

CHAPTER I

INTRODUCTION

Human Immunodeficiency Virus is the leading challenge of current era to all nations of the world. While it has been seen that the pandemic exists in every country of the world, but prevalence and capacity to cope with it varies considerably in different countries and different social groups within each country. Where, in developed countries, HIV prevalence has been stabilized or even gone down among the groups that were most severely hit initially; in developing countries HIV poses a serious threat to the development of nation. Most of the new cases are reported from the developing countries. HIV is not only a medical problem, but due to its close association to individual's life and its different dimensions (facets), it has become the first priority of all health related issues, socio-economic development and well being of human kind.

Distribution of the effects of HIV pandemic is shared unequally, within the global community both economically and demographically (Barnett and Rugalema, 2001). Poor societies bear the most of the burden of HIV pandemic worldwide and due to feeble infrastructure, response to HIV is slow in poor societies, which is an important cause of rapid increase in the number of PLHIV in poor societies. HIV related illness typically strikes at the most productive age group of society and the consequences of the pandemic on the economic growth of affected regions is substantial at both the micro and macro levels (Collins and Rau, 2000; Forsythe, 2002; Lim, 2001). At the world stage, the major focus has been Sub Saharan African Region (SSAR), as it bears the most of the burden of HIV pandemic worldwide. In the recent years a need has been felt to address the issues pertaining to the nature, cause and consequences of HIV pandemic in South East Asian Region (SEAR). In this region, India accounts around sixty percent of all PLHIV. In a country like India, with vast geographical and regional disparities, HIV prevalence is determined by numerous factors. As per the new revised estimates 2.4 million people were living with HIV in India in 2009 (NACO, 2010). The disease has no cure and hence is a real threat to the life. This thesis is an attempt to examine the socio-economic aspects of PLHIV households. It can provide help in planning effective intervention strategies. A comparative analysis of economic position of PLHIV at different stages of infection can provide better

information on appropriate intervention. As HIV/AIDS is not only a health related matter, socio-economic dimensions of HIV infection should also be given due consideration. A huge absolute numbers of people living with HIV in India are of great concern for the country.

- More than half of India's total population is young, and most of the cases of HIV infection are seen in the population aged 15-49 years, which is considered to be the adult population and counts to be the most productive years in the life span of an individual (NFHS-III).
- Eighty five percent of HIV infections are due to unsafe sexual practices in India (NACO).
- Flourishing sex work in the streets of the metropolitan cities and the clients of FSW are the bridge population between the HRG and general population, which is considered to be LRG in the society.
- HIV is spreading at a faster rate in SEAR and India is the leading country in terms of absolute number of PLHIV in the region.
- Twenty six percent of India's total population is living below the poverty line (BPL) (Planning Commission, India). This group of the population is more vulnerable to HIV infection due to their deprived social and economic status in the society and there exists a close interlink between behaviour, economic status and HIV infection (Cameron).
- In the metropolitan cities, slum dwellers and their health priority is closely associated with HIV infection. Awareness, knowledge and practices for prevention of HIV, are poor in those areas.

Keeping in view the above mentioned facts, an attempt is made to investigate the consequences of HIV/AIDS at household level. This thesis is primarily focused on the socio-economic aspects of PLHIV and their psychological well being.

1.1 HIV AND AIDS

HIV is an acronym to Human Immunodeficiency Virus that causes Acquired Immunodeficiency Syndrome (AIDS), a condition in humans in which the immune system begins to fail, leading to life threatening opportunistic infections (OI), some of which are rarely seen in the life span of a normal human being.

AIDS is the later, most advanced stage of HIV related illness, when, due to compromised immune system; different opportunistic infections attack the body and ultimately cause death. Hence, when someone dies of AIDS, it is usually opportunistic infections or other long term effects of HIV infection that cause death. AIDS refers to the body's immune compromised state that can no longer stop OIs from developing and becoming so deadly.

1.2 HIV-STRUCTURE AND REPLICATION

HIV is a member of genus LentiVirus, part of the family of Retroviridae. LentiViruses have many common morphologies and biological properties. They are characteristically responsible for long duration illness with a long incubation period. HIV is about 120 nm in diameter (120 billionth of a meter, around 60 times smaller than a red blood cell).

HIV primarily infects vital cells in the human immune system such as:

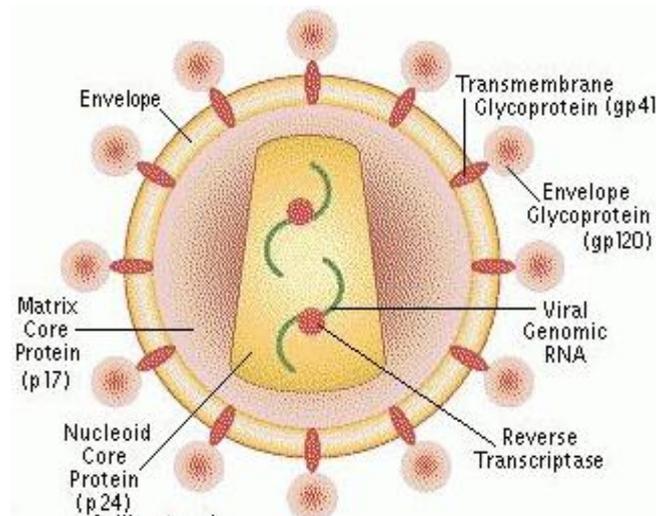
- a. Helper T cells (specifically CD4+ T cells)
- b. Macrophages
- c. Dendritic cells

HIV takes over CD4 cells and turns them into the virus factory that produces thousands of viral copies. As the virus continues to replicate itself in the body, it damages and kills CD4 cells, weakening the immune system. HIV infection leads to low level of CD4+ T cells through three main mechanisms:

- i. Direct viral killing of infected cell
- ii. Increased rate of apoptosis in infected cell
- iii. Killing of infected CD4+ T cell by CD8 cytotoxic lymphocytes that recognize cells.

In the medical science the term Viral Tropism, refers to cell types which HIV infects. HIV enters the macrophages and CD4+ T cells by the absorption of glycoproteins on its surface, to receptors on the target cell followed by the fusion of the viral envelop with the cell membrane and the release of the HIV caprid into the cell.

Diagram 1.1: A Diagrammatical Presentation of HIV is given As Follow



Human Immunodeficiency Virus (HIV)

1.3 SPECIES OF HIV

Medical science has identified two species of HIV that infect human:

1. HIV-1
2. HIV-2

HIV-1 is the virus that was initially reported and termed Lymphotropic AdenoVirus (LAV). It was more potent and relatively easily transmitted and is the cause of the majority of HIV infections globally.

HIV-2 is less transmittable than HIV-1 and is largely confined to West Africa. It is transmitted much less frequently by Mother to Child Transmission (MTCT) and sexual route than HIV-1.

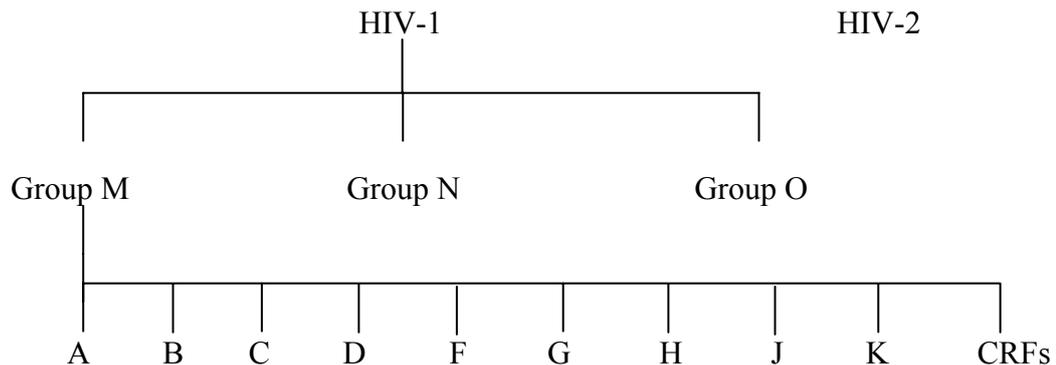
The strains of HIV-1 can be classified into three groups:

- a. Major group (M)
- b. The outlier group (O)
- c. New group (N)

These three groups may represent three separate introductions of simian immunodeficiency into human beings. Group O appears to be restricted to West Central Africa and Group N discovered in 1998 in Cameroon, is extremely rare. More than 90 percent of HIV-1 infection belongs to HIV-1 group M. Within the group M, there are known to be at least nine genetically distinct subtypes of HIV-1. These subtypes are A, B, C, D, F, G, H, J and K.

Occasionally, two virus of different subtype can meet into the cell of an infected person and mix together their genetic material, to create a new hybrid virus. Many of these new strains do not survive for long, but those that infect more than one person are known as Circulating Recombinant Forms (CRFs).

Chart1.1: The Classification of HIV Strains and CRFs Is Shown In The Following



In India most of the identified HIV cases belongs to HIV-1 subtype C category.

1.4 MODES OF TRANSMISSION

There are four main modes through which HIV can be transmitted from one person to another:

- a. Unsafe sexual practices
- b. Non-sterilized needle shared among Intravenous Drug Users (IDUs)
- c. Transfusion of contaminated blood and blood products
- d. Vertical transmission from HIV positive mother to child (MTCT)

1.4 – A. SEXUAL TRANSMISSION

Although all types of sexual practices can transmit HIV, some practices are riskier than others. Intercourse without condom and which can cause bleeding is most likely to transmit HIV. In an HIV infected person, HIV infected cells are found to be highly concentrated in semen, cervical, vaginal fluid and blood. When a HIV infected person has unsafe sexual practices with an uninfected person, HIV infected cells, through these fluids, come in contact with cells of the other person, causing a high probability of his/her being HIV infected. Unprotected receptive anal intercourse is the riskiest possible, because during anal intercourse the rectal lining often tears slightly,

exposing blood vessels to infected cells in semen. Most of the reported cases of HIV infection are due to unsafe sexual practices worldwide.

1.4 – B. NON-STERILIZED NEEDLES AND SYRINGES

When needles and syringes are reused without adequate sterilization, contaminated blood can pass from one person to another. This route of HIV transmission is far common among drug users in urban areas of USA, Europe, Argentina, Brazil and Thailand. In India majority of HIV cases in Northern Eastern states (Manipur, Nagaland) are due to this particular mode of transmission (NACO).

1.4 – C. TRANSFUSION OF CONTAMINATED BLOOD

HIV contaminated blood supplies spread the virus very efficiently. Contaminated blood carries the virus and it easily transmitted into the body of another person at the time of transfusion of blood. This particular mode of transmission can account for infection in hemophiliacs, and recipients of blood products.

1.4 – D. VERTICAL TRANSMISSION

Vertical transmission is the transmission of infection from mother to child at the time of pregnancy, labor, or through breast feeding. Most prenatal HIV transmission is thought to occur during pregnancy, which may occur in the uterus during pregnancy. HIV may also be transmitted during child birth when the baby comes in the contact with mother's blood and cervical section. It is possible for the baby to become infected through its mother's breast milk. In absence of treatment, the transmission rate between the mother and child is about 25 percent. HIV-2 is transmitted much less frequently by MTCT and sexual route.

HIV has been found at low concentration in the saliva, tears and urine of infected individuals, but there are no recorded cases of infection by these secretions and potential risk of transmission is negligible.

1.5 GENESIS OF HIV

HIV though believed to come into reporting in early 80's, earliest possible four cases of HIV infection are as follow:

- 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 from an American teenager who died in St. Louis in 1969.
- HIV found in tissue samples from a Norwegian sailor who died around 1976.

A study in 2008 dated the origin of HIV to between 1884 and 1924, much earlier than previous estimates. The researchers compared the viral sequence from 1959 (the oldest known HIV-1 specimen) to the newly discovered sequence from 1960. They found a significant genetic difference between them; demonstrating diversification of HIV-1 that occurred long before the AIDS pandemic was recognized. Scientists suggest a long history of HIV in Africa and call Kinshasa “*the epicenter of HIV/AIDS*” pandemic in West Africa. Though the HIV infection remained silent in that period of time, in 1977-78 first case of AIDS problem occurred in United States of America (USA) and Haiti in Africa. In 1979, Kaposi’s sarcoma related infection first appeared in Africa and Europe. Likewise, in 1981, same infection was reported in USA in Gay Men. WHO estimated that there have been at least, 50,000 cases of HIV related illness since 1980 and the disease may have first appeared in late 1970’s in Zaire about the same time that it first appeared in USA and Haiti. Genesis of growth of HIV infection is categorized in the following categories:

- Spread of AIDS
- Science and Prevention
- National Action
- Treatment
- Global Action

1.5 – A. BEFORE AND DURING 1970’S

It was believed that HIV (virus that causes AIDS), probably transferred to human beings in Africa between A.D 1884 to 1924. The dominant feature of this period was silence, and during this period spread was unchecked and approximately, 100,000-300,000 persons may have been infected by the time (Jonathan Mann). HIV entered

Haiti around 1966. HIV entered in USA around 1970. By 1980, HIV had spread to at least five continents (North America, South America, Europe, Africa and Australia).

1.5 – B. 1981-1986

Kaposi's sarcoma, a rarest case of skin cancer was found in gay men in New York (NY) by March 1981. At the same time, there was an increase in the number of rare lung infection *Pneumocystis carinii* pneumonia (PCP) in California and NY. Later, in December 1981, it was clear that the disease affected other population groups, when the first cases of PCP were reported in IDUs. In 1982, the disease still did not have a name, with different groups referring it to different ways. It was called "Gay Compromised Syndrome" (GCS), "Gay Related Immune Deficiency" (GRID), "Acquired Immunodeficiency Disease" (AID), "Gay cancer" or "Community-Acquired Immune dysfunction". Later on, cases were reported in Haitians, as well as haemophiliacs.

The acronym AIDS was suggested in a meeting in Washington in July 1982. AIDS was first properly defined by Center for Disease Control (CDC) in September 1982. In 1983, AIDS cases were reported among non drug using women and children. In May 1983, doctors at the Institute Pasteur in France reported that they had isolated a new virus, which they suggested might be the cause of AIDS. The cause of AIDS is unknown, but it seems most likely to be caused by an agent transmitted by intimate sexual contact, through contaminated needles, or, less commonly, by percutaneous inoculation of infectious blood or blood products. By the end of the year, the number of AIDS cases in the USA, had increased to 3,064 and of these 1,292 had died.

In 1984, scientists identified HIV (initially called HTLV-III or LAV), as the cause of AIDS. At the same time western scientists became aware about the wide spread of HIV infection in the African region. By the end of 1984, there had been 7,699 AIDS cases and 3,665 AIDS deaths in the USA, and 762 cases had been reported in Europe. In the UK there had been 108 cases and 46 deaths.

In 1985, HIV test was licensed for screening blood supplies. The first case of HIV was reported in the world's most populous county China. In 1986, cases of HIV infection were reported from most of the countries of the world. More than 38,000 cases were of AIDS were reported from 85 countries. The first case of HIV infection was reported in Madras (now Chennai) and simultaneously some cases of AIDS were reported from Bombay (now Mumbai) in India.

1.5 – C. 1987-1992

In March 1987, the U.S. Food and Drug Administration (FDA), approved AZT, the first ART drug for treatment of AIDS. World Health Organisation had been notified of 43,880 cases of AIDS in 91 countries. The first HIV case was officially recorded in the Soviet Union. In 1988, a world summit of ministers of health was held in London to discuss a common AIDS strategy.

WHO intended to promote an annual World AIDS Day and the first such day would be on 1st December 1988. By March 1st 1989, 145 countries had reported 142,000 cases of AIDS to the World Health Organisation. There were more developments with respect to treatment, when the results of a major drug trial known as ACTG019 were announced. ACTG019 was a trial of the drug AZT. A huge absolute number of HIV infections were reported in India.

In 1990, WHO estimated that eight million people were living with HIV across the world. The International AIDS Society (IAS) announced that no further IAS sponsored conference would be held in a country that restricted the entry of HIV infected travelers. In 1991, the red ribbon became the international symbol for AIDS awareness worldwide. At the end of 1991, about 450,000 AIDS cases had been reported to the Global Programme on AIDS (GPA) / World Health Organisation (WHO). It was estimated that 5-7 million men and 3-5 million women had been infected with HIV. Of these 9-11 million HIV-infected adults, nearly 1.5 million were estimated to have progressed to AIDS. Thailand launched Asia's most extensive HIV prevention programme.

In 1992, in response to rising HIV prevalence, the Indian government decided to allocate \$100 million to the National AIDS Control project over the next five years, which amounted to more than 15% of the national health budget. Most of this money would come from a World Bank loan. Experts predicted that within five years, there might be more people affected by AIDS in India than in any other country. Government of India set up National AIDS Control Organization (NACO), to oversee the formulation of policies, prevention and control programmes relating to HIV/AIDS.

1.5 – D. 1993-1998

In 1993, it was found that AZT is of no use for the PLHIV, who were in the earlier stage of infection. Scientists had found that HIV 'hides out' in lymph nodes and similar tissue, early in the course of infection. The World Bank believed that AIDS would have little demographic effect but recognized that it was a serious threat to health and economic development. At the end of 1993, the estimated numbers of AIDS cases worldwide were 2.5 million.

In 1994, it was examined that AZT could help to prevent Mother to Child Transmission (MTCT) to a great extent and due to extensive awareness about the same and prevention strategies; infant HIV infection began to fall in most of the developing countries. By July 1994, 985,119 cases of AIDS were reported to World Health Organization (WHO).

In 1995, United Nations Program on AIDS (UNAIDS) was established. In 1996, it was found that combination antiretroviral treatment was highly effective against HIV. Global spending on AIDS in low and middle income countries rose to \$300 million. In 1997, HIV related illness death began to decline in developing countries, due to new drugs. Brazil was the first country, to begin providing free combination treatment. In the other developing countries only a tiny minority could have access to treatment of HIV infection. It was estimated that 22 million people were living with HIV worldwide (WHO). Estimates of HIV/AIDS cases in India, Myanmar (Burma), Bangladesh and Nepal were put at 3 million, 350,000, 20,000, and 15,000 respectively.

In June 1998, the company AIDSvax started the first human trial of an AIDS vaccine using 5,000 volunteers from across the USA. UNAIDS estimated that during the year a further 5.8 million people became infected with HIV, half of them being under 25. Sub-Saharan Africa was home to 70% of people who became infected with HIV during the year. South Africa was having the highest number of PLHIV worldwide. It was estimated that one in seven new infections in Africa were believed to be occurring in South Africa.

1.5 – E. 1999-2004

The UK Government announced that all pregnant women in Britain would be offered an HIV test in an attempt to reduce the number of babies infected with HIV. In 1999

World AIDS Day campaign, "Listen, Learn and Live!" continued to focus on people under 25. By the end of 1999, UNAIDS estimated that 33 million people around the world were living with HIV/AIDS and that 2.6 million people worldwide had died of the disease in 1999, more than in any other year since the epidemic began.

In 2000, in Botswana, as many as one in four adults and four of every ten pregnant women were estimated to be infected with HIV. According to the UNAIDS report, there were 34.3 million people infected with HIV worldwide, of whom 1.3 million were children under the age of 15. It was predicted that AIDS would cause early death, in as many as half of the teenagers living in the hardest hit countries of southern Africa, causing population imbalances. In particular, it was predicted that two thirds of 15 year-old children in Botswana would die of AIDS before they reached 50. Meanwhile, four million people were reported to be living with HIV in India, the country with the second largest population with HIV in the world. In September 2000, the first phase of a new vaccine trial was launched in Oxford. The trials were sponsored by the International AIDS Vaccine Initiative.

In 2001, in UN Special Session, world leaders set the long term targets on HIV/AIDS. The Indian drug company Cipla offered to make AIDS drugs available at reduced prices to the international aid organization Medicines Sans Frontiers (MSF). Cipla's offer to produce drugs at a price less than \$1 per day put further pressure on multinational drug companies. United Nations Secretary-General Kofi Annan called for spending on AIDS to be increased tenfold in developing countries.

In 2002, Ukraine became the first nation in Europe to have one percent of its adult population infected with HIV. Botswana became the first African country to begin providing antiretroviral treatment through the public sector. In April 2002, the South African government promised to start providing Nevirepine to HIV-positive pregnant women and their babies, to reduce the risk of HIV transmission. The US Agency for International Development (USAID) announced it was adopting a new approach to preventing sexual transmission of HIV around the world, which would be known as "ABC" (Abstinence, Being faithful and Condom use).

In 2003, AIDS drugs become more affordable for the developing countries. The "3" by "5" campaign (three million PLHIV to be provided affordable ART treatment by 2005) was launched to widen the access of AIDS treatment. The first AIDS vaccine candidate to undergo a major trail was found to be ineffective. Reports suggested that

the rate of HIV prevalence in Swaziland was highest in the world with almost four out of ten adults infected.

In 2004, USA launched a major initiative called “PEPFAR” to combat HIV worldwide. South Africa started providing ART free of cost. In March 2004, the US Food and Drug Administration approved the first oral fluid rapid HIV test. Government of India launched the national antiretroviral programme in April 2004. In 2004, Special emphasis was given to the health and immediate requirement of women and the theme for Worlds AIDS day 1st December, 2004 was Women, Girls, HIV and AIDS.

1.5 – F. 2005-2007

By late 2005, it was clear that the World Health Organization’s “3 by 5” plan would fail to achieve its goal of 3 million people on treatment in resource-poor countries by end of the year.

In 2006, studies found that circumcision can reduce HIV infection to a great extent through sexual activities. Annual Global AIDS spending in low and middle income countries rose to \$ 8.9 billion. It was estimated that \$14.9 billion would be needed for a truly effective response. Twenty eight percent of PLHIV in developing countries, who needed treatment for HIV, were receiving it.

In 2007, according to new estimates, 33 million people were living with HIV worldwide. A large-scale international microbicide study was halted in January after preliminary results found that the product was not achieving its aims of preventing HIV infection in women. In July, it was revealed that new methods of sampling led to a massive reduction in the estimated number of people living with HIV in India. Previous estimates had suggested that there were around 5.7 million people living with HIV in India, giving it the largest HIV caseload in the world. The new figures suggested that the actual total was somewhere between 2 and 3.1 million people - around 60% lower than the original estimate - and placed India third after South Africa and Nigeria for countries with the highest HIV infected populations. The previously inflated HIV numbers for India were due to figures being obtained in areas of particularly high HIV prevalence and taken from samples from surveillance sites visited mainly by pregnant women, injecting drug users and prostitutes. A major HIV vaccine trial being carried out in the USA and South Africa had to be halted, after initial results showed the vaccine to be ineffective. *Dr. Kevin De Cock*, Director of the

AIDS department at the World Health Organization remarked: *“For the first time, we are seeing a decline in global AIDS deaths.”* an estimated 2.1 million people died due to HIV related illness in 2007, down from around 2.3 million in 2005.

In 2008, India’s National AIDS Control Organization (NACO) began to roll out government funded second-line antiretroviral treatment. In 2009, select health centers across eight states in India rolled out second line treatment after the scheme was piloted in Chennai and Mumbai

1.6 HIV-A MUTLI FACETED ISSUE

Ever since the first case reported in 1981, HIV was considered as a major health problem especially to those who are socially, economically considered as a marginalized group of society. Gradually, it seized the attention of social scientists, when it broke out as a pandemic, worldwide. It was realized that bio-medical is not the only problem associated with the HIV infection; in fact it is a multifaceted issue and problem. Issues /problems, which gave upswing to the HIV infection, are both cause and consequence of HIV infection. In a nutshell, problems which are associated with HIV infection can be categorized in the following categories:

- a. Bio-medical problem
- b. Socio-economic problem
- c. Demographic problem
- d. Cultural problem
- e. Gender related problem

1.6 – A. BIO-MEDICAL PROBLEM

At the early onset of HIV infection it was considered as a major health related problem. It was considered as a deadly disease, which led to death only. In the African region it was called “Slim Disease”. HIV infection has a long incubation period, and sometimes the symptoms are not visible to a long period. Thus a healthy looking person may also be carrying HIV infection and in ignorance can pass the infection to another person. HIV attacks at the T helper cell called CD4+ cells and leaves the body prone to several opportunistic infections. In the developing countries, there is found to be a very strong correlation between the HIV infection and opportunistic infections. In India, itself it was found that there was a close association between HIV infection and Tuberculosis. HIV is a serious challenge for the scientists,

as till now, there is no cure for HIV. ART can suppress the progression to a time, but it cannot eradicate the virus from the body. From the point of view of an individual carrying HIV infection, ART means lifelong treatment. Once an individual is put on ART, he cannot stop taking medication.

1.6 – B. SOCIO-ECONOMIC PROBLEM

As more and more cases began to be reported from almost from all regions of the world, it was realized that the epidemic is not only driven by behavioural aspect. Infact, it is deep rooted in the socio-economic set up. In the early 90's it drew the attention of many social scientists, to estimate the socio-economic causes and consequences of HIV/AIDS. HIV has severe impact on the socio-economic life of an individual. Socio-economic aspects (social status, economic wellbeing, educational and occupational status), which are the causes of HIV, are its deadly consequences as well. In societies, where talking about sexual issues is a taboo, HIV infection brings a curse for the whole household. As most of the people, are aware of just one mode of HIV transmission, *i.e.* unsafe sexual practices or multiple sex partners. It causes discrimination against the person who is HIV positive. HIV related stigma and discrimination, force PLHIV to live in silence. Thus, it hinders access of health facilities. In the families, PLHIV found themselves, stigmatized and discriminated. HIV has significant negative impact on the household economy. Socially and economically, it leads to weaken the household. In India, people living with HIV come from incredibly, diverse backgrounds, cultures and lifestyles. In India, like any other country, HIV is considered to be "*someone else's problem*"- as something that affects people living on the margins on the society, whose lifestyles are considered immoral.

1.6 – C. DEMOGRAPHIC PROBLEM

High prevalence of HIV in a particular region is a serious threat to the demography of that region. In SSAR, which is worst hit by the pandemic, serious demographic impact was visible in various countries of the region. Demographic impact of HIV is usually centered on mortality (To a much lesser extent fertility), increased level of orphanhood and implication for economic growth. Empirical evidence from SSAR depicts that high HIV prevalence rate may lead to decrease in life expectancy. HIV has reversed the gain in life expectancy and improvement in child mortality in many

countries. Average life expectancy is now 49.9 years in sub-Saharan Africa; in the absence of AIDS, it would have been about 62 years (UN Department of Economic and Social Affairs [UNDESA], 2005). In Botswana, life expectancy has dropped to 34, a level not seen since before 1950 (UNDESA, 2005). HIV related illness is the leading cause of mortality in adult population (15-49 years) (WHO-2004). It is the fourth most common found cause of death in world and leading cause of death in SSAR. Increase in number of PLHIV means, loss of productive human resources to a great extent due to morbidity. Though, in India HIV prevalence is very low and not a severe demographic problem, but due to its large population size, slight increase in prevalence rate may lead to add millions to the number of PLHIV in nation.

1.6 – D. CULTURAL ISSUES

Cultural complexities, do promote the HIV transmission. In some societies, promiscuous behavior is acceptable for male, which may leave the female counterpart prone to HIV transmission to a great extent. Similarly, homosexual behavior is considered as crime in many countries hence, leading to risky behavior. In India, as per Indian Penal Code (IPC) section 377, unnatural sexual activities are considered as crime. Thus, those who indulge in these types of practices, are hidden in the society and this type of sexual activities do take place in the risky environment, without any protection most of the time. These types of activities put them at elevated risk to HIV infection. Recently, decriminalization of same sex activities itself has not ensured safer sexual activities due to cultural complexities in a society like India. Hence, cultural complexities and behavioural complexities make different groups of society more vulnerable to HIV infection.

1.6 – E. GENDER ISSUES

HIV has played a very crucial role in further widening the gap of gender inequalities. Men and women have sharply different social and economic roles, differential access to income and resources, different economic behaviours, including different patterns of consumption and expenditure, and are subject to different legal arrangements. Due to this vast diversity, HIV consequences are also drastically varied. Women are more stigmatized and discriminated. They are often blamed to bring curse in the family. Domestic violence, physical, mental and sexual abuse cases against women make them more vulnerable to HIV infection. Moreover, leaving aside their own health

priority, they have to take care of ill member of family. Thus, it would not be wrong to say that HIV has further accentuated the gender gap.

1.7 OBJECTIVES OF STUDY

The major thrust of this thesis is to assess “*Socio-Economic consequences of HIV*”. This thesis highlights the socio-economic conditions of PLHIV and their households. It has been observed that in case of PLHIV, it is not only the individual but the entire family that suffers, due to the economic crunch and social stigma. This thesis attempts to reflect the actual condition prevailing at household level. A comparative analysis of PLHIV economic condition at different stages of the infection can provide better information for appropriate intervention. Following are the different objectives of the study that can be encapsulated:

- To assess the background characteristics of household with PLHIV.
- To examine/assess the economic burden of infection at household level.
- To examine the differentials in the economic burden at different stages of infection.
- To acquaint coping up strategies.
- To assess the impact on the social status of household and impact on the quality of life enjoyed by PLHIV.

This study intends to assess the background characteristics of PLHIV in the Pune city and their socio-economic conditions. Social impact of HIV infection is expected to be a threat to the whole family structure. Stigma and societal discrimination against the PLHIV and other family members has been a matter of great concern.

At the micro level, the present study provides a realistic view of the actual economic condition in the PLHIV families. In the present study, we had examined the impact on the consumption, income and productivity level of household. The economic impact is likely to be dependent on the income level and source of livelihood of PLHIV.

The present study assesses the economic impact of HIV infection at the base level of economy *i.e.* household level. Pattern of spending is known to change considerably, mainly due to the increased need of nutrition and medication. An in-depth analysis of economic conditions of PLHIV is carried out in the study.

The economic burden can be categorized into two parts:

- Direct Economic Burden
- Indirect Economic Burden

Direct burden is further categorized as medical cost and non-medical cost. Medical costs comprise treatment and medication cost, hospitalization cost and treatment cost for the opportunistic infections (OI). Non-medical cost comprises travelling cost and cost incurred on the attendee.

Indirect economic burden comprises expenditure on the increased nutritional requirements, wages lost due to morbidity, other fringe benefits denied on job and loss of job.

Another important aspect of the study is comparative evaluation of economic conditions at different stages of infection categorized by CD4 counts, to examine how the progressing infection from one stage to another leads to change in economic condition of household (HH). To define HIV related illness, we have used Center for Disease Control (CDC) definition to define HIV related illness in the adults and adolescents. This is based on a matrix notation, in which category C and CD4/ μL less than 200 in each category defines full blown AIDS cases. Table 1.1 shows the CDC classification system for HIV infection:

Table 1.1: Center for Disease Control (CDC), Classification of HIV Infection as Per CD4 Count

| CD4 cell Categories | Clinical Categories | | |
|-------------------------------------|---|---|------------------------------------|
| | A Asymptomatic, Acute HIV, or PGL | B Symptomatic Conditions,#* not A or C | C AIDS-Indicator Conditions* |
| (1) ≥ 500 cells/ μL | A1 | B1 | C1 |
| (2) 200-499 cells/ μL | A2 | B2 | C2 |
| (3) < 200 cells/ μL | A3 | B3 | C3 |

for symptomatic conditions, * For AIDS-indicator conditions¹

HIV infection in the family is a serious challenge to those who belong to lower strata of the society. Due to HIV infection and increased financial burden, their condition worsened.

One of the main aspects of the study is to assess the quality of life of PLHIV. Attitude of community towards PLHIV, social acceptance, accessibility of primary health care facilities and availability of someone's help to take care of patients are some key

¹ For complete list of symptomatic condition and AIDS indicator see appendix III

issues in this regard. Quality of life is a normative concept. World Health Organization (WHO) defines quality of life as *“as individual’s perceptions of their position in life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards and concerns”*. Taking into consideration this definition of quality of life, the World Health Organization has developed WHOQoL index and a brief version of the same WHOQoL-BREF. To assess the quality of life of PLHIV, WHO has developed WHOQoL-HIV index and a brief version of it WHOQoL HIV-BREF. In this study, WHOQoL HIV-BREF instrument is used to assess the quality of life of PLHIV.

This thesis is divided into nine chapters. The first chapter comments on the rationale and objectives of this study, apart from commenting on the various aspects of HIV infection. In the second chapter, HIV prevalence, incidence and case load in the world, Asia, India, Maharashtra and Pune city in recent years is explored. The third chapter presents detailed literature on the concerned subject. In the fourth chapter, the methodology used for conducting the household survey in Pune city and qualitative research methods used for gathering information is discussed. The fifth chapter studies the economic profile of people living with HIV (PLHIV) and economic consequences of HIV infection at household level, by a detailed analysis of socio-economic status, consumption pattern and consumption level at household level. Chapter six examines economic burden of HIV related illness and out of pocket health payments. Chapter seven, attempts to measure social implications of HIV infection on family in general, and on the individual, in particular. The social stigma attached with HIV is the major inhibiting factor in response to HIV infection. This chapter tries to capture the magnitude of stigma and discrimination faced by PLHIV at various social settings. Chapter eight explores the psychological and emotional stress of HIV infection among PLHIV respondents. This chapter captures the quality of life aspect among PLHIV respondents. The concluding chapter nine summarizes some broad conclusions and offers some suggestive policy implications based on the findings of the thesis in the light of government AIDS policy and National AIDS Control Programme III.

