse and thereby fight against the spread of HIV/AIDS.

## 3.1 INTRODUCTION

By the time you come to this unit, you would have learnt the basic information about HIV/AIDS. As you are aware, substance abuse is a big social problem all over the world. But many may not be aware of the connection between substance abuse and HIV/AIDS. This unit aims at telling you about this connection. It must be admitted that in a short unit like this only a few basic facts can be presented. It is hoped that this unit will enable you to think about the growing menace of substance abuse and its various implications on the society. It will further show how substance abuse is one of the contributory factors for the spread of HIV/AIDS. The following questions are important in the context of HIV/AIDS and drug abuse.

- Are drug addicts more prone to acquiring HIV?
- If yes, how is drug addiction one of the causes for acquiring HIV?
- Are there any statistical data available to show the connection between substance abuse and HIV?

## 3.2 SUBSTANCE ABUSE AND ITS EFFECTS

Before looking at the connection between HIV/AIDS and substance abuse it is good to know something about substance abuse. The very term substance abuse means using a substance or a chemical in the improper way or using a chemical in a wrong way. A substance as it is used in the term, substance abuse, is a chemical or a drug that is used for the purpose of mood altering or intoxication. Some of these substances may have medicinal value and used under prescription by a physician. When they are used for the purpose of getting mood alteration it is called substance abuse. Most of these substances are addictive by nature.

According to the definition of WHO a person becomes an addict when:

i) he has the compulsive desire to continue to take the drug.

ii) he is willing to get it by any method.

iii) he increases the dose in such a way that he becomes psychologically and physically dependent on its effect.

iv) if the physical or mental faculties or both are affected due to taking the drug, the person may be termed an addict.

It must be noted that all those who take drugs do not become addicts. But anyone who abuses drugs can be called a substance abuser.

Addiction leads to many health hazards. It spoils the physical health and mental health of a person and some of the damages are irreversible. Many abused drugs can cause instantaneous death if they are consumed

in excess. In the same way the withdrawal symptoms when some of the drugs are stopped are equally horrible and painful. Take for example, a heroin addict who stops taking the drug. He will have unbearable sweat and experience chills and also painful twitches and muscular spasms. An overdose of cocaine may cause undue anxiety and panic resulting in an extreme state of agitation which causes hallucination. Addiction to cocaine will cause nervousness and insomnia (sleeplessness) and a mental state similar to paranoid psychosis. The use of stimulants like amphetamine produces delirium, panic and hallucinations and also feelings of persecution. Cannabis or Ganja addicts also experience panic and restlessness and can get respiratory diseases such as bronchitis. LSD may cause an unprecedented depression even giving rise to suicidal tendency. Alcohol consumption leads to accidents caused by double vision, lack of coordination of movements and reflexes and impaired judgement. It causes many physical and neuro-psychiatric disorders.

It is also a known fact that a substance abuser pays heavily for his habit. Addiction drains one's finances and leads to untold miseries in middle class and low income group families. It interferes with the tranquility of family life. Very often addiction is the major cause of domestic violence. It also serves as the cause for crimes. An addict loses respect in society and is usually found to be dishonest in dealing with money. Street children involved in substance abuse often have an untimely death due to lack of care and treatment. Stealing, selling, borrowing and pawning are some of the ways in which an addict raises money to get the drugs. Addiction leads to loss of manpower and is also the cause behind many industrial and road accidents.

Intravenous-drug taking is one of the major causes for the spread of Human Immunodeficiency Virus and Hepatitis B/C Virus. AIDS was detected in a heroin drug abuser in West Jersey, U.S.A in 1982. This unit shows how substance abuse serves as a major cause of the spread of HIV/AIDS.

**Vulnerability of Substance Abusers**

How are substance abusers more vulnerable to getting infected by HIV? In the basic course on HIV/AIDS we discussed different ways by which HIV spreads. Having multi-partner sex, transfusion of infected blood and use of unsterilised needles have close association with substance abuse. In order to understand this one should know something about the life of an addict, how a substance abuser makes money and the different ways of taking drugs. Have you ever come across one who takes hard-core drugs? Do you know the different kinds of substances abused by people? Have you ever thought how these substance abusers get money to sustain this habit? A knowledge of all these is necessary to understand the connection between substance abuse and the spread of HIV/AIDS. It is a known fact that the incidence of HIV infection is higher among substance abusers. For example HIV infection is a great problem among those in Manipur who inject drugs, some of the other North-Eastern states as well as the metropolitan cities in the country. In fact this is the case with substance abusers all over the world. The sections below will explain to you the link between substance abuse and HIV infection.

## 3.3 DIFFERENT KINDS OF DRUGS

Those who study substance abuse divide the substances into different categories:

*Gateway drugs:* Gateway drugs are those that initiate a person into the world of drugs. Cigarette, cigar and various preparations of tobacco meant for chewing and the 'gutkas' now very popular with students and youth are examples of this. A person who takes gateway drugs is more prone to slipping into the world of drugs.

*Legal drugs:* Legal drugs are those that are allowed to be sold in the market. Very often it is the government which serves as the seller or distributor and it has control over the sale and distribution. As it is sold with the knowledge of the Government, the Government has various methods of regulating the distribution through licensing, imposing heavy taxes, restricting the timings of sale and taking legal action on those who do not follow regulations. In India IMFL (Indian Made Foreign Liquor and Beer, Brandy, Rum, Gin, Wine, Whisky, Vodka etc.), and arrack, toddy and fenny belong to this category.

*Illegal or hardcore drugs:* Hardcore drugs or illegal drugs are those substances prohibited by law. The Government machinery can take legal action like imprisonment, imposing fine etc. on those who possess, distribute or consume it. Substances like cannabis, opium, brown sugar and cocaine belong to this category. There are many who abuse substances or drugs that are available in the form of tablets, liquids and injections available in medical shops.

Various types of drugs of addiction are available to our youth. Some are addicted to many drugs whereas some are addicted to one drug. The commonly abused drugs may be categorized as:

*Depressants:* Depressants are those drugs which tend to depress the

central nervous system. Though the popular belief is that alcohol provokes a person, it in fact comes under this category. Barbiturates, methaqualone and benzodiazepines and tranquilizers like valium and calmpose are depressants.

*Stimulants:* Stimulants are those drugs which tend to stimulate the central nervous system. They temporarily enhance wakefulness, stimulate the mood and even make one forget fatigue. Amphetamines, which some use to keep themselves awake belong to this category.

*Hallucinogens:* Hallucinogens distort the perception and the users may feel confused and disoriented. The experience of one who takes hallucinogens may vary from visions of joy and splendour to unbearable waking nightmares. LSD is a popular hallucinogen. As LSD interferes with perception there is a higher incidence of accidents due to wrong judgements. There is also a high risk to life as a slight overdose can cause instantaneous death.

*Narcotics:* Narcotics are used to suppress pain but they are abused to alter moods. Most of the abused drugs are derivatives from the narcotic substances in three plants, namely, poppy, coca and cannabis. Drugs derived from the plant poppy are known as opiates. Opium which is the dried milk of the plant poppy contains morphine and codeine. Various synthetic opiates are used as painkillers. Pethidine, a synthetic opiate is a commonly abused drug. Heroin, a white crystalline powder, bitter in taste is an opium derivative. Regular users have health problems as it affects food intake. Brown sugar which is a crude form of heroin is a very commonly misused illegal drug in India. It is a dangerous drug as it has highly addictive properties. Cocaine, which was not known to the Indian youth until the early 90's is now available in Indian cities. Various derivatives of the plant cannabis are popular drugs among the Indian youth. Compared with the price of other illegal drugs the various forms of cannabis—hashish, bhang, ganja and marijuana are available at an affordable price.

You should be aware that due to various reasons, a youth who comes into contact with drugs and tries it once out of curiosity may continue to take it and become a confirmed addict in due course.

### The Different Methods of Drug Intake

There are many ways in which the drug abusers consume drugs or substances. The very common way is oral intake, that is drinking or swallowing. Alcohol is usually drunk and opium is swallowed. Smoking is another way of taking drugs. For example cannabis or ganja is usually smoked. Drugs like heroin and cocaine are sniffed or sent through the nostrils—this is called inhalation Another method is intake with needles or injecting the drug. Drug injection is the method that has a close link with the spread of HIV/AIDS. This will be discussed in depth in the following sections. The table below gives information about the different types of drugs and how they are taken.

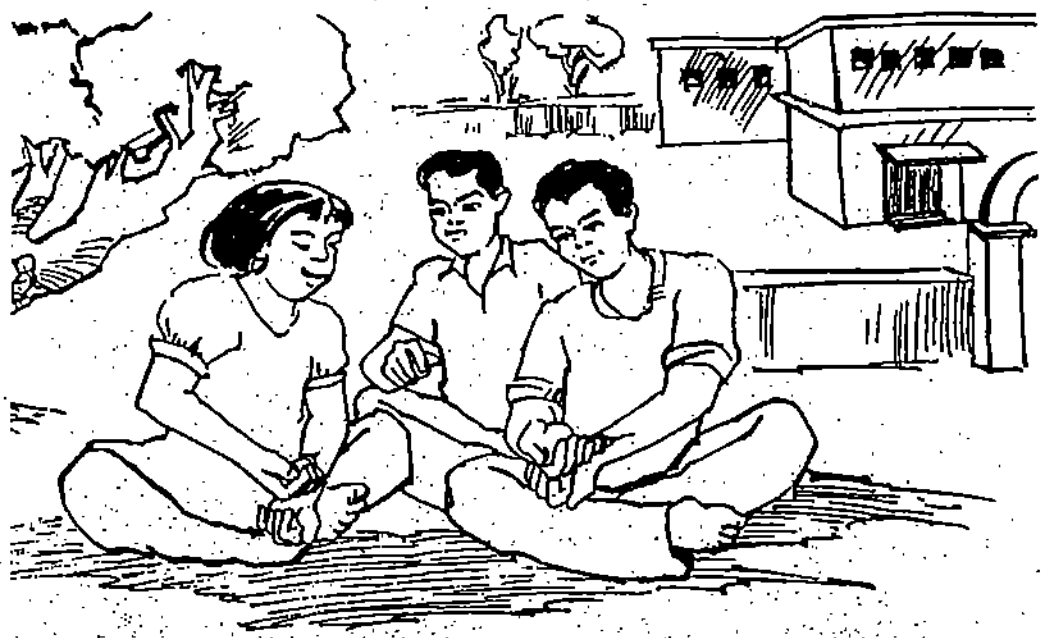

**Table 3.1**

**Types of drugs and how they are taken**

| S. No. | Category | Drugs | Methods of Use |
|---|---|---|---|
| 1 | 2 | 3 | 4 |
| 1. | NARCOTICS | Opium<br>Morphine<br>Codeine<br>Heroin | Orally taken and smoked<br>Orally taken, smoked, injected<br>Orally taken, injected<br>Injected, smoked, snorted<br>Orally taken, smoked |
| 2. | DEPRESSANTS | Barbiturates<br>Methaqualone<br>Benzodiazepines<br>Alcohol | Orally taken, injected<br>Orally taken, injected<br>Orally taken, injected<br>Orally taken |
| 3. | STIUMLANTS | Cocaine<br><br>Amphetamines | Snorted, orally taken, smoked, injected<br>Orally taken, injected |
| 4. | HAULLUCIOGENS | LSDS<br>Mescaline<br>Phencyclidine | Orally taken<br>Orally taken<br>Smoked, orally taken, injected |
| 5. | CANNABIS | Ganja/Hashish<br>Marijuna | Smoked, Orally taken |

## Check Your Progress 1

i) According to the WHO definition, when does a person becomes an addict?

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ii) How would you categorise the commonly abused drugs?

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iii) What are the four major methods of taking drugs?

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## 3.4 LIFE OF AN ADDICT

Now you have an idea about the world of substances, the different drugs of abuse and the different methods of intake. But to understand how a substance abuser is more prone to contracting HIV/AIDS we should know something about the life of an addict. Probably you have never seen a hard-core addict. In the Indian social context it may not be possible for many to see a hard core drug abuser injecting a drug. Some of you may not even be aware of this method.

Your attention is drawn to the definition of addiction given by WHO earlier in this unit. It is sad to note that many of our youth today are caught unawares in the drug trap. Drugs have become easily accessible to the youth. An article published in 'India Today' January 31, 1994 says that 35 per cent of our young people in the cities occasionally indulge in smoking, 30 per cent in drinking beer, 12 per cent in consuming alcohol and 0.5 per cent in taking drugs. It is estimated that in India 16.2 per cent of addicts are initiated into drug taking in the age group 10-15, 48.6 per cent in the age of 16 to 20 and 29.7 per cent in the age of 21 to 23 and only 6.5 per cent after the age of 26. The statistical data available are frightening. Now people in their teens and 20's land themselves in psychiatric clinics with drug-related problems. It is estimated that 20 per cent of the admissions in NIMHANS, Bangalore have alcohol-related problems.

In this section our main aim is to understand the life and behaviour of an addict. It is good to know the names of the above addictive substances. Some of these are easily available. You should also know that some of these substances are very expensive. Some substances are so addictive that an addict finds it almost impossible to survive without it. The withdrawal symptoms are so severe that a drug-addict dreads it. As there is a compulsive desire, and as an addict is physically and psychologically dependent on substances he usually tries to raise money to buy his drugs at any cost. He is so dependent on the substances that he gets withdrawal symptoms when he stops taking substances. An addict usually begs, borrows, steals, tells lies, cheats to get money to keep his habit going. Probably some of us might have had the experience of encountering an addict, trying to extract money from us under some pretext. Have you ever thought how an addict manages to get money when all his attempts to raise money to buy drugs fail? It will be a worthwhile exercise to closely watch the life of an addict and observe his fund-raising enterprise. When all other doors are closed he embarks on a selling spree. He starts selling whatever he can lay hand on—vessels, watch, furniture, jewellery and, if a student, even his text books. What more does he have to sell? Two easily available factors with an addict are his or her blood and body. This is how substance abuse is closely linked with professional blood donation and prostitution.

## 3.5 SUBSTANCE ABUSE, BLOOD DONATION AND HIV/AIDS

From what you have been reading till now you would have understood how addictive substance abuse is. Probably you never thought that an addict raises quick money by selling his own blood. It is established that many of the hardcore drug addicts are HIV positive. Don't you think there is a great risk of the recipient of blood getting HIV if it is from an unknown professional blood donor? Is it not a greater risk if the professional blood donor happens to be a drug addict?

**Case Study**

Anita is 4 years old doing her L.K.G in an English medium school. Born to her parents after five years of married life, she received a lot of affection and petting from her mother Shanthi and father Shankar. Anita had some problems in her intestine and she had to undergo a surgery. The parents were very upset and they did not want to take chances. They were rich enough and so they took her to the best hospital. The doctor suggested transfusion of one pint of blood after surgery. An agent, brought a professional blood donor and this was a big relief to Shankar. Anita's surgery was successful and within a month she started going back to school. But soon she complained of persistent cough and fever. The doctor who operated on her said that the cough and fever had nothing to do with the surgery. So she was referred to a good physician. The physician conducted several tests and got the permission of Shankar for screening her blood for HIV. To the utter despair of Shankar and Shanthi, Anita was found HIV positive. The physician asked some searching questions and came to the conclusion that Anita got the killer virus from the blood of the professional blood donor. So, he enquired about the blood donor. Shankar did not know his name or whereabouts and all that Shanthi remembered was his face and that he was smelling of alcohol when she thanked him for donating blood.

Now reflect on the following:

i) What is the future of Anita?

ii) How could she have avoided the present problem?

iii) What is the mistake committed by Shankar?

iv) What would have been the blood donor's motive behind donating blood?

v) How would he have got HIV?

vi) Can such a mishap occur to someone dear to you?

vii) Can you think of the ways in which this could have been avoided?

## 3.6 SUBSTANCE ABUSE AND SEXUAL ACTIVITIES

After going through the case study in the previous section you would be asking a very pertinent question: How did the donor get HIV? You may have asked another question too: Do only addicts carry HIV? Some of

5) Counselling of seropositive persons
6) Approval of diagnostic kits
7) Promotion of epidemiological studies on AIDS
8) Preparation of a plan of information dissemination
9) Funding of institutions and associations concerned with counselling and care in the AIDS context.

**USSR**

In 1987, the Health Ministry of the USSR issued regulations requiring the following to be tested:

1) Blood and tissue donors
2) Nationals returning from assignments abroad of more than one month's duration
3) Aliens intending to reside in the country for more than three months
4) Persons belonging to 'high-risk' groups, ie recipients of multiple blood 5 transfusions, drug dependent persons, homosexuals and prostitutes
5) Contacts of AIDS patients or carriers of the virus identified in epidemiological investigations

**Norway**

Norway developed an integrated programme for the control of AIDS as early as 1985 which addressed the following aspects:

1) Objectives and basic principles
2) Epidemiological surveillance
3) Measures to prevent the spread of infection, and
4) Ethical issues

Norway was also one of the first countries to address the issue of transmission of AIDS from one dental patient to another. It concluded there is no risk involved in this context and comprehensive measures were introduced for the control of HIV infection in dental services It also recognised AIDS and HIV infection as 'occupational injuries' in the case of health professionals and others involved in professional activities exposing them to HIV infection.

In 1987, France and Belgium introduced legislation waiving certain restrictions on advertising condoms and provided for access to clean syringes and needles. France also imposed mandatory standards for condoms. Spain established a National Commission for the Coordination and Monitoring of Programmes for the Prevention of AIDS in 1987. In the same year Italy established a National AIDS Control Commission. By a law in 1986, Iceland classified the HIV infection as a sexually transmitted disease. United Kingdom became one of the first countries to enact legislation concerning access to HIV testing kits. Sweden enacted comprehensive legislation on diverse forms of potential HIV transmission

via the hospitals and laboratories. Detailed provisions were laid down to prevent the transmission of HIV through infected wastes.

## 3.4 HIV LAW IN THE 1990's

Let us now discuss some of the HIV/AIDS legislative measures adopted by some of the countries in Europe in the 1990's.

Legislative response has shown major differences both quantitatively and qualitatively. Owing to legal, political, administrative, social realities, countries have tended to enact hard or soft laws. Hard laws included statutory laws and implementing regulations. Soft laws are the guidelines, circulars etc.

In Albania there are specific provisions on AIDS in the 1993 law on the control of communicable diseases. It provided for establishment of a National Commission to address issues in the prevention and control of AIDS. Blood safety provisions required all donors to be tested for HIV infection on each occasion when they donate blood. Another resolution provided for free supply of medicines for AIDS patients.

In Austria, the 1994 ordinance dealt with quality control and assurance with in the context of diagnosis of HIV infection and testing. Another Ordinance of the same year addressed the issue of evidence of the presence of HIV infection and indicator diseases for AIDS. A 1993 Decree pointed out that seropositivity alone is not subject to notification.

In 1994, in Belgium provisions requiring testing for HIV-1 and HIV-2 were included in the Law on blood and blood derivatives. In 1991, an AIDS Prevention Agency and the Scientific and Ethical Council on AIDS Prevention for the French Community was established.

In Denmark, in 1993, procedures for notifying AIDS cases and seropositivity for HIV were defined. In the same year, a law to provide compensation to HIV positive minors, persons contaminated as a result of blood transfusions was passed. Modalities were also set forth in 1994 for testing of donated blood for HIV-1 & 2.

Maximum legislative activity relating to HIV/AIDS in Europe has taken place in France. Some of the legislator's are listed below:

- International coordination of AIDS control was addressed in a May 1994 Decree.
- Measures to avert any risk of HIV-1 & 2 infection, designed to prevent the transmission of infectious diseases in the use of human organs, tissues and cells, are included in a decree of 1992/94.
- Establishment of an experimental programme for therapeutic accommodation for AIDS patients through a circular in 1994.
- Another circular of 1994 states AIDS control to be an essential requirement of public health, with absolute priority given to prevention.

- A whole series of legislative texts have addressed the issue of transfusion safety, including the institutional, organisational and administrative aspects.

Germany has had only limited legislation in this regard. In 1995 a law was introduced for establishment of the Humanitarian Assistance for Persons who have become HIV-infected as a result of Blood Products.

In Italy, the Decrees of 1991 and 1992 set up services for the domiciliary treatment of persons affected by AIDS and associated pathological conditions. Another 1992, law offers compensation for HIV infection through blood or blood product transfusion. A series of laws in 1992/ 1983 dealt with HIV/AIDS in prisons. Another 92 decree required all donated blood and plasma units to be tested for HIV-2. The AIDS project-objective for 1994-96 places emphasis on prevention, care, training, coordination and research.

**Russian Federation**

The 1995 Federal Law on the Prevention of HIV infection offers detailed provision on 'Guarantees by the State'. They are the following:

1) Regular dissemination of information to the population, notably through the mass media, on available means for the prevention of HIV infection;
2) Epidemiological surveillance on the spread of HIV of HIV infection in the territory of the Russian Federation;
3) Development of means for the prophylaxis, diagnosis and treatment of HIV infection; and the control of the safety of medical preparations, biological fluids, and tissues used for diagnostic, therapeutic and scientific purposes;
4) Availability of medical testing for the detection of HIV infection, including anonymous testing, accompanied by counseling before and after testing, and the assurance of the safety of such medical testing both for persons being tested and for persons carrying out the test;
5) Free provision of all forms of qualified and specialist medical care to HIV-infected persons who are Russian citizens; free supply of medicaments to such persons with in the framework of out-patient or in-patient care; and free transport for such persons to and from the place of treatment with in the confines of the Russian Federation;
6) Development of scientific research on the problems of HIV infection;
7) The inclusion, in the teaching programmes of education establishments, of thematic problems as part of moral and sexual education;
8) Social and housing assistance to HIV infected citizens; and arrangements for such persons to receive training, professional retraining, and work adjustments;
9) Training of specialists for carrying out measures for preventing the spread of infection;

10) Development of international cooperation and regular exchange of information within the frame work of inter-national programmes for prevention of the spread of HIV infection.

The chapter on 'Medical Care for HIV-infected Persons' include provisions for testing (voluntary and mandatory), conditions for the entry of aliens, the consequences of detection of HIV infection, the right to a second medical test, certain rights of HIV infected persons, and the development of a programme for the prevention, diagnosis, and treatment of HIV infection. There are also provisions for 'Social protection of HIV infected persons and members of their families' and 'Social protection of persons exposed to a risk of HIV infection in the performance of their professional duties.'

As far as Spain is concerned the National Commission for the Coordination and Monitoring of AIDS Prevention Programmes serves as the agency responsible for programmes for HIV/AIDS prevention and control undertaken by the public administration. Another Decree of 1993 established a programme for social assistance to persons infected by HIV from procedures carried out with in the public health system. This included HIV infected persons with haemophilia and blood transfusion recipients who were treated before compulsory testing for HIV infection was instituted. A Commission on Assistance to Persons Affected by HIV was established in 1993.

An Ordinance of 1993 in Switzerland requires the authorisation of the Federal Office of Public Health for the marketing of in vitro diagnostic kits, including those intended for the diagnosis of HIV infection. The one on HIV studies established detailed standards and criteria for carrying out epidemiological studies on HIV.

In 1991 an extensive Law in Ukraine on the Prevention of AIDS and the Social Protection of the Population was enacted. It established mandatory testing for persons engaged in prostitution and self-injecting, drug-dependent persons. Certain conditions applied to the aliens as well. Confidentiality was safeguarded. There were chapters on:

- The obligations of HIV-infected persons and all persons subject to medical testing for AIDS;
- Social protection of HIV-infected persons, persons suffering from AIDS, and members of their families;
- Social protection of members of the medical professionsî at risk of being infected with HIV; and
- Liability for violating the legislation on the control of AIDS , including criminal law provisions.

## 3.5 HIV LAW IN THE UNITED STATES OF AMERICA

HIV was first detected in the US in 1981. Therefore it is apt that we discuss the extent of legislative measures this country has adopted with regard to the management of HIV/AIDS.

The burden of the HIV infection and AIDS falls disproportionately on drug users and gay men as well racial minorities. AIDS related laws have been enacted in every states of the US. Most of these are superimposed on existing legislation governing communicable and sexually transmitted diseases. Litigation related to AIDS has touched all major social institutions in the USA: schools, health care, blood supply, judiciary, prisons and the military. It has also left strong impressions on the principles of privacy, freedom of speech and association, and liberty. AIDS has sparked litigation between sexual partners and family members.

**Education**

Conflict between public health and morals is more evident in the educational programmes in the schools. Federal funds could not be used to provide AIDS prevention materials as these 'promote or encourage' homosexual activities. Religious groups challenged mandatory AIDS education programme as a violation of its freedom of religion.

**Blood Supply**

The safety of the national blood supply was questioned as early as 1982. In March 1983, the US Centers for Disease Control had recommended self-deferral of donors who had engaged in high-risk behaviour. Most of the US states treat blood as a service rather than a product, thus avoiding strict liability. By adopting a standard of negligence rather than strict liability, courts support the integrity of the voluntary blood supply. Infected patients have brought claims for relief and some juries have awarded substantial damages.

**Reporting**

All the states require reporting of AIDS while more than half of the states also demand reporting of HIV-positive test results. Many states have adopted a system in which a person can be tested anonymously for HIV infection with no reporting requirement as reporting could discourage persons at higher risk of HIV to avoid testing.

**Testing and Screening**

HIV testing or screening has been challenged in variety of settings including the judiciary, correctional systems, health care, public health, insurance and employment. It has been challenged under theories like the informed consent, discrimination under the Americans with Disabilities Act, and the search and seizure under the Fourth Amendment of the US Constitution. Federal Courts have upheld screening in the Departments of State, Defence and in the Job Corps as well as for emergency service personnel such as the fire fighters and para medics.

Courts have permitted testing of doctors and nurses for HIV infection, particularly when they are involved in invasive, exposure-prone procedures. Some courts have found the testing, where there is no clear public health rationale, to be unlawful. In many states written informed consent of the patient is required for HIV testing.

## Criminal Law

Many prosecutions have been undertaken in the USA for risking transmission of HIV infection. They have been brought under the general criminal law for attempted murder, assault with dangerous or deadly weapon, or simple or aggravated assault.

There are also Federal Laws that require the states to test sex offenders for HIV infection once they are convicted for being eligible to get certain grants.

## Privacy and Confidentiality

Ethical reasons strongly support the need to protect the privacy of HIV infected persons. If the confidentiality of treatment is not ensured then patients keep away from HIV testing, counselling and treatment and no more trust their doctors. There is social stigma attached to HIV infection and disclosure of health information can cause great emotional, social and economic harm to the person concerned. There is also the embarrassment, social isolation, loss of employment, chances of employability, insurance or insurability or even housing. Though most of the states have laws protecting the confidentiality of HIV related information, there are rules permitting the disclosures in special circumstances to ambulance and emergency room workers, police, prison officials, health care workers, school officials etc. In the same manner media too has made inroads in passing on information on the HIV status to the public at large.

## The Right to Know

The HIV epidemic has created two conflicting and important legal and ethical obligations. The need to protect the privacy of the ones infected by HIV and the duty to inform persons who may be exposed to HIV are two compelling reasons working against each other. On the one side is the social stigma, isolation and discrimination of the HIV infected person if his privacy is not maintained while on the other hand the public has a right to know if their sexual or needle sharing partner/s are HIV positive. Doctors are faced with a dilemma: confidentiality towards patients and legal obligations to inform persons of the risk to HIV infection. Reconciliation between obligations of right to privacy and the right to know has to be worked out according to the situations. Where the risk of contracting HIV is remote, right to privacy should be absolute. The right to know would be stronger when there is a sexual or needle sharing partner. The ideal law should give power to the health care professionals to disclose the information when it is necessary to avert the risk of transmission.

## Discrimination

Discrimination on the ground of HIV infection is universally condemned in the USA. Such discrimination violates the tenets of individual justice and it is also against public health.

Discrimination based on an infectious condition is as inequitable as discrimination based on race, gender or disability. HIV-specific anti discrimination statutes are enacted in most of the States making it

unlawful to discriminate in jobs, public accommodations, housing etc. Another set of laws like the Rehabilitation Act, Fair Housing Act and Americans with Disabilities Act etc. prohibit discrimination against persons with disabilities.

The most important law so far prohibiting discrimination against HIV/ AIDS patients is the Americans with Disabilities Act of 1990. Disability includes diseases and infections which are communicable or otherwise. Persons with HIV are clearly covered by this Act. All Disability statues enforce reasonably good treatment of the HIV patients in the hospitals and work places. They also force the land lords or owners of public accommodation not to unfairly exclude them. The legislatures as well as the judiciary in the USA have responded reasonably well in the areas of confidentiality and anti discriminatory laws. But the government has many times succumbed to political pressures and have allowed morality to be more important than health.

**Check Your Progress II**

1) Can you name any four European countries that ihitiated HIV laws in 1980's ?

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2) What steps were taken by France to handle the HIV epidemic?

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3) Summarise the HIV related efforts in the USA in the sphears of discrimination.

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## 3.6 HIV LAW IN THE ASIA-PACIFIC REGION

Having gone through the legal measures adopted by countries in Europe as well as the United States of America, let us now turn to the Asia-Pacific Region. Several countries have made legal provisions to deal with issues arising out of HIV.

**Sri Lanka**

There are no HIV/AIDS specific laws in Sri Lanka. The three prevailing laws under which the epidemic can be dealt are:

Contagious Diseases Ordinances No.8 of 1966

Venereal Diseases Ordinance no.27 of 1938 and

Quarantine and Prevention of Diseases Ordinance No.3 of 1897.

The contagious Diseases Ordinance of 1966 requires every case of smallpox, cholera or other disease which may from time to time be named to be notified to a police officer or other officials. AIDS related issues may be covered under the clause 'other disease'.

Venereal Diseases Ordinance of 1938 permits only registered or authorised medical practitioners to treat venereal diseases.

The most important one in the context is the Quarantine and Prevention of Diseases Ordinance of 1897. It gives powers to the health authority in respect of identification and control of contagious diseases. Under this law the doctor is to report a case of HIV infection with all particulars of the patient. Segregation of the infected person is authorised. There is no provision for confidentiality of the information provided.

**Thailand**

Thailand has a disproportionate number of HIV/AIDS patients and it has great socio-economic, political and legal consequences. Poverty, discrimination, budgetary demands etc. indicate that HIV/AIDS is no more a medical disease but it is also a socio-economic and political

disease. From the angle of law, HIV/AIDS is equally a legal disease for Thailand. The National Plan for the Prevention and Control of AIDS (1992-96) established a more enlightened frame work for action on HIV/AIDS.

*Public Health*

The main law in this sector is the Infectious Diseases Act, 1980. Section 8 of this Act empowers the authorities to order infected persons to appear for examination, to detain them, and to order measures of protection. Under section 10 authorities may order the infected to leave their employment. Through decisions in 1985 and 86, AIDS was classified as one of 'the diseases requiring notification'. This legal obligation overrode the principle of confidentiality between patients and doctors. The measures adopted under the Act are draconian and in conflict with the international human rights standards advocating voluntariness and humane measures with safeguards against discrimination.

In 1990-91 there were strong lobbies for enacting more reactionary laws having stricter measures and punishments against those with HIV/AIDS. However due to heavy attacks from various quarters the proposed AIDS Bill was not passed and AIDS was also removed from the list of diseases requiring notification.

Thailand has had 22 coups since 1932 to 19991 and 15 constitutions during this period. The 1991 constitutuion also has a chapter on citizens rights, but they are not justiciable. These rights are also constrained by the notion of national security including public health.

There is no substantive law on privacy in Thailand Confidentiality on the part of medical personnel and other authorities in caring for those with HIV/AIDS is given under section 323 of the Criminal Code. It is as follows:

"Whoever discloses any private secret which became known or communicated to him by reason of his functions as a competent official or his profession as a medical practitioner shall be punished with imprisonment not exceeding six months for fine not exceeding one thousand baht, or both."

Civil action may also be taken under section 420 of the Civil Code which establishes tortious liability as follows:

A person who, wilfully or negligently, unlawfully injures the life, body, health, liberty, property or any right or another person, is said to commit a wrongful act and is bound to make compensation therefore.

In practice these provisions are not used against doctors and others who violate the rights of those with HIV/AIDS. The chief reasons are the general reticence to sue doctors, inaccessibility of the judicial system and fear of exposure of one's identity.

*Family and Law*

AIDS is a contributing factor towards family breakup. As the number of

infected persons go up, pressures are building up on the families. There is no law to provide subsidies to families. There is also no provision for social security to help the poor. However such facilities are advocated under the National Plan on AIDS.

*Prisons*

Untill recently prisoners were tested for HIV/AIDS with out their consent and segregated if they tested positive. But at least in theory this has changed now. Condoms are not generally available in prisons where unprotected sex is part of the enviornment. Needles and other impliments affiliated with drug injection are prohibited.

*Employment*

The National Plan for the Prevention of AIDS rejects compulsory testing for employment. But rejections of potential employees on the basis of HIV/AIDS and dismissals of actual employees due to the same are very common. Though there are a number of labour laws with implications for HIV/AIDS, the dismissed employees do not approach the courts due to the fear of exposure of their identity.

*Criminal Law*

According to the criminal code liability arises from intentional acts, but negligence may also give rise to liability. A key concern in Thailand is the suppression of drugs trade. The provisions of the Dangerous Drugs Act, 1979 can be used to detain those with HIV/AIDS where they are related to drug addiction. Two other important Acts in this regard are the Prostitution Suppression Act 1960 and Entertainment Places Act, 1966. Prostitution is illegal in Thailand, but it is rampant. There is also a thriving prostitution traffic and trade in the country which affect both men, women and children. Courts have powers to send prostitutes having HIV/AIDS to rehabilitation programmes. Prostitution is the most closely linked factor for the spread of AIDS in Thailand.

Thailand has a myriad of laws relevant to HIV/AIDS. Most of the times they are remedial rather than preventive. Some times they are reactive or reactionary. Poor law enforcement defeats all the good legal intentions.

**Malaysia**

The Ministry of Health has prepared a Plan of Action that provides guidelines for the surveillance, prevention and control of HIV/AIDS in the country. The main statute in this area is the Prevention of Infectious Diseases Act, 1988. HIV is the only disease included in Part 2 of the Schedule. Section 2 of the Act deals with surveillance while Section 3 provides for the confidentiality.

AIDS was first notified as an infectious disease in May 1985. Section 10 of the Act requres all those who come to know the existence of AIDS to notify the officer in charge. Doctors who treat AIDS patients are to notify the same. Persons running boarding houses are to inform if they come to know of any of the inmates infected with HIV. Failure to notify is an offence under section 10 (3) of the Act.

*Testing*

The normal practice in Malaysia is to obtain written consent from the patient or the next of kin for all tests/treatment administered. But in the case of patients suffering from TB, sexually transmitted diseases, patients with high risk behaviours like homosexuals, prostitutes, drug users etc, a written consent is not necessary. Compulsory testing with out consent of the patient in the above categories is authorised by section 14 of the 1988 Act. It also provides for removal to a quarantine and detention for the purpose of treatment. Persons in custody are being tested for identifying those HIV-infected. Prisoners, intravenous drug users in Rehabilitation Centers, sex workers in places of refuge etc are routinely screened. Under the Act compulsory treatment is prescribed, but due to the financial constraints medicines are not available or the patient have to purchase them.

The Women and Girls Protection Act 1973 criminalises the commercial sex sector. All employees of massage parlors are to undergo annual medical check up to help. This helps to identify HIV-infected persons. Since brothels are illegal, there is no provision for regular examination of the sex workers despite the undisputed fact that brothels exist and prostitution is a thriving trade. Doctors who treat HIV infected persons are to inform the sexual partners of their infection.

The Immigration Act 1959/63 prohibits persons suffering from contagious or infectious disease entry into the country. Tourists and visitors are not tested for HIV but those known to have the virus are refused entry. Migrant workers are subject to strict blood tests for HIV infection. There is no right to information in Malaysia and this may be used in a positive way to maintain confidentiality. The Penal Code has a section on obscenity laws. However materials having educational information on HIV/AIDS will not be prosecuted against.

In Malaysia there is the practice of requiring prospective employees to undergo medical examination. Employers do not want to be burdened with cost of treatment and this will apply to people with HIV infection. There is no law that directly prohibits discrimination in employment. Employers have the right to terminate the service of the employees with due notice. An employee may challenge his termination if it is solely on the ground of his HIV status.

*Women and HIV*

Women who are not economically independent may not insist on safe sex even when they fear their husbands may have contracted HIV or other sexually transmitted diseases as they need the support. As termination of pregnancy by a registered doctor is legalised, women with HIV can get abortions done if they so desire.

**Indonesia**

The first case of AIDS was recorded in 1987as foreign tourist died in Bali. Legal approach to AIDS is based on the Basic Constitution of 1945, Epidemic Law, Quarantine Law, the Health Law etc.

Surveillance and notification of AIDS is being done. Testing and counselling are implemented voluntarily. Confidentiality of the HIV status is guaranteed. Compulsory treatment is not applied. Preventive measures like quarantine is not allowed for HIV/AIDS cases. There exist no brothel laws as prostitution is illegal in Indonesia. Normally medical information is confidential unless asked for by patients or their families. There is no special law dealing with the right of people living with HIV/AIDS. Though there is no legal discrimination against HIV/AIDS patients, it exists for cultural and religious reasons. The duty to treat AIDS cases has been applied to all government hospitals. People living with HIV/AIDS have the same rights as other people in accommodation, employment, schools etc.

HIV/AIDS policy for prisons and institutions are the same as applied to the general public. Testing is done voluntarily. Segregation of HIV-infected prisoners is not permitted. Counselling, care and support is provided by various ministries. There is no special HIV/AIDS policy for work places and policies with regard to sick leave, disability support, occupational health safety etc are similar like other diseases.

**Singapore**

There are few laws, policies and regulations enacted specifically to deal with AIDS in Singapore. Amendment in Infectious Diseases Act 1985 is meant to deal with epidemic. The Act calls for notification, testing, isolation and quarantine as well as penal provisions. Under the Act, the penal provisions would deter the infected persons from coming forward to be identified.

Every blood donor is required to complete a statutory declaration before he donates blood about his practising safe sex. This declaration also perpetuates the myth that homosexuals are more disposed to AIDS. Every work permit holder is required to undergo HIV tests to get the permit renewed. The Singapore national employersí federation has declared HIV infection to be contracted outside the workplace and not their responsibility. Termination of an HIV infected employee is permissible if a number of other employees refuse to work with him.

Singapore's political culture based on Confucian ethics places community interests above all else. The tendency therefore is to curb the rights of the infected individuals and the politicians are accused of playing to popular ignorance.

**Check Your Progress III**

1) Comment briefly on the legal provision in Thailand with regard to HIV and employment.

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2) Summarise the Malaysian approach to HIV testing.

## 3.7 LET US SUM UP

After a thorough study of the unit you have a fairly clear picture as to how the international community is preparing to face the global epidemic. We have seen the differences in approach between the developed nations and some of the countries in the Asia Pacific. We also now know what more needs to be done to really face the crisis of this proportions affecting millions of people especially from the poor and from the socio-economically undevelop populations

## 3.8 KEY WORDS

**Laws of Neutrality** : The status of a state committed to a declared policy of non participation in a war between other states (international law).

**Mischief Rule** : Rule of interpretation to see the mischief sought to be cured by parliament.

**Municipal Law** : The law of a nation or state as distinguished from international law.

**Police** : A department of government responsible for the preservation of public order, detection of crime and enforcement of civil law.

## 3.9 MODEL ANSWERS

**Check Your Progress 1**

1) Define the HIV law.

"HIV related law can be defined as that branch of the law that specifically addresses the problems, issues and challenges posed by the HIV epidemic".

2) What do you understand by regulation of blood and blood products and screening?

The main concern under regulation of blood and blood products screening is to protect the supply of blood by requiring tests to be undertaken and to discourage AIDS/HIV patients as well as the high risk groups from donating blood. In the same manner restrictions are also placed on donating semen, tissues, organs etc.

3) Who are the people who are normally asked to under go HIV tests?

Certain categories of population including marriage applicants, pregnant women, new borns, hospital patients, mentally ill or retarded patients, prisoners, commercial sex workers, intravenous drug users sex offenders as well as foreigners visiting some countries are asked to undergo HIV tests.

**Check Your Progress II**

1) Name any four European countries that initiated HIV laws in 1980s

Austria, Norway, France and Belgium.

2) What steps were taken by France to face the HIV epidemic?

France had taken various steps to face HIV epidemic. Some of them are listed below:

— International coordination of AIDS control was addressed in a May 1994 Decree.

— Measures to avert any risk of HIV-1 & 2 infection, designed to prevent the transmission of infectious diseases in the use of human organs, tissues and cells, are included in a decree of 1992/94.

— Establishment of an experimental programme for therapeutic accommodation for AIDS patients through a Circular in 1994.

— Another Circular of 1994 states AIDS control to be an essential requirement of public health, with absolute priority given to prevention.

— A whole series of legislative texts have addressed the issue of transfusion safety, including the institutional, organisational and administrative aspects.

3) Summarise the HIV related efforts in the USA in the spheare of discrimination?

Discrimination on the ground of HIV infection is universally condemned in the USA. HIV-specific anti discrimination statutes are enacted in most of the States making it unlawful to discriminate in jobs, public accommodations, housing etc. Another set of laws like the Rehabilitation Act, Fair Housing Act and Americans with Disabilities Act etc. prohibit discrimination against persons with disabilities. The most important law so far prohibiting discrimination against HIV/AIDS patients is the Americans with Disabilities Act of 1990. Persons with HIV are clearly

covered by this Act. The legislatures as well as the judiciary in the USA have responded reasonably well in the areas of confidentiality and anti discriminatory laws.

**Check Your Progress III**

1) Comment briefly on the legal provision in Thailand with regard to HIV and employment.

The National Plan for the Prevention of AIDS in Thailand rejects compulsory testing for employment. But rejections of potential employees on the basis of HIV/AIDS and dismissals of actual employees due to the same are very common.

2) Summarise the Malaysian approach to HIV testing.

The normal practice in Malaysia is to obtain written consent from the patient or the next of kin for all tests/treatment administered. But in the case of patients suffering from TB, sexually transmitted diseases, patients with high risk behaviours like homosexuals, prostitutes, drug users etc, a written consent is not necessary. Persons in custody are being tested for identifying those HIV-infected. Prisoners, intravenous drug users in rehabilitation centers, sex workers in places of refuge etc. are routinely screened.

## 3.10 FURTHER READINGS

UNDP (1993). Law, Ethics and HIV. Proceedings of the UNDP Inter Country Consultation, CEBU, Philippins.

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(The unit has borrowed heavily from the above books for the material and quotes directly from them).