Chapter 1

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Perhaps no disease is more strongly identified with the late twentieth century than Acquired Immuno Deficiency Syndrome, commonly known as AIDS (Kshatriya, et al., 2005: 69). AIDS is one of the most serious threats to human health of which life has ever faced. Over the last few decades, AIDS, caused by Human Immuno Deficiency Virus (HIV) has been identified as a major public health crisis and a research priority all over the world. With the deleterious effects on mankind, it was described as the most serious health problem since the bubonic plague of the fourteenth century. Once enter into the body's immune system and allow the otherwise controllable opportunistic infections to invade the body in due course of time and cause additional fatal multi-system disease as prescribed by this syndrome, AIDS, over a certain period of time. The disease has been first among the risk groups in an epidemic form and then to the general population in a pandemic nature (Singh, 1998: 2).

Research on attitudes towards people with AIDS indicates homophobic attitudes to be common (ie fear of homosexuals or of one's own sexual feelings). Because AIDS is typically associated with homosexual/bisexual behaviours and intravenous drugs, many people rationalize their feelings that most people who get AIDS are getting what
they deserve, or only have themselves to blame. These types of beliefs and attitudes cause people to avoid those with AIDS, or to reject people with AIDS based on their lifestyle or their HIV disease (Sharma, 1996: 16).

At one point of time, HIV/AIDS was considered a disease only for the people outside the mainstream society (e.g., homosexuals, bisexuals, intravenous drug users, and other groups discriminated against and ostracized) but now, it has become a part of every society and has turned into every family's problem. It has entered into the flow of the mainstream society. A young bubbly child may be HIV positive as much as a young innocent looking widow. Anyone can be infected, everybody is at risk. It cuts through classes and castes, young and old and infects across customs and cultures. No one is immune from it.

The HIV/AIDS epidemic has posed an unprecedented challenge to communities, nations and to the international community: a challenge to human survival, human rights and human development. It is difficult to visualize the devastating effect of the HIV of epidemic within our lifetime and beyond. The spread of the virus initiates an inevitable chain of consequences which will continue for decades, for generations. The matter of these repercussions is so devastating that despair and fatalism would seem to be the only rational responses.

Any discussions of the HIV/AIDS epidemic in regard only to its related statistics, its treatment, its diagnosis, means of transmission, and history would be insufficient. Such a discussion must be unrestricted
by the consideration of the attitudes and beliefs associated with HIV/AIDS; social or economic status; class and poverty; intravenous drug use; and sexual, ethnic and racial attitudes and beliefs.

Often it is not until large number of the population are infected and many have progressed to AIDS or associated diseases such as tuberculosis that there is the possibility of a national consensus on the urgency of the matter. It is usually only at this stage that the voices of public health officials, health workers and the infected and their families finally begin to be heard.

The virus HIV has crossed many lanes and terrains across nations and continents leaving behind trauma and disasters. A quick glimpse through the history of infection and early cases will give the picture of the mode of infection across the globe.

1.1. History of HIV/AIDS

HIV/AIDS lay relatively dormant for many decades. Then, for unknown reasons, it burst out of its African origins, and to date has become the scourge of 40 million people worldwide, plus 25 million more who have died. Scientists tried to trace the origins of the epidemic. A dozen of AIDS cases were retrospectively identified in 1978 – 79. Scattered cases of HIV infection or AIDS were identified in the United States and Haiti between 1972 and 1976. (Singhal & Rogers, 2003: 48 – 49).
The first documented case of AIDS in the United States was identified in 1980 by a young immunologist, Dr. Michael S. Gottlieb, at the University of California, Los Angeles. He detected from his patient who had candidiosis, a thick, white coating in his mouth. This patient also had a complaint of weight loss. Soon, many patients with weight loss, fever and candidiosis were referred to Gottlieb. All were gay men. They all had problems with their immune system. Amidst criticisms and disbelief, Dr. Gottlieb reported about the first five AIDS (this name was not used at the time) cases was published on 5th June 1981 in the CDC’s (Centre for Disease Control) weekly medical surveillance report, Morbidity and Mortality Weekly Report (MMWR).

The fact that the epidemic’s first victims appeared at the same time in three locations (Los Angeles, New York, and San Francisco) was disquieting and ominous. It is now known that many thousands of individuals at scattered locations around the world were already HIV-positive at this time, although they had not yet shown the symptoms of AIDS.

From the beginning, it was recognized that the epidemic spread through sexual networks in an alarming exponential process (Singhal & Rogers, 2003: 52). The CDC epidemiologists assumed that a virus was being transmitted through sexual contact among the first 40 male patients with the AIDS, and that it caused an immune deficiency in the human body, which allowed various infections to them remain
unchecked. A year or two later, after this conclusion was supported by other evidence, AIDS was given its name, “Acquired Immune Deficiency Syndrome”. At that stage, the virus causing AIDS/HIV was mainly being transmitted by the exchange of bodily fluids among gay men when they engaged in unprotected anal intercourse. Being HIV-positive usually led, after a latency period of several years, to diagnosis with AIDS symptoms. Death then followed a few years later (Singhal & Rogers, 2003: 52).

Today, it has spread to all the continents of the world. There is no country which is free from HIV/AIDS. It has spread from the high risk to the low risk general population and from urban to rural areas. It has invaded communities that previously had little to do with the epidemic. UNAIDS estimated that while 1209 million people were living with HIV/AIDS in 1992, a decade later, by the end of 2002, we had 42 million people living with HIV/AIDS. This reflects a global development crisis of huge proportions. This statistics masks the fact that 27.9 million people already died of AIDS. Out of 42 million, 19.2 million are women, 19.6 million are men and 3.2 million are children. Although 14,000 new HIV infections are occurring everyday, of which 49.6 percent are women 0.5 million people are acquiring HIV infection every year, of them 800,000 are children (Lisam, 2004: 11).

The world is now almost 30 years into the HIV/AIDS crisis with no vaccine in sight and with relatively few effective and sustainable prevention programmes. While numerous programs have been mounted
throughout the world since the first AIDS cases were reported in the early 1980’s, the AIDS epidemic is out of control in many nations of Africa and Asia. Over 65 million people have been infected with HIV, of which over 25 million have died of AIDS. Worldwide, some 14,000 people are infected everyday, 95 percent of them in developing countries. Although the rates of HIV infection and AIDS deaths have declined in the richer nations of the developed world, infection rates are soaring in developing countries. AIDS is now the leading cause of death in Africa, and the fourth leading cause of death globally (Singhal & Rogers, 2003: 24).

1.2. Pattern of HIV/ AIDS Epidemic and Situation in India

The epidemic was relatively late in coming to India, compared to many other countries (it was five years since the first AIDS cases had been identified in Los Angeles) (Singhal & Rogers, 2003: 115). The first HIV positive case was reported from Chennai (erstwhile Madras) in May 1986 by Dr. Suniti Solomon from among a cluster of six commercial sex workers. UNAIDS has estimated that there are 4.58 million people living with HIV/AIDS by the end of December 2002, which is about 0.8 percent of the adult population of India. India is having about 10 percent of the global HIV/AIDS burden. By the end of November 2003, NACO has reported 57,781 AIDS cases in India (Lisam, 2004: 38). This is grossly under-reported because majority of the people with HIV/AIDS do not come to the government hospitals. They seek treatment from private hospitals, who do not report AIDS cases to the NACO. By the end of
2008, there was a decline in the HIV/AIDS cases. Provisional estimates show that there are 22.7 lakhs people living with HIV/AIDS in India by the end of 2008 with an estimated adult HIV prevalence of 0.29 percent (NACO Annual Report 2009 – 10: 4). All states and union territories have reported HIV/AIDS cases. No state or union territories is free from AIDS.

In India, about 84.53 percent of HIV infections are through sexual transmission – both heterosexual and homosexual, 3.36 percent is through sharing of needles and syringes among the injecting drug users, another 3.27 percent through blood transfusion and 2.14 percent through prenatal (Lisam, 2004: 40). Still the pattern of epidemic shows a great variance across the country.

In Maharashtra and Tamil Nadu, it is mainly sexual transmission whereas in Manipur, it is mostly through sharing of needles and syringes among injecting drug users. However, any state may have multiple epidemics. Mumbai has got about 20,000 to 40,000 injecting drug users, many of them HIV infected. Chennai has got a very high percentage of HIV seroprevalence among the injecting drug users. Manipur is reporting increasing number of sexual transmission – through the female sexual partners of injecting drug users, commercial sex workers, homosexuals, migrant workers, etc (Lisam, 2004: 40).

The epidemic pattern shows great variance across the country. The worst affected states are Maharashtra, Tamil Nadu, Andhra Pradesh, Karnataka, Manipur and Nagaland. Maharashtra reported the highest
number of seroprevalence rate among the pregnant women, i.e. 1 percent or more. In other words, the HIV prevalence rate among the adult population in this state is 1 percent or above. The pregnant women are the surrogate representative of the general population. These six states reported more than 80 percent of all HIV positive and AIDS cases. These six states are taken as Category–I States or High Prevalent States (Lisam, 2004: 40).

In the beginning, the HIV positive case was reported only from people with high risk behaviour like commercial sex workers, injecting drug users, STDs patients. Now, the epidemic is no longer confined to these high risk groups. During that time, it was known as "concentrated epidemic". From the findings of the nation-wide sentinel surveillance, it is now understood that the HIV seroprevalence rate among pregnant women attending antenatal clinics is increasing slowly and steadily. The pregnant women are the surrogate representative of the general population. If the HIV seroprevalence rate among pregnant women is one percent, it means that the HIV seroprevalence rate in the adult general population is one percent. The HIV prevalence rate among injecting drug users in Manipur was more than 80 percent in 1997 and more than 44 percent of the female spouses of IDUs were HIV infected. The HIV seroprevalence rate among pregnant women was more than one percent. Similar situations have been observed in the other states of Maharashtra, Tamil Nadu, Andhra Pradesh, Karnataka and Nagaland where the HIV seroprevalence rate among the high risk prevalence
groups is more than five percent and the prevalence among pregnant women is more than one percent. These findings show that the HIV infection is spreading from the high risk to the pregnant women.

1.2.1. Routes of Transmission

NACO, in its Annual Report, 2009 – 10 reported that information from persons testing positive for HIV at the Integrated Counseling and Testing centers across the country during 2009 – 10 shows that 87 percent of HIV infections are still occurring through heterosexual routes of transmission. While parent to child transmission accounts for 5.4 percent of HIV cases detected, injecting drug use is 1.6 percent, Men who have Sex with Men (MSM) is 1.5 percent and contaminated blood and blood products account for one percent.

The primary drivers HIV epidemic in India are unprotected paid sex/commercial female sex worker (FSW), unprotected sex between men and injecting drug use. It is estimated that there are 12.6 lakh female Sex Workers, 3.5 lakh Men who have Sex with Men (MSM) with High risk and 1.9 lakh injecting drug users in India. Though sex worker account for 0.5 percent of adult female population, they account for 7 percent of HIV infected females. Sex worker continues to act as the most important source of HIV infections in India due to the large size of clients that get infected from sex workers.

As per National Behavioural Surveillance Survey in 2006, 2.4 percent of adult males, i.e., around 73.5 lakh adult males have visited
commercial sex worker during the year prior to the survey. Men who buy sex, i.e., clients of sex workers are the single most powerful driving force in India's HIV epidemics and constitute the largest infected population group in the country. These men then transmit the infection to their wives affecting several low risk women in the society. Long-distance truckers and single male migrants constitute a significant proportion of clients of sex workers.

In India, about 53 - 84 percent of HIV infections are through sexual transmission, both heterosexual and homosexual, 3.36 percent is through sharing of needles and syringes among the injecting drug users, another 3.27 percent through blood transfusion and 2.14 percent through pre-natal (Lisam, 2004: 40).

In Maharashtra and Tamil Nadu, it is mainly sexual transmission whereas in Manipur, it is mostly through sharing of needles and syringes among injecting drug users. However, any state may have multiple epidemics. Manipur is reporting increasing number of sexual transmission – through the female sexual partners of injecting drug users, commercial sex workers, homosexuals, migrant workers, etc (Lisam, 2004:40).

1.2.2. Concentrated Epidemic

The overall HIV prevalence among different population groups in 2003 – 09 continues to portray the concentrated epidemic in India, with a very high prevalence among High Risk Groups – IDU (9.2 percent),
MSM (7.3 percent) FSW (4.9 percent) and STD clinic attendees (0.49 percent) (NACO Annual report 2009 – 10).

HIV epidemic in India is heterogeneous in its spread. The worst affected states are Maharashtra, Tamil Nadu, Andhra Pradesh, Karnataka, Manipur and Nagaland. Some states, districts and blocks showing high prevalence levels compared to others. At the state level, 60 percent of the HIV burden is in the six high prevalence states. Except Andhra Pradesh and Nagaland with a median HIV prevalence of one percent, all other states have shown less than one percent HIV among ANC attendees. Among IDUs, Chandigarh, Punjab, Delhi, Mumbai and Manipur have shown high levels of HIV prevalence and MSM and FSW (NACO Annual Report, 2009 – 10: 5).

In the beginning, the HIV positive case was reported only from people with high risk behavior like commercial workers, injecting drug users, STDs patients. Now the epidemic is no longer confined to these high risk groups. During that time, it was known as “concentrated epidemic”. From the findings of the nationwide sentinel surveillance, it is now understood that the HIV seroprevalence rate among pregnant women attending antenatal clinics (ANC) is increasing slowly and steadily. Pregnant women are a surrogate and representative of the general population (Lisam, 2004: 43).

If the HIV seroprevalence rate among pregnant women is one percent, it means that the HIV seroprevalence rate in the adult general
population is one percent. The HIV seroprevalence rate among injection drug users in Manipur was more than 80 percent in 1997 and more than 44 percent of the female spouses of IDUs were HIV infected. The HIV seroprevalence rate among pregnant women was more than one percent. Similar situations been observed in the other states of Maharasthra, Tamil Nadu, Andhra Pradesh, Karnataka and Nagaland where the HIV groups is more than five percent and the prevalence among pregnant women is more than one percent. These findings showed that the HIV infection is spreading from the high risk to the general population (Lisam, 2004: 44).

1.2.3. Manipur Scenario

Manipur is a victim of illegal international drug trafficking. Manipur is geographically very close to the notorious “Golden Triangle”, which is geographically composed of northern Thailand, northern and eastern Myanmar and Laos. Myanmar is the world largest single producer and exporter of heroin drug, accounting for between 40 percent and 60 percent of world supply. The purest form of heroin, locally known as “Number 4” is the major export form of the drug. Heroin from Myanmar began to appear in Manipur in the mid seventies. Soon Manipur became a “User State” by early eighties. Drug traffickers often indulged in “self-testing of heroin” and consequent needle sharing with traders in Mandalay or Kalewa town in Myanmar as a part of their drug purchasing behavior and in the process they got infected with HIV (Lisam, 2004: 2).
The first HIV positive case in Manipur was reported in February, 1990 from the blood samples among a cluster of "Injecting Drug Users". The number of HIV positive cases among IDUs and pregnant mother attending government hospital reached 55.4 percent and 0.8 percent respectively by the end of 1994. It went on increasing till 1998 to 72.8 percent among IDUs and 1.69 percent among pregnant mothers. At present, 31,972 individuals officially live with HIV/AIDS in Manipur as recorded by Manipur AIDS Control Society (since 1986 till March 2009). Out of the total number, 8,053 persons are females. So far the total number of death recorded is 625 individuals (Singh, 2006: 35).

In Manipur, the HIV epidemic has spread from injecting drug users to their female spouses, to the commercial sex workers, to the men having sex with men and again from them to the migrant workers, truckers and patients with sexually transmitted diseases (Lisam, 2004: 3).

Today, AIDS has become the number one killer of young people in Manipur. 92 percent of the HIV positives in Manipur are the young people below 40 years of age. Young people below 30 years constitute about 58.46 percent (Lisam, 2004: 3). AIDS has become a common household word in Manipur. Young people got infected and later died of AIDS. Most of their widows and children also become infected. Most of these women and children are dying and some have already died. It has become a threat and has become the source of an alarming situation in the society. At one point of time, people thought that HIV/AIDS will
never come to Manipur and Manipur conservatism will protect the people from HIV/AIDS. But HIV/AIDS has found itself a dominating position in our midst breaking and crossing over all barriers and is a life threatening reality.

According to the epidemiological analysis of HIV/AIDS in Manipur (for the period September, 1986 – March, 2009) reported by Manipur AIDS Control Society (MACS), out of the total number of 237865 blood samples screened, 25655 samples are reported as HIV positive and 4363 are reported as AIDS cases. And number of death due to AIDS among the samples screened is 625. And out of the 4363 cases, 3188 are males and 1175 are females. Out of 625 deaths due to AIDS, 503 are males and 122 are females. Till October 2010, there are 36854 people infected with HIV in Manipur. Out of them 9904 are women. So the number of infected women is on the rise (MACS Report).

1.3. Anti-retroviral Therapy (ART)

In the very early years of the AIDS epidemic, diagnosis of an individual with HIV was a certain death sentence. The only question was how soon an HIV-positive individual would develop AIDS, and die from an opportunistic infection. These opportunistic infections could be treated, of course, but an individual with AIDS would soon be sick with another opportunistic infection, and then another. An individual with AIDS lived in pain, dying a slow and painful death. Anti-retroviral drugs have dramatically enhanced the quality of life of AIDS patients.
The anti-retroviral drugs are neither a prophylactic nor a cure for AIDS. They simply disrupt a various stages in the life cycle of the virus, as it invades the T lymphocyte white cells in the human body and convert them into factories producing further generations of HIV. The anti-retroviral are a kind of chemical miracle, in that they reduce an individual's viral load so low that it cannot be detected. Thus, the onset of AIDS, and the opportunistic infections that come with it, is delayed indefinitely, if a person living with AIDS/HIV takes the triple cocktail of drugs for the rest of his life (Singhal & Rogers, 2003: 127).

However, taking the anti-retroviral involves a grueling, long-term regiment of treatments. Very unpleasant side-effects come with the triple cocktail. Nausea, headache and insomnia may result from AZT (Azidothymidine). The toxic effects of the triple cocktail are so strong that 20 percent to 30 percent of HIV positive individuals cannot take the anti-retroviral therapy. Certainly no one would chose to take the anti-retroviral if they had any options.

At one point of time, the cost of anti-retroviral made them completely unaffordable for almost everyone in the developing countries of Latin America, Africa and Asia. But now, they are made available free of cost.

1.4. HIV/AIDS: More than a biomedical problem

The topic of HIV/AIDS is a multifaceted issue which cannot, and should not, be reduced to medical terminology and factual information
alone. HIV/AIDS is very much a human and social problem that cannot be addressed merely as a public health and medical issue (Sharma 1996: 1). AIDS, with its biological complexity and dynamic nature has social, economic, cultural and psychological determinants, which are still in the process of being understood (Priya & Reddy, 2005: 6). Being global, the AIDS crisis is multi-pronged and multi-cultural in character (Mathur, 2005: 34).

Given the growing recognition of its far-ranging effects across all domains of society, HIV/AIDS is an increasing significant social factor, among others, that warrant consideration in ethnographic description, analysis and theorization (Harrison, 2005: 2).

The momentum with which AIDS spreads in different countries is not uniform. Given the biomedical standpoint that HIV is an infection with negligible variations across regions, the facts that some nations are more vulnerable than others complicates the situation further. This is despite the common denominator that people with AIDS are kept away from and in this sense, they emerge as new communities of “untouchables”, “outcasts” and “marginalized”. What distinguish AIDS in different regions are culture (comprising of beliefs, values, morals, rituals – in fact, the entire way of life), cultural perception and cultural strategies for dealing with it. Those infected with HIV, therefore, cannot be said to constitute a uniform, homogenous category (Mathur, 2005: 35).
UNESCO Division of Cultural Policies and Intercultural Dialogue Document (2004) clearly mentions, “The term ‘culture’ has to be understood not only as ‘arts and creativity’, but also as including ways of life, traditions and beliefs, representatives of health and disease, perceptions of life and death, sexual norms and practices, power and gender relations, family structures, languages, and means of communication, etc. Based on this understanding of culture, we can see that culture influences our behavior in many ways: in taking or not taking risk of contracting HIV/AIDS, in being supportive towards or discriminating against people living with HIV and their families, etc. Therefore, culture has to be seen as an important factor in the HIV/AIDS epidemic. HIV/AIDS must also be acknowledged as a social, economic and political issue – not simply a medical one”.

Culture has been included in the UNAIDS framework as one of the five key contextual domains which needs refocusing communication interventions. This domain, while it lies outside the skins of individuals, influence HIV/AIDS related health behavior (Singhal & Rogers, 2003: 216).

Many cultural practices are responsible for the spread of HIV. The dormitory system is prevalent among many Indian tribes such as Rang-bang among the Bhotia of Uttarakhand, Gitiora among Munda and Ho and Dhumkuria or Jonkerpa among the Oraon of Jharkhand, Ghotiel among Muria of Chhattisgarh. The sexual practices of these dormitories provide many chances for the spread of HIV infection because a person
shares multiple sexual partners. The institution of dormitories might appear to be the mechanisms facilitating multiple sexual partners but such activities were confined to community boundary. However, recently, the non-tribal men are found taking part in the dormitory activities, making the group more vulnerable from the point of view of sexual health (Patnaik & Mehrotra, 2005).

Rules of marriage such as levirate and surrogate also pave a way for the spread of HIV infection. Among the Rongmei (Kabui), it is preferable for a widow to marry her husband’s younger brother. If the widow happens to be HIV positive, there is most likely a chance of her infecting her second husband. It is found that most of the young widows are wives of those who had died of AIDS. This practice is also found in many other tribes of Manipur.

If culture is responsible for the transmission of HIV, it can be the means for HIV prevention. Communication strategists often viewed culture as static and mistakenly looked upon people’s health beliefs as cultural barrier. This is a predominantly negative view. Culture has often been singled out as the explanation for the failure if HIV interventions. However, culture can be viewed in terms of its strength, and attributes to a culture that are helpful for HIV/AIDS prevention, care and support programs should be identified and harnessed (Singhal & Rogers; 2003: 217 – 218).
Taking culture into consideration is so important because a person does not live outside a society, free from his societal obligations. Like Channa (2005) has mentioned that when we identify a PLWA (or PWA), we must identify him/her not only as a social person living with a condition but also as a social person living within a cultural milieu. Such a person has a social personhood, is embedded within familial and social relationship and occupies a position of relative power within the social system. He or she by virtue of this position is made meaningful by a set of cultural norms and values. Thus, the term PLWA cannot be a uniform category, but contains within itself many based on age, sex, social class and position.

Example can also be cited of the Senegalese case. Several socio-cultural and spiritual dimensions of Senegalese strengthened the nation’s effective response to HIV/AIDS; for instance, the cultural norms with respect to the universality of marriage, the rapid re-marriage of widow and widower and divorcee, moral condemnation of all forms of sexual cohabitation not sanctioned by religious beliefs; extended social networks of parents, cousin, relatives, neighbours and others, that served to control irresponsible sexuality. The fear of dishonouring one’s family and the subsequent “what will they say?” syndrome exercise a strong check on individual behavior. So, cultural beliefs assist HIV prevention in Senegal (Singhal & Rogers, 2003: 218).
Singhal & Rogers (2003) also quoted Thoraya A. Obaid, Executive Director, United Nations Population Fund as "To prevent the spread of HIV/AIDS, you need behavioural change, and you can't have behavioral change without looking at people's cultural context". For health projects to be effective, the cultural values, beliefs and practices of the targeted community need to be thoroughly understood. Only then can communication strategies accentuate the positive undercurrents of a culture, reducing (a completely overcoming) the effects of opposing forces.

A sound basis for any preventive health intervention according to them is to conduct data-gathering in the nature of the epidemic, on how people are coping with it, and how their cultural customs affect the epidemic and its control. Behavioural change models for HIV/AIDS communication programming begin with ascertaining the knowledge, attitudes, behavioural intentions, and behavioural practices of individuals regarding HIV prevention, care and support. Gaps in knowledge, attitude and behavior among a targeted audience can be identified, and communication interventions are then targeted to addressing these deficiencies at the individual level.

1.5. HIV/AIDS and Women

Globally, HIV/AIDS is the leading cause of death among women of reproductive age. The percentage of women living with HIV and AIDS varies significantly between different regions of the world. In areas such
as Western and Central Europe and Oceania, women account for a relatively low percentage of HIV infected people. However, in regions such as Sub-Saharan Africa and the Caribbean, the percentage is significantly much higher.

Sub-Saharan Africa

In 1985 in Sub-Saharan Africa, there were as many as many HIV infected men as there were women. However as the infection rate has increased over the years, the number of women living with HIV and AIDS has overtaken and remained higher than the number of infected men. In 2007 there were around 12 million women living with HIV and AIDS, compared to about 8.3 million men. UNAIDS have estimated that around three quarters of all women with HIV live in Sub-Saharan Africa.

Sub-Saharan Africa is one region of the world where the majority of HIV transmission occurs through heterosexual contact. As women are twice as likely to acquire HIV from an infected partner during unprotected heterosexual intercourse than men, women are disproportionately infected in this region.

The Caribbean

The Caribbean has also seen an alarming increase in the number of HIV infected women, and again the main mode of HIV transmission is through heterosexual sex. Young women are approximately 2.5 times more likely to be infected with HIV than young men.
Commercial sex has been identified as one of the key factors in the Caribbean HIV epidemic. A study of HIV prevalence among female sex workers in Georgetown, Guyana, showed that a very high number – 30.6 percent – were infected with HIV. Female sex workers are frequently thought of as being at a higher risk of HIV exposure as they often are not in a position to insist that their customers wear condoms. Alarmingly it has been reported that men will still pay more money for unprotected sex with a sex worker. This means that sex workers are not only at risk of becoming infected with HIV, but that if they are already infected, they can pass the virus on to their clients.

The Americas

In the USA, African American and Hispanic women account for 80 percent of AIDS cases, even though they represent less than one fourth of all women. The Centres for Disease Control and Prevention (CDC) estimates that in the USA, the number of newly HIV infected women increased from 2004–2007. The centre’s latest calculations from 2007 estimate that more than 278,000 women and adolescent girls are living with HIV or AIDS in America.

The main way in which women get infected with HIV in the USA is through heterosexual sex. The other main transmission route among women is injecting drug user which accounts for 26 percent of HIV infections. Generally in industrialized countries, the epidemic has had a
disproportionate affect on women of the population such as ethnic minorities, immigrants and refugees.

In Latin America, around 30 percent of adults living with HIV and AIDS are women. The epidemic started primarily among sex workers and men who have sex with men, but in recent years has spread to the general population. It is now thought that in some South American countries, heterosexual sex accounts for a large majority of HIV transmission.

Asia

UNAIDS estimates that around 4.7 million adults are living with HIV in Asia, approximately 35 percent of them are women. The number of women living with HIV and AIDS in Asia varies greatly between different countries, and in places largely affected by the epidemic, such as India, the numbers vary between different states. Although women are often perceived to be low risk of HIV infection because it is not common to have more than one lifetime sexual partner, a great number of women are put at risk of HIV infection as a result of their husbands having unprotected sex outside of marriage or injecting drugs. It has been estimated that 90 percent of women living with HIV in Asia were infected by their husband or long-term partner.

The number of adults living with HIV and AIDS in India is estimated to be 2.4 million. According to the National AIDS Control Organisation (NACO), women account for 39.3 percent of these. As HIV
transmission in India is largely through heterosexual contact, the infection rate for women is increasing, and the low economic and social status of women continues to be the barrier to preventing new infections.

In countries such as Holland, Vietnam and Pakistan, HIV transmission is largely through injection drug use. Not only are female injecting drug users (IDUs) at high risk of contacting HIV but also increasing numbers of women are becoming infected with HIV from male IDU partners.

At the end of 2008 it was estimated that out of the 31.3 million adults worldwide living with HIV and AIDS, around half are women. It is suggested that 98 percent of these women live in developing countries. The AIDS epidemic has had a unique impact on women, which has been exacerbated by their role within society and their biological vulnerability to HIV infection.

Generally women are at greater risk of heterosexual transmission of HIV. Biologically women are twice more likely to be infected with HIV through unprotected heterosexual intercourse than men. In many countries women are less likely to be able to negotiate condom use and are more likely to be subjected to non-consensual sex.

Additionally, millions of women have been indirectly affected by the HIV and AIDS epidemic. Women's childbearing role means that they
have to contend with issues such as mother to child transmission of HIV. The responsibility of caring for AIDS patients and orphans is also an issue that has a greater effect on women.

Roy (2005) considers the epidemic as gender issue. It disproportionately affects women and adolescent girls who are socially, culturally, biologically and economically more vulnerable. For women, vulnerability to infection and risk-taking is increased by cultural attitudes that make it inappropriate for women to be knowledgeable about sex or Sexually Transmitted Infections (STIs); also they are not able to afford treatment sometime. Although HIV/AIDS affects both men and women, women are more vulnerable because of biological, social, cultural and economic factors.

The underlying causes and consequences of HIV/AIDS infections in men and women vary, reflecting differences in biological, sexual behavior, social attitudes, economic power and vulnerability. Social inequality between the sexes limits women’s access to care and services. It also reduces the opportunities of both men and women to acquire knowledge about safer sexual practices and to develop skills to protect themselves from HIV. There is a large difference in attitudes towards men and women’s sexuality; both within and outside of marriage. Women known to have HIV/AIDS are more likely to be rejected by their family, denied treatment, care and basic human rights. Yet, women and
girls tend to bear the main burden of caring for sick family members, including men living with HIV/AIDS.

1.5.1. Biological make-up

The physiological differences in a genital tract make female more vulnerable to HIV/AIDS than any other STDs. Many women suffer asymptotic STDs, which are not diagnosed or treated. The presence of untreated STD in both men and women greatly enhance the risk and facilitate HIV transmission. Vulnerability to STD, therefore, implies a greater vulnerability to HIV infection. Moreover, women, being receptive partners run a greater risk of acquiring HIV through single unprotected sexual intercourse. An early estimation by Anderson et al (1991), assumed two times greater probability of contracting HIV from men to women than vice versa, whereas UNAIDS (1997) estimated that the risk is twice or four times higher. This is due to physiological and genital mucus, because infected male semen contains higher concentration of virus. Since female surface area is larger and semen is in contact for longer period with female genital tract, the virus is much safer inside the female tract and can remain infectious even after. The sperm itself had died. Many women have erosions and small sores on the cervix. By itself, this is not dangerous but exposing even a small sore to the HIV is extremely dangerous (Lisam, 2004: 285).
1.5.2. Social attitude

Social construction of sexuality and gendered discourse on male-female relation inevitably influence negotiation in sexual relationships and have an impact on practices of safer sex (Sharma, 2005: 90). Sexual decision making is always with males. Women have no control over sexual matters. Women cannot negotiate anything regarding condom use or the type of sex, sexual posture, etc. women cannot question their husband’s fidelity. Though monogamy and fidelity are expected behaviour for both partners, these are more binding on the women, while women are expected to tolerate male transgressions of these standards. Moreover, it is an accepted social norm almost in every society that men can seek out for younger women and not vice versa. The usual social norm is that men usually prefer younger women as their wives or sexual partners. Sexual relationship of a woman with older men may put themselves at risk of HIV infection (Lisam, 2004: 85).

1.5.3. Economic condition

Women usually have a low socio economic status. Poverty, illiteracy, ignorance, gender inequality, unemployment, male migration, urbanization, lack of economic opportunities forces women to exchange sex for money, food and favours to meet their basic essential needs. Even in the family, women have to negotiate. Women are expected to provide for the needs of their families in return for which they are promised protection and social esteem. Women’s social and economic
dependency on the husband deprived them of the power to negotiate within the marriage.

1.5.4. Health issue

Women are more likely to have blood transfusion because of abortion or anaemia or any other complications of pregnancy or child birth. During the process, she may get HIV infection unless cue care is taken. Moreover, many of the STDs remain symptom less in women. Even if there is a symptom, she may not seek timely medical treatment. The chance of a woman reaching medical facility is usually low. All these factors contribute to increasing risk of HIV infection for women (Lisam, 2004: 285).

1.6. Review of literature

Biomedical constructions of health and illness as objective categories have long been challenged by social theorists. As part of this critique, Persson et al (2003) made an analytical distinction between the domains of doctors and patients to highlight differences in perspective and power. They explore with reference to 16 men living with HIV and the way in which they negotiate medical discourse and technology in relation to lived experience and conversely, how they interpret their own bodily symptoms in light of clinical construction of health. The study was carried out based on their illness narratives.

A similar form of such a study was carried out by Andrade and Anderson (2008). They studied how mind-body therapies such as
Progressive Muscle Relaxation Training and Guided Imagery (PMRT–GI) are effective in treating stress and anxieties in chronically ill persons like people living with HIV. The purpose of this study was to identify key elements of an effective and culturally acceptable PMRT–GI intervention for economically disadvantaged persons with HIV. The research was carried out among 24 participants from African American, White and Hispanic backgrounds using phenomenological method.

Anderson and Spencer’s (2002) study was based on the foundation that cognitive representations of illness determine behaviour. How persons living with AIDS image their disease might be key to understanding medical adherence and other health behaviours. A purposive sample of 58 men and women with AIDS were interviewed. Using Colaizzi’s phenomenological method, rigor was established through application of verification, validation and validity.

Barrero and Castro (2006) describe and conceptualize the experience of stigma in a group of children living with HIV and evaluate the impact of Access to highly Anti–Retroviral Therapy (HAART) over the social course of AIDS and over the children experiences of stigma. Description was also given how access to HAART changes the lived experience of children, reduces new challenges in AIDS care such as adolescents’ sexuality and treatment adherence.

On the other hand, with the introduction of HAART, the person is seen neither to be getting well or dead. A study of a case of AIDS
dementia where hope is taken as forked – either the reversal of the present condition or death, at least an end to the present situation is seen in the works of Kelly (2007). The study was conducted on the care giver, the patient is like a ‘living dead’ – where he is neither living nor dying. At this juncture even death seems like a hope.

Caregivers of people living with HIV/AIDS also provide useful insights of the lives of those people they care for as also revealed by the study of Carlisle (2000). The researcher explores informal carers’ experiences in care giving for people living with HIV and AIDS. The search for meaning encompasses the way in which carers find meaning in care giving. Finding meaning in care giving is a powerful way to achieve a balance between the costs of care giving and personal reward.

Based on analyses of life histories of 12 men living with AIDS who attempted to return to paid employment, Braveman et al (2003) present how different individuals interpret and respond to an experience such as the onset of disability. Findings suggest that the men who demonstrated progressive narrative recreated an identity including a view of themselves as workers and recaptured a sense of competence. Men with regressive narratives showed little change in either identity or competence. The study contributes to our understanding of how the framing of an illness or disability by an individual may influence the progression of his life history narrative.
Trainor and Ezer (2000) explores how seven men who believed they were dying from an AIDS related illness began the process of rebuilding their lives following a course of successful combination therapy. Three major themes emerged. ‘Back to living’ was the realization that they were going to live. Realizing ‘my life has changed’ was associated with living with uncertainty, appearing healthy while living with AIDS, and letting go of their preoccupation with physical well-being, ‘readjusting my life’ was associated with a change in daily routines, re-evaluating of their sense of self, questioning their relationship, reengaging with society, and developing new life plans. Findings suggest that these participants felt living had become more difficult.

The study carried out among 63 gay samples of persons with HIV reveals the nature of identity transformation. Tewksbury and McGaughey (1998) draw their conclusion on a pendulum model of identity transformation. Individual experiences and responses to illness are explored. Three critical milestones are identified – testing for HIV antibodies, disease validation and diagnosis, and disclosure of HIV positivity. The three transformed identities are “Being HIV positive”, “Living with HIV” and “Person with AIDS”. Identities are examined as fluid constructs, drawing upon aspects of both the physiological and social aspects of self.
One work that comes closest to the present study is the study of developing a community-based definition of needs for persons living with chronic HIV by Sankar and Luborsky (2003). Drawing on focus group conducted among African American, Hispanic and White people with HIV in Detroit, Michigan, the researchers show that expressions of needs related to the lived experience of HIV vary among racial and ethnic groups and between genders, relating in an experientially distinct set of needs.

While various aspects of HIV/AIDS have been studied in varied forms, a plump study of women with AIDS across cultures based on their lived experiences has not yet been come across. The present study deals in three stages – the past experiences, the present situation, the question of death which is taken for granted as their near future. The study is carried out exclusively on the basis of the experiences of the women as primary data.

1.7. Rationale of the study

Unlike our understanding of acute disease experience, which can be grouped within parameters defined as categories of medical diagnosis and treatment, understanding the experience of AIDS requires that we expand our analytic frame to include variables and perspective created by the beliefs, behaviours, context and culture of participants. It is the experience of living with the chronic illness that generates the needs people identify as much as those related to the clinical features of
the disease. Though anti-retroviral are not a cure for AIDS, the triple cocktail postpones death in most cases, and can return individuals who are very sick to a healthy state. Thus, AIDS became a chronic, rather than an imminently fatal disease.

Social scientists have emphasized that the nature of the HIV illness depends on the social and cultural location of the patient. These social and cultural differences extend beyond the domain of beliefs to inform actual care practices and thus may affect medical outcomes. Finding a useful and valid way to identify a culturally informed understanding of the needs associated with HIV remains a trenchant problem for public health agencies at this juncture in the HIV pandemic.

Specifically, breakthroughs in HIV treatment, and its subsequent redefinition as a chronic illness, have compounded the ways in which HIV is understood and lived. Indicative of a more general trend within contemporary western medicine, what makes HIV health further susceptible to interpretation is that HIV has become a condition where disease progression and treatment success are measured by medical technology at a bodily level that is imperceptible to most people. This scientific computation of HIV health excludes, and often conflicts with, lived experience or other significant markers and meanings whereby people with HIV may interpret their health.

Thus, an understanding of health grounded in the concreteness and contextuality of lifeworlds, exploring how matters of health and
illness become embodied in particular life histories, absorbing personal
and social significance from the circumstances in which they transpire.

Hence, the present study is an attempt to explore the meanings of
life given by the women with AIDS through their lived experiences.

1.8. Problem Identification

The proposed study will try to
1. understand the perception of experiences lived through by women
   living with AIDS
2. explore the meanings given to the past experiences by the subjects
   themselves
3. know the various shades of perception, shaped by their respective
   culture
4. examine the cross-cultural dimension of the experiences.

1.9. Objective of the study

The present study aims at giving the following contributions:

1. It will be an academic contribution and will broaden its horizon:
   The academic world always provides a room for new things that
are useful for the society. The study of HIV/AIDS can be lifted up to a
new higher realm. In other words, a more holistic study can be carried
out through the understanding of such contributions of the subject like
the present study.

2. It will help the social planners:
Through the understanding of the present study, the social planners can adopt certain strategies to provide guidelines as well as provisions for this section of people who genuinely need special attention. Recognition of their rights as human beings at home and outside will give them more power and courage to stay alive and contribute to the society. The social planners can provide certain diplomatic strategies to do away with the stigma and discrimination that "kill" them.

3. It will contribute in giving guidelines to the HIV/AIDS policy:

Though the issue of HIV/AIDS has been declared as a multifaceted one, the issue is seldom tackled as said. The problem is dealt more in term of a biomedical one. But this biomedical treatment needs to go side by side with other aspects like the social, the economic, the spiritual and others. Learning about their needs and from their own experiences and own words will throw light in giving more provisions that are more humane.