



Indira Gandhi National Open University  
School of Social Work

**MSWE-001**  
**HIV/AIDS: STIGMA,**  
**DISCRIMINATION AND**  
**PREVENTION**

**HIV and AIDS: Nature and Epidemiology**

**1**



**MSWE-001**  
**HIV/AIDS: Stigma,**  
**Discrimination and**  
**Prevention**

Block

# 1

## **HIV AND AIDS: NATURE AND EPIDEMIOLOGY**

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## **COURSE INTRODUCTION**

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The course MSWE-001 on “HIV/AIDS”: Stigma, Discrimination and Prevention” is a special course having four blocks. HIV infected and the affected face discrimination from across the board. Even after two decades of living with HIV, there is widespread discrimination in most societies. This course will explain various aspects of stigma and discrimination in the context of HIV apart from describing other issues associated with HIV/AIDS.

The first block on “HIV and AIDS: Nature and Epidemiology” has 5 units which will discuss about various theories on the origin of HIV/AIDS, modes of transmission, its impact on the family and community, the factors related to the spread of the disease and types of testing and issues related to treatment.

The second block on “HIV and AIDS in Special Populations” deals with the types of preventive measures undertaken to control the spread of HIV infection, HIV/AIDS among women and children, workers of organized and unorganized sector, and the partnership of NGOs and the corporate sector in HIV/AIDS prevention.

The third block on “Interventions” discusses about the behavioural aspects in the context of prevention of HIV/AIDS, counselling in the content of youth and children, injecting drug users, sex workers etc. It also elaborates the legal aspect of HIV/AIDS to some extent.

Block four deals with Stigma and Discrimination in the context of HIV/AIDS. It also elaborates on personal and social response to the disease and what role a social worker can play in addressing the issue of stigma and discrimination in relation to HIV/AIDS.

Thus, this course will equip you with the required knowledge and information about various aspects of HIV/AIDS and particularly on stigma and discrimination.

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## **BLOCK INTRODUCTION**

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This block on “HIV and AIDS: Nature and Epidemiology” is the first block of the course on MSWE-001- HIV/AIDS: Stigma Discrimination and Prevention. This block has five units.

The first unit: “AIDS: Nature and Demography” will give you a brief history and the various theories on the origin of HIV/AIDS. You will also learn about the stages of infection of HIV/AIDS, its modes of transmission and the process of testing and diagnosis.

The second unit: “Social and Economic Implications” elaborates on the impact of HIV/AIDS at different settings: family, community and at macro level. It talks about how HIV/AIDS causes irreversible damage to the human capital.

The third unit: “Socio-Cultural Content of HIV/AIDS” talks about the factors that are related to the spread of HIV/AIDS. It deals with gender issues, socio-economic and socio-cultural factors.

The fourth unit: “Testing of HIV/AIDS” describes about HIV testing, various types of HIV testing and the guidelines to be followed while testing for HIV.

In the fifth unit: “Treatment and Care, Vaccine Issues” you will learn about the treatment of HIV/AIDS. You will have an understanding about the comprehensive treatment and care as well as the issues concerning AIDS vaccine.

Thus, after going through this block you will have a basic understanding of some issues related to HIV/AIDS.

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# UNIT 1 AIDS, NATURE AND DEMOGRAPHY

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## 1.0 OBJECTIVES

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AIDS is an epidemic of global proportions and hence a concern of the entire world. As an epidemic, AIDS affects not just the individual suffering from the disease, but the entire family, the community and the country. Prevention of the transmission of HIV, which causes AIDS, is the most important strategy to reduce the impact of the epidemic. Knowledge about HIV and AIDS, and how HIV is transmitted is very important in preventing the spread of the epidemic. Still more important is the challenge in helping those affected by HIV and AIDS to live positively and to care for themselves.

On completing this unit, you will be able to understand:

the nature of HIV/AIDS in terms of the stages of infection, the mode of transmission, the process of testing and diagnosis;

the history and controversial theories on the origin of HIV/AIDS;

the prevalence and incidence of HIV/AIDS in a specific population.

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## 1.1 INTRODUCTION

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Acquired Immunodeficiency Syndrome (AIDS) emerged as the most dreaded disease of the century. This is dreaded not because of the fact that death is certain, but it is also due to the stigma and social ostracism that is attached to its very name. AIDS continues to be a major concern of research, which requires broad ranging structural analysis of the overall health care sector as well as the social, political and economical forces that influence its shape and content both in the western world and in the developing countries. AIDS is just the tip of an iceberg of a host of social problems ranging from poverty, accessibility to adequate health care, disenfranchisement and discrimination. The time has come not just to say “no” to unwanted sex or unprotected sex or unwanted conception, it is time to say no to inequity, to discrimination and lack of choice.

Human Immunodeficiency Virus (HIV), a lentivirus that belongs to the retrovirus group, is said to cause HIV /AIDS. Acquired Immunodeficiency Syndrome (AIDS) has emerged as one of the most serious public health problems in the country after first being reported in 1986. The initial cases of HIV/AIDS were reported among commercial sex workers in Mumbai and Chennai and injectable drug users in the northeastern states of Manipur. The disease is spread rapidly in the areas adjoining these epicenters. Currently Andhra Pradesh, Tamil Nadu, Maharashtra, and Manipur put together account for two-third of the total AIDS cases in the country.

Today, 34.3 million adults and children worldwide are estimated to be living with HIV. The pandemic is most severe in sub-Saharan Africa, which has 24.5 million people infected with HIV-1, accounting for almost 9% of the total population in the 15 to 49 years age group. The latest UNAIDS and WHO estimates shows that there are 38.6 million people with HIV, 63.2% are in sub Saharan Africa, 21.4% are in Asia, 5.2% in Latin America, 4.1% in North America/Europe, 3.9% in Eastern Europe/Central Asia, and 2.2% in other parts of the world. Conservative estimates way back in 1998 show that eleven men, women and children were being infected per minute. More than 95% of all HIV infected people are now living in the developing world.

In this unit you will be basically introduced to the nature of HIV and AIDS, its history and origin, the epidemiology and demography of HIV/AIDS. We will also discuss how the understanding of the profile of the disease is important for social workers' further intervention in preventing and controlling the spread of the epidemic.

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## **1.2 NATURE OF HIV/AIDS**

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People have been warned to be conscious about HIV and AIDS for over twenty years now. AIDS has already killed millions of people, millions more continue to become infected with HIV, and there is still no cure. So AIDS will be around for a while yet. AIDS is one of the biggest problems facing the world today and nobody is beyond its reach. Everyone should know the basic facts about AIDS.

### **Understanding HIV/AIDS**

The disease AIDS was first detected in 1981. AIDS (Acquired Immuno Deficiency Syndrome) is a medical condition. People develop AIDS because HIV has damaged their natural defenses against diseases. It is caused by a virus which was isolated and identified in 1983 as the Human Immunodeficiency Virus (HIV). HIV is a virus belonging to a family of viruses called retroviruses (known to mutate randomly) and lentiviruses (long acting i.e., once they enter the human body, the individual is infected for life and can transmit the virus to other). HIV can be passed from one person to another. Anyone can become infected with HIV through contact with the bodily fluids of someone who has already contracted HIV. HIV stands for the 'Human Immunodeficiency Virus'. Someone who is diagnosed as infected with HIV is said to be 'HIV+' or 'HIV positive'. HIV has a number of tricks that helps it to evade the body's defences, including very rapid mutation. This means that once HIV has been contracted, the immune system can never fully get rid of it.

There isn't any way to tell just by looking if someone's been infected by HIV. In fact a person infected with HIV may look and feel perfectly well for many years and may not know that they are infected. But as the person's immune system weakens they become increasingly vulnerable to opportunistic illnesses, many of which they would have fought off easily in the past. The only reliable way to tell whether someone has

HIV is for them to take a blood test which can detect infection from a few weeks after the virus first entered the body.

A damaged immune system is not only more vulnerable to HIV, but also to the attacks of other infections. It would not always have the strength to fight off things that would not have bothered it before. As time goes by, a person who has been infected with HIV is likely to become more and more ill often until, usually several years after infection, they become ill with one of a number of particularly severe illnesses. It is at this point in the stages of HIV infection that they are said to have AIDS indicative of the number of immune system cells left in their body dropping below a particular point. AIDS is an extremely serious condition, and at this stage the body has very little defence against any sort of infection.

AIDS can only be acquired through the contact of body fluids from an infected person to uninfected person. HIV enters the human body and attacks the immune system; mainly infected certain cells called CD4 cells (or T4 cells). HIV is found in the blood and the sexual fluids of an infected person, and in the breast milk of an infected woman. HIV transmission occurs when a sufficient quantity of these fluids get into someone else's bloodstream. There are various ways a person can become infected with HIV.

### **Stages of Infection**

When a person is infected with HIV, it usually takes about 3 to 6 months for the antibodies to show in a blood test. This period is commonly referred to as the 'window period'. When a blood test detects the presence of antibodies, the person tested is referred as 'sero-positive' or 'anti-body positive'. During this 'window period' an infected person can unknowingly infect others. The progress of HIV infection varies and should not be viewed as a definitive cycle of events. However, it is possible to identify the key elements of the clinical stages of HIV infection. They can be broadly classified into three categories.

#### **1. Initial Symptoms of HIV Infection**

In the early stages of HIV infection (within weeks), the person may develop a flu like illness, similar to glandular fever with symptoms of body ache, rash and swollen lymph glands. The person appears to get well after a few days. By this time the person may be considered a carrier capable of readily passing on the virus to another person. However, not all infected people (carriers) develop this kind of initial illness.

#### **2. Asymptomatic HIV Infection Latent Period**

As with some other illnesses, this is a period in which the person who is living with HIV shows no apparent symptoms. This period, called the latency period, may range from several months to several years and differ from individual to individual. The person with HIV may look and feel healthy, and remains so for many years. But, the person can pass on the virus to another person even while he or she looks healthy.

#### **3. Symptomatic HIV Infection**

People with HIV begin to feel sick with minor illnesses such as rashes, infections of the mouth such as oral thrush, loss of weight (about 10% of the body weight), persistent fever, night sweats, loss of energy and extreme tiredness, easy bruising and bleeding and prolonged diarrhea. This period of symptomatic illness is sometimes



referred to as ‘AIDS Related Complex’ (ARC) or as the period of active HIV infection.

### **Transmission of HIV**

HIV is transmitted only when contaminated blood and body fluids come in contact with the blood and mucous membranes of healthy individuals. Semen and vaginal secretions, in particular, contain substantial concentrations of HIV. Though sweat, tears and saliva, are also body fluids, they contain very low concentrations of the virus and hence do not present a risk of transmission of HIV.

Ways in which one can be infected with HIV:

#### Unprotected sexual intercourse with an infected person

Sexual intercourse without a condom is risky, because the virus, which is present in an infected person’s sexual fluids, can pass directly into the body of their partner. This is true for unprotected vaginal and anal sex. Oral sex carries a lower risk, but again HIV transmission can occur here if a condom is not used - for example, if one partner has bleeding gums or an open cut, however small, in their mouth.

#### Contact with an infected person’s blood

If sufficient blood from an infected person enters a healthy person’s body, then it can pass on the virus.

#### Mother to Child transmission

From mother to child HIV can be transmitted from an infected woman to her baby during pregnancy (HIV can cross placenta and infect the foetus), delivery (contact with the mother’s infected blood) and breastfeeding (breast milk being fluid contain a certain concentration of the virus). There are special drugs that can greatly reduce the chances of this happening, but they are unavailable and cannot be afforded in much of the developing world.

#### Use of infected blood products

If blood or blood product is contaminated, HIV can be transmitted during transfusion of blood or blood products. Therefore, blood from all donors should be screened. Similar precautionary screening should be done in case of organ or tissue transplants. Many people in the past have been infected with HIV by the use of blood transfusions and blood products which were contaminated with the virus in hospitals, for example. In much of the world this is no longer a significant risk, as blood donations are routinely tested.

#### Injecting drugs

People who use injected drugs are also vulnerable to HIV infection. In many parts of the world, often because it is illegal to possess them, injecting equipment or works are shared. A tiny amount of blood can transmit HIV, and can be injected directly into the bloodstream along with the drugs.

It is not possible to become infected with HIV through:

Sharing crockery and cutlery

Insect / animal bites

Touching, hugging or shaking hands

Eating food prepared by someone with HIV

Toilet seats

## Test for HIV

The body defends itself against each new viral infection by manufacturing proteins called ‘antibodies’. The presence of these antibodies is a positive indicator of infection. It is similar to HIV. However, after a person is infected with HIV, it can take up to 3 months for the antibodies to develop and detected. A person should be tested only after window period. To detect HIV antibodies in the blood, a number of different tests have been developed. Two of the most widely used tests are ELISA (Enzyme Linked Immuno Sorbent Assay) and the Western Blot Kit Test. However, a new method of detecting and identifying the virus in the blood called polymerase chain reaction (PCR), has been developed.

## HIV facts and myths

Around the world, there are a number of different myths about HIV and AIDS. Here are some of the more common ones:

*‘You would have to drink a bucket of infected saliva to become infected yourself’* . . . Yuck! This is a typical myth. HIV is found in saliva, but in quantities too small to infect someone. If you drink a bucket of saliva from an HIV positive person, you won’t become infected. There has been only one recorded case of HIV transmission via kissing, out of all the many millions of kisses. In this case, both partners had extremely badly bleeding gums.

*‘Sex with a virgin can cure HIV’* . . . This myth common in some parts of Africa is baseless and totally untrue. The myth has resulted in the rape of many young girls and children by HIV+ men, who often infect their victims. Rape would not cure anything and is a serious crime.

*‘It only happens to gay men / black people / young people, etc’* . . . This myth is false. Most people who become infected with HIV did not think it would ever happen to them. They were proven wrong.

*‘HIV can pass through latex’* . . . Some people have been spreading rumours that the virus is so small that it can pass through ‘holes’ in latex used to make condoms. This is untrue. The fact is that latex blocks HIV, as well as sperm, preventing pregnancy too.

### Check your progress I

**Note:** a) Write your answers in the space provided.

b) Check your answer with the model answers at the end of this unit.

1) What are the ways in which you can be infected with HIV/AIDS?

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## 1.3 HISTORY AND ORIGIN OF HIV/AIDS

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### The origin of AIDS and HIV and the first cases of AIDS

The origin of AIDS and HIV has puzzled scientists ever since the illness first came to light in the early 1980s. For over twenty years it has been the subject of fierce debate and the cause of countless arguments, with everything from a promiscuous flight attendant to a suspect vaccine programme being blamed. So what is the truth? Just where did AIDS come from?

Listed below are four of the earliest recorded instances of suspected HIV infection:

A plasma sample taken in 1959 from an adult male living in what is now the Democratic Republic of the Congo.

A lymph node sample taken in 1960 from an adult female, also from the Democratic Republic of the Congo.

HIV found in tissue samples obtained from an American teenager who died in St. Louis in 1969.

HIV found in tissue samples from a Norwegian sailor who died around 1976.

The first recognised cases of AIDS occurred in the USA in the early 1980s. A number of gay men in New York and California suddenly began to develop rare opportunistic infections and cancers that seemed stubbornly resistant to any treatment. At this time, AIDS did not yet have a name, but it quickly became obvious that all the men were suffering from a common syndrome.

The discovery of HIV, the Human Immunodeficiency Virus, followed soon. While some were initially resistant to acknowledge the connection (and indeed some remain so today), there is now clear evidence to prove that HIV causes AIDS. However we have a research study led by Paul Sharp of Nottingham University and Beatrice Hahn of the University of Alabama, which made the discovery during the course of a 10-year long study into the origins of the virus. They claimed that this sample proved that chimpanzees were the source of HIV-1, and that the virus had at some point crossed species from chimpanzees to humans. They concluded that wild chimps had been infected simultaneously with two different simian immunodeficiency viruses which had “viral sex” to form a third virus that could be passed on to other chimps and, more significantly, was capable of infecting humans and causing AIDS. These two different viruses were traced back to a SIV that infected red-capped mangabeys and one found in greater spot-nosed monkeys. They believe that the hybridization took place inside chimps that had become infected with both strains of SIV after they hunted and killed the two smaller species of monkey.

It has been known for a long time that certain viruses can pass between species. Indeed, the very fact that chimpanzees obtained SIV from two other species of primate shows just how easily this crossover can occur. Being animals ourselves, we are just as susceptible. When a viral transfer between animals and humans takes place, it is known as zoonosis.

Below are some of the most common theories about how this ‘zoonosis’ took place, and how SIV became HIV in humans:

## Controversial theory on the origin of HIV/AIDS

### *The 'Hunter' Theory*

The most commonly accepted theory is that of the 'hunter'. In this scenario, SIVcpz was transferred to humans as a result of chimps being killed and eaten or their blood getting into cuts or wounds on the hunter. Normally the hunter's body would have fought off SIV, but on a few occasions it adapted itself within its new human host and become HIV-1. The fact that there were several different early strains of HIV, each with a slightly different genetic make-up (the most common of which was HIV-1 group M), would support this theory: every time it passed from a chimpanzee to a man, it would have developed in a slightly different way within his body, and thus produced a slightly different strain.

### **The Oral Polio Vaccine (OPV) Theory**

Could production of the oral polio vaccine have contributed to the spread of HIV? Some other rather controversial theories have contended that HIV was transferred iatrogenically (i.e. via medical interventions). One particularly well-publicized idea is that polio vaccines played a role in the transfer.

In his book, "The River", the journalist Edward Hooper suggests that HIV can be traced to the testing of an oral polio vaccine called Chat, given to about a million people in the Belgian Congo, Ruanda and Urundi in the late 1950s. To be reproduced, live polio vaccine needs to be cultivated in living tissue, and Hooper's belief is that Chat was grown in kidney cells taken from local chimps infected with SIVcmz. This, he claims, would have resulted in the contamination of the vaccine with chimp SIV, and a large number of people subsequently becoming infected with HIV-1. The fact that the OPV theory accounts for just one (group M) of several different groups of HIV also suggests that transfers must have happened in other ways too. This indicates the fact that HIV seems to have existed in humans much much before the vaccine trials were ever carried out.

### **The Contaminated Needle Theory**

This is perhaps an extension of the original 'Hunter' theory. In the 1950s, the use of disposable plastic syringes became commonplace around the world as a cheap, sterile way to administer medicines. However, to the African healthcare professionals working on inoculation and other medical programmes, the huge quantities of syringes needed would have been very costly. It is therefore likely that one single syringe would have been used to inject multiple patients without any sterilization in between. This would rapidly have transferred any viral particles existing (within a hunter's blood for example), from one person to another, creating huge potential for the virus to mutate and replicate in each new individual it entered, even if the SIV within the original person infected had not yet converted to HIV.

### **The Colonialism Theory**

The colonialism or 'Heart of Darkness' theory is one of the more recent theories to have entered into the debate. It is again based on the basic 'hunter' premise, but more thoroughly explains how this original infection could have led to an epidemic. During the late 19th and early 20th century, much of Africa was ruled by colonial forces. In areas such as French Equatorial Africa and the Belgian Congo, colonial rule was particularly harsh and many Africans were forced into labour camps where sanitation was poor, food was scarce and physical demands were extreme. These

factors alone would have been sufficient to create poor health in anyone, so SIV could easily have infiltrated the labour force and taken advantage of their weakened immune systems to evolved into HIV. A stray and perhaps sick chimpanzee with SIV might have made a welcome extra source of food for the workers.

### **The Conspiracy Theory**

Some say that HIV is a ‘conspiracy theory’ or that it is ‘man-made’. A recent survey carried out in the US for example, identified a significant number of African Americans who believe HIV was manufactured as part of a biological warfare programme, designed to wipe out large numbers of black and homosexual people. Many believe that this was done under the auspices of the US Federal ‘Special Cancer Virus Program’ (SCVP), possibly assisted by the CIA. Linked in to this theory is the belief that the virus was spread (either deliberately or inadvertently) to thousands of people all over the world through the smallpox inoculation programme, or to gay men through Hepatitis B vaccine trials. While none of these theories can be definitively disproved, the evidence given to back them up is usually based upon speculation. Moreover, it ignores the clear link between SIV and HIV or the fact that the virus has been identified in people as far back as 1959.

### **The Pattern of the Spread of HIV Infection: Global Scenario**

There are said to be a number of factors that may have contributed to the sudden spread of HIV, most of which occurred in the latter half of the twentieth century. They are listed as follows:

#### **Travel**

International travel has undoubtedly played a major role in the spread of HIV.

Both national and international travel undoubtedly had a major role in the initial spread of HIV. In the US, international travel by young men making the most of the gay sexual revolution of the late 70s and early 80s, would certainly have played a large part in taking the virus worldwide. In India, the virus are supposedly spread along truck routes and between towns and cities within the country itself. Similarly, war bases of the US Army in Phillipines and Taiwan, where soldiers decamped, later evolved into brothels, hinting of a similar route of spread. We also witness an inadvertent growth of sex related tourism in destinations such as Goa, Thailand and Kovalam. Thus, the process of transmission in a global pandemic is simply too complex to blame on any one group or individual.

#### **The Blood Industry**

As blood transfusions became a routine part of medical practice, an industry to meet this increased demand for blood began to develop rapidly. In some countries such as the USA, donors were paid to give blood, a policy that often attracted those most desperate for cash; among them intravenous drug users (IDUs). During the early stages of the epidemic, doctors were unaware of how easily HIV could be spread and blood donations remained mostly unscreened. This blood was then sent worldwide, and unfortunately most people who received infected donations went on to become HIV positive themselves.

#### **Drug Use**

The 1970s witnessed an increase in the availability of heroin. It was the respective wars especially the Vietnam War, the civil war in the African subcontinent and later

the other conflicts in the Middle East that stimulated a growth in intravenous drug use. This increased availability together with the development of disposable plastic syringes and the establishment of ‘shooting galleries’, where people could buy drugs and rent allied equipment, provided another route through which the virus could be passed on.

**Urbanisation, Migration and Alienation**

The rapid industrialization forced large populations to migrate from the rural to urban area and settlement in slums bordering the cities and industries. Moving away from primary groups into secondary groups has lead to alienation. Such moving away from the family, the absence of social control (community mores) and the inability to gain sexual gratification rendered individuals vulnerable to prostitution. Thus, brothels close to these squalors owing to the unprotected and indiscriminate sex too fuelled the epidemic.

**Check Your Progress II**

**Note:** a) Write your answers in the space provided.

b) Check your answer with the model answers at the end of this unit.

1) What are the different theories on the origin of HIV/AIDS?

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**1.4 EPIDEMIOLOGY**

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**Definition of AIDS case**

WHO and National AIDS Control Organization (NACO) have given the definition of AIDS on the basic certain criteria which are given below:

**Clinical AIDS in an adult**

Positive test for HIV antibody detected by two separate tests using two different antigens and any one of the following criteria:

1. a. Weight loss of greater than 10% of body weight or cachexia.  
 b. Chronic diarrhoea of more than 1 month duration, chronic coughs for more than 1 month duration.
2. Disseminated, military or extra – pulmonary tuberculosis.
3. Neurological impairment that restricts daily activities.
4. Candidiasis of the esophagus diagnosable, Dysphagia with oral candidiasis.
5. Kaposi’s sarcoma.

**Clinical stage progression**

Stage I : HIV infection - asymptomatic/acute primary infection (sero conversion)

Stage II : Early (asymptomatic) disease (CD4 count >500/mm<sup>3</sup>)

Stage III : Intermediate HIV infection (CD4 200-500/mm<sup>3</sup>)

Stage IV : Late stage HIV disease (CD4 50-200/mm<sup>3</sup>)

Stage V : Advanced HIV Disease (CD4<50/mm<sup>3</sup>)

### **Clinical case definition for AIDS in Children**

At least two major signs associated with at least two minor signs in the absence of known cases of immuno-suppression.

#### **Major Signs**

- a. Weight loss or abnormal slow growth
- b.
  1. Failure to thrive;
  2. Recurrent/persistent diarrhoea of over one month duration;
  3. Recurrent bacterial infections, e.g., lower respiratory infection.
  4. Recurrent fever of over one month duration
- c.
  1. Candidiasis
  2. Tuberculosis
  3. Herpes Zoster

#### **Minor Signs**

- a. Generalized lymphadenopathy
- b. Oropharyngeal candidiasis
- c. Repeated common infection
- d. Persistent cough for over a month
- e. Generalized dermatitis
- f. Confirmed maternal HIV infection.

#### **Risk of Transmission**

Transmission dynamics reveal how HIV-1 spread in a population. Such an understanding helps in designing control program. The basic reproductive rate  $RO$ , is the average number of infectious contacts by one infected individual. An infectious contact is a person who would transmit the infection if his/her partner is non-infected. For an epidemic to occur, each infected individual must on an average make infectious contacts with more than one individual ( $RO$  must exceed 1).  $RO = B(C+D)$ , where  $C$  is rate of partner change, and  $D$  is the infectiousness. This equation is affected by individual, social and psychological factors (partner selection, sexual and social network), family dynamics (type of family, economic conditions, etc.), community factors (type of neighbourhood, social capital, health services, etc.), and national and international factors (war, development and health policies)

The problem of injectable drug use through needles has emerged as a serious problem firstly in Manipur and other North Eastern States and also in metropolitan cities such as Mumbai, Chennai, Kolkata and Delhi. The problem of HIV/AIDS has added a new dimension as sharing of injection equipment for narcotic drug use is one of the most efficient routes of HIV transmission and is considered to be much more risky than unprotected sexual contact. While most of the Injecting Drug Users (IDUs) are male, their female partners are not known to be in the habit of injecting drug use. The latter therefore suffer from the risk of sexual transmission from HIV-infected

IDUs without their knowledge. It has also been noticed that majority of the IDUs are youth in their most productive age group of 15 – 25 years. Government therefore considers it as a serious issue and is committed to adopt appropriate strategies for preventing the risk of transmission through injecting drug use.

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## 1.5 DEMOGRAPHY AND PREVALENCE OF HIV/AIDS

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### Burden of HIV/AIDS

India has experienced a sharp increase in the estimated number of HIV infections, from a few thousand in the early 1990s to steeply increasing 3.5 million in 1998. 3.86 million in 2000, 4.58 million in 2002 and 5.21 million in 2004. In 2005, it was reported that there were 5.7 million people infected with HIV in India. With a population of over one billion, the HIV epidemic in India will have a major impact on the overall spread of HIV in Asia and Pacific and indeed worldwide.

Globally India has the second largest population in the world as far as numbers of HIV positive cases (2.5 million) are concerned. South Africa (5.4 million) ranks first. Controversy prevails regarding the absolute number of HIV cases in India. The UNAID in 2006 emphasized that India is having approximately 3.7 million HIV cases instead of 5.7 million. Recently, the Indian Government corrected the numbers and stated that it was 2.5 million and that estimates were calculated wrongly previously (NACO 2007).

The following are the estimates of the AIDS epidemic in the country:

The UN Population Division projects that India's adult HIV prevalence will peak to 1.9% in 2019. There were 2.7 million AIDS deaths in India between 1980 and 2000 as per UN estimates. As per projections, 12.3 million AIDS death will occur during 2000-2015, while 49.5 million deaths are expected to occur during 2015 – 50 (UN 2003). NACO reported 1,11,608 AIDS cases in July 2005.

India is experiencing multiple epidemics. More than 100 districts have sentinel sites reporting sero prevalence of more than 1% among women visiting ante-natal clinics. The epidemic is slowly moving beyond its initial focus among sex workers. Sub epidemics are evolving with potentially explosive spread among groups of injectable drug users (IDUs) and among Men having Sex with Men (MSM). It is now seen in all age group and sexual route is the major cause of transmission. The number of women are far on the increase.

About 89% of the reported cases are occurring in sexually active and economically productive age group of 15 – 44 years.

Recent research shows that many men are bisexual, i.e. they have sex with men as well as with women. In 2002, behavioural surveillance in five cities among men who have sex with men found that 27% were reportedly married, or living with a female sexual partner. In a study conducted in a low income group of Chennai in 2001, 7% men who have sex with men were HIV positive. 76% of the Indian population had heard of HIV/AIDS; the figure was 93% for urban males and 65.2% for rural women. In Bihar, only 21.5% of the adult population and in UP only 27.6% had ever heard of HIV/AIDS. While 71% of Indians were aware of the sexual route of HIV transmission, only 18.6% of rural women had heard of the linkage. Attention and research currently focuses on areas with high recorded prevalence, but there is concern about what might be



happening in the vast areas of rural India, for which especially there is little data.

The annual sentinel surveillance surveys have divided States and Union territories in India into four broad categories:

**High prevalence:** Maharashtra, Tamil Nadu, Manipur, Andhra Pradesh, Karnataka and Nagaland States which have HIV prevalence rates exceeding 5% among groups with high-risk behaviour and 1% among women attending antenatal clinics in public hospitals.

**Moderate epidemics:** Gujarat, Pondicherry and Goa, where HIV prevalence rates among population with high risk behaviour has been found to be 5% or more, while HIV prevalence remains below 1% among women attending antenatal clinics.

**Low prevalence:**

*High vulnerable states:* these states are where migration was rampant, and where weak health infrastructure existed. HIV prevalence rates among vulnerable population are below 5 percent and less than 1 percent among women attending antenatal clinics.

*Vulnerable states:* All other states and Union Territories fall into the low prevalence category.

### **The HIV/AIDS situation in Different States**

Andhra Pradesh has one of the fastest advancing HIV/AIDS prevalence rates in India. In 2002, the ANC prevalence rate was 1.25% and NACO has estimated that more than 400,000 people are living with HIV in Andhra Pradesh, the second highest number after Maharashtra State. This is 10% of the total HIV cases in India and ninety percent of the infections in the state occur through sexual transmission.

HIV infection has increased noticeably in Goa in the past couple of years. The ANC prevalence rate increased from 0.5% in 2001 to 1.38% in 2002. This could be due to tourism.

In Karnataka the mean prevalence among ANCs was 1.13 % in 2001 and 1.75% in 2002. In 2001 there were four districts with an ANC prevalence of 2 percent or more, and these are located in the southern part of the state, in and around Bangalore, bordering with Tamil Nadu, or northern Karnataka's "*Devadasi* belt". *Devadasi* women are a group of women, who historically, have been dedicated to the service of gods. Over the years, this evolved into sanctioned prostitution – as a result many women from this part of the country are supplied to the sex trade in big cities such as Mumbai.

The geographical proximity of Manipur to Burma, and therefore to the Golden Triangle, has made it a major transit route for drug smuggling owing to its availability. However, the transmission route to the state is no longer confined to injecting drug users. It has spread further to the female sexual partners of IDUs and their children. The prevalence of HIV/AIDS in ANC cases in Manipur was 1.12% in 2002 and among injectable drug users at three surveillance sites, the HIV prevalence was extremely high - 39.06%. Similarly high prevalence of HIV among drug users was recorded in Mizoram (70%), Nagaland (10.28%) and Tamil Nadu (33.8%).

## Affected Population

The majority of the reported AIDS cases occurred in the sexually active and economically productive 15 - 49 year age group. Although HIV/AIDS is still largely concentrated in at risk populations, including commercial sex workers, injecting drug users, and truck drivers, the surveillance data suggests that the epidemic no longer confined, but is moving beyond these groups in some regions and into the general population through bridging population. It is also moving from urban to rural districts.

The epidemic continues to shift towards women and young people. It has been estimated that 38% of adults living with HIV/AIDS in India at the end of 2003 were women. In 2004, it was estimated that 22% of HIV cases in India were house wives with a single partner. The increasing HIV prevalence among women can consequently be seen in the form of increased mother to child transmission of HIV and paediatric HIV cases.

**Sex workers:** Mumbai, the country's largest brothel based sex industry, with over 15,000 sex workers poses a major challenge for HIV prevention. A study in Surat found that HIV prevalence among sex workers had increased from 17% in 1992 to 43% in 2000.

**Injecting Drug Users (IDUs):** HIV infections among Injecting Drug Users (IDUs) first appeared in Manipur. Here, in the city, the level of HIV infection was 61% in 1994 and increased to 85% in 1997. In 1998, it stabilized around 80.7%. Injectable drug use is also a major problem in urban areas such as Mumbai, Kolkata, Delhi and Chennai. Recent survey data indicate that most IDUs had at some stage shared their needle and syringe. A majority of drug users are male. However, females are also involved and presented more HIV positives as compared to non – drug addicts females. There is increased number of widows of addicts, many of them are HIV positives.

**Migrants:** According to the 1993, National Sample Survey in India, 24.7% of the population had migrated, either within India, to neighboring countries or overseas. Applying this percentage to the mid – 2003 population about 264 million Indians are mobile. Being mobile in itself, does not present a risk factor for HIV transmission. The migrants often live in unhygienic conditions in urban slums. Long working hours, relative isolation from the family, and geographical mobility may foster casual sexual relationships that make them highly vulnerable to STDs and HIV/AIDS. Migrant workers tend to have little access to HIV/STD information, voluntary counselling and testing, and health services. Regionalism, as well as cultural and language barriers cuts their access to such services. Returning or visiting migrants, many of who do not know their status, may infect their wives or other sexual partners in their home community.

**Truck Drivers:** India has one of the largest road networks in the world and an estimated 2 to 5 million long distance truck drivers and helpers are part of this network. The extended period of time that they spend away from their families placed them in close proximity to “high risk” sexual networks, and often results in their increased number of sexual contacts. During their journeys the driver often stop at ‘dhabas’, roadside hotels that usually provide food, rest, sex workers, alcohol and drugs. They pick up the women, have sex with them and leave them at some other ‘dhabas’, where they encounter other drivers, get picked up and get used by other drivers and local youth. As a result truck drivers also play a crucial role in spreading STDs and HIV throughout the country.

### Check your progress III

**Note:** a) Write your answers in the space provided.

b) Check your answer with the model answers at the end of this unit.

1) List the population which are mostly affected by HIV/AIDS and why?

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## 1.6 LET US SUM UP

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The history of AIDS is a short one. As recently as the 1970s, no one was aware of this deadly illness. Since then the global AIDS epidemic has become one of the greatest threats to human health and development. At the same time, much has been learnt about the science of AIDS, as well as how to prevent and treat the disease.

Although HIV and AIDS are found in all parts of the world, some areas are more afflicted than others. The worst affected region is sub-Saharan Africa, where in a few countries more than one in five adults is infected with HIV. The epidemic is spreading most rapidly in Eastern Europe and Central Asia, where the number of people living with HIV increased 150% between 2001 and 2007.

AIDS is caused by HIV, a virus that can be passed from person to person through sexual fluids, blood and breast milk. Certain types of behaviour carry a higher risk of HIV transmission. People particularly vulnerable to HIV include injecting drug users, commercial sex workers (CSWs) and men who have sex with men (MSM). In many people's minds, HIV and AIDS are closely linked with these groups, which can lead to even greater prejudice against people already treated as outsiders. Yet, the vast majority of HIV infections are transmitted through sex between men and women. Nearly half of all adults living with HIV are female. As a sexually transmitted infection, HIV particularly affects adolescents and young adults. Deaths of young adults have an especially damaging impact on their families and communities: skills are lost, workforces shrink and children are orphaned. Apart from inadequate funding, major obstacles in tackling the global AIDS epidemic include weak infrastructure and shortages of health workers in the worst affected countries. Political or cultural attitudes also cause significant damage; for example, some authorities oppose condom promotion, while others refuse to support needle exchanges for injecting drug users. Many are reluctant to provide young people with adequate education about sex and sexual health.

Another very serious issue is stigma and discrimination. People known to be living with HIV are often shunned or abused by their very own community members, employers and even health workers. As well as causing much personal suffering, this sort of prejudice discourages people from seeking HIV testing, treatment and care.

Based on recent trends it is likely that AIDS around the world will keep getting worse for many years to come. Millions more will become infected with HIV and millions will die of AIDS. Therefore, Social Work as a profession needs to focus more on the prevention and control of the epidemic by generating awareness and

removing the various myths and misconceptions. We also need to adopt an approach where in the stigma and discrimination attached to the disease would be eliminated.

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## 1.7 KEY WORDS

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**HIV:** HIV is a lentivirus, which like all viruses of this type, attack the immune system. Lentiviruses are in turn part of a larger group of viruses known as retroviruses. The name 'lentivirus' literally means 'slow virus' because they take such a long time to produce any adverse effects in the body. They have been found in a number of different animals, including cats, sheep, horses and cattle. However, the most interesting lentivirus in terms of the investigation into the origins of HIV is the Simian Immunodeficiency Virus (SIV) that affects monkeys.

**Virus:** Viruses cannot survive on their own and can multiply only in human or animal bodies. Viruses infect the cells that make up the human body and replicate (make new copies of themselves) within those cells. A virus can also damage human cells, which is one of the things that can make a person ill.

**Immune System:** The immune system is a group of cells and organs that protect your body by fighting disease. The human immune system usually finds and kills viruses fairly quickly. What makes HIV so dangerous is that it attacks the immune system itself - the very thing that would normally get rid of a virus. It particularly attacks a special type of immune system cell known as a CD4 lymphocyte.

**WBCs:** White blood cells are a very important part of what is called the immune system. The immune system, with its WBCs, defends the body from infections. It recognizes bacteria, viruses and other organisms that are foreigner or dangerous to the body and begins to attack them. It also starts generating specific substances termed antibodies which act against the particular diseases – causing organism that has infected the body.

**Demography:** It has a Greek origins **demos** (people) and **graphein** (to draw, describe). This is the study of population, especially with reference to size and density, fertility, mortality, growth, age distribution, migration, and the interaction of all these with social and economic conditions.

**Epidemiology:** It is derived from Greek **epi** means upon, **demos** denote population, and the combining form – **logy** means the study of. Thus, epidemiology is the study of factors that determine the occurrence and distribution of disease that afflicts (affects) a population.

**Safe Sex:** Safe sex refers to sexual activities which do not involve any blood or sexual fluid from one person getting into another person's body. If two people are having safe sex then, even if one person is infected, there is no possibility of the other person becoming infected. Examples of safe sex are cuddling, mutual masturbation, 'dry' (or 'clothed') sex.

**Safer Sex:** Safer sex is used to refer to a range of sexual activities that hold little risk of HIV infection. Safer sex is often taken to mean using a condom for sexual intercourse. Using a condom makes it very hard for the virus to pass between people when they are having sexual intercourse. A condom, when used properly, acts as a physical barrier that prevents infected fluid getting into the other person's body.

**Risk Kissing:** There has only been one documented instance of HIV infection as a result of kissing out of all the millions of cases recorded. This was as a result of

infected blood getting into the mouth of the other person during open-mouthed kissing, and in this instance both partners had seriously bleeding gums.

**Unprotected sex:** It is only risky if one partner is infected with the virus. If your partner is not carrying HIV, then no type of sex or sexual activity between you is going to cause you to become infected - you cannot 'create' HIV by having unprotected anal sex, for example. You also cannot become infected through masturbation. In fact, nothing you do on your own is going to give you HIV; it can only be transmitted from another person who already has the virus.

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## **1.8 FURTHER READINGS AND REFERENCES**

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## **1.9 ANSWERS TO CHECK YOUR PROGRESS**

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### **Model Answer I**

- Unprotected sexual intercourse with an infected person
- Contact with an infected person's blood
- Mother to Child transmission
- Use of infected blood products
- Injecting drugs

### **Model Answer II**

- The Hunter Theory
- The Oral Polio Vaccine Theory
- The Contaminated Needle Theory
- The Colonialism Theory
- The Conspiracy Theory

**Sex workers**

**Intravenous Drug Users**

**Migrants:** Migrant workers tend to have little access to HIV/STD information, voluntary counselling and testing and health services. Cultural and language barriers worsen their lack of access to such services. Returning or visiting migrants, many of who do not know their status, may infect their wives or other sexual partners in the home community.

**Truck Drivers:** The extended period of time that they spend away from their families placed them in close proximity to “high risk” sexual networks, and often results in their increased number of sexual contacts.

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## UNIT 2 SOCIAL AND ECONOMIC IMPLICATIONS

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### Contents

- 2.0 Objectives
- 2.1 Introduction
- 2.2 Household Level Impact of HIV
- 2.3 Sectoral Impact of HIV
- 2.4 Macro-Level Impact of HIV
- 2.5 Let Us Sum Up
- 2.6 Key Words
- 2.7 Further Readings and References
- 2.8 Answers to Check Your Progress

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### 2.0 OBJECTIVES

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HIV has not remained as an epidemic only, rather has become a developmental concern. It has been more than two decades since first HIV case was detected in India. At that time, since the number and proportion of people with HIV were quite low, impact at macro-level was hardly felt and consequently assessed. At present, with more than 5 million cases of HIV in India, economy is experiencing the pinch of the pandemic. This unit aims to appraise the adverse economic and social impact of HIV and AIDS, mainly at three levels: individual/household, sectoral and national or macro-levels. In this unit, the socio-cultural context of the discussion would primarily be India, though at times, situational analysis of other countries would be referred into. After reading this unit, you should be able to understand the:

- economic impact of HIV and AIDS at the family and community levels
- assess the socio-economic bearing of the pandemic on the economy of the nation
- irreversible damage of the pandemic on human capital
- changing demographic aspects and social institutions, and their functioning
- changing family dynamics and care-giving issues

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### 2.1 INTRODUCTION

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There were about 34.3 million adults and children living with HIV/AIDS in 2001. In 52 countries, more than 1 percent of all adults carry the virus. The AIDS pandemic has claimed more than 18 million lives since it was first detected in the early 1980s. The pandemic is most severe in sub-Saharan Africa, with 24.5 million people infected with HIV in the region (WHO, 2006). Approximately 5 million people are living with HIV/AIDS in India today. Although India's adult HIV-prevalence rate is low at about 0.8 percent, this converts into staggering numbers due to India's enormous population.

It is painfully clear that HIV/AIDS is not just another infectious threat to health. HIV/AIDS is destroying the traditional social fabric of the societies and is a threat to all aspects of sustainable development. Studies on impact of HIV/AIDS on demographic aspects indicate the classic population pyramid in developing countries will be radically changed with the advent of HIV/AIDS, within the next two decades. Never before has the world experienced death rates of this magnitude, among young adults of both sexes and across all social strata. It is hard to imagine how societies will be able to cope with such dramatic changes, where the old will have to care for their children and grandchildren, and where the youth will have to take responsibility for caring for family members at a much younger age than they do today. Although the pattern and severity of the pandemic is not as drastic in other continents as it is in Africa, it is of concern to all societies and will remain so for the foreseeable future.

In this unit we would examine the impact of HIV/AIDS on various aspects of social, political, and economic life, especially with reference to less developed countries. It is believed that HIV has influenced, most often negatively, the social institutions such as family and community relations. A look into the actual and probable devastation that HIV has brought about or would bring about, indeed would give us the necessary insight to reduce vulnerabilities associated with it and make us better equipped to deal with the infection, improve response, and strengthen social institutions.

We would also look into some of the salient effects of HIV/AIDS, both direct and indirect, from the decline in productivity that result from early mortality, to increased burdens on households and states that stem from caring for infected persons. We would analyze the effects on households, the growing orphan problem and gender relations. We would also review a variety of economic effects, including on economic growth, on corporate firms, agriculture, health sector, and so on. It may be noted that for the purpose of the study, we may categorize the impact of HIV into socio-economic impacts, macro-micro-level implications, both of which are highly interlinked issues. Response to HIV infection at the level of households affect the supply of labour, which influence the responses of employers and workplace, which produce macro-level consequences. Similarly, the responses of national and international institutions determine the choices and alternatives available to individuals and families. Further, the impact of HIV/AIDS on economic institutions has the potential to influence many other institutions as well, including education, health care, government, and the law.

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## **2.2 HOUSEHOLD LEVEL IMPACT OF HIV**

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At the micro-level, economic constraints due to HIV infection are quite obvious and visible. Income losses, at the household level are on various accounts – reduced work capacity, expenditure for treatment and care, reduced time to work and earn, caregivers' inability to work full time, premature death of an AIDS afflicted member of the household, funeral costs and so on.

At the household level, the most frequently felt impact of HIV is increased spending on treatment and care, even if the cost of anti-retroviral therapy is not taken into account. Stated otherwise, meeting the cost of management of opportunistic infections is quite an uphill task especially for families with financial constraints. Further, affordability of anti-retroviral drugs is not easy for most of the households affected with HIV/AIDS. The World Health Organization (2003) estimates that, of the six million people who currently need anti-retroviral treatment in the developing world, only 8 percent are receiving it. In Africa where more than half of the PLHA (People



Living with HIV/AIDS) reside, this figure drops to 2 percent. When seen in the context of poverty, most of the HIV infected people would remain out of the purview of Anti-retroviral therapy that could elongate their lifespan.

Next, HIV most often attacks the productive age group of 15 to 35 years, designated as youth. It consequently affects the ability to work and earn and there is substantial loss of earning and income of households having members infected with HIV. There is reduced earning due to frequent ailments and reduced ability to work due to the infection. Another dimension of this accentuated vulnerability is reduced employability due to stigma associated with the infection. So, people afflicted by HIV, face problems in getting job due to stigma and discrimination associated with HIV, and also retaining it because of deteriorating body's health and immunity. In India, in consonance with many of the other developing nations, almost 93percent of the people are engaged in unorganized sector and more often than not, engaged in physically strenuous and hazardous jobs. With HIV infection, stamina and energy drops significantly and so significantly too affects the ability to work.

Sunder and Singh (2006), in their research, confirmed that six states with high prevalence namely Maharashtra, Tamilnadu, Karnataka, Andhra Pradesh, Manipur, Nagaland have households affected on the economic front due to HIV. In economic terms, seriously affecting their capacity to earn as compared to 'no-AIDS'. The medical condition of the people living with HIV/AIDS reduce savings as treatment cost is manifold. In this context, it is important to note that the long term impact of HIV varies depending upon the initial economic condition of the households. So, the rich or the economically better off families have greater resilience in absorbing the economic shock brought by HIV infection and on the other hand poorer families may be pushed below poverty line while trying to cope with the crisis of infection.

There have been many studies that indicate on higher work participation rate among the children and the elderly on account of lowering or the lack of work participation by the young HIV infected family member(s). Sunder and Singh (2006) in their study have found that families affected by HIV are under greater financial strain, often losing breadwinners and having less money to spend on education and health care of children. They often respond by taking their children out of school and adding them to the labour force, contributing to the abundance of unskilled labour and further accentuating the problem of child labour. Likewise, households affected with HIV may also change the skill composition of the future work force, as young people are forced to forgo education and training, in order to join the work force and contribute to household financial resources.

There is rapidly growing number of AIDS orphans. According to the UN, the disease has resulted in more than 14 million AIDS orphans, since the epidemic began (Hagen, 2002) and this number is projected to increase to some 40 million in Africa by 2010 (Foster and Williamson, 2000). Orphanhood has adverse impact on children. In general, children who lose one or both parents to AIDS, are at risk of leaving school or falling behind their age group in school. Additionally, even before the parent dies, the child is required more in the household to help with domestic work. On becoming orphaned, some children stay home to take care of their siblings, and therefore do not go to school. The long-term effect is a loss of productive human capital. Researchers have also noted the deterioration in nutritional, health and educational status as the impact on the child of losing one or both parents. It has also been found that with the loss of the mother as caregiver, the health of orphans often gets worse. HIV can have a greater impact on children as the surviving parent is likely to die too if also infected, and because of the enormous economic burden due to a prolonged

period of illness. Needless to add, the emotional impact of losing one or more parents to HIV/AIDS is distressing, and can be intensified if a child is abandoned (especially, once the cause of death of the parent is known). As AIDS is often associated with promiscuity, prostitution, or other unacceptable behaviour, the AIDS orphans get stigmatized and is alienated. These problems, along with economic difficulties, may force orphans to migrate to cities, joining the already large number of street children, who in turn become more at risk of HIV infection and transmission through sexual work and exploitation to secure their basic needs.

Children, at times, after the death of one parent may have to live with step-parent(s), which has its whole gamut of consequences ranging from exploitation - verbal, physical, sexual - at home, to desertion, and finally taking on urban streets. Many other AIDS orphaned children live with their grandmothers or in child-headed households, taken care of by older siblings. Grandmothers who have traditionally 'retired' from active life are forced back to take up new child-rearing responsibilities and at times, even earn for livelihood. According to a study in Zimbabwe, the large majority of main caregivers were females over 60 years of age caring for their grandchildren (WHO, 2002). Further, studies conducted in Thailand, have found that AIDS victims return to their parental homes at late stages of the illness, imposing an unexpected burden of care on elderly adults (Knodel and Van Landingham, 2003). As older parents in developing countries commonly expect to rely on adult children for support, the loss of children also affects parents in the long-term. Rather than relying on their children, the elderly are finding themselves caring for children and grandchildren, causing extreme financial strain. Impacts on the health of elderly parents include, physical strain from care-giving, extra work required for needed expenses, as well as potential exposure to opportunistic diseases such as TB and a host of other physical illnesses (WHO, 2002).

The effects of care-giving can vary across households, with most facing a decline in living standards due to the costly long term treatment, loss of income as the sick and their caregivers drop out of the workforce, funeral expenses, all of which can lead to debt and poverty (Danziger, 1994; WHO, 2002). Indeed, a study of household expenditure due to AIDS in Tanzania found that the cost of medical care and funerals exceeded the annual income of many households, largely due to the long duration of this disease. Further, the price of antiretroviral treatments as determined by pharmaceutical companies as well as the government subsidies will also be a strong determinant in the future impact on families. Caregivers also face many problems such as constrained relationships with in-laws, exhaustion due to care to HIV positive relative, stress of seeking additional sources of income, etc. (Magadi, 1992). Emotional strain, burnouts due to demanding care, psychological stress related to poverty, inability to care for one's children, and overall despair takes a heavy toll, particularly on mothers. Thus, we analyze that even if the families are doing their best to cope with crisis of HIV/AIDS, in future, the stress of caring for the growing numbers of people with AIDS as family members, may put the existing family structures under extreme pressure.

Researches have shown that many families, with no assets to sell, are often forced to borrow substantial sums of money for the care and treatment of HIV positive relative, putting great financial strain on the households. As families are less able to save, less capital is available for investment, threatening the education and skill development of the children.

Another reason for loss of income of the household is reduced work time of uninfected members primarily on account of providing care and support to the infected member.

So, we see that presence of even one infected member has multifarious economic impact.

Gender plays crucial role in defining the vulnerability to HIV as well as bearing the brunt of it. Gender inequality is further accentuated by AIDS. Females, biologically, socially and psychologically, are more vulnerable to HIV infection than their male counterparts. In traditional societies like India where mere discussion about sexual or reproductive health is a taboo, one can assess the amount of difficulty a woman faces in trying to enforce condom use to male partner, along with added pressure to have children. This makes it very difficult for many women to control their own sexuality, health, and well-being. Right now, limiting the scope of the discussion, we focus on the economic vulnerability of the women. Traditionally, money is not spent on the health care needs of females and they are socialized to remain apathetic towards their health concerns, particularly the sexual and reproductive diseases. Their need for economic self-reliance is hardly given any attention. Further, care for those affected by HIV/AIDS falls disproportionately on females and they usually operate as unpaid primary caregivers to those affected by HIV/AIDS, which takes a heavy toll on them physically, economically and psychologically. In many instances, women, the prime caregivers, are also infected with HIV, thus their health needs are regarded secondary. Providing long term care to HIV infected family member with scarce economic resources and ignoring the needs of their own ailing body, exhaust these women. It becomes all the more shattering when they have to face stigmatization, blame and abandonment from their own relatives and community people.

Widowhood further brings economic hardship along with stigma and discrimination. Widows are also vulnerable to denial of legal rights to property or inheritance. Combined with blame and abandonment by in-laws, this can lead to the loss of shelter and any means of subsistence, resulting in poverty. This forces women to fend for themselves and their children by engaging in sex work for their family's survival. This in turn amplifies the risk of HIV spread as the societal discrimination and stigma discourages women from being tested and even telling family and others about their sero-status, leaving them without the much needed support and treatment.

Gender discrimination and inequality not even spares young girls, who are likely to be the first ones to be taken out of school when economic constraints pinches the family affected by HIV. They have to care for younger siblings and, at times, may be pressurized to engage in sexual activities at a tender age, as men seek to marry younger girls to avoid risk of infection, and as girls needs to secure resources for their livelihoods. There is enough evidence that to show that AIDS has actually increased women's exploitation and abuse in myriad of ways.

Presence of an HIV infected family member adds to the health vulnerability of other family members, though indirectly. HIV predisposes a person to tuberculosis, fungal infection, pneumonia and other communicable infections, which, especially, makes young children vulnerable to these infections.

Lastly, the stigma and discrimination on account of AIDS are particularly severe in India and often at times, due to actual or even perceived fear of stigma and discrimination, individuals infected with HIV do not reveal their HIV status and deny themselves healthcare services. This indeed makes the situation all the more precarious. Experiential and empirical data bring out that many people with HIV in need of medical attention travel a long way (often away from their residence) to access healthcare services far off from their place of residence in order to maintain

anonymity and also not to let their neighbourhood and community know about their sero-status, which indeed is not a cost effective proposition.

**Check Your Progress I**

**Note:** a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1) Enlist five main ways in which HIV infection affects the households.

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### 2.3 SECTORAL IMPACT OF HIV

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The impact of HIV pandemic has gone beyond the households affected with the infection and it has started influencing sectors like health, tourism, agriculture, transportation and industry. In this unit let us analyze impact of HIV on some of the prominent sectors, to begin with the agriculture sector, which has the highest unskilled labour intensity.

**Agriculture sector:** There is widespread agreement that HIV/AIDS exacerbates economic vulnerability. HIV/AIDS is assumed to bring the proportions of devastation similar to those such as droughts and floods, thereby threatening the sustainability of rural communities. Loss of labour power due to AIDS destroys family life as well as agricultural patterns. Researchers argue that households with infected adults generally experience a decline in agricultural production and may opt for shift in cropping patterns requiring less labour and financial inputs which in turn may result in reduced food production and quality. In addition, decreased labour input in crop production due to increased rate of morbidity and mortality among labourers, the area under cultivation may be reduced. The costs of taking care of chronically ill relatives or orphans substantially lowers the capacity to utilize appropriate inputs (seed, fertilizer, etc.), which lowers the crop production. Further, HIV/AIDS infected/affected households tend to switch cropping patterns that demand lesser labour inputs even compromising with the better returning long duration crops.

Poverty adds to AIDS vulnerability to many fold. It lowers the income and food purchasing-power of households and HIV/AIDS lowers household food and cash crop production. Small farmers may have to mortgage or sell off their piece of land for want of money. When they are left with no money to make initial investment for crop production, they often migrate to urban centers. Another pull factor for migration is better healthcare infrastructure in urban areas. Cities often provide hostile environment to these migrants and many, especially women, are left with no choice but to engage themselves in sex work for survival. These factors further accentuate transmission of HIV infection. With increasing numbers and proportions of workforce

in agriculture giving into morbidity and mortality due to AIDS, this primary sector shrinks in meeting the requirement of food production of the nation and contributing its share to GDP.

**Education:** HIV/AIDS would threaten educational institutions by precipitating a shortage of both teachers and students. The direct effects of the disease on the health and numbers of teachers and students are perhaps most obvious. The effects may be classified to be on the demand side or supply side. Impact that lower the demand for education may be listed as - the premature mortality of women of reproductive age due to AIDS reducing the number of children ever born. HIV-infected children dying of AIDS reduces the number of primary school enrollees. The economic burden of an HIV-infected parent may reduce the ability of households to afford school fees and uniforms or force children to engage in income-generating activities and food production instead of attending school. Children (particularly females) may be needed to provide care for sick relatives. Orphaned children may not attend school if they do not receive financial and social support from the extended family. Orphaned children as well as HIV positive children may not attend school if they feel stigmatized or are subject to discrimination. The educational performance of children from HIV-infected households may also suffer, leading to higher rates of drop out. HIV-infected young adults have a shortened time horizon (if they know they are infected) and are less likely to pursue higher education.

Further, it is anticipated that the teaching manforce may be impacted vide a disproportionate loss of teachers to AIDS mortality, creating a shortfall of educated manpower, raising pupil-teacher ratio. High rates of absenteeism among HIV-infected teachers and absenteeism due to care of sick relatives and funeral attendance drains on the efficiency of the education system. The epidemic may have disparate effects on rural areas as HIV-infected teachers in rural areas may request transfer to urban areas to access medical care. But higher rates of HIV infection in urban areas may create shortfalls in urban areas. The quality of education declines as less experienced and less qualified teachers are hired to fill vacancies. Teacher morale may be affected by the loss of colleagues, and by the increased work load their absence creates, which in turn lowers the quality of education.

**Health:** Health services play a crucial role in AIDS prevention, care, and treatment. While in the developed nations, the health care system has taken prime responsibility for providing palliative care for AIDS patients, in heavily affected developing countries such formal care is almost non-existent. Instead, households, families, and kin are the primary caregivers of people afflicted with HIV/AIDS. Nonetheless, the epidemic has had an obvious and profound effect on the healthcare institutions in the developing world. Demands for public health education and treatment can place burdens on health care institutions that shift infrastructure, personnel, and financial resources away from meeting other basic healthcare needs. HIV/AIDS-focused health care centers funded by foreign charities will siphon skilled medical labour away from state-run hospitals and clinics by offering higher salaries, leading to acute staffing deficits. In response to the pandemic, the state may reallocate resources meant for providing essential social services such as potable water, sewage services, educational facilities, childhood vaccination programmes and other developmental infrastructure. In most developing countries, there is acute scarcity of supplies, infrastructure and resources and organised responses to AIDS are dramatically taxing the healthcare systems even when additional resources have been provided by foreign donors. Research studies have shown that many healthcare workers are at risk of burning out, and that patients with other ailments may be suffering as time and scarce resources

are dedicated to AIDS patients (London, 2003). Thus, high budgetary allocation for the health sector, is done at the cost of some other sector. Most of the countries are allocating big share of the public health expenditure on prevention, care and treatment of HIV. When compared with a hypothetical “no-AIDS” scenario, the huge budgetary allocation on HIV could have been utilized on other crucial aspects such as poverty alleviation, education and infrastructure development of the country.

**Market Economy:** HIV/ AIDS has general impact on markets as it reduces substantially the number of consumers as well as their financial resources. There are myriad direct costs for firms and employers whose workforce is drawn from a population with high HIV prevalence. These costs include lower productivity due to poor health, absenteeism and sick leave; absenteeism of ill workers or workers with infected family members; absenteeism by healthy workers attending the funerals of co-workers; health claims and cost of treatment; pension and retirement claims; funeral costs borne by employers; the costs of training and recruiting workers meant to replace the ill and dying, instability due to increased turnover, recruitment as well as escalated training costs. There are indirect costs to firms of HIV/AIDS including the psychological effects on uninfected workers that may result in lowered morale due to high turnover, fear of death, and loss of interest. Responses to direct and indirect costs may vary, but include voluntary and mandatory testing of current and potential employees, provision of health care and anti-retroviral drugs (either directly or through a health plan), as well as awareness generation programmes.

It may be noted that these responses of the corporate sector may not be entirely humanitarian, as firms realize that it may be less expensive to provide drug treatment than endure the costs of a sick workforce with a high mortality rate. Pre-employment HIV screens are illegal, but firms sometimes use them to reduce HIV-related costs by avoiding the hire of infected employees. Some firms may respond to these costs in less compassionate ways, by terminating employees found to be infected, limiting or eliminating health insurance coverage, and changing the terms of retirement pensions. At times, individual firms tend to reduce the costs on account of HIV/AIDS to individual firms by shifting responsibility for dealing with the impact of AIDS on their workforce onto families and households, communities, governments, and other organizations.

High prevalence of HIV may lead to shortage of skilled labour and often makes both types of labour – skilled and unskilled – more costly and less productive. Status and skill level of the infected workers determine, to some extent, the response of the firm; companies may provide treatment cost, health care and other benefits to highly skilled and professional workers, while limiting these benefits or even terminating the services of unskilled or semi-skilled infected employees as it is more difficult to replace skilled and qualified staff due to a general shortage of skilled workers. In addition, HIV holds the potential to erode the skill base of future workers, as young people leave school to engage in economically productive activities to support their family which has lost a breadwinner to AIDS. HIV infection can change the cost of acquiring human capital, which may lead organizations to depend on a generation of new workers with lower skills.

**Armed Forces:** Infection rates among the armed forces have been found to be higher than in the general population. It may be attributed the following factors: the military forces are highly mobile, face frequent dislocation, are prone to casual sex and are deployed in socially disrupted and conflict zones that make the armed forces indulge in risky behaviours. It suggests that the spread of the diseases in the armed forces will have both direct and indirect impacts on national and regional security.

Further, high rates of prevalence may weaken the army, and may reduce the ability of the nations to engage in local and regional peace-keeping activities.

**Check Your Progress II**

**Note:** a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

- 1) Briefly discuss the impact of HIV/AIDS to transportation sector, with HIV infection expanding fast among trucking crew in India.

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## 2.4 MACRO-LEVEL IMPACT OF HIV

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One of the most direct macro-level effects of HIV/AIDS is on the demographics – size and structure of population. Demographers have projected that HIV/AIDS may fundamentally change the age structure of heavily affected societies by ‘hollowing out’ the middle of the age distribution (Bongaarts, 1996). The population structure will change from the typical ‘age pyramid’ into a chimney-shaped structure because the HIV/AIDS epidemic affects youth the most. This age group of youth, 15 to 35 years, would primarily be squeezed in the age-pyramid due to the pandemic, affecting the traditional population structure. The effect of HIV/AIDS on the size of populations is primarily influenced by two factors: AIDS-related mortality as well as changes in fertility that can be attributed to HIV. The sharp decrease in numbers of children reflects child mortality due to HIV/AIDS as well as a reduction in the number of live births due to adult mortality and reduced fertility in HIV infected women.

Most of the severely affected countries, especially in the African continent, are already seeing significant reversals in development indicators due to the HIV pandemic. Therefore, while HIV/AIDS is commonly understood to be a medical or public health problem, it is becoming clear that, in terms of its causes and consequences, the pandemic is deeply embedded in the social, political, and economic processes that shape the development of nations. Accordingly, successful responses to the pandemic depend not only on the development of medical treatment and behavior change, but also on political will, cultural understanding, the preparedness and capacity of health care systems and the achievement of broader development goals.

However, the massive influx of funds required to accomplish the provision of HIV treatment will certainly require the reallocation of funds from other health and non-health related purposes such as defence, infrastructure, education, and economic development. So, for most developing countries, realizing the Millennium Development Goals (MDGs) of eliminating HIV/AIDS would be quite tough proposition.

Researches that compared the existing ‘with AIDS’ scenario to a hypothetical ‘no AIDS’ scenario, have brought out that the pandemic is likely to decrease overall economic growth, decline the rate of progress in almost all the sectors (primary,

secondary and tertiary) and depress productive output (also differentially in the sectors that supply more unskilled workers) as a result of worker morbidity. It would also influence foreign investment as the comparative advantage of investment in developing nations is the availability of cheap labour. The cost of an HIV-infected workforce and its consequences (as discussed above) make the proposition much less attractive for international investment, and may lead to capital flight into regions with lower prevalence.

With rapidly increasing proportion of HIV positive people, there is an increased pool of infected individuals, which enhances the risk of transmission to the uninfected population, if precautions are not taken. This also implies a growing cost of care and treatment of a constantly increasing number of infected persons over longer periods of time, in terms of providing antiretroviral drugs. In this regard it may be noted that in developed nations of North America, Europe and Australia HIV has become a chronic ailment like diabetes, thanks to accessibility and affordability of antiretroviral therapy. However, fruits of these biomedical advances have not been able to reach to the overwhelming majority of those who require it, mainly in developing nations. As a consequence, developing countries would be taking many more years in transforming HIV infection from a fatal illness into a chronic condition for most of its PLHA.

Researches suggest that the economic impact of HIV on developing countries will be substantial. Impacts are not only the morbidity and mortality of HIV infected people which may result in shortened life-expectancy but also include a loss in human capital even among non-infected youth as they are forced to forgo education for early participation in labour market in order to care for the sick, thereby losing on skill acquisition and educational development. McPherson (2003) has pointed out that a major consequence of HIV infection is the shortening of decision horizons—a person who has HIV/AIDS is unlikely to plan for the future by saving or obtaining education, and decisions will be made in reference to the present. By extension, the aggregated effects of these shortened horizons in communities with a high prevalence rate are likely to have implications for everyone, including the uninfected, in ways that may have dire consequences for the economy of the nation as a whole. Researches predict that the much higher level of disease does seriously threaten economic growth, with expected economic relationships distorted, including a decline in GDP per capita. Unfortunately, the regions with the highest HIV prevalence also tend to be underdeveloped, and have unstable economic conditions, corruption, red-tapism and less-than-democratic governments, poor social security, meager infrastructures, and unskilled labour (UNAIDS, 2003). Countries hard-hit by AIDS would be having much difficulty in creating and maintaining many of the elements essential to economic development, including a large, skilled, productive labour force, an attractive environment for investors and a population with income to spend on consumer products.

A substantial number of studies have examined the past and future impact of HIV/AIDS on specific countries. The general consensus is that although quantifying the impact is difficult, the potential damage is great, especially in countries with high-prevalence. Nations with high HIV prevalence are also burdened with the costs of prevention, treatment and mitigation of the impact of AIDS, especially when employers are able to effectively shirk the burden. On the contrarily, if employers are forced to bear these costs, countries are likely to have a difficult time attracting investment (Lewis 2002). This means that in addition to the more direct impacts of HIV on development as discussed earlier, nations have fewer resources available to fund



economic development initiatives, including crucial elements such as infrastructure, education, and training, as scarce resources are directed to mitigate the consequences of AIDS. All of these factors further threaten a nation's ability to pay off debt and attract investment, which are especially vital to the economic development necessary to give nations the ability to reduce poverty and prevent and treat AIDS.

Some of the indirect effects of HIV/AIDS on national economies come from the projected demographic impact on population growth. Because the disease sickens and kills during key working and childbearing years, it will affect the workforce not only in the present and near-future, but according to demographic projections, for decades to come. About 90percent of India's reported HIV cases are among 20-45 year-olds, the most economically productive segment of the population. If HIV continues to spread at the current rate, India could experience a diminishing labour pool, which could, in turn, affect in the long term, economic prosperity, foreign investment, and sustainable development.

Next, let us look at the impact of treatment. It is observed that most of the infected people in Africa, where the epidemic has been most disastrous, are without access to modern therapies. Even within regions and nations, access to these treatments is uneven. In the wealthy United States, with a sophisticated and well-developed healthcare infrastructure, there is inequality in access to current anti-retroviral treatments, with the poor and minorities being at the disadvantage (AIDS Alert 1999, 2002). In many of the Sub-Saharan African countries, the meager proportion of people, who have access to anti-retrovirals, are disproportionately urban, wealthy and well connected. A key difficulty is that even though foreign funds for ART drugs are available, many of the hardest-hit countries have weak healthcare infrastructures making accessibility a major issue for most of the needy infected people. Lack of transportation facilities and high expenses make it difficult for most of the PLWHA to access far off hospitals and clinics for ART. Healthcare institutions are themselves understaffed and undersupplied, and coupled with stigmatized attitudes towards PLWHA, their functioning gets constrained further. The AIDS epidemic has weakened an already fragile health care system, which is even less equipped to implement treatment programmes for HIV/AIDS, even when funds are available.

Further, the aggregated impact of large numbers of HIV infected workers may have other effects on other levels of the economy. Regions with high HIV prevalence do not attract foreign investment, thus, further exacerbating the problem of poverty. The macro-level economy is quite interconnected with household decision-making and outcomes. One of the key effects of AIDS tends to be an increase in migration, as rural livelihoods become untenable, creating strain for urban labour markets and instability in the provision of food through agriculture. All these factors create a vicious cycle of poverty, further accentuated by HIV infection, lack of sufficient resources for poverty alleviation programmes as well as HIV mitigation interventions, which further deepens the vulnerability to poverty and HIV infection in future generations too. The State's role in these situations is also limited by poor economic conditions and scarce resources being transferred for care and treatment of HIV infected population. Researchers have identified poverty as the epidemic's primary social determinant. Poverty leads to vulnerability. Poverty leads to riskier behaviours, either by favouring transactional sex, or by driving migration. For example, increases in poverty and food insecurity may increase malnutrition, which catalyses the advancement of HIV infection. Further, poor infected people cannot afford the cost of ART and hence expect the state to provide it free of cost or at highly subsidized rate. Providing anti-retrovirals to people who need them is essentially throwing them

in a lifeline, and once given, it is nearly impossible to take them away. Thus, extending this treatment to people who cannot afford to provide it for themselves comes with obligations, and creates dependency for a large number of people on the government and/or foreign aid for the rest of their lives. This kind of dependence adds to the vulnerability as availability of ART is subjected to fluctuations in voluntary donations, foreign aids, political motivation, commitment and leadership (see: de Waal 2003). The economics of providing ART from a health budget perspective and the potential impact on companies and households, productivity growth, structural changes, addressing inequalities and delays in progress and development of the nation is quite significant.

**Check Your Progress III**

**Note:** a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1) Write short note on impact of HIV on progress and development of a nation.

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## 2.5 LET US SUM UP

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The pandemic of HIV is widely acknowledged to be the most severe health crisis of modern times. HIV continues to spread at alarming rates throughout the world, and India is one of the most badly affected countries. In this unit, we have discussed some of the socio-economic consequences of HIV/AIDS in developing countries, with special reference to India.

At the household level, loss of income due to incapacity to work, expenditure on treatment, low employability due to HIV associated stigma and discrimination, gender issues, strains in care giving especially to women and elderly were discussed. Migration and commercial sex are among the commonly adopted strategies by the families affected with HIV. Children infected and affected by the epidemic are likely to have less access to formal education and intergenerational knowledge transfer.

At the sectoral level, the unit covered impact of HIV on health sector and discussed how poor healthcare infrastructure further adds to the problems of PLHA. People engaged in agricultural work switch to less labour intensive crop production, and are often left with little resources and manpower to provide required inputs. HIV has widespread implications. Impact of HIV on education sector was discussed from demand as well as supply side. Impact of armed forces was also covered briefly. Fewer children access education and so also are the teaching force affected. The unit discussed at length the impact of HIV on corporates and firms. Employers

bear the cost of losing employees to AIDS, training newly recruited ones, bearing health expenditure and funeral costs.

Lastly, we discussed macro-level impact of HIV, which includes decline in progress and development of the nation as scarce resources are reallocated for the treatment and care of HIV infected population. Costs of the epidemic include increased expenditures for health care, prevention and education programmes, costs of caring for dependents of the ill and deceased, providing ART and increased spending on funerals. There would be drastic change in demographics due to mortality to AIDS, mainly affecting the young population. HIV/AIDS epidemic threatens the already vulnerable economies and political systems.

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## **2.6 KEY WORDS**

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**PLHA:** People Living with HIV/AIDS. The term is used to include people who are infected with HIV and also those who are suffering from AIDS.

**ART:** Anti-retroviral therapy. This covers a wide range of medicines/drugs that slows the growth of HIV in the body and prolong the life span of people infected with HIV.

**Sectoral impact of HIV/AIDS:** It is the socio-economic assessment of the effects of HIV infection on various sectors of economy like agriculture, health, education, etc., as compared to a hypothetical 'no-AIDS situation'.

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## **2.7 FURTHER READINGS AND REFERENCES**

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## **2.8 ANSWERS TO CHECK YOUR PROGRESS**

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### **Check Your Progress I**

1) Five main ways in which HIV infection affects the households are:

Expenditure on medication for management of opportunistic infections.

Capacity to work reduces and hence income also reduces.

Employability is lowered / reduced because of stigma and discrimination.

Family equations change: Elderly who are superannuated have to work harder in bringing up their grandchildren, taking care of ailing offspring(s) suffering from AIDS.

Children have to give up their education to earn livelihood or to care for their ailing HIV positive parent(s)/younger siblings.

### **Check Your Progress II**

- 1) There have been multi-prong effects of widespread HIV infection among truckers. With greater numbers of trucking crew getting infected with HIV, it is going to create serious problems with transportation industries affecting the supply of essential goods of daily use, other goods required directly and indirectly for the progress and development of various industries, as truckers carry these items from state to state across the country. Poor health of truckers due to HIV infection would lead to delays and inability to timely delivery of consignments. Death of truckers due to AIDS would affect labour supply at the workplace and crumbling of family well-being.

### **Check Your Progress III**

- 1) HIV/AIDS indeed has become a developmental concern especially for countries with scarce economic resources. The State is expected to spend on care and management of PLHA, provide subsidized ART and other facilities. However, this is done at the cost of other social services and needs of general population like curbing illiteracy, poverty, constructing roads and dams and so on. Further, AIDS affected regions/countries do not attract foreign investment and a huge financial resource that could have helped in the progress and growth of the nation. Sick and dying human resource cannot take active part in the progress and development of any nation.

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## UNIT 3 SOCIO-CULTURAL CONTEXT OF HIV AND AIDS

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### Contents

- 3.0 Objectives
- 3.1 Introduction
- 3.2 Socio-Cultural Milieu
- 3.3 Gender Issues
- 3.4 Socio-Economic Determinants
- 3.5 Let Us Sum Up
- 3.6 Key Words
- 3.7 Further Readings and References
- 3.8 Answers to Check Your Progress

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### 3.0 OBJECTIVES

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It is often assumed that causes of HIV/AIDS are primarily behavioural and hence the major preventive interventions focus on informing public to avoid certain risky behaviours say, multiple partners, unprotected sex, and sharing of infected needles. However, HIV/AIDS is much more complex and intricate an issue. There are certain socio-cultural factors that increases the vulnerability towards HIV infection. They may seem to be unrelated but significantly contribute to the transmission of HIV infection. In this unit, you will be exposed to the socio-cultural factors that hasten the spread of HIV. After reading this unit you would be able to:

- identify specific socio-cultural factors as distinct from the biological ones, that increase the vulnerability to HIV infection;
- evaluate the role of gender in increasing the vulnerabilities towards HIV spread;
- and
- appraise the impact of macro-level issues such as poverty, migration, health infrastructure, etc., on the spread of HIV.

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### 3.1 INTRODUCTION

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It may be noted that at the biological level, all human beings are equally vulnerable to HIV infection. It means that if exposed to the virus, through sexual intercourse or through blood products, any average person can develop HIV infection. There is no innate biological resistance to HIV infection. Thus, there is equality of biological probability to HIV infection among all human beings.

Further, a person indulging in any of the identifiable risky behaviours (such as unprotected penetrative sex with infected partner, sharing infected needles with injecting drug users, transfusion of infected blood, etc.) increases the individuals' chance of HIV infection. HIV requires specific, visible and identifiable actions/behaviours for transmission to occur. However, it may be noted that individual behaviour is connected to societal norms, expectations, values, conflicts, processes

and responses. Therefore, it is very important to study these socio-cultural factors that accentuate vulnerability to HIV infection. Certain noteworthy factors accentuating HIV vulnerability may well be described – socio-cultural construct of masculinity and femininity, poverty, migration, infrastructure, accessibility to information and services, political will, and so on.

Vulnerability to HIV infection may be categorized at various levels - at the individual level it is illustrated in terms of sexual preferences, awareness level and indulgence in risky behaviours; programmatic vulnerability refers to the extent to which the services meet individual needs; and societal vulnerability encompasses the socio-cultural and economic factors that create risk-inducing circumstances namely poverty and migration catalyzing HIV transmission.

The discussion on socio-cultural context of HIV would remain incomplete if gender construct and associated values, traditions are not included. Since, you would be getting an opportunity to study vulnerabilities associated with gender in the further Blocks. Here, in this unit, these topics would be described only briefly. Let us take a look at some of these factors at length in these subsequent sections.

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## 3.2 SOCIO-CULTURAL MILIEU

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Certain socio-cultural factors that influence vulnerability to HIV infection may be categorized as follows, although, in reality, it is quite difficult to differentiate and segregate the collective impact of these dynamic variables.

**Culture of silence:** The socio-cultural milieu of Indian society does not encourage the overt communication about sexual issues. These issues are NOT supposed to be discussed; talking about sex is a taboo. Parents, teachers and other adults often do not tell the children and adolescents about sex and sexuality. The only source of information they have is their peer group – who are not capable of providing scientific and accurate information. The half cooked information or lets say ‘misinformation’, is compounded by myths and misconceptions that indeed add to the vulnerability to sexually transmitted infections including HIV. A myth such as “having sex with a virgin will cure STDs” is often illogical and is of disastrous consequences.

**Changing family patterns, functioning and roles:** Forces of social change such as urbanization, industrialization, modernization and globalization have brought about significant changes in the family patterns and functioning. The nuclear family system is replacing joint families; alternate family patterns such as single parent families, women headed families, childless families are becoming increasingly visible in the society. Family cohesion is decreasing and family disintegration is on the rise. The family’s role to provide solace, comfort, recreational opportunity, protection, catharsis of pent of emotions is increasingly being taken over by outside agencies such as peers, colleagues, recreational clubs, television, cinema and the like. Monogamy and faithfulness of marriage partner cannot be ensured as, extra-marital sex is on the rise often in a clandestine manner,. All these factors increase the risk of HIV infection.

**Sex at workplace:** Forces of social change described above have also brought change to the workplace culture, ethos and patterns. Especially in cosmopolitans and metropolitans, workplace is characterized by cut throat ruthless competition, fast pace of work, pressures to meet deadlines, little time to relax and rest, late working hours, resulting in excessive stress and tension and lack of time and energy

to be spent creatively with family members. Career oriented families are emerging where both husband and wife are equally aspiring to quickly ride the ladder of success, may be at the cost of decision to remain childless. Corporate life, BPOs have given the opportunity to both sexes to mix freely and be together for longer working hours. At workplace, casual sex is becoming quite common for various reasons like – for many it acts as a stress buster, for some it is opportunity to meet unfulfilled the needs due to failed marriage and for others it may be the price to be paid for out of turn promotions and other incentives. This makes people more vulnerable to HIV infection.

**Men buying sex:** Data project that almost 85percent of HIV infection are through unprotected sex, which includes men buying sex or having sex with commercial sex workers. Men across the world buy sex for various reasons - wanting to avoid emotional involvement, lack of sex or not enough sex in marriages, wanting to experience power, variety or certain kinds of sexual experiences, thrills, loneliness or old age. These men are usually ordinary citizens and not sexual deviants. In societies with equitable gender relations, men respect the right of their wives or partners to refuse sex and visiting sex workers is like a ‘safety valve’ that lessened the strain on their modern relationships. In some societies, going to a sex worker is often a mark of the onset of manhood, with young boys being taken to brothels by their peers. Young boys generally visit sex workers for ‘experimentation’ and for learning skills of sexual intimacy, which increases the risk of HIV transmission. In patriarchal societies, where rigid sexual segregation, silence and taboo around sex are the norms, where sex is limited to procreation and there is lack of communication on sexuality with spouse. Visiting sex workers is considered as the only possible way of getting close to women without upsetting social norms. In societies like India, males buying sex often have highly moral positions on women; they consider sex workers as bad and promiscuous women but do not think it incongruous or immoral for themselves to visit sex workers. Sociologists are of the view that act of men buying sex is a kind of safety valve where men could get rid of their excess sexuality, thus preventing them from attacking ‘good women’ (in other words ‘chaste’ traditional wives and daughters).

**Attitude towards sexuality:** In societies like India, socialization process, in myriad of ways, tend to develop negative attitude towards sex, sex organs and sexuality. A culture of silence and the lack of accurate information regarding sexual anatomy and physiology make adolescents ignorant about sexuality, developing a negative emotional attitude toward sex organs and matters related to sexuality. It is not uncommon for adolescents to perceive their sexual organs as dirty and to refrain even from looking at them. Such negativism is particularly very common among females, and to certain extent with the males. As a consequence, many myths crop up around sexual issues making adolescents and youth prone to reproductive tract infections (RTI) and sexually transmitted infections (STI). Adolescents are likely to be curious and yet ill-informed, with sources of knowledge being peers or unscientific literature, which may cause irreparable harm later in life. Many adolescents adopt high risk behaviour due to the numerous myths and lack of skills – especially ability to deal with peer pressure effectively. Thus, ignorance about sexual functioning and STI, unhealthy curiosity about sex, peer pressure and lack of appropriate skills may facilitate transmission of STI/HIV, particularly in the backdrop of low levels of literacy.

**Adolescence and vulnerability:** Research findings show that, most often than not, adolescents and youth, both males and females, display an abysmal lack of

knowledge on sexual health issues. Also, adolescents initiating their sex life early are more likely to have multiple and high risk partners, and are less likely to use condoms. Further, experimentation with alcohol and drugs are associated with high-risk sexual behavior. Media arouses sexual interest but does not provide accurate information about sexuality. Youth may not be candid about their sexual experiences out of fear of stigma and labels especially in case of same sex behavior. Young people often lack information they need to affect safe, healthy decisions; this may lead to serious consequences such as teenage pregnancy and childbirth, unsafe abortions and STIs including HIV, to mention a few.

**Violence on women as the mark of manhood:** Studies have indicated that violence on women, both physical and sexual, has been a predominant aspect of social construct of manhood. It is equally noteworthy, that even many of the women ‘accept’ being victims of violence and treat manifestations of violence as socially accepted behaviour of men. Beating, sexual coercion, marital rape are some of the violent behaviours that threaten the physical as well as mental well-being of perpetrator as well as victim, including increased risk of HIV infection. Thus, a woman’s vulnerability is far more than her male counterpart.

**Check Your Progress I**

**Note:** a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1) Briefly explain how social workers can intervene in reducing the risk of HIV transmission among adolescents.

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### 3.3 GENDER ISSUES

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The then UN Secretary General Kofi Annan had very rightly articulated that today, AIDS has “a woman’s face” (2003). Gender roles and relations directly and indirectly influence the vulnerability to HIV infection, as mentioned below:

**Biological Vulnerability:** Physiologically, susceptibility to HIV infection among women is more than double than men due to a larger mucosal surface area of the vagina being exposed during heterosexual intercourse, coupled with the fact that semen has a higher concentration of HIV than vaginal fluid. Adolescent and young women, initiating their sex life at early age, are for obvious reasons at a higher risk to HIV infection. In the Indian context, cultural practices such as child marriages, early marriages, as well as forced marriages, increase this risk.

**Marriage as Vulnerability:** Research studies have shown that more than four-fifths of HIV positive women worldwide had contracted infection from their husbands or primary partners. Lack of knowledge, combined with their inability to negotiate condom use, places women, whose husbands have multiple partners, at risk of HIV



infection. In fact, it was noted that more than 90percent of women infected with HIV in India were married and monogamous. Studies have indicated that sexual coercion in marriage is widespread in India. Research done on married couples in Mumbai found that women commonly have sexual relations against their will and many husbands believe that sex is their right in a marriage. Also, women respondents generally did not report condom usage. Women in coercive sexual situations have little ability to negotiate safer sex and are highly vulnerable to STI/HIV. Notably, Indian law does not consider marital rape an offense. Even in situations where women perceive that they are at risk, negotiating condom use requires overcoming their traditionally submissive role and image in sexual relations as well as a cultural emphasis on fertility. Next, the role of women as care-providers also makes them vulnerable as there have been innumerable instances of HIV-positive men (called 'HIV crooks') marrying women without informing them of their HIV status, in order to have someone to care for them in their illness.

**Socio-demographic Factors:** Certain socio-demographic factors further compound these vulnerabilities. Factors such as illiteracy (35 percent females and up to 72percent rural women illiterate as per 2001 census) and exposure to mass media (40 percent women have no exposure to mass media) affect women's knowledge of HIV. On an average, women in India marry at 19.7 years of age and a significant proportion of them become pregnant during their first year of marriage. As mentioned earlier, younger women are biologically more susceptible to HIV infection. Sexual violence, exploitation, child sexual abuse and trafficking of women and children are other gendered experiences that females face in their life cycle, increasing their vulnerability to HIV.

**Gendered Power Relations and Information Accessibility:** Cultural taboos on sex related matters signify that women are usually less informed or ignorant about spread of HIV infection and its prevention. Data indicates that 95 percent of Indian women do not have comprehensive knowledge about ways of preventing HIV/AIDS (National Family Health Survey, 2005). Majority of women have maintained that they had no knowledge of sex-related issues until they got married and many got to know of HIV only after being infected (see UNIFEM, 2005). As a consequence, awareness level of women is much lower than their male counterparts with respect to HIV infection. Awareness being low, expecting safe behaviour is out of the question. Gendered power dynamics also underlie sexual relations. The imbalance of power within the home curtails a woman's ability to negotiate the terms of sex and thereby increases her vulnerability to HIV. Reportedly, women have difficulty discussing sexual relations with their husbands, including contraception. Societal pressure on motherhood and fertility impedes use of barrier contraceptives for women of reproductive age thereby increasing their chances of STI/HIV. Although media campaigns are slowly breaking taboos, societal norms still largely dictate the extent to which programmes can directly address sexual behaviour.

**Economic Vulnerability:** Patriarchal social structure is characterized by women's economic dependence on men, which also results in skewed distribution of economic resources to their disadvantage. In the context of HIV/AIDS, women, as caregivers and/or as infected, have to work harder to meet the medical expenditure of the infected males in the family, while ignoring and postponing their own treatment needs. Chronic malnutrition, which has its roots in socialization practices as per patriarchal social norms, render a woman's body weaker to fight against the infection. Also, economic disadvantage creates barriers in accessing information about HIV/AIDS, making the poor more vulnerable to infection. More often than not, women face

economic hardship in accessing and utilizing healthcare services, which includes transportation cost, foregoing daily wages and so on. This economic dependence also forces them to exchange sex for survival. Studies have shown that poverty is overwhelmingly the root cause of women bartering sex for economic gain or survival.

**Violence and Vulnerability:** The reality of many women's lives is that vulnerability to domestic violence and HIV coexist — domestic violence directly and indirectly exacerbates vulnerability to HIV and HIV status increases vulnerability to violence. Sexual coercion or violence in marriage most likely occurs without condom use, and thus increases women's vulnerability to STIs and HIV. Quite obviously, violent sexual acts such as rape are likely to result in vaginal tearing or lacerations, thus dramatically increasing the risk of contracting an STI or HIV. In addition, fear of violence or abandonment often prevents women from discussing fidelity with their partners or asking their partners to wear a condom. Further, accusations of infidelity are closely correlated with incidents of domestic violence. On the other hand, studies have brought out that sero-positive married women are subject to emotional abuse, violence, stigma within the home and community and even abandonment. Reportedly, women are accused of infidelity and/or thrown out of the home, on being tested positive. Life stories of women living with HIV demonstrate them being discriminated against and facing violations of their human rights as a result of their HIV status. Women are generally blamed for their husband's infection, subject to beatings and torture, neglect and discrimination within their home, denied of inheritance and property rights, have their children taken away from them, are unable to access health care or legal support, and ultimately are deserted by marital and natal family, especially after the death of an HIV positive husband.

**Access to Health Care Services:** Due to certain socio-cultural factors, females have less access to health care including HIV/AIDS services, than their male counterparts. Salient reasons are a culture of silence on sex issues; women cannot avail services, and they generally keep on ignoring and denying their health concerns, which in the case of HIV infection becomes dangerous and may shorten their life-span. Further, actual perceived stigma and discrimination related to HIV; healthcare infrastructural lacuna; shortage of trained medical staff, more specifically females and particularly in rural areas limits access. As discussed earlier a lack of knowledge about availability of health services, in the background of illiteracy and limited exposure to media also hinders utilization of health services by females. Data reflecting the fact that nearly 40percent of people living with HIV in India are women, while only 25percent of beds in AIDS care centres are occupied by women, confirm the presence of above mentioned factors.

**Stigma and Discrimination:** In a number of societies, like India, women are mistakenly perceived as the main transmitters of sexually transmitted diseases (STD's). In patriarchal social structure women are at the disadvantage in terms of resource and power distribution and it is easier for the society to blame them despite the fact that they are only victims. The differential treatment of sero-positive men and women can be traced back to skewed power structure prevalent in the society. Men are likely to be 'excused' for their behaviour that resulted in the infection, whereas women are not. In India, for example, the husbands who infected their female partners may abandon them blaming them for transmitting infection. It is often said that if AIDS doesn't kill a woman, stigma will.

### Check Your Progress II

**Note:** a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1) Enlist four vulnerability aspects of gender vis-à-vis HIV.

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## 3.4 SOCIO-ECONOMIC DETERMINANTS

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With respect to transmission dynamics, there is now sufficient epidemiological evidence of social determinants that play a significant role in enhancing the vulnerability to HIV infection. Salient ones are: poverty, migration, awareness levels, infrastructure and State capacity. Let us understand these factors in some detail in the context of HIV/AIDS.

**Poverty** is one of the most compelling factors that force people to indulge in risky behaviours, which act as contingent condition to HIV infection. There are certain impeding factors that make poverty as crucial force in putting people at risk of HIV infection. First, poverty greatly accelerates people’s vulnerability by restricting access to information and services. Many people living below poverty line do not know the meaning and implications of their sero-positive status and many others die of AIDS without having slightest of knowledge about it. Second, lack of resources for subsistence forces women to sell sex for survival. With inability to find any other occupation, many women below poverty line resort to sex work as the only option for a living. Third, poverty creates a vicious cycle of illiteracy, lack of skills, unemployment and underemployment, ignorance and inhibited access to information and services for development. Fourth, poor people migrate to other places with better livelihood options. Migration has traditionally been a survival strategy for people, especially those below poverty line. This phenomenon indeed makes a person vulnerable to HIV infection, as discussed below.

**Migration:** People, more often than not, migrate to urban centres in search of better livelihood options. In South Asia, annually, more than 200 million people are estimated to migrate within and between countries in the region, in desperate search for a better life. There are many push factors leading to migration such as poverty, landlessness, low agricultural productivity, marginalization, lack of opportunities for employment and growth, domestic or community conflict, political unrest, natural calamities, war, terrorism, and so on. Likewise, better opportunities for livelihood, education and growth due to urbanisation and industrialization, increased access to information, improved system of mobility and communication are some of the pull factors that lure people to migrate to urban centres. With growing mismatch between pockets of economic activity and deprivation brought about by the new global economic order, migration is on the rise. Then, how process of migration accentuates the vulnerability of people to HIV infection?

Most often than not, migrants have rosy picture about the places of destination, with little or no knowledge about the complex mix of vulnerabilities that await them on the way. Reportedly a large number of migrants face an acute risk of exploitation, physical violence, sexual abuse and socio-political marginalization, alienation and discrimination. A recent study by UNDP demonstrates that HIV is a manifestation of the inequalities and deprivation faced by migrants. Hostile and lonely environments, separation from families, lack of access to information and services and social support systems can lead to social and sexual practices that make them more susceptible to HIV exposure. At the individual level, migrants may face isolation, loneliness, exploitation, hardships, and hostility from host societies, separation from family and partners, strains in relationships, and the like. For men, gender related norms and economic needs force them to migrate without their families in search of work, creating situations that foster multiple sexual relationships that may lead to HIV infection. At the source, there is increased single parent households and extra burden on women who stay behind. And, when the migrants return they may infect their wives. These factors make the social environment conducive for HIV to thrive. As the epidemic spreads wider, the link between migration and HIV is emerging stronger than ever before. However, it may be noted that migration in itself is not a vulnerability factor for HIV, but it is the unsafe process of migration that creates conditions of vulnerability.

**HIV/AIDS can be a Driving Force of Migration:** People living with HIV/AIDS (PLHA) may be driven to migrate or leave their homes because of stigma and discrimination they face, lack of sufficient health services and non-availability or poor access to treatment. Further, at times, migrants hide their HIV status due to the fear of stigma and discrimination, and thereby transmit the infection further.

**Utilization of Health Services:** Many migrants live in indeterminate state, having no stay or work permit in the host country and live in constant fear of deportation. Any contact with official government agencies, even if related to health matters, increases the fear of being reported to the police and is, therefore, often accompanied by suspicion. This factor, combined with the hardships of daily life, makes providing HIV testing, care, support and treatment particularly challenging for these populations. Added to this, migrants, particularly from poor economic background, are often working individuals, subject to poor and unstable living and working conditions, and often face language barrier and acute cultural differences at destination places. Such conditions usually mean that they have limited access to reliable and culturally appropriate information on HIV/AIDS and health services.

**Social Service System:** There is a seemingly unrelated but strong relation between the health infrastructure and HIV transmission – a poor public health system amplifies the spread of STI and HIV. Reportedly, STIs greatly enhance HIV transmission by up to 100 folds while effective diagnosis and treatment of STIs can decrease HIV incidence by 40 percent. Thus, lack of STI diagnosis and treatment services would be a significant determinant of HIV epidemics. This provides a direct link to policy level implications and health care infrastructure available to people and, of course, the budgetary allocations on public health. Inadequate funding of healthcare may lead to unsafe practices such as re-use of needles and syringes, denial and delay in providing treatment to HIV patients, limited availability to ART and PMTCT medicines and the like. Wide-spread AIDS-related stigma and discrimination in healthcare settings force sero-positive people to hide their status and thereby limit access to treatment. Likewise, lack of access to clean water and electricity are hypothesized to favour the spread of HIV due to poor hygiene, thus weakening the immune system of the poor.

**Role of Mass Media:** Two decades ago, messages were mostly aimed at raising awareness about how AIDS was transmitted and they did so by creating fear through messages such as 'AIDS kills'. Consequently, stigma and discrimination became rampant as people started avoiding, isolating and rejecting PLHA from almost all walks of life. Fear of stigma and discrimination became so overpowering that people hesitated to get tested. At times, PLHA hide their sero-status and even do not maintain 'safe' behaviours, thereby infecting others.

**Human Trafficking:** In South Asia, human trafficking has increased drastically over the past few decades. Apparently, trafficking takes place for various purposes like domestic labour, organ transplant, forced labour, organized begging, adoption, sex work, forced marriage and so on. Traffickers are mainly organized networks, recruitment agents, relatives, parents, guardians and husbands. Even though males are trafficked, most often the victims are young girls and women from poor and illiterate families. Irrespective of purpose of trafficking, sexual exploitation is constant. Trafficking reduces freedom of choice, access to information and accelerates vulnerability to HIV manifolds.

**Disasters:** Though seemingly unrelated, disasters enhance vulnerability to HIV. Floods, cyclones, droughts, earthquakes, land slides are common in India - 65 percent of the landmass in India is prone to earthquakes, 40 million hectare land is prone to floods (12 percent of the total land in India), 8000 km long coastline with two cyclone seasons (8 percent of the total land) show the vulnerability of huge population groups living at these places. These apart, manmade disasters such as fire, accidents, terrorism, etc., accentuate vulnerability to HIV. These disaster situations lead to forced migration due to disaster. People may have to stay in rescue and rehabilitation camps and are in shock, grief, insecurity, due to heavy toll of life, tearing down of infrastructure, major loss of livelihood, which has far reaching economic and social consequence. In such situations poor are more vulnerable and many women have to engage themselves in commercial sex. Such an environment is a breeding ground for HIV transmission.

**Tourism:** Every year millions of tourists, from within the country and abroad, visit places of tourism. Though tourist spots are places of high socio-economic transactions, often times they are also risk zones in terms of HIV transmission. Research studies have shown that tourism is also associated with high rate of risk behaviours (casual unprotected sex, men having sex with men, injecting drug use and pedophilic relationships). Many times, tourists show impulsive behaviours, while the host population exhibit compulsive behaviours. Tourists do not, generally, share the ethos, values and cultural norms of the host community and are driven by enjoyment, experimentation and freedom. On the other hand, host community is often afflicted with poverty and deprivation and hence vulnerable to exploitation and HIV transmission.

**People/Occupations with High Mobility:** Armed forces, business communities, and a variety of new-age jobs due to globalization demand high mobility as job requirement. These people have to leave their families for longer duration of time and may indulge in forced/casual/commercial sex in order to avoid loneliness, frustration, alienation, insecurity and the like. Unnatural sexual practices are also on rise among these population groups. All these situations make the individuals involved at high risk of HIV.

### Check Your Progress III

**Note:** a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1) Briefly describe how poverty accentuates vulnerability to HIV.

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## 3.5 LET US SUM UP

Biological vulnerability to HIV is equal among all human beings. There exists certain social factors that put specific population groups into more risk than others. In this unit, we discussed the socio-cultural determinants of HIV infection. A culture of silence due to taboo with regard to any sort of discussion on sex and sexuality makes adolescents vulnerable to HIV. Lack of adequate information along with prevalent myths and misconceptions about sexuality, masculinity and femininity has the capacity to fuel the spread of HIV pandemic. Social change reflected in family structure and functioning, workplace culture and our attitudes and behaviours also accentuate HIV vulnerability.

Feminization of HIV is a new phenomenon. A patriarchal social structure, skewed power relations, gender roles and expectations, gender associated violence along with biological vulnerability speed up the HIV spread. Stigma and discrimination and care giving issues with regard to gender vulnerability were discussed.

Socio-economic determinants such as poverty, illiteracy, unemployment along with gender discrimination leads to migration, provide fertile grounds for HIV spread. Migrants are inhibited to access information and healthcare system. At the place of destination, factors such as exploitation, loneliness, alienation, insecurity, home-sickness– all these factors drive migrants to indulge in risky behaviours and render them vulnerable to HIV infection. Back at home, they infect their spouses and sex partners.

Lack of adequate healthcare infrastructure also inhibits care and treatment of migrants. Tourism and human trafficking are also highly linked to transmission of the pandemic.

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## 3.6 KEY WORDS

**Migration** is the crossing of the boundary of a political or administrative unit for a minimum period of time. It includes the movement of refugees, displaced persons, uprooted people as well as economic migrants. Internal migration refers to a move from one area (a province, district or municipality) to another within one country. International migration is a territorial relocation of people between nation-states.

**Mobility:** This term denotes movement of people from one place to another temporarily or permanently for a host of voluntary and/or involuntary reasons.

**Source:** It is the native place from where people move to other places.

**Transit:** The places through which people pass, rest or halt for some time and then move ahead.

**Destination:** The place where people go and settle temporarily or permanently.

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### **3.7 FURTHER READINGS AND REFERENCES**

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### **3.8 ANSWERS TO CHECK YOUR PROGRESS**

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#### **Check Your Progress I**

- 1) Social workers may provide adequate knowledge about sexuality issues, HIV and other sexually transmitted infections in different settings like schools (as school social workers), community (CBOs, youth groups, adolescent groups), families (as family centred social work practitioners). Social workers, with their knowledge and skill base, are able to address under the wrap issues and myths, misconceptions related to HIV and even encourage the adolescents not to give in to wrong demands and pressures of their peers. Breaking the culture of silence is a must. Creating conducive environment where adolescents get the adequate information is required. Social workers would be able to make a dent into the situation if they ensure that communication is barrier free and adequate knowledge is passed on to the adolescents.

#### **Check Your Progress II**

- 1) Four vulnerability aspects are:
  - a) Biologically women are more vulnerable to HIV as exposed mucous surface area of vagina is more and because semen has greater viral load than vaginal fluid.
  - b) Patriarchal socialization practices drive females to remain aloof of issues related to their reproductive and sexual health, which also inhibit their accessibility and use of healthcare services.
  - c) Economically, dependence on spouse and family makes it difficult for them to avail care and support services and ART.
  - d) Violence and exploitation on women in terms of domestic violence, trafficking, sexual abuse put them at risk of HIV infection.

### Check Your Progress III

- 1) Poverty coupled with illiteracy restricts access to information and its usage that can prevent them from HIV. It acts as a push factor for migration to urban centres leaving their family back at home. Treatment faced by migrants at urban centres often fills them with frustration, grief, alienation, home-sickness and they may indulge in casual/commercial sex work. Women are forced to sell sex for survival, may face exploitation and trafficking which accentuates their vulnerability to HIV infection. Child labour and children at streets, vulnerable groups to HIV, are the outcomes of poverty.



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## UNIT 4 TESTING OF HIV/AIDS

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### Contents

- 4.0 Objectives
- 4.1 Introduction
- 4.2 HIV Testing
- 4.3 HIV Testing: Types and Ethical Issues Involved
- 4.4 HIV Testing Sites, Procedures and Management
- 4.5 Let Us Sum Up
- 4.6 Key Words
- 4.7 Further Readings and References
- 4.8 Answers to Check Your Progress

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### 4.0 OBJECTIVES

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AIDS, because of the absence of any viable cure till date, is a much dreaded illness. Because of the very reason, individuals become anxious as to whether they would have contracted HIV after casual sex. It should be stated emphatically that no person can be declared as HIV positive merely on the basis of presence of certain symptoms. The only way to confirm whether one has HIV is to get an HIV test done. There are many types of HIV tests available with different specificity and sensitivity. Some of these tests detect antibodies while others test directly the presence of virus in the body. In this unit, the reader would be briefed about various types of tests available for testing HIV.

The unit would also cover the protocols and guidelines to be followed while testing for HIV. You would also be able to understand certain ethical considerations around HIV testing like confidentiality, partner notification and the like. After reading this unit you would also be able to know about certain specific tests required to ascertain the health status of sero-positive people to initiate ART for them.

Lastly, as social workers, this knowledge would help you to guide and refer the suspected HIV cases, as well as people living with HIV/AIDS to visit the physicians or testing centers. It is cautioned that the information given in the unit is not the substitute of any medico person.

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### 4.1 INTRODUCTION

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HIV infection has a unique status in the galaxy of diseases. HIV status brings with it stigma, discrimination, isolation and alienation, not only to the person affected but also to his/her family and relatives. Therefore, HIV testing means a lot to any person suspected to have it; a positive result is perceived to be no less than a death sentence.

However, ignorance is not bliss in this case. Getting HIV test is very much needed for reasons more than one. First, it would help the medical management and treatment of HIV and related ailments. Doctors are in a position to give proper medical advice in order to prolong the AIDS stage. Secondly, HIV testing, often anonymous, ensures blood safety through blood donation. This would minimize HIV transmission through

infected blood transfusion. Thirdly, anonymous HIV testing is done in sentinel surveillances in order to monitor the trends of HIV prevalence, which, in turn, helps in evaluating the existing interventions and designing the future programmes for prevention, diagnosis and treatment of HIV infection in the specific population groups as well as in the general population. Fourth, HIV testing and knowledge about one's own sero-status helps a person plan personal as well as family's future, if the result is positive. The counsellors would provide information regarding maintaining healthy and positive life style and prolonging life span. Fifth, HIV testing may induce behaviour change and prevent further transmission through counselling process. Motivating the client for partner notification is an important aspect of the post-test counselling process. Sixth, for anxious clients who get negative test results, it brings peace of mind of individuals who have been or are indulging in high risk behaviour(s). They would be eventually be dissuaded from unsafe practices and risky behaviour. Seventh, HIV testing is also helpful in identifying asymptomatic individuals, who are engaging in high risk behaviour, so that they do not suffer a sudden break down during the AIDS phase and so that life can be extended. Eighth, HIV testing would help those testing negative to be careful in future, and ensure that they do not indulge in risky behaviours through motivation during counselling. Ninth, HIV testing of pregnant woman can reduce the chances of parent to child transmission to a large extent, if proper medication is taken in. Finally, HIV testing would also help in prophylaxis in the hospitals and reducing the chances of healthcare functionaries from getting HIV infection.

All these benefits of HIV testing are sidelined due to rampant stigma and discrimination prevalent against HIV positive persons. Lack of a conducive social environment, drive many HIV positive persons to hide their sero-status and infect others. Therefore, much emphasis is given on confidentiality in HIV testing and declaration of its results. In subsequent sections, we would be learning about these aspects in the form of guidelines and protocols to be followed during HIV testing.

HIV testing may be mandatory in certain situations or voluntary in most cases. It may be anonymous as in the case of surveillance studies and blood donations, or distinctive and specific, when done voluntarily. Let us first understand different types of tests available, and their characteristics necessary in order to ascertain the HIV status of an individual.

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## 4.2 HIV TESTING

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The only way to ascertain if an individual has HIV is to take an HIV test. HIV status cannot be diagnosed through symptoms, as HIV and AIDS symptoms are not specific, and may be indicative of many other illnesses, which is why an HIV test is the only way to receive a definitive diagnosis.

Generally blood is the body fluid taken for testing of HIV. The test shows the presence or absence of human immuno-deficiency virus in the body. There are mainly three types of HIV tests - the first type of test is the **HIV Antibody Test**; the second is the **Antigen Test**; and the third type is called the **PCR Test**.

One of the most popular HIV Antibody tests is the ELISA Test. ELISA is the acronym for Enzyme-Linked Immunosorbent Assay. It is the standard HIV test that looks for antibodies in a person's blood. When HIV (which is a virus) enters a person's body, special proteins called antibodies are produced. Antibodies are the body's response to an infection. An antibody test is the most common type of test

used to diagnose HIV in individuals. Although HIV antibodies appear in blood within 2-8 weeks after infection, they usually become detectable only after 3 to 12 weeks with the assays that are available currently. This period following the entry of HIV into the body and the appearance of detectable levels of antibodies with the available test kits is called the 'window period'.

So if a person has specific antibodies against HIV in their blood, it means they have been infected with HIV. However, there are only two exceptions to this rule. First, babies born to positive mothers retain their mother's antibodies for up to 18 months, which means they may test positive on an HIV antibody test, even if they are actually HIV negative. This is why babies born to positive mothers may receive a PCR test after birth (about this test you would learn subsequently in this section only). Secondly, some people who have taken part in HIV vaccine trials may have HIV antibodies even if they are not infected with the virus.

ELISA is a commonly performed screening test. Screening assays must detect all positive sera, that is, should be highly sensitive even if some false positive results do occur. Standard HIV antibody (ELISA) tests are at least 99.5% accurate when it comes to detecting the presence of HIV antibodies. This high level of *sensitivity*, however, means that their *specificity* (ability to distinguish HIV antibodies from other antibodies) is slightly lower. Therefore, results of a screening test are never used as the final interpretation of HIV status, and individual is never identified on the basis of one screening assay as technical errors can occur. The serum reactive in screening assay is subjected to confirmatory tests (as per policy and strategy of testing) to be classified as reactive in repeated assays. Therefore confirmatory tests are recommended, which may be ELISA itself or Western Blot or PCR, rapid tests like latex, red cell, comb test, line test, dot-blot assays. In general, in resource-poor settings with relatively high prevalence, a second ELISA test may be used to confirm a diagnosis. The second test is usually a different commercial brand. When two tests are combined, the chance of getting an inaccurate result is less than 0.1%. It may be noted that as per the WHO guidelines, a three-kit ELISA test is used in government hospitals, three kits of different brands so as to ensure correct results to the maximum levels.

Any HIV positive result given by an ELISA test must, therefore, be confirmed using a second test. Secondary tests include:

**Western Blot Assay** – It is one of the oldest but most accurate confirmatory antibody tests. It is complex to administer and may produce indeterminate results if a person has a transitory infection with another virus.

**Indirect Immunofluorescence Assay** – It is just like the Western blot, but uses a microscope to detect HIV antibodies.

**Line Immunoassay** – It is commonly used in Europe. It reduces chances of sample contamination and is as accurate as the Western Blot.

Among these tests, Western blot test is used as a confirmatory test in most of the countries. This test can separately detect antibodies to various HIV proteins. If several types of antibodies are detected then the result is positive; if no antibodies are detected then the result is negative. If the test appears to show only one or two types of antibodies then the result is called indeterminate or inconclusive. There are two main reasons why this can happen. First, it may be that the person has only recently become infected with HIV, and has not developed antibodies. Second, the test may be showing a weak reaction to other antibodies unrelated to HIV. An

indeterminate result indicates that further testing is required. Either the Western blot may be repeated a few weeks later, or a different test (such as PCR) may be used. The risk of a false positive during confirmatory testing is extremely tiny - around 1 in 250,000 for the Western blot, for example.

**Rapid test:** A rapid HIV test is also an antibody test. The advantage of a rapid test is that you do not have to return to get your test result - results are usually available within a few minutes or hours. Rapid tests are single-use and do not require laboratory facilities or highly trained staff. This makes rapid tests particularly suitable for use in countries with limited resources. Though the test is 'rapid' at providing results, it is still an antibody test, so it is advisable to wait for three months after any risk behaviour before taking it. This makes rapid tests very suitable for VCT in resource poor countries. They are rapid, easy to perform and do not require sophisticated equipment, technical expertise and are mostly cost effective. Some of them, particularly comb tests, line tests, etc., are also discriminatory for HIV 1 and HIV 2 antibodies.

The second type of test is an **antigen test**. It is also known as P24 antigen test. Antigens are the substances found on a foreign body or germ that trigger the production of antibodies in the body. The antigen on HIV that most commonly provokes an antibody response is the protein P 24. The P 24 antigen is a protein that is part of HIV. During the first few weeks after someone becomes infected with HIV, p24 is produced in excess and can be detected in the blood serum (although as HIV becomes fully established in the body it will fade to undetectable levels). P24 antigen tests are sometimes used to screen donated blood, but they can also be used for testing for HIV in individuals, as they can detect HIV earlier than standard antibody tests. Some of the most modern HIV tests combine P24 and other antigen tests with standard antibody identification methods to enable earlier and more accurate HIV detection. Because the p24 test can detect HIV infection before the HIV antibody test can, it is used for diagnosing HIV early in the course of infection. It is usually recommended that this test is taken 3-4 weeks after possible exposure to HIV.

The third type of test is a **PCR test**. HIV tests that detect the genetic material of HIV itself (rather than antibodies or antigens) are known as PCR tests. PCR stands for Polymerase Chain Reaction. The whole process of extracting genetic material and testing it with a PCR test is referred to as Nucleic Acid-amplification Testing or 'NAT'. PCR tests detect the genetic material of HIV itself, and can identify HIV in the blood within two or three weeks of infection.

PCR tests come in two forms: DNA PCR and RNA PCR. Babies born to HIV positive mothers are usually tested using a DNA PCR because they retain their mother's antibodies for several months, making an antibody test inaccurate. Blood supplies in most developed countries are screened for HIV using an RNA PCR test, which can produce positive results several days before a DNA test. Both types of test can be used to measure the amount of virus that is present within a person's body (referred to as 'viral load' tests). When a person already knows that she or he is infected with HIV, they may also have a **viral load** test to detect HIV genetic material and estimate the level of virus in the blood. This can be performed using either an RNA or DNA PCR test. PCR tests are not often used to test for HIV in adults, as they are very expensive and more complicated to administer than a standard antibody or P24 test. However, they may be offered in special circumstances, or by private clinics where patients are willing to pay. NAT generally gives positive results much sooner than standard antibody testing, making it useful in situations where

early diagnosis is necessary. An RNA PCR test will produce a positive test result within two to three weeks. A DNA PCR test will provide positive results within three to four weeks (sometimes sooner). False positive results are more common than false negatives due to the PCR Test's sensitivity; hence, all positive results must be double checked using a standard antibody test.

Most people develop detectable HIV antibodies within 6 to 12 weeks of infection. In very rare cases, it can take up to 6 months. It is extremely unlikely that someone would take longer than 6 months to develop antibodies. Getting tested earlier than 3 months may result in an unclear test result, as an infected person may not yet have developed antibodies to HIV. The time between infection and the development of antibodies is called the window period. During the window period, people infected with HIV will not yet have antibodies in their blood that can be detected by an HIV test. However, the person may already have high levels of HIV in their blood, sexual fluids or breast milk. People can transmit HIV to another person during the window period even though they do not test positive on an antibody test.

Further, it is also important that one is not exposed to further risk of getting infected with HIV during the window period. The test will be accurate only if there are no other subsequent exposures between the time of possible exposure to HIV and the test. A negative test at three months will almost always mean a person is not infected with HIV. If an individual's test is still negative at six months, and they have not had unprotected sex or shared needles again in the meantime, it means that they do not have HIV, and will not therefore go on to develop AIDS.

**Check Your Progress I**

**Note:** a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1) What are the situations when a person who is not HIV positive may still show presence of antibodies against HIV in the body?

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2) What reasons would you offer as a counselor for your client who is suspected of HIV but is unwilling to go for testing?

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### 4.3 HIV TESTING: TYPES AND ETHICAL ISSUES INVOLVED

HIV testing has become a delicate issue for reasons more than one. Associated stigma and discrimination has given HIV a unique status. People, after being tested HIV positive, face wide discrimination in their family, community, work place and even at healthcare institutions. Researches have shown that in hospitals, treatment of suspected cases of HIV is postponed till their test results are out and if they are sero-positive, they may have to face denial of treatment. Surgeons would decline from any invasive procedures on suspected and confirmed HIV positive persons, physicians would not even touch them, paramedical staff would show revulsion and detestation and through direct and indirect cues and signs the HIV status of the patient would be disclosed to all.

Positive HIV test results have brought much of exploitation, dehumanizing treatment, overt discrimination and oppression to people. Hence, many hide their sero-status, others maintain anonymity by accessing far off health services avoiding the nearby ones. Initially, doctors would order for HIV test of their suspected patients and without any information, consent or counseling, the patients were forced to get their test done, which would initiate an unending process of stigma, discrimination and oppression. However, NGOs and socially enlightened people had filed Public Interest Litigation (PIL) against the health care institutions for uninformed and mandatory HIV testing followed by discrimination and denial of further treatment in myriad of ways.

This mandatory testing of persons suspecting of carrying HIV infection have created much hue and cry in the country. Testing for HIV, which is merely a biological test, has developed ethical, moral and legal dimensions. Testing without explicit 'consent' of the patients i.e. mandatory testing has proved to be counterproductive in the long runs in the control of HIV epidemic. Mandatory testing can drive the target people underground and make it more difficult for launching intervention. The Government of India's take on this was that there is no public health rationale for mandatory testing of a person for HIV. On the other hand, such an approach could be counterproductive as it may scare a large number of suspected cases from getting detected. People would refrain from knowing their sero-status and getting information, counseling to take appropriate measure to improve their quality of life. When people go undetected, transmission of HIV in the community would be assume proportions no less than a fire in a forest.

Therefore, HIV testing carried out on voluntary basis with appropriate pre and post-test counseling is considered to be a better strategy, and in consonance with the national policy on HIV testing as well as the WHO Guidelines. The government has maintained that HIV testing should be a part of overall comprehensive preventive and promotive programmes. Testing by itself does not result in behavioural changes that can restrict transmission of HIV to others and therefore, testing should be a part of total control programme providing social support, means and skill to reduce or eliminated risk behaviour. The policy guidelines of the government on HIV testing maintains that –

No individual should be made to undergo a mandatory HIV testing

No mandatory HIV testing should be imposed as a precondition for employment for providing health care facilities during employment.

Adequate voluntary testing facilities with pre-test and post-test counselling should be made available throughout the country in a phased manner. There should be at least one HIV testing centre in each district of the country, for voluntary testing in the Government Sector.

No citizen will be forced to undergo an HIV test;

The main ingredients of Voluntary Testing are Informed consent after pre-test counselling, confidentiality and post-test counselling at the time of disclosing of positive as well as negative results. HIV testing for the purpose of confirmation of the sero-status of an individual must always be undertaken after pretest counselling and informed consent. Testing without informed, written and explicit consent, has proven to be counterproductive and has driven the HIV positive individuals underground. This makes prevention and intervention more difficult. Pretest counselling also enables the individuals to face the HIV test results (refer for details in next block).

As per the government policy and international guidelines, the confidentiality of the test results (both negative as well as positive) should be strictly maintained in most cases. This is to respect the privacy and rights of the individuals and to protect them from discrimination, victimization and stigmatization. The test results, the name or the identity of the individuals, and such other details must never be divulged loosely. The test report must be placed in a sealed envelope marked 'confidential' and must be submitted to the clinician who requisitioned the test. The records in the laboratory must be kept secure to prevent access by unauthorized persons. The results are never to be communicated via telephones/fax/emails, etc. Confidential testing means that the results of any HIV test performed will not be revealed to anybody except designated clinic staff, and in some cases, specific public health officials. Confidential testing will usually require a person to give their details (name, age, address) to the clinic performing the test. They then have to contact or return to the clinic after to get the results (unless a rapid test is used). The clinics are legally bound to not reveal personal details and test results. Private doctors also perform HIV tests. In case an individual does not want their name associated with their test, anonymous HIV testing may also be offered. Anonymous testing can either be ensured by a patient giving a false name and address (which can create difficulties if a person tests positive and needs to be informed), or can be specifically requested.

Anonymous unlinked HIV testing is a form of testing used worldwide for research and surveillance purposes, most commonly among pregnant women. Blood samples taken routinely for other tests are additionally tested for HIV. No personal information is taken and there is no way of linking the test results back to the person being tested. The results have no direct individual use but can provide important information for estimating HIV prevalence and incidence.

Though National AIDS Prevention and Control Policy unequivocally said there should be no discrimination in matters of employment to an HIV positive person and that they should be guaranteed rights enjoyed by other members of society, many employers fire their employees on being detected HIV positive, even if their sero-status does not hamper in their job responsibility in any ways. One Constable had approached the Andhra Pradesh Administrative Tribunal, stating that though he cleared the written tests and was provisionally selected for the post of Sub-Inspector, but was denied promotion only because he tested positive for HIV. The Tribunal had rejected his claim going strictly by the Andhra Pradesh Revised Police Manual, which prohibited entry of persons who are HIV positive into government service. He appealed before the Andhra Pradesh High Court, which allowed his claim. Even

the Ministry of Labour maintained that “it was wrong to deny employment or promotion to anyone just because he had tested positive for HIV, sero-positive persons should be guaranteed equal rights to education and employment as other members of the society”. National AIDS Prevention and Control Policy also assert that HIV status of a person should be kept confidential and should not in any way affect his right to employment, position at workplace, marital relationship and other fundamental rights.

There are some of the knotty issues associated with HIV testing. One of them is partner notification. Though international guidelines stress that counsellors can only motivate and persuade the sero-positive clients to notify their sex partners about their HIV status, they shall not notify clients’ partners themselves. However, in India, the Supreme Court, in response to a case filed by an HIV positive widow whose husband hide his sero-positive status at the time of marriage, questioning who is responsible for this, gave the verdict – “it is the responsibility of the healthcare workers to notify the partner if the clients do not do so”. It seems to be a breach of confidentiality but is needed to save the life of many women whose only risk behaviour is their marriage.

There are situations when rights of PLHA come in conflict with those of their partners. It is the right of the PLHA to decide who needs to know his HIV positive status. However, if he decides not to notify his partner, then it would be injustice to his partner. Further, doctors also claim that they need to know the HIV status of the patient for his/her treatment. Relatives or caregivers, in the hospital, also insist to know the sero-status of their patient. However, responding to such precarious issues, the NACO guidelines indicate that only partner notification is a must, while medical staff, doctors and nurses, need to observe universal precautions. If there is a need to break confidentiality at the time of partner notification these steps should be followed: first encourage client to tell on his own to his partner about his HIV positive status; if he is adamant not to disclose, then warn and if he still does not notify, then counselor should inform.

Another knotty issue whether or not children should know their status as well as their parents’ HIV status. It is recommended that as soon as possible, children should be informed about their own HIV status as well as that of their parents, and that parents themselves should inform the child. Children are able to absorb the shock if parents themselves notify them. In situations where they come to know from outside sources contoured with stigma, labeling and derogation, it has found to have detrimental effects on children.

### Check Your Progress II

**Note:** a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1) What is the difference between mandatory, voluntary and routine HIV testing?

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## 4.4 HIV TESTING SITES, PROCEDURES AND MANAGEMENT

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As seen in earlier sections, HIV test is not merely a biological or pathological test. It involves many complexities, dilemmas, moral and ethical concerns, legal issues, human rights and social justice. In this context, let us first understand the sites for HIV testing. In most countries, there are many places for testing of HIV. It is recommended that one gets the HIV test done at a health clinic or at a specialist HIV/AIDS Voluntary Counselling and Testing (VCT) site. At these sites, often doctors, trained counsellors, and other health professionals are available to provide required inputs. HIV testing is done in the pathology labs in hospitals, private labs, dispensaries and so on. However, NACO has initiated establishment of Integrated Counselling and Testing Centres (ICTC) at various places, where people can come and get their HIV test done after informed consent and proper counseling with surety of confidentiality. The ICTC is an extremely important component of HIV/AIDS care, prevention and control programme. Its services are holistic and integrated as it serves as an entry point for HIV counseling, testing, treatment of opportunistic infections, ART, psychosocial support and referral to appropriate services.

According to NACO guidelines, the ambiance and infrastructure of ICTC should be conducive for the client to confide in the counsellor and undergo testing. ICTC should be easy to locate and there should be proper sign boards and use of symbols for non-literate clients. Its name should be non-stigmatized one, easily understandable and preferably in local language. The waiting area should be in close proximity to the counselling and blood collection site. It should be well lit and with adequate ventilation and sufficient sitting space. It should have toys for children accompanied by parents, books, posters, brochures, IEC materials to provide information related to STI/HIV. There should be two separate rooms for counseling – one each for the male counselor and the female counsellor. The rooms should be sound proof so as to ensure confidentiality. Further, core staff should comprise of ICTC manager, counsellors and lab technicians. Guidelines insist that qualification for counsellors should be masters in the discipline of social work or psychology, with counselling as a separate paper and essentially with practical exposure to counselling/casework.

Let us briefly look at the procedure for counselling and testing. The client on reaching the centre is registered, and he/she is given a personal identification number/digit (PID). Client is administered pre-test counselling during which he/she is informed about HIV, how it spreads, how it causes disease, window period, possible need for testing, implications of positive and negative test results, false negative and false positive test, the risk behaviours, the treatment, and services available. This information is updated and is conveyed to the client in a language understood by him/her. On the basis of knowledge gained, the client makes informed decision to either undergo HIV testing or not. If the client agrees, a written informed consent is given to him/her for signing. The next step is the collection of blood sample as per the blood collection guidelines, and the client is asked either to wait, if there is facility/time to do rapid testing. Otherwise, the client is issued a paper with his/her PID Number and requested to collect the report on a specified date, usually by the third day.

Generally, at ICTC, the rapid HIV testing is performed in accordance with the guidelines. Results are interpreted and report is prepared as negative, positive or indeterminate. Necessary entries are made in the relevant registers. The client comes to collect the report, which is given during post test counseling. In case of the report

being negative, the counselling is aimed at reducing the chance of risk behaviour. The client is also educated regarding strategies of risk reduction. In case the test result is positive, the client is provided psychosocial support and is informed about availability of treatment and other services. This is done to help the client cope with the positive result and in order to give him/her hope. Importance of safe behaviour is stressed again to prevent secondary transmission of HIV. In case, the result is indeterminate the client is called for repeat testing after 14-28 days. In case, the result continues to be indeterminate, the client is referred to National Reference Laboratory for further testing. If required, the client is referred to ART Centre. In case the female client is pregnant, she is referred to PPTCT centre for further management. All the records are maintained at the ICTC as per the guidelines, and confidentiality of test is maintained. The client is counselled to get the spouse/children tested for HIV. The client is provided referral as per the requirements.

It is generally recommended that the HIV test is done in a health care setting. However, in some countries 'home sampling' kits are available. With a home sampling kit, a person can take a sample (usually a blood sample) and then send it to a laboratory for testing. A few days later the person phones up a special number, gives their individual identification code, and is given the result over the phone. If the result is positive then a professional counsellor will provide emotional support and referrals. For home sampling, the major advantages are convenience, privacy and anonymity. However, the major disadvantage of this approach is lack of opportunity for pre-test and often post-test counselling, where client is prepared for test results and also provided useful information with regard to prevention of transmission of HIV and its management.

Now-a-days, HIV test kits are also available for testing at home. It maintains confidentiality and anonymity, but without any scope for counselling. Reactive test results must be confirmed by further testing at a clinic. If purchased over the internet, there could be no guarantee regarding the genuineness of test kit nor the accuracy of the test results. In the event of an incorrect result, there may be no legal recourse.

Currently, HIV testing is done in serum/whole blood and plasma. In some countries other body fluids like urine, sputum, etc., are also used. In India, other than blood and blood products, HIV testing on urine and saliva have not been evaluated nor validated.

In recent times, a large number and wide range of rapid tests of high quality have become available and are currently being used worldwide in various situations like emergency cases, points of care like VCTC, ICTC, PPTCTCs, etc. Different types of rapid tests are: dot blot assay, lateral flow assay, dip-stick, comb test, etc. Their advantages are follows: they are easy to perform, very rapid, requires no complex equipment and only limited infrastructure. Some assays can be stored at room temperature, such tests have wide temperature range stability, can be used at remote peripheral labs and in situations when same day results are required. Management of waste generated by rapid test is easier to dispose off.

**Tests Related to Management of HIV:** Many pathological tests are conducted on PLHA for assessing their health status depending upon the types of ailments cropping up in the body. As you are aware, out of a wide range of opportunistic infections, a few may afflict the health of PLHA. Depending upon the symptoms, doctors suggest certain pathological tests for the PLHA such as tests for Haemoglobin, ESR, tuberculosis, bacterial and fungal infections, and so on. However, one specific test done on PLHA is CD4 count test that needs mention.

Now, let us attempt to understand what the CD4 test is. It may be reiterated that HIV attacks type of immune cells called the T-helper cells. These cells carry a protein called CD4 on their surface, which HIV uses to attach itself in the body. The T-helper cells play an important part in the immune system by helping to coordinate all the other cells to fight illnesses. A major reduction in the number of T-helper cells can have a serious effect on the immune system. HIV damages many T-helper cells and as a result, there are fewer cells available to help the immune system. A CD4 test measures the number of T-helper cells (in a cubic millimetre of blood). Someone uninfected with HIV normally has CD4 count between 500 and 1200 cells/mm<sup>3</sup>. In a person infected with HIV the CD4 count declines over a number of years. Doctors often use test of CD4 count as a parameter to appraise health status of PLHA and even to take decision regarding when to start antiretroviral treatment for HIV.

In most of the countries, generally the CD4 test is used to determine when a person should start treatment. Though there is variation between the guidelines on initiation of ART between different countries, treatment is generally recommended when the CD4 test indicates a count less than 350 cells/ mm<sup>3</sup>. When this happens, other factors may also be taken into account, such as viral load and opportunistic infections. The World Health Organisation (WHO) has a method of describing the different stages of HIV disease based on clinical symptoms, known as the WHO staging system for HIV disease and is useful for healthcare settings with poorly equipped medical facilities. The table below shows the WHO guidelines to starting treatment in countries with limited resources, based upon the stages of HIV disease and whether a CD4 test is available or not.

WHO clinical staging	CD4 testing unavailable	CD4 testing available
1 Primary HIV infection	Do not treat	Treat if CD4 count is below 200
2 Clinically asymptomatic stage	Do not treat	
3 Symptomatic HIV infection	Treat	Consider treating if CD4 count is below 350 start treating before CD4 count falls below 200
4 Progression from HIV to AIDS	Treat	Treat irrespective of CD4 count

Before ART is initiated basic clinical assessment is generally carried out. This includes determination of existing medical conditions (such as hepatitis, TB, pregnancy, injecting drug use and major psychiatric illness), assessment of current medications (including traditional and herbal medications), weight measurement and assessment of patient readiness for therapy.

**Check Your Progress III**

**Note:** a) Use the space provided for your answer.

b) Check your answer with those provided at the end of this unit.

1) Differentiate between HIV testing at home and at designated sites like ICTC.

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## 4.5 LET US SUM UP

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In this unit, we learnt about various types of testing like testing of antibodies (ELISA, Western Blot, rapid tests), test of P24 protein linked to HIV virus and PCR test to detect presence of virus and/or its load in the body fluid. Antibody test because of its cost effectiveness, accuracy, specificity and sensitivity is considered to be the standard one and is widely used in voluntary screening of HIV. PCR is costly but is not dependent on window period for its accuracy. Likewise, P24 test also detects presence of virus in early periods of infection.

Mandatory testing has had boomerang effect, because, of associated stigma and discrimination, suspected people declined from testing. Voluntary testing associated with pre-and post-test counselling is considered ideal and is recommended in the NACO policy on testing. Pre-test counseling provides needed information, prepares individuals for the results and is a platform for taking informed consent. Post-test counseling aims at behaviour change, adopting healthy, safe life style and linkage with needed services. Partner notification is a delicate and sensitive issue if client is unwilling to disclose his/her sero-status to his/her sexual partner. The Supreme Court issued a directive making it the duty of healthcare functionary to inform the partner of the client, if he/she after persuasion does not do so. Children should also be informed about their sero-status preferably by their parents as early as possible.

Integrated Counseling and Testing Centres are popular sites of HIV testing, management and care. Adequate procedures are in place to ensure confidentiality and conducive environment to clients coming for testing and care. Testing at these sites is considered better than home testing. Next, certain pathological tests such as CD4 count tests are important, so as to manage health status of sero-positive clients.

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## 4.6 KEY WORDS

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**Sensitivity of HIV test:** it is the accuracy with which a test can confirm the presence of an infection. Tests with high sensitivity show few false negatives and are meant to be used to screen blood prior to transfusion and ensure blood safety.

Sensitivity =  $\frac{\text{True Positive (TP)}}{\text{TP} + \text{False Negative (FN)}} \times 100$

TP + False Negative (FN)

**Specificity of HIV test** refers to the accuracy with which a test can confirm the absence of an infection. Tests with high specificity show few false positives and are to be preferred for the diagnosis of HIV infection in an individual.

Specificity =  $\frac{\text{TN (True Negative)}}{\text{TN} + \text{FP (False Positive)}} \times 100$

TN + FP (False Positive)

**Window period:** It is the time period between the initiation of HIV infection in the body and development of antibodies to levels that make it detectable using the currently available assays.

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## 4.7 FURTHER READINGS AND REFERENCES

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1. Greene, K., Derlega, V.J., Yep, G.A. & Petronio, S. (2003): Privacy and Disclosure of HIV in Interpersonal Relationships: A Sourcebook for Researchers and Practitioners. New Jersey: Lawrence Erlbaum Associates.

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3. Kalichman, S.C. (1998): *Preventing AIDS: A Sourcebook for Behavioral Interventions*. New Jersey: Lawrence Erlbaum Associates.
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## **4.8 ANSWERS TO CHECK YOUR PROGRESS**

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### **Check your progress I**

- 1) The two situations are:
  - a) Babies born to positive mothers retain their mother's antibodies for up to 18 months, which means they may test positive on an HIV antibody test, even if they are actually HIV negative. b) Some people who have taken part in HIV vaccine trials may have HIV antibodies even if they are not infected with the virus.
- 2) As counselors we would motivate the client who is frightened of taking an HIV test on following points:

Rather than spending days, months and even years, worrying about the possibility of having HIV, it is better to know your status.

If you are diagnosed as HIV negative, you would get peace of mind. You would be encouraged to adopt a safe and healthy behaviour.

If you are diagnosed as HIV positive, you can be offered emotional support, and advice on what to do next. Doctors would be able to manage and treat you in a better way after knowing your sero-status, which also includes initiating antiretroviral treatment if necessary (and available).

You can also take measures to ensure that you protect your partner and your offspring from getting HIV.

### **Check your progress II**

- 1) Mandatory HIV testing means that undergoing HIV test is compulsory and one cannot refuse it. Voluntary testing gives the individuals choice over whether to be tested or not. It means that it is the conscious, informed and 'free' choice of individuals to get tested for HIV. Routine testing means the test is automatically performed, like in cases of pregnancy, organ donation, unless the individual concerned raises an objection and 'opts out'. Both voluntary and routine HIV tests require a person's full written or verbal consent.

### **Check your progress III**

- 1) HIV testing at home is done using rapid test kits, where an individual can easily detect his/her sero-status without involving any healthcare functionary. This ensures full confidentiality and anonymity. However, pre-post test counselling is not available to individuals opting for HIV testing at home. Contrary to this, ICTC ensures informed consent to the client along with pre-post test counselling. At the ICTC, complete and adequate knowledge is provided to the clients during regarding HIV, safe behaviours, risk reduction, partner notification, ART, support groups, services and so on. These are unavailable if testing is done at home.

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## **UNIT 5 TREATMENT AND CARE, VACCINE ISSUES**

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### **Contents**

- 5.0 Objectives
- 5.1 Introduction
- 5.2 HIV/AIDS Treatment
- 5.3 Comprehensive Treatment and Care
- 5.4 Issues Concerning AIDS Vaccine
- 5.5 Let Us Sum Up
- 5.6 Key Words
- 5.7 Further Readings and References
- 5.8 Answers to Check Your Progress

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### **5.0 OBJECTIVES**

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Treatment and care for AIDS patient were non-issues in the initial reports of the NACO (National AIDS Control Organization). The issue of care was taken up as one of the key components only during the Second Phase of the National AIDS Control Project (1999-2004). Most of the literature on AIDS documents the need for care and treatment of opportunistic infections. But data from various studies shows how the patients are left to fend for themselves. The need for emotional support and a sufficient diet for AIDS patients also emerge as central concerns. Therefore separating one from the other at the level of intervention would prove ineffective. Hence, they will be dealt with together in this unit.

This unit will enable the learner to:

- understand the drugs and therapy used for treatment of HIV/AIDS
- appreciate the various types of care required for and given to people living with HIV/AIDS (PLHAs)
- vaccine trials and the emergent ethical issues

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### **5.1 INTRODUCTION**

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For the first decade and a half after the discovery of HIV there was neither a cure nor any treatment available. The mutative nature of HIV makes it difficult to invent a vaccine, a cure or for that matter an appropriate treatment. HIV attacks the immune system, which defends the human body against pathogens. When the balance tilts against the immune system, the people living with HIV/AIDS (PLHA) become more susceptible to opportunistic infections (OIs). With the body's immune system incapacitated to defend itself against OIs, the PLHA ultimately succumbs to them.

In this unit we will examine how with the introduction of combination ARV (Anti-Retroviral) therapy in 1996, HIV became a manageable disease for the vast majority of PLHAs. However, the prohibitive costs of the drugs and the necessary monitoring tests make ARVs unaffordable for most PLHAs, especially those living in developing

and least developed countries. In developed countries, the cost of ARVs has been borne mostly by the State and partly through insurance. As a result, there has been a marked decrease in the number of deaths on account of HIV in the past 10 years. On the other hand the number of deaths in developing countries due to HIV continues to spiral. As HIV largely affects the young and productive populations, economies in some countries have been affected by the HIV pandemic.

We will also discuss on how the expanding access to treatment provides an incentive for people to come forward to be voluntary tested for HIV. Even as ARV treatment and treatment for OIs helps suppress the disfiguring symptoms of AIDS, it also helps allays people's fears of contracting the 'fatal' disease. As a social worker we need to develop a cumulative effort which would be to break the barriers of stigma and discrimination, which need to be overcome for effective prevention strategies.

Comprehensive HIV/AIDS care is therefore the need. Different disciplines ranging from medical care to social support are needed. Social workers can work in settings such as clinical care and nursing care; in providing counselling and psychosocial support to individuals; generating opportunities for employment or financial support; locating appropriate housing in "appropriate" neighbourhoods; providing care and support of orphans and widows; as well as training in the care and prevention for home caregivers, etc.

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## **5.2 HIV/AIDS TREATMENT**

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The first line of management for a PLHA is ensuring her/his healthy lifestyle. The second is the treatment of OIs. The most occurring OIs in India are Tuberculosis, Candidiasis, Cryptosporidiasis, Herpes Zoster, Toxoplasmosis, Bacterial Pneumonia, Cryptococcal Meningitis, PCP and Kaposi's sarcoma; all of which are treatable and curable. As the viral count increases and the immune system is compromised, it becomes essential to try and restore the balance by lowering the viral load in the body of a PLHA. ARVs do this, enabling PLHA to live longer, healthier lives.

### **Anti-Retroviral Therapy**

The first drug discovered in 1987, acted in the *reverse transcriptase* enzyme so that pro-virus DNA would not be formed. Since then, various drugs acting on the reverse transcriptase have been discovered. Two groups of drugs: 1) Nucleoside Analogue and 2) Non-nucleoside analogue were discovered and used until 1998. These were the drugs, which acted on the enzyme protease, which helped in the maturation of m-RNA to mature virions. These drugs were known as protease inhibitors. In effect, the anti-retroviral drugs, acts on the various stages of the life cycle of the virus in the human body stopping the replication of the virus; nevertheless, it does not get the virus out of the human cell where they are firmly integrated. However, these drugs remain very costly, and the Government of India has pledged to support provision of drug program with the help of DFID, Clinton HIV Initiative, USAIDS, and other funding agencies.

The WHO, in 2002, included ARVs in its Model List of Essential Medicines. This list presents, "a list of minimum needs for a basic health care system, listing the most efficacious, safe and cost effective medicines for priority conditions". The ARVs included and also available in India are as follows:

1. Reverse transcriptase inhibitors
  - (i) Nucleoside analogue: AZT (azidothymidine, zidovudine) – 100 mg each tablet; DDC (zalcitadine) – 75mg each tablet; Stavudine – 100 mg. tablet each; Lamivudine – 150mg. tablet each; Didanosine; Di – deoxyadenosine (ddA).
  - (ii) Non-nucleoside analogue: Nevirapine – 200 mg. tablet each; Delavirdine, Sustiva, thiobenzimidazoline derivatives.
2. Protease Inhibitors
  - (i) Saquinavir (SQV)
  - (ii) Ritonavir (RTV)
  - (iii) Indinavir (IDV)
  - (iv) Nelfinavir (NFV)

Currently 107 government hospitals are providing ART and CD4 count test free of cost. ART is also available for children in 87 centres. In addition, ART is also being provided by the private sector. National AIDS Control Programme (NACP)-III has scaled up this service to a large number of people through effective public-private partnership as well as community partnership.

The WHO has also release guidelines for a public health approach to the scaling up of ARVs in resource limited settings. According to the National Guidelines for Clinical Management of HIV/AIDS, nearly all these drugs are available in India. There has been some debate over the efficacy of combination ARVs. However, it is now accepted that ARVs “reduces viral replication, prevent the emergence of resistance and, ultimately, prevent treatment failure for a significant amount of time”. ARVs thus lead to improved rates of mortality and morbidity, prolonged lives and improve the quality of life. Different views have been posted on when ARVs should be commenced. In order to provide uniformity the WHO has issued guidelines, which lay down when ARVs should be started.

### **Treatment of HIV-related opportunistic infections**

As the immune system becomes increasingly damaged by HIV, it becomes more susceptible to opportunistic infections. These infections would usually be fought off by a healthy immune system, but a low CD4 cell count means opportunistic infections such as PCP (a type of pneumonia) can be life-threatening. If one of these illnesses becomes a serious problem, antiretroviral treatment may be advised immediately. Treatment should only be started once the person is ready. A lot of commitment is needed, since following a drug regime can be quite demanding and in most circumstances, the treatment will have to be taken for life. Once it is decided that treatment should be started, doctors will advise of the various HIV drugs and combinations available, which might be most suitable.

Some opportunistic infections are easier to treat than others. Effective treatment depends on health services being able to procure, store, select and administer the necessary drugs and to provide related treatment, care and diagnostic services to monitor health status and treatment response. A few opportunistic infections and symptoms such as candidiasis of the mouth, throat or vagina (thrush), herpes zoster (shingles) and herpes simplex can be managed effectively through home-based care. In a home-based care setting, diagnosis is made by observing symptoms. Some opportunistic infections may be diagnosed by observation or using a microscope, and treated where there is minimal health infrastructure. Such infections include pulmonary tuberculosis and cryptococcal meningitis.



In a setting with reasonable infrastructure, the facilities available include X-ray equipment and culture facilities. Using these, opportunistic infections such as extrapulmonary tuberculosis, cryptosporidiosis, isopsoriasis, PCP and Kaposi's sarcoma can be diagnosed and treated. Opportunistic infections such as Toxoplasmosis, MAC and Cytomegalovirus infection can be diagnosed and treated in places with advanced infrastructure. Treating these infections is often impossible in resource poor countries. Many developing countries lack the advanced equipment and infrastructure (such as CT scanning) needed to treat these complex infections.

**Check your progress I**

**Note:** a) Write your answers in the space provided.

b) Check your answer with the model answers at the end of this unit.

1) What do you understand by Opportunistic Infections (OIs) in HIV/AIDS? What are the most commonly occurring OIs in India?

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### 5.3 COMPREHENSIVE TREATMENT AND CARE

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In this section we will discussed on various critical issues that needs to be considered while providing comprehensive treatment and care to HIV patients. We will talked about comprehensive treatment and care which consists of a number of different elements, including voluntary counselling and testing (VCT), food and nutrition, support for the prevention of onward transmission of HIV, follow-up counselling, protection from stigma and discrimination, spiritual support, the provision of antiretrovirals (ARVs), treatment of STIs, management of nutritional effects, prevention and treatment of opportunistic infections (OIs), traditional treatment, palliative care, preparing for death, family and orphan support.

Therefore in this section we will specially focused on the role of Social Workers while providing comprehensive treatment and care, considering the fact that people suffering from HIV/AIDS have differing needs according to their stage of infection

#### Critical issues for treatment programmes

The following issues need to be considered before, during and after providing treatment and care not only to the PLHAs but to their family members as well:

#### Counselling, testing, and treatment awareness

HIV counselling and testing is particularly important as a starting point for access to other HIV/AIDS-related services. If a person does not know they are infected, they cannot get any treatment or care. In most cases, people are diagnosed HIV positive only when they are already seriously ill. At this point, there are fewer opportunities for cost-effective interventions. Therefore the Social Worker should, in addition to providing enough HIV counselling and testing facilities to meet demand, it is important to encourage people to use these services. Raising awareness of the

benefits of treatment provides people with an incentive to learn their HIV status, and so should help to increase demand. However, in many societies fear of stigma and discrimination remains a serious barrier to testing. The Social Worker should work diligently to help overcome this problem, by moving towards offering every patient an HIV test as a routine part of health care, regardless of symptoms.

Before starting ARVs, a PLHA must be counselled and the treatment should be started only after obtaining voluntary informed consent from the client. All the factors must be considered to determine whether ARVs can be sustained lifelong, and also to ensure that there is availability of alternate drug regimens in the event of treatment failure.

### **Helping people to meet programme requirements**

As a social worker we should understand that in order to help patients, who are most likely to benefit from antiretroviral treatment, it may be necessary, for example, to arrange transportation in order to help people meet these requirements. Also, the treatment strategy may require people to find the support they need to cope with the demands of treatment, whether it be from friends, family or support groups. Those who have alcohol dependence, substance abuse, or depression, need to be helped to overcome their problems before they start treatment. One of the main obstacles in accessing health care in general is the cost involved. The same insurmountable barrier exists for PLHAs who try to access ARVs. The Indian pharmaceutical industry took the lead in lowering prices of ARVs resulting in a world wide decline in prices. Despite this, the cost of ARVs coupled with the cost of monitoring tests is approximately Rs. 4,000 per month for the first line of treatment per month, making the treatment inaccessible for most PLHAs in India.

### **Nutrition**

Even in the absence of treatment, someone who has HIV is likely to remain healthy for longer if they have an ample and nutritious diet. The need for good nutrition also applies to those who are receiving treatment, especially because some of the drugs should be taken on a full stomach, and moreover, little is known about the effects of antiretroviral on malnourished people. Furthermore, if someone lacks an adequate food supply, they are less likely to be able to adhere to a daily treatment regimen. Hunger is a much more immediate problem than the threat of AIDS, and desperate people may even resort to selling their drugs to feed themselves and their families. For all of these reasons, we should consider nutritional support to be a key component of AIDS treatment programmes.

### **Treatment for other infections**

By the time someone reaches the stage of HIV infection at which treatment is required, they are often suffering from opportunistic infections such as Tuberculosis and Candidiasis. Treatment centres must be able to provide medication for these infections as well as the underlying HIV infection. Social workers must also educate patients regarding the possible harmful interactions between antiretroviral and other pharmaceutical drugs as well as alternative therapies.

### **Reliable supply chains**

Antiretroviral drugs can stop working if they are not taken every single day. It is therefore essential to maintain an uninterrupted supply of medication, from the factories where the drugs are made all the way down to the rural villages where they are

needed. This difficulty exists in India because of the chronically weak and unreliable distribution systems for all kinds of medicines. Transport and communication networks too are often very poor. Social Workers needs to develop initiatives to remedy this situation or network with those international agencies which have taken initiatives in this regard, which include the AIDS Medicines and Diagnostics Service (AMDS), whose partners include UN agencies, USAID, the Clinton Foundation and various other non-governmental organizations. AMDS collects and distributes information about drug pricing and supply chains, as well as providing technical assistance to supply chain managers.

### **Trained Staff**

Shortage of trained staff is one of the most serious problems facing antiretroviral treatment programmes. One reason for the paucity of health workers in poor countries is the international poaching of doctors and nurses by the cash rich Europe and North America. Skilled professionals are lured abroad by better working conditions and much better pay. This migration satisfies the needs of the rich countries, but drains resources from nations that can ill afford to lose the workers on whom they had spent so much money for training. In response, as a social worker we should be working hard to expand recruitment and training schemes and try to influence policy makers.

### **Treatment Adherence**

Ensuring thorough follow-up care is not only important on an individual level (as the drugs are only effective if taken everyday for life), but is also important on a public health level, since it reduces transmission of drug resistant HIV. Therefore a major challenge for social worker is ensuring adherence, as unfortunately not all PLHAs can benefit from ARVs treatment. A significant number cannot tolerate ARVs because of toxicity and/or due to drug resistance. Once ARVs are commenced, they have to be continued for life.

### **Universal Access**

It is relatively easy to provide treatment where there is good infrastructure in the form of voluntary testing centres in antenatal clinics as well as the availability of medicines. It is much harder to move into rural areas and reach people who have little or no contact with health services or community organizations or NGOs, or to reach marginalized groups such as refugees, prisoners and injecting drug users. Social Workers need to look for innovative ways to reach the most underserved population groups as they strive for universal access. One example is the use of mobile outreach services to take drugs from treatment centres to outlying communities on a regular basis.

### **Traditional Healers and Medicine**

Social Workers need to understand that, traditional treatments for HIV/AIDS can be attractive as they are accessible, culturally appropriate and acceptable. They may also be affordable in resource poor countries like India. However, there is little evidence that such therapies are safe or effective in treating HIV infection. Whilst some of the traditional treatments may be helpful, others may do more harm than good. Traditional medicine should not replace more proven modern treatments if they are available. However, in the absence of such treatments, traditional medicine can be promoted as a feasible option if it relieves pain and makes the patient feel better. So also, traditional healers especially faith-healers, exorcists, magic-men may

be integrated as first line contact points who may encourage interface with the health services.

## **End of Life Care**

### **Palliative Care**

End of life care is an important part of palliative care. In many resource poor countries, the existing health infrastructure is inadequate to provide care in a hospital for people who are approaching the end of their life. Often, the only option available for care of people with AIDS is care at home, and even when hospital care is available this may not be what people want. Whether in a hospital, hospice or home, palliative care aims to provide comfort and support for people who are terminally ill and, ultimately allow them to die with dignity. This can involve controlling pain, treating symptoms such as diarrhoea and vomiting, relieving psychological or spiritual anguish, and also supporting families and caregivers.

### **Preparing for Death**

It is often believed that it is not appropriate to talk about the fact that somebody is going to die, and that mentioning death will in some way hasten it. However, for those who wish to discuss death, an open discussion, ideally from early diagnosis, can help dying people to feel that their concerns are heard, that their wishes are followed, and that they are not alone. Most people yearned to be assured that they will be remembered. Encouraging friends and family to share stories or memories of the person's life makes the person feel loved and cared for. People nearing death, are frequently afraid of dying in great pain. Social workers or carers should be able to reassure patients that pain relief will be carried out up to the point of death. Another great worry is what will happen to patient's dependants after they die. Where ever possible, the social worker should make plans for dependants and partners. Although it can be distressing to discuss such issues, formulating plans may help reduce anxiety. Negotiating a will can also prevent family conflict and ensure that partners and children are not left destitute. This is particularly important in India, where 'property grabbing' is a widespread phenomena.

Practical issues to be discussed before death include:

- custody of children
- family support
- drafting up a will
- funeral costs
- future school fees

Emotional issues to be discussed before death could include:

- resolving old quarrels, especially with close relatives capable of providing social support
- assuring the patient and family members that they are loved
- sharing and shaping hopes for the future especially for children who are left behind
- bidding goodbye to caregivers and providers

### **Family and orphan support**

Looking after someone with HIV can be very daunting and distressing task for family members, partners and friends. And the need to offer counselling to partners

and families following the death of a family member or friend is often overlooked, particularly in resource poor countries. Counselling can help a person to discuss their loss and to mourn appropriately. The process of grieving may last many months, and possibly even years. Further still, family members may have unresolved fears about HIV infection for themselves, social workers can help to come to decisions about HIV testing. However, for some people a single counselling session may be sufficient to clarify their thoughts and relieve them of their feelings and reassure them that they are coping as best as they can under the given circumstances. Other people may need several sessions. Some people may even never completely come to terms with a loss, particularly that of a child. The impact of the loss of life differs across families and communities. An even more distressing fact is what happens to a child's life, she or he loses a parent. More than 15 million children under 18 have lost one or both parents to AIDS. Caring for these children affected by HIV/AIDS requires concerted action at all levels. In the countries hardest hit by HIV/AIDS, care for orphans lies often with their extended families or communities.

**Check your progress II**

**Note:** a) Write your answers in the space provided.

b) Check your answer with the model answers at the end of this unit.

- 1) List down some of the critical issues that need to be considered by a Social Worker while providing treatment and care to HIV/AIDS patients.

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## 5.4 ISSUES CONCERNING AIDS VACCINE

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Public health officials have placed enormous hope on the potential of an HIV vaccine to bring the global HIV/AIDS epidemic under control. For decades, vaccines have proven to be among the most powerful and cost-effective disease prevention tools available. Vaccines if discovered, will also have potential advantages over existing HIV prevention interventions; they can reach populations that otherwise have limited access to health care and especially prevention services, and they need not depend on consistent and sustained behavior change by millions of individuals.

An HIV vaccine capable of controlling the pandemic would need to satisfy several criteria. It would need to be effective against multiple strains (or clades) of HIV, especially those predominant in developing countries. It would have to be made accessible to at-risk populations throughout the world, including populations with minimal ability to purchase the vaccine. And it would have to be deliverable in developing countries with rudimentary health care infrastructures. Each of these priorities presents special challenges to scientists and policymakers. Yet numerous scientific, ethical, public policy issues and challenges remain before a vaccine can reach all those who need protection from HIV. In the next section of the unit we will discuss the various issues concerning the vaccine, ranging from ethical to accessibility and try to locate social workers role in the whole process.

## The Status of Research

Vaccines against HIV are being developed, and remain in various stages of clinical trials, yet none have proven effective till date. It is important to conduct research to find an effective vaccine because:

The availability of a safe, highly effective and accessible preventive HIV vaccine would be a valuable complement to other preventive interventions, significantly contributing to the interruption of the chain of transmission of HIV.

Well conceived HIV immunization strategies could reach populations where other interventions are not sufficiently enough.

Research on preventive HIV vaccines is providing new information on the possible use of vaccines as therapeutic interventions, to be used in association with anti-retroviral therapies (ARTs), which could lead to its lowering in the cost of the treatments and to an increase in their long term efficacy.

The candidate vaccines need to be tested on healthy human volunteers through sequential phases. Phase I and II trials provide data on the safety of the candidate vaccines and on their ability to induce immune responses specific to HIV. These trials are done among small numbers of volunteers (50 – 200 per trial). Depending of the results obtained, candidate vaccine can proceed to large scale phase III trials, to obtain their efficacy in inducing protection against HIV infection or AIDS. For scientific reasons, Phase III trials are done in populations with high incidence of HIV infection, involving thousands of volunteers.

Since 1987, more than 30 HIV candidate vaccines have been tested in approximately 60 Phase I/II trials, involving more than 10,000 healthy volunteers. Most of these trials have been conducted in the United States and Europe; several have also been conducted in developing countries such as Brazil, China, Cuba, Haiti, India, Kenya, Peru, Thailand, Trinidad and Uganda. The results have confirmed the safety of the vaccines, and have provided important scientific information to develop newer generations of candidate vaccines with better ability to induce anti – HIV specific immune responses. Nearly all vaccines are based on being able to induce a strong enough CTL (Cytotoxic T-Lymphocytes) response to afford protection. The best vaccine would be the one which can stimulate both antibodies and CTL response. Some of them are:

AIDSVAX, a gp 120 based vaccine that has reached to Phase III clinical trials.

CTL inducing vaccines which can prime the CTLs to target a range of viral proteins and not just those on the outer surface of the virus. Unlike neutralizing antibodies, it will not stop an infection, but by killing infected cells, the CTLs can hold down viral load in the body.

A recombinant adeno-associated virus (rAAV) acts as vector (harmless virus) carrying three genes of the HIV subtype C, the strain that is common in India and South Africa. These viral vectors are capable of infecting cells naturally, and evoking an immune response.

Modified Vaccina Ankara (MVA) acts as vector, and it carries six HIV genes that have been optimized to match those strains circulating in India.

Sub unit vaccine: a vaccine that contains only part of the virus or other micro-organism. HIV subunit vaccines produced by genetic engineering are referred to as recombinant subunit HIV vaccines.

The WHO-UNAIDS HIV Vaccine Initiative is collaborating with national authorities, laboratories and scientists working with HIV vaccine development and evaluation across the different continents.

### **Incentives for Private Sector Involvement**

Despite the urgent public health need, HIV vaccine research is at best a questionable financial investment; private sector pharmaceutical and biotech companies, which play a critical role in vaccine design and manufacture, have not raced to develop a vaccine for HIV. The scientific challenges are daunting, and the development timeline is long, expensive, and unsure. In addition, the vast majority of people who need an HIV vaccine live in developing countries, where there are few resources to pay for health care or vaccines. This concern about the lack of a paying market in developing countries discourages private companies that fund HIV vaccine research from investing in research on products particularly suitable for lower-income countries.

The lack of private sector enthusiasm for HIV vaccine research is troubling for public health advocates because much of the expertise to develop and manufacture vaccines rests in private sector companies. A range of incentives can be proposed by social workers to encourage private sector investment in HIV and other priority vaccines.

### **Issues for Trial Participants**

It is likely that multiple large-scale trials of several HIV vaccines will be necessary before a highly effective product is identified. These trials will involve thousands of volunteers around the world over several years. Clinical trials of HIV vaccines raise important concerns about participant protections and research ethics.

Some HIV vaccine candidates may engender an antibody response in vaccines, causing trial volunteers to test “positive” on standard HIV antibody tests even though they are not truly infected with HIV. In the India, a positive HIV test result could lead to severe discrimination in health insurance and to social stigma. The simple fact of participating in an HIV vaccine trial may cause someone to be labeled a “high-risk” individual, a gay person, or a drug user. It is incumbent upon researchers to ensure they have adequate protection in place to warn trial participants about these risks and assist them if they should encounter problems. Confirmatory testing technology that can distinguish between vaccine-induced infection and actual infection should be accessible to all those enrolled in vaccine trials.

### **Ensuring Access to an HIV Vaccine**

Developing an AIDS vaccine does not guarantee its use. For example, the highly effective vaccine for hepatitis B has been available in the industrialized nations for over 17 years, yet this vaccine has only recently become accessible in much of the developing world. Health advocates and public health officials agree that it is unacceptable for an HIV vaccine to follow the standard decade or longer delay between licensing in rich countries and availability in developing countries. Ensuring simultaneous access to an HIV vaccine in rich and poor countries alike involves many challenges. Since, HIV vaccines employ advanced technology, and may be expensive compared with current vaccines, a major issue is the severely limited health care resources in poorer countries for purchase of HIV vaccines. In addition, marginal health care infrastructures in many developing countries will render it difficult to distribute a vaccine. And vaccination programs will have to be adapted to reach the risk groups that need an HIV vaccine most urgently. Current immunization

programs in developing countries focus on reaching children, but it is sexually active adolescents and adults that will most immediately need a vaccine for HIV. A part of the challenge will be to involve many countries reluctant to acknowledge that young people are sexually active. Still more challenging is to reach the highly mobile or displaced populations with a vaccine.

There are several proposals for accelerating access to HIV vaccines in the developing world. International organizations including the World Bank are considering establishing purchase funds to buy HIV and other vaccines. These funds could be financed with donations from industrialized governments and major foundations. Governments could also encourage tiered-pricing structures, in which vaccine purchasers in industrialized countries pay a significantly higher price for the vaccine than poor countries and aid organizations. IAVI has developed innovative intellectual property agreements with its research partners that will facilitate more rapid access to HIV vaccines in developing countries. Elected officials, other policymakers, and public health leaders in these countries will also need to make acquisition and distribution of HIV vaccines a priority.

**Check your progress III**

**Note:** a) Write your answers in the space provided.

b) Check your answer with the model answers at the end of this unit.

1) Why is it important to conduct research to find an effective vaccine for HIV/AIDS?

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## 5.5 LET US SUM UP

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The most effective treatment programmes are those that are truly community-led. Governments, health providers and non-governmental organizations should strive to mobilize all sectors of society to achieve the fastest possible rate of expansion in terms of HIV allied services. This means harnessing the united strengths of community organizations, faith-based groups, employers, families and people living with HIV themselves.

The issue of AIDS as is the case with other illnesses, is very much developmental one. There is an urgent need to develop an integrated understanding of medical and developmental issues. The need to forge multi sectoral and integrated initiatives for AIDS is of much importance as for other illnesses. The virtual non-existence of the General Health Services has crucial implications for care. The infections that affect the AIDS patients and require care and treatment for prolonging a productive life are illnesses that affect all. Adequate access to an effective GHS with a working referral system would ensure sufficient and affordable treatment to mitigate suffering. The intangible inputs of responsiveness, empathy, technical effectiveness of care and confidentiality especially in the case of AIDS, are critical elements that need to be fed into the training of medical personnel.



For many years, the assistance provided to people living with HIV in poor countries has largely consisted of home-based palliative care and helping people to prepare for death, and some support organizations still regard this as the only help they can give. There is therefore a real need to change attitudes – to let people know that, with sufficient effort, treatment can be provided to save lives even in the least developed places on earth.

Despite all the challenges inherent in HIV vaccine development and delivery, a preventive vaccine for AIDS remains the best hope to end the global epidemic. Researchers, public health leaders, governments, private organizations and companies, and affected communities must work together closely to accelerate research and delivery of HIV vaccines that can stem the tide of new infections throughout the world.

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## 5.6 KEY WORDS

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**ARVs:** They are drugs, which inhibit the replication of HIV, thereby decreasing the viral load and increasing the number of CD4 cells. This helps in prolonging the life of a PLHA. Once commenced, the treatment has to be continued for life.

**CD4 test:** HIV attacks a type of immune system cell called the T-helper cell. This cell carries on its surface a protein called CD4, which HIV uses to attach itself to the cell before gaining entry. It measures the number of T-helper cells (in a cubic millimeter of blood). Someone uninfected with HIV normally has between 500 and 1200 cells/mm<sup>3</sup>. In a person infected with HIV the CD4 count declines over a number of years.

**Opportunistic Infection:** People with advanced HIV infection are vulnerable to a host of infections and malignancies. These are called ‘opportunistic infections’ because they take advantage of the opportunity offered by a weakened immune system.

**Palliative Care:** Palliative care is the type of care that controls the symptoms, reduce pain, and improves the quality of life of patients and their families facing life-threatening illness. Particular attention is given to the prevention, assessment, and treatment of pain and other symptoms, and to the provision of psychological, emotional and spiritual support.

**Vaccine:** Vaccines stimulate the body’s immune system to provide against infection or disease.

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## 5.7 FURTHER READINGS AND REFERENCES

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## 5.8 ANSWERS TO CHECK YOUR PROGRESS

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### Check Your Progress I

People with advanced HIV infection are vulnerable to infections and malignancies that are called 'opportunistic infections' because they take advantage of the opportunity offered by a weakened immune system.

The most occurring OIs in India are Tuberculosis, Candidiasis, Cryptosporidiasis, Herpes Zoster, Toxoplasmosis, Bacterial pneumonia, Cryptococcal meningitis, PCP and Kaposi's sarcoma; all of which are treatable and curable.

### Check Your Progress II

Counseling, testing, and treatment awareness

Helping people to meet programme requirements

Addressing Nutritional requirement

Treatment for other infections

Ensuring reliable supply chains for medicine and trained staff

Treatment retention

Moving towards universal access

Promoting traditional healers and medicine as a feasible option where treatment is inaccessible

Palliative care including preparing for death and discussing practical issues like Custody of children; Family support ; Making a will; Funeral costs; Future school fees etc.

Discussing Emotional issues before death like Resolve old quarrels; tell patient and family members that they are loved; Share hopes for the future especially for children who are left behind; Say goodbye to carers and providers

Providing family and orphan support

### Check Your Progress III

The availability of a safe, highly effective and accessible preventive HIV vaccine would be a valuable complement to other preventive interventions, significantly contributing to the interruption of the chain of transmission of HIV.

Well conceived HIV immunization strategies could reach populations where other interventions are not sufficiently enough.

Research on preventive HIV vaccines is providing new information on the possible use of vaccines as therapeutic interventions, to be used in association with anti retroviral therapies, which could lead to its lowering in the cost of the treatments and to an increase in their long term efficacy.