CHAPTER - 1

INTRODUCTION

The present study focuses on the body of knowledge associated with Human Immunodeficiency Virus (HIV) and the Acquired Immune Deficiency Syndrome (AIDS), representing complexity not present in any other disease. HIV infection is not only an extremely complicated disease process but it also transcends the boundaries of biomedicine. Disease and the respective body of knowledge co-exist and it reflects the complexities of this socially constructed reality (Huber, 1998). Social constructionists posit that reality is constructed through dynamic socialization and that the sociology of knowledge must examine the process in which this reality construction occurs (Berger and Luckmann, 1966). Sociology of knowledge deals not only with empirical knowledge relative to various societies but also with the processes by which body of knowledge become established as social realities. In essence, reality evolves through continued socialization, yielding outcomes that result from social interactions, negotiations and power. Therefore, the broad objective of the study is to explore how this particular disease is being constructed by the people in the society at large.

HIV/AIDS continues to grow at an epidemic rate, often in tandem with the number of reported cases. Various domains shape the construction of HIV/AIDS as chronic disease, including the political, social, economic, legal, philosophical, psychological, religious and spiritual ramifications associated with the illness. The societal construct within which the body of knowledge concerning HIV/AIDS exists and further mirrors the complexities of the malady and the various controversies associated with it (Huber, 1998).

Infection with the human immunodeficiency virus results in a complex chronic disease process, complicated by various non biomedical factors. The disease itself is characterized by a constellation of signs and symptoms that culminate in a diagnosis of acquired immune deficiency syndrome. Ultimately, most individuals infected with HIV die of AIDS-related causes. From a biomedical perspective, what differentiates HIV from other chronic disease processes is the variety of opportunistic infections commonly associated with AIDS as well as HIV related dementia and the wide variation in the dying trajectory. Although there have been numerous therapeutic advances where HIV is concerned, drug regimens, when available and accessible
have not proven uniformly effective. Combination therapy involving antiretroviral and protease inhibitors, while greeted with much fanfare, has proven to be a great disappointment to the many HIV infected individuals who have failed to improve while taking the drug cocktails (ibid.).

Further exacerbating the medical complexities of the illness, HIV is complicated by myriad factors outside the biomedical arena such as economic, legal, political, psychological, religious, social and spiritual that compounds the chronology of the disease. These components of an individual’s psychosocial reality exist in tandem with the biophysical illness with stigma trajectory corresponding to disease course progression. Although the spatialization of disease has been plotted along a historical continuum that forms the foundation for modern medicine, the politics and stigma associated with HIV/AIDS prevents the illness from advancing to its ultimate position in the sequence. The pathological continues to exist within a socially defined set of spaces. As well as affecting the emotional, mental and physical well being of the HIV-infected individual, these non biomedical complications dramatically impact education and prevention efforts, treatment advances and coping mechanisms. The repercussion of infection and disease manifestation is much more than an individual life event. In fact, given the multifarious nature of the pathological, HIV transcends the boundaries of life and death (Huber, 1998).

Since the beginning of the epidemic in the early 1980’s, information has been viewed as a key resource in efforts to prevent HIV transmission, manage various disease complications and ultimately prolong life. As HIV/AIDS related information was initially limited, however, in size, scope and availability, underground press networks, supported largely by affected individuals and community-based organization newsletters now being indexed by the National Library of Medicine for inclusion in its HIV specific bibliographic database, AIDSLINE. The AIDS pandemic, in effect has witnessed a confluence of roles regarding information creators, seekers and providers. This paradigmatic shift has resulted in a non traditional scientific communication model where traditional consumers of information are very often producers and traditional producers are consumers. In a traditional scientific communication model, information is generated by researchers, disseminated, accumulated, distilled and applied in the clinical arena. Practical information, when made available, is watered down into lay terms for public consumption. However, in this non traditional model, traditional consumers are active contributors to the discourse. As a result, HIV related information is currently produced and
consumed at virtually every level i.e., individual, institutional, organizational, community, local, regional, national and international level.

Further complicating access to HIV related information; the knowledge within the various disciplines concerning the epidemic is growing exponentially. The literature continues to increase in volume parallel to the rise in the number of documented cases of AIDS worldwide. In addition, HIV related information is currently produced in every conceivable format – audiovisual and electronic prints are present in all disciplines and for those affected by the pandemic.

Societal perceptions and individual perspectives fashion the typical behaviour of the HIV/AIDS epidemic with the course of disease progression spoiled by stigma and discrimination. Complexities associated with both the irrational condition and the body of knowledge concerning HIV/AIDS exists within and because of social constructs circumscribing the pandemic. Illness, information and intricacies are all entwined, evolving relative to both scientific advances and social interactions (Huber, 1998).

It is a well known fact that HIV/AIDS is not solely a medical phenomenon and yet much of the discourse that it has been dominated by the medical field. This is not to say that HIV/AIDS does not exist as a medical phenomenon, but rather since its first appearance in the late 1970’s and early 1980’s (Berer & Ray, 1993), it has come to take on a whole host of meanings dominating politics, economics, and society. For instance, HIV/AIDS has come to be a debate between life and death and in Africa where medical treatments are costly, life and death is not merely chosen by the individuals who have HIV or AIDS status. Life and death is debated by politicians and by all social institutions. Hence HIV/AIDS is not simply a disease or a natural disaster that created trouble in society today; rather it is also a metaphor. This indicates that HIV/AIDS is constructed in a variety of ways that gives meaning to people with or without HIV/AIDS status. While it is crucial to understand the disease as a medical phenomenon, it is equally important to understand its meanings and significance (Treichler, 1998).

The medical life of HIV/AIDS indicates the biomedical approach towards HIV/AIDS in which medical technology and research use a particular language to define it and perhaps set its boundaries. For example, one can learn that HIV can be transmitted through blood, vaginal fluid, semen and breast milk from people who have HIV (AIDS Org., 2001). This knowledge defines then how one can get HIV and how one can avoid contracting HIV. HIV/AIDS is a disease like
any other disease, although perhaps in greater prevalence. It is an illness that insists upon precautions in order to avoid it. Failing to avoid it means consequences such as medical treatment, hospitalisation, prognosis and death. Stigma, marginalisation, morality, panic and fear are words that often do not belong under the medical institution, however much one faces such discursive accounts within their experience (Esat, 2003: 9).

**HIV/AIDS: The Present Scenario**

According to UNDP (2006), “The AIDS Epidemic is a Global Catastrophe.” During the last two decades, HIV (Human Immune Deficiency Virus) and AIDS (Acquired Immune Deficiency Syndrome) has become a pandemic around the globe. In the early years, when HIV/AIDS was diagnosed, it was an epidemic which occurred in few countries only. But comparing to that old saying, it has now become a pandemic because of the number of deaths occurring throughout the world and few countries in African continent have already reached an alarming state. According to UNAIDS (2006) and WHO (2006), not even a single country has been left where no evidence of HIV/AIDS has occurred. No doubt, the huge quantum of HIV/AIDS is found in Sub Saharan Africa where 28.1 million people are combating with HIV/AIDS and many more are still prone to this contagious illness. Not only in Sub Saharan Africa but now it pose a threat to Non African Counties. The South and South East Countries have a rough estimate of 6.1 million people living with HIV/AIDS.

According to United Nations (2001), the total number of people living with HIV/AIDS is 40 million in which 2.5 million are the children who are below the age of 15 years. The number of deaths due to HIV/AIDS has already reached 3 million in which 500,000 are children who are below the age of 15 years. Estimates of 11.8 million people who are in the age group of 15 – 24 years are living with HIV/AIDS worldwide. Nearly 6,000 young people become HIV infected every day. At least 10.4 million children under the age of 15 years have lost their mother or both the parents to HIV/AIDS (UNAIDS/WHO, 2006). After African continent, India has been placed at the second position to receive the maximum number of HIV/AIDS cases worldwide.

According to National AIDS Control Organization (2009), India is one of the largest and most populated countries in the world, with over one billion inhabitants. Of this number, it's estimated that around 2.47 million people are currently living with HIV/AIDS in which women estimated to be 0.93 million (37.7 percent) and children are estimated to be 0.07 million (2.9
percent). The estimated adult prevalence rate of HIV/AIDS is 0.36 percent. HIV emerged later in India than it did in many other countries. Infection rates soared throughout the 1990s, and today the epidemic affects all sectors of Indian society, not just the groups such as sex workers and truck drivers with which it was originally associated. In a country where poverty, illiteracy and poor health are rife, the spread of HIV presents a daunting challenge (c.f. www.avert.org).

HIV/AIDS: A Prologue

As the name hold, HIV stands for Human Immune Deficiency Virus and AIDS stands for Acquired Immune Deficiency Syndrome. HIV is the beginning stage and AIDS is the late stage of the same virus. The former can lead to the later stage. HIV is a unique virus which weakens the body and collapses the immune system which is commonly known as the defence mechanism of the body. As a result, the HIV infected individuals become more vulnerable to many life threatening infections. Any HIV positive can live or may continue to live a perfectly normal life without showing any physical symptoms. Such a stage is known as HIV non symptomatic stage. But once the virus progresses and when HIV is converted into AIDS, the infected person will show some physical symptoms. Such a stage is called as HIV symptomatic stage (Zostrow, 2000).

The word AIDS stand for Acquired Immune Deficiency Syndrome where the term Acquired refers to what is caught as opposed to be inherited. The term Immune Deficiency describes the state in which the body’s immune system is depleted, so as a result, the body is unable to defend itself against the development of certain conditions, particularly opportunistic infections. Finally, the term Syndrome refers to group of signs and symptoms of illness (which further results in body’s defence). Moreover, the term AIDS is used when a disease has progressed and the person develop one or more serious infections or conditions. AIDS is the later stage of HIV which develops frequently when the immune system is totally collapsed by HIV and further develops lifelong symptoms (UNAIDS, 2006). Those who develop what clinicians refers to as “frank” or “full blown” AIDS become vulnerable to a number of serious and frequently fatal so called opportunistic diseases and malignancies (Bolaria, 1988).

The term virus in Latin denotes poison, an appropriate name since no cure exists for any virus, although preventive vaccines have been developed for such viruses as the measles, polio and hepatitis B. The HIV virus, which is so small that 16,000 can sit on the head of a pin,
invades a living white blood cell and reprograms it to reproduce the virus. The infected cell now becomes a miniature virus factory. One virus can make an astounding 10 billion copies of itself in a day, with a mutation rate of 1 in 10,000. This notorious rate of random mutation can make HIV resistant to drugs. The rapid mutation also makes the development of a vaccine very difficult. The HIV infects a type of white blood cells known as T Lymphocytes, also called T helper cells. They protect human body against infections. The CD4 (Cluster Differentiation 4) counts measures the strength of an individual’s immune system. A healthy adult has between 700 and 1500 CD4 cells per cubic millilitre of blood. Over a period of years, the T cells count of HIV positive individual drops to a critical level, below 500, a sign of a depressed immune system. Below 200, the individual usually develops opportunistic infections and medically, this stage is the stage of AIDS (c.f. www.avert.org).

Based on genetic similarities, the numerous virus strains may be classified into types, groups and subtypes. There are two types of HIV: HIV-1 and HIV-2. Both types are transmitted by sexual contact, through blood, and from mother to child, and they appear to cause clinically indistinguishable AIDS. However, it seems that HIV-2 is less easily transmitted, and the period between initial infection and illness is longer in the case of HIV-2. Worldwide, the predominant virus is HIV-1, and generally when people refer to HIV without specifying the type of virus they will be referring to HIV-1 (ibid.). The relatively uncommon HIV-2 type is concentrated in West Africa and is rarely found elsewhere (Panda, 2002: 22).

The evidence of pressure of HIV 2 makes stronger the case for adopting a test system that could detect antibodies for both HIV 1 and HIV 2. HIV 1 was identified in 1983 by Dr. Robert Gallo and other medical scientists at the National Cancer Institute in Bethesda, Maryland. At about the same time Dr. Luc Montagnier of the Pasteur Institute in Paris isolated HIV 2 from AIDS patient. These two Human HIV Viruses are distinguishable by their genome makeup today, but are believed to have had a common ancestor in Africa (Singhal et al., 2003).

HIV 1 mutates very rapidly and Simian Immune Deficiency Virus crossed over to human as Human Immunodeficiency Virus. As the result of mutation, 11 different subtypes of HIV 1 have been identified and are designated as A to K. Subtype B is found in America, Japan and Europe while subtype C predominates in South Africa and India (and is responsible for 55 percent of HIV 1 infection globally). Subtype E is found in Thailand. The strains of HIV-1 can be classified into four groups: the “major” group M, the “outlier” group O and two new groups,
N and P. These four groups may represent four separate introductions of simian immunodeficiency virus (SIV) into humans (*ibid.*).

**Transmission of HIV/AIDS**

The spread of the HIV/AIDS to an unaffected person occurs through anal or vaginal intercourse, exchange of blood through transfusion or from infected mothers to their infants before or during birth or possibly from breast feeding (Cockerham, 1978). So it is clear that a person who has HIV carries the virus in certain body fluids, including blood, semen, vaginal secretions and breast milk. The virus can be transmitted only if such HIV infected fluids enter the bloodstream of another person (NACO, 2006). This kind of direct entry can occur (1) through the linings of the vagina, rectum, mouth and the opening at the tip of the penis; (2) through intravenous injection with a syringe; or (3) through break in the skin such as cut or sore. Usually, HIV is transmitted through:

- **Unprotected sexual intercourse (either vaginal or anal) with someone who has HIV:** Women are at greater risk of HIV infection through vaginal sex than men, although the virus can also be transmitted from women to men. Anal sex (whether male to male or male to female) poses a high risk mainly to the respective partner because the lining of the anus and rectum is extremely thin and is filled with small blood vessels that can be easily injured during intercourse. As per the physiology, the males can ejaculate within the vagina which poses a great risk to women to get HIV infection but a female is not going to give anything to a male. So if an infected female has sexual intercourse with a non-infected male, there is a least possibility that the male will get HIV. It further depends on the viral load of the female.

- **Sharing needles or syringes with someone who is HIV infected:** Laboratory studies show that infectious HIV can survive in used syringes for a month or more. That’s why people who inject drugs should never reuse or share syringes, water or drug preparation equipment. This includes needles or syringes used to inject drugs. Other types of needles such as those used for body piercing and tattoos can also carry HIV. Few studies have shown that the current strains of the virus are very fragile organism, unable to survive for more than a few seconds under the room temperature when not inside the body of human
being. But when an infected needle is reused, there is great risk of transmission of HIV infection as HIV is able to find its host from the human blood and can regenerate itself.

- **Contaminated blood transfusion**: Any person who receives blood drawn from any HIV infected person can transmit HIV to the recipients of the same blood. Sometimes the donor is in incubation period in which HIV antibodies are not detected are considered to be HIV negative. Later on, it can infect the person to whom the blood transfusion is made. Unknowingly and unwantedly, the recipient is prone to contact HIV from the infected blood.

- **Infection during pregnancy, childbirth or breast feeding (mother to infant transmission)**: Any pregnant women who may have been exposed to HIV, even if the exposure occurred years ago is likely to transmit the disease to the child. In the U.S., mother to infant transmission has dropped to just a few cases each year because pregnant women are routinely tested for HIV. Those who test positive can get drugs to prevent HIV from being passed on to foetus or infant and they are counselled not to breast feed (NACO/WHO/UNAIDS, 2006).

Just as important or perhaps even more important is to know how the virus does not spread among people. HIV is not transmitted by day to day contact. Among these are hugging, kissing, eating, drinking, swimming, working, travelling together and other social settings. One cannot become infected from a toilet seat, a drinking fountain, a door knob, drinking glasses and food. HIV is not an air borne or food borne virus and it does not live long outside the body (NACO, 2006). One question often asked by people is whether HIV can be transmitted through bites of mosquitoes and other insects. Fortunately, experiments by artificially infected mosquitoes showed that unlike the malaria parasite or dengue virus, HIV has neither a life cycle nor does it multiply in mosquitoes. The doubt that mosquitoes may take blood of an HIV infected person and may act like a ‘flying needle’ has also been removed on epidemiological grounds. Studies in a large number of households of people living with AIDS or HIV infected persons in Africa revealed that transmission to an uninfected person occurred only through sexual partners. Children and other adults in the household remained free of HIV, despite having casual contacts with HIV/AIDS patients and despite the large number of mosquitoes in the
environment (Pavri, 1992). HIV virus is no doubt very fragile virus but noticeably, it is unable to survive under the room temperature when not inside the human body.

According to NACO (2006), there is no reason to fear that a mosquito or other insect could transmit HIV from one person to another through HIV infected blood left on its mouth parts. Several reasons help explain why this is so. First, infected people do not have constantly high levels of HIV in their blood streams. Second, insect’s mouth retain only very small amount of blood in and on their surface. Finally, scientists who study insects have determined that biting insects normally do not travel from one person to the next immediately after injecting blood. Rather, they fly to a resting place to digest the blood meal.

**Window Period**

Unfortunately, there are no initial symptoms or signs of the disease but in time to come any illness affecting the infected person is prolonged because the body’s immune system is paralyzed by the virus and ultimately being unable to recover the person who is affected by opportunistic infections. Tuberculosis is the most common infection in HIV positive (Samant, 2000). The HIV virus produces illness for a long time. The interval between the exposure to virus and the manifestation of the disease syndrome is called the Incubation Period commonly known as Window Period. HIV infected person generally remain overtly healthy during this period although they may harbour the virus in blood and acts as the carriers of HIV (Pavri, 1992). During the lengthy incubation period, the individual appears to be healthy (Samant, 2003) but they can still transmit the infection to others during this symptom-free period. Meanwhile, if the infection is not detected and treated, the immune system gradually weakens and AIDS develops (Laskar *et al.*, 2010: 287).

The Incubation or the Window Period can be described as the time it takes for a person who has been infected with HIV to ‘sero convert’ (if tested positive) for HIV antibodies. During this period, HIV replicates in the blood and lymphnodes. Patient can be highly infectious and may or may not be symptomatic. A person who tests during the window period may receive HIV negative test result even though; he/she may be HIV positive. Prior to testing, it is important to determine the risks and possible exposure must be followed by retesting at the end of window period. The initial time period for window period is from three to six months (NACO 2004).
The World Health Organization (WHO) has identified four stages of HIV infection. Each stage represents a decline in the immune system characterized by more serious and frequent opportunistic infections (Usdin, 2005: 70).

**Stage 1:** There are usually no signs that a person is infected. Lymph glands may be swollen but essentially the person is healthy and can remain in this stage for many years.

**Stage 2:** With moderate immune deficiency the body becomes more prone to illness. Minor skin problems, colds and weight loss may occur during this phase. Herpes Zoster (also known as Shingles) often also occurs.

**Stage 3:** With an increasingly compromised immune system, more serious problems begin to occur. These include profound weight loss, chronic diarrhoea, fever, oral thrush (a fungus in the mouth), vaginal thrush, pneumonia and tuberculosis (TB).

**Stage 4:** This stage is characterized by very serious diseases, some of which are seldom found in HIV negative people. These include a lung infection known as Pneumocystis Carinii Pneumonia (PCP), oesophageal thrush (a fungal infection in the throat), infections of the brain such as toxoplasmosis and cryptococcal meningitis, severe diarrhoea, continued profound weight loss and cancers such as Kaposi’s sarcoma (c.f. www.who.int).

**HIV/AIDS: The Chronicle**

In the late 1970’s, the first clue of a strange new disease began to turn up in certain European hospitals. A Danish doctor, Dr. Grethe Rask had practiced medicine in a remote hospital in Zaire. Rask became ill in 1975, returned to Denmark and died in 1977, grasping for breath. A Biopsy showed that the cause of the death was the rare Pneumocystis Carinii Pneumonia (PCP), a type of Pneumonia carried by the birds. Other mysterious cases of PCP presented themselves to the doctors, especially in hospitals in Paris. A handsome young Air Canada flight steward frequently visited Paris during the period. His name was Gaetan Duga. He was later to become famous for his role in transmitting the virus in United States. Years later, when much more was known about HIV/AIDS; scientists tried to trace the origin of epidemic. A dozen 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. The earliest known case of HIV 1 has been identified in one of 1,213 stored blood samples that were gathered in 1959 in Africa.
The individual designated ‘L70’, was an adult male with a sickle – cell trait and a glucose deficiency, living in Kinshasa, Democratic Republic of Congo. Using the sophisticated mathematical models and computer tools and knowing that L70’s infection probably had ancestors in the B, D and F subtypes of HIV 1, biologists estimate that the first HIV case occurred in Africa in the 1930’s (Singhal et al., 2003). 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. His first patient sought medical care because of weight loss. He had candidacies, a thick white coating in his mouth. One week later, this patient was readmitted to the UCLA Medical Hospital with fever and Pneumocystis Carinii Pneumonia (PCP). Soon, local physicians in Los Angeles referred several more patients with weight loss, fever and candidacies to Gottlieb (ibid.). All were young gay men and all of them had shared a sexual life style that was different. In another words, these men were homosexuals, colloquially called ‘Gays’. Since the syndrome was first recognized in gays, not only in USA but subsequently in Europe and Australia, it was called as “Gay Related Immune Deficiency” (GRID). Since the syndrome was first recognized in them, not only in USA but subsequently in Europe and Australia, it was called ‘Gay Related Immunodeficiency’ (GRID) (Pavri, 1992; Herek, 1999). A little later, cases of HIV/AIDS were identified among drug addicts, especially Intravenous Drug Users (IDU). Most of these found to be affected with AIDS started dying and thus the peculiar combination of sex and death attracted attention and gave rise to many myths and misconceptions (Bolaria, 1988).

The Morbidity and Mortality Weekly Report (MMWR) of 3rd July 1981 reported a cluster of cases of Kaposi Sarcoma (KS), a rare type of skin cancer usually found among the elderly men of Mediterranean ancestry (Singhal et al., 2003; Whiteside, 2008). These cases were also identified in New York and San Francisco. The KS patients have blue, purple and brownish patch on their skin. All the individuals in the cluster were young gay men. The fact that epidemics’ first victim appeared at the same time in three locations – Los Angeles, New York and San Francisco – were disquieting and ominous (Annexure I). We know now that many thousands of individuals at scattered locations around the world were already HIV positive at the time, although they had not yet shown the symptoms of AIDS. Many young men had Kaposi Sarcoma (KS) while other had Pneumonia (also an unusual illness among otherwise healthy young men in the United States). Within weeks, yet more cases were reported to the CDC. Four
Haitians in Miami died of opportunistic infections. They had a low level T-Lymphocytes but surprisingly, the Haitians were not Gays.

The new disease was very puzzling and it was starting to spread rapidly. Epidemiologists of the CDC galvanized into action, seeking to understand the new epidemic. It was spreading like a biological chain letter (Singhal et al., 2003). Evidence also suggests that the HIV/AIDS epidemic began roughly at the same time in several parts of the world, including USA and Africa (NACO, 2006). Earlier also, civilization had witnessed devastating global epidemics or pandemics but AIDS however appeared to be very different. Because of early stamp of homosexuality and Intravenous Drug Use (IDU) among those who died, the patients with AIDS were not called AIDS patients but were termed as ‘Victims’. This word implies a kind of helplessness, a feeling that these patients were being sacrificed due to some ritual preformed by them or under such conditions. Perhaps, the word ‘Victim’ was applied to show that these persons were sacrificed because of the ‘Wrath of God’. Soon enough, there came to light another group of AIDS patients who had no peculiar life style of risky behaviour. This group consisted of persons (children and adults) who had received blood transfusion or blood products. When more and more women got AIDS, it was found that a child born of these women developed AIDS. All these persons were also identified as Victims, but now they were qualified as ‘Innocent Victims’ so as to discriminate between the ‘guilty’ ones. With the widening of the people ‘at risk’ of contracting AIDS, it further gave rise to panic. Panic, because it was already recognized by scientists that some infectious agent could be responsible because there was no known measure available for stopping further spread of this yet unidentified agent (Pavri, 1992).

Tracing the history of HIV/AIDS is like unravelling a mystery story. Several hypotheses have been proposed to explain the origin of HIV/AIDS pandemic. Some of these have been strange and some even offensive. Sir Fred Hoyle, a former Astronomer Royal, postulated that the virus came from the outer space. There were allegations against a certain country concerning ‘germ warfare’. In the present circumstances, the idea of bacteriological warfare may be seen embarrassingly silly but at the time, these allegations had to be refuted at length by the other country. Among the offensive ones were the suggestion about the alleged use in some countries in Africa of monkey blood for sexual stimulation. It was said that the male blood for males and the blood of female monkey for the females was inoculated directly in the pubic area, in the thighs and back, were supposed to have transmitted the virus. There were also some plausible,
even logical, suggestions made on scientific basis. One can say that the history of HIV/AIDS is not clear.

By looking at the history, it can be said that the individuals from different milieu gave different interpretations regarding this illness. To a large extent, endeavour was laid down not to depict the nature and origin of this disease but rather to prove their own identity. In other words, it can be extracted from their ideas that their presentation regarding the origin of HIV/AIDS has led to social construction of this illness since their ideas related to the origin of the virus remain vague. No one knows exactly about the origin of the virus but by looking at the importance of this illness, more and more people have tried to make their mark in this field.

**Theories of 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 (c.f. www.avert.org).

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

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, Rwanda and Burundi 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 (Simian Immunodeficiency Virus – Chimpanzee). 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. Many people have contested Hooper's theories and insist that local chimps were not infected with a strain of SIVcmz that is closely linked to HIV. Furthermore, the oral administration of the vaccine would seem insufficient to cause infection in most people (SIV/HIV needs to get directly into the bloodstream to cause infection - the lining of the mouth and throat generally act as good barriers to the virus). The fact that the OPV theory accounts for just one (group M) of several different groups of HIV also suggests that transfer must have happened in other ways too, as does the fact that HIV seems to have existed in humans before the vaccine trials were ever carried out (ibid.).

**The Contaminated Needle Theory**

This is 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 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 (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 (ibid.).

**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. It was first proposed in 2000 by Jim Moore, an American specialist in primate behaviour, who published his findings in the Journal AIDS Research and Human Retroviruses. 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 become HIV. A stray and perhaps sick chimpanzee with SIV would have made a welcome extra source of food for the workers (ibid.).

Moore also believes that many of the labourers would have been inoculated with unsterile needles against diseases such as smallpox (to keep them alive and working), and that many of the camps actively employed prostitutes to keep the workers happy, creating numerous possibilities for onward transmission. A large number of labourers would have died before they even developed the first symptoms of AIDS, and those that did get sick would not have stood out as any different in an already disease-ridden population. Even if they had been identified, all evidence (including medical records) that the camps existed was destroyed to cover up the fact that a staggering 50% of the local population was wiped out there. One final factor Moore uses to support his theory is the fact that the labour camps were set up around the time that HIV was first believed to have passed into humans - the early part of the 20th century (ibid.).

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 say this was done under the auspices of the US federal ‘Special Cancer Virus Program’ (SCVP), possibly with the help of 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 supposition and speculation, and ignores the clear link between SIV and HIV or the fact that the virus has been identified in people as far back as 1959 (ibid.).
HIV/AIDS: The Indian Saga

At the beginning of 1986, despite over 20,000 reported AIDS cases worldwide, India had no reported case of HIV or AIDS. There was recognition, though, that this would not be the case for long, and concerns were raised about how India would cope once HIV and AIDS cases started to emerge. One report, published in a medical journal in January 1986, stated: “Unlike developed countries, India lacks the scientific laboratories, research facilities, equipment, and medical personnel to deal with an AIDS epidemic. In addition, factors such as cultural taboos against discussion of sexual practices, poor coordination between local health authorities and their communities, widespread poverty and malnutrition, and a lack of capacity to test and store blood would severely hinder the ability of the Government to control AIDS if the disease did become widespread” (Singhal et al., 2003).

Later in the year, India’s first cases of HIV were diagnosed by Dr. Suniti Solomon, a microbiologist Professor at the Madras Medical College in Chennai among sex workers in Chennai, Tamil Nadu. It was noted that contact with foreign visitors had played a role in initial infections among sex workers but when the commercial sex workers were asked that if they had non-Indian customers, they reported that they had not. That means that HIV was already circulating within India. HIV screening centres were set up across the country, there were calls for visitors to be screened for HIV. Gradually, these calls subsided as more attention was paid to ensuring that HIV screening was carried out in blood banks (ibid.: 115).

In 1987 a National AIDS Control Programme was launched to co-ordinate national responses. Its activities covered surveillance, blood screening, and health education. By the end of 1987, out of 52,907 who had been tested, around 135 people were found to be HIV positive and 14 had AIDS. The Indian government officials smugly and morally proclaimed that AIDS was a foreign disease and that the epidemic could never spread in a family centred society like India’s. They were decidedly wrong. Most of these initial cases had occurred through heterosexual practices, but at the end of 1980s a rapid spread of HIV was observed among injecting drug users (IDUs) in Manipur, Mizoram and Nagaland - three north-eastern states of India bordering Myanmar (Burma) (ibid.).
Table 1.1
Important Landmarks of HIV in India

<table>
<thead>
<tr>
<th>Period</th>
<th>Events</th>
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<tbody>
<tr>
<td>April 1986</td>
<td>First Cluster (ten prostitutes) of HIV sero-positives detected in Madras, Tamil Nadu</td>
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<tr>
<td>May 1986</td>
<td>First patients of final stage disease detected in Bombay, Maharashtra who was recipient of unscreened blood transfusion during cardiac surgery in USA</td>
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<td>Dec 1986</td>
<td>First sero-positive male detected from STD clinic in Tamil Nadu</td>
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<td>July 1987</td>
<td>First sero-positive blood donor in Vellore, Tamil Nadu</td>
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<td>July 1987</td>
<td>Spouse to spouse transmission (same donors wife)</td>
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<td>Oct 1987</td>
<td>Detection of sero-positive infant (born to above mentioned parents)</td>
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<tr>
<td>April 1988</td>
<td>First indigenous case of full-blown HIV disease in an India</td>
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<td>Jan 1989</td>
<td>Evidence of HIV antibodies in indigenously produced blood products.</td>
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<td>Jan 1989</td>
<td>Evidence of exposure to HIV among a high proportion of donors used by commercial manufacturers followed by a government ban on production</td>
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<tr>
<td>July 1989</td>
<td>Government gazette notification for mandatory screening of blood donors for freedom from HIV antibodies</td>
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<tr>
<td>Jan 1990 – Feb 1990</td>
<td>Recognition of a cluster of sero-positives in IV drug users in north-east India</td>
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<tr>
<td>Jan 1990 – Feb 1990</td>
<td>Important issues concerning hospital practices arising out of an incident of embalming a body of patient of HIV disease</td>
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<tr>
<td>Jan 1989</td>
<td>Emergence of a highly responsible press on the AIDS scene in India</td>
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<tr>
<td>July 1992</td>
<td>Constitution of the National AIDS Control Organization at state level</td>
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<tr>
<td>Oct 1992</td>
<td>Establishment of the National AIDS Research Institute, Pune by Indian Council of Medical Research (ICMR)</td>
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Source: Khorshed M. Pavri, 1992
At the beginning of the 1990s, as infection rates continued to rise, responses were strengthened. In 1992 the government set up NACO (the National AIDS Control Organization), to oversee the formulation of policies, prevention work and control programs relating to HIV and AIDS. In the same year, the government launched a Strategic Plan for HIV prevention. This plan established the administrative and technical basis for program management and also set up State AIDS bodies in 25 states and 7 union territories. It was able to make a number of important improvements in HIV prevention such as improving blood safety (ibid.).

By this stage, cases of HIV infection had been reported in every state of the country. Throughout the 1990s, it was clear that although individual states and cities had separate epidemics, HIV had spread to the general population. Increasingly, cases of infection were observed among people that had previously been seen as ‘low-risk’, such as housewives and richer members of society. According to Singhal et al. (2003), HIV infection is now common in India; exactly what the prevalence is, is not really known, but it can be stated without any fear of being wrong that infection is widespread… it is spreading rapidly into those segments that society in India does not recognize as being at risk. AIDS is coming out of the closet (ibid.).

In 2001, the government adopted the National AIDS Prevention and Control Policy. During that year, Prime Minister Atal Bihari Vajpayee addressed parliament and referred to HIV/AIDS as one of the most serious health challenges facing the country. The Prime Minister also met the chief ministers of the six high-prevalence states to plan the implementation of strategies for HIV/AIDS prevention. HIV had now spread extensively throughout the country. In 1990 there had been tens of thousands of people living with HIV in India; by 2000 this had risen to millions. In 1999, 1,400 Indian citizens were estimated to be infected each day (ibid.).

Looking at the intensity of the disease, National AIDS Control Project (NACP) was launched which was funded primarily by a World Bank IDA Credit of US$ 84 million in 1992 – 1999. NACP – I was a start up investment to launch intervention for HIV prevention, so as to slow the spread of HIV, and mitigate the impact of AIDS. During the same year, Government of India succeeded in setting up the National AIDS Committee, the National AIDS Control Board, the National AIDS Control Organization (NACO) and the State AIDS cells. While significant progress was achieved in building some capacity at state levels, but, there remaining some significant limitations in the implementation of NACP. The centralization of planning and implementation did not facilitate divergent priority setting and management across state
governments. There was uneven implementation of project activities at state levels. The sentinel surveillance could not be conducted across all states and this led to inadequate information regarding the progress of the epidemic. Vulnerable groups were not all identified and issues surrounding care and support of people living with HIV/AIDS could not be fully addressed. The IEC remained somewhat limited and community involvement was inadequate.

The second National AIDS Control Project was commenced in November 1999, similarly with IDA World Bank funding, and has recently been extended to March 2006. The outcomes envisaged in the Second National AIDS Control Project are to keep HIV sero prevalence below 5 percent of the adult population in high prevalence states, below 3 percent in the moderate prevalence states and below one percent in the low prevalence states. Through the second National AIDS Control Programme (1999 – 2006), NACO has build upon previous achievement, in several key areas, identified gaps and sought to bridge these.

An annual HIV sentinel surveillance survey has been institutionalized over the years, in order to monitor trends of HIV infection in specific high risk groups as well as low risk groups. For the purpose of HIV sentinel surveillance, high risk segments of the population include people attending STD clinics, MSM (men having sex with men) clinics and drug de addiction centres. Low risk segments include mothers attending antenatal clinics, and in fact this category is taken as proxy for the general population. Sentinel surveillance for HIV was first organised in 1994 at 55 sentinel sites which grew to 180 HIV sentinel sites in 1998. These continued to increase from 2002 – 2004, the number of HIV sentinel sites grew from 384 to 670. During the year 2002, the HIV sentinel surveillance round was conducted from 1st August 2002 to 15th November 2002 in 384 sentinel sites with inclusion of 64 new sites. During year 2003, the sentinel surveillance round was conducted from 1st August 2003 onwards in 455 sentinel sites with inclusion on 71 new sites (NACO, 2004).
The year 2007 is another important year in the history of the country’s fight against HIV/AIDS, with the third phase of National AIDS Control Programme (NACP – 3) beginning this year. Based on the lessons learnt from and achievements of Phase 1 and 2, India had now developed the Third Phase of National AIDS Control Programme (2007 – 2012). The design of NACP – 3 implementation plans has gone through a very wide range of consultations at national, state and district levels. NACP – 3’s priorities and thrust areas draw heavily from its experience in the previous two phases. In particular, the process underscored the need for consolidation of gains and addressing the programmatic gaps and weakness. With the total proposed financial requirements of 11,585 crore including budgeting and extra budgeting support, the overall goals of NACP – 3 is to halt and reverse the epidemic in India over the next five years (NACO Newsletter, 2007).
HIV/AIDS: A Numerical Falsification in India

Accurate statistics are important because they represent aspects of human realities, shape public perception and form a scientific basis for government policies. A reliable surveillance system and realistic estimates allow us to understand the prevalence, magnitude, distribution and mode of spread of a disease. These data are critical prerequisites for designing effective prevention, support and mitigation strategies. They can also stem the current culture of denial and scapegoating and encourage politicians and the Indian public to accept that there is a problem which requires their attention (Kadiyala, 2004).

It just may be premature to start celebrating that the case load for people infected with the dreaded Human Immunodeficiency Virus (HIV) has come down by half to 2.47 million as per the latest estimate released by the Government. There is an unknown methodology adopted by the National AIDS Control Organization (NACO) to arrive at this optimistic figure. What is crystal clear now is that the spectre of a giant AIDS holocaust waiting to explode in India, is not a scenario that was based on any reality, to that extent that phantom of an AIDS time bomb or A bomb has certainly been defused. If the Government estimate is accurate, then the most unintelligent and highly alarmist estimate that by 2010 India will have 20 – 25 million HIV positive cases came from the Central Intelligence Agency (CIA) of America through its 2002 report from the National Intelligence Council. In the past years UNAIDS has on several occasions questioned the veracity of the NACO data but now it seems that they will eat a humble pie. A multi pronged methodology, fresh mathematical models and a noble community based dataset had given confidence to the then Union Minister Anbumani Ramadoss to say that ‘there are estimated 2 to 3.1 million people infected with HIV/AIDS’ down from the government’s own figure of 2006 which put the same number at 5.2 million which according to the minister, who himself was a medical doctor, a ‘reason to be happy’ (ibid.).

While complementing the work of NACO in putting the brakes on the AIDS epidemic, Ramadoss also added a word of caution by saying that while ‘experts from India and round the world were consulted and after a lot of hard work, the results were shown that there are an estimated 2 million to 3.1 million people infected with HIV/AIDS with a prevalence level of about 0.36 percent. While the prevalence appears to be less than the previous estimate of 0.9 percent, these figures are not comparable. By using the same methodology for the past years that
we used this year, there is only a marginal reduction in the prevalence. Moreover, in terms of human lives affected, the numbers are still large and worrying. There is no doubt in my mind that we cannot let down our vigil but continue to work hard to ensure that the HIV/AIDS are under total control’ (c.f. Bagla, 2007). These cautionary words of wisdom come from an earthy politician who probably comprehends how flawed surveys and exit polls can be.

The statistical distortion with reference to the aggregate number of people living with HIV/AIDS (PLWHA) in India was a propaganda fabricated by the Ministry of Health and Family Welfare (MOHFW) and National AIDS Control Organization (NACO). With the escalating number of cases in India, presentation of the distorted figure was an obvious blunder made by the Governing bodies. It aimed at validating the result oriented endeavours of the government in reversing the catastrophic impact of the HIV/AIDS pandemic in India. However, the fact cannot be ignored that revealing the accurate figures may lead to pandemonium within the country in the form of xenophobia. The hype against the reversing of HIV/AIDS figures in India was an ideal quintessence to the social construction of reality, a reality that was structured elegantly by the echelons.

**HIV/AIDS: The Social Constructionist Perspective**

The basic contentions of the argument are implicit in its title, that reality is socially constructed and that the sociology of knowledge must analyze the process in which this occurs. The key terms in these contentions are ‘Reality’ and ‘Knowledge’; terms that are not only current in everyday speech, but that have behind them a long history of philosophical inquiry. Sociological interest in questions of ‘reality’ and ‘knowledge’ is thus initially justified by the fact of their social relativity. What is ‘real’ to a Tibetan monk may not be ‘real’ to an American businessman. The ‘knowledge’ of the criminal differs from the ‘knowledge’ of criminologist. In other words, we contend that the sociology of knowledge is concerned with the analysis of the ‘Social Construction of Reality’ (Berger and Luckmann, 1966).

The sociology of knowledge is concerned with the relationship between human thoughts and social context within which it arises. The sociology of knowledge derived its root proposition from Karl Marx, that man’s consciousness is determined by his social being. To be sure, there has been much debate as to just what kind of determination Marx had in mind. What concerned Marx was that human thought is founded in human activity and the social relations
brought about by this activity. ‘Substructure’ and ‘Superstructure’ are best understood if one views them as, respectively, human activity and the world produced by that activity (Huber, 1998).

Although a person's conception of reality, fear and danger, abnormality and stigma, health and beauty may be very individual, this perception, to a large extent, is culturally patterned. Events, actions, attitudes, and beliefs are mediated by historical and cultural factors. Individual reality is a social construction and not necessarily an absolute truth. Personal conceptions are reflective of a much larger construct, one that transcends any individual. The relationship, however, between individual perception and social construct is an integral one in that dynamic socialization that shapes the construction of reality (ibid.).

Social construction is a general term sometimes applied to the theories that emphasize the socially created nature of social life. Of course, in one sense all sociologists would argue this, so the term can easily become devoid of meaning. Social construction emphasizes the idea that society is actively and creatively produced by human beings. They portray the world as made or invented rather than merely given or taken for granted. Social worlds are interpretive nets woven by individuals and groups. For Berger and Luckmann (1966), the basic features of social order are captured in the principle that ‘Society is a human product, Society is an objective reality, Man is a social product’ (Marshall, 2004). But the question is that why human beings socially construct the reality?

Reality is constructed within three realms; social, physical and individual and is composed of societal definitions and interactions. Social, physical, and personal realities operate in conjunction to construct and define an individual's reality. Social reality is moulded within the context of societal circumscription of the individual bounded by his or her culture. This spatial reality is grounded in social action and interaction. A physical reality also exists, independent of social reality, as a paradigmatic structure present at the instance of every situation. Physical objective reality consists of an individual's surroundings and current set of circumstances. Social reality responds, in part, to physical reality where physical reality is the existing situation. The situation, however, is defined by one's social reality. In addition, each individual possesses a personal reality based on that person's unique perspective. Personal reality, consciously and unconsciously, is shaped through socialization (Huber, 1998).
Social reality, physical reality, and personal reality interact simultaneously to form one's cumulative perception of what is real. This cumulative perception then, when combined with other individuals' realities derived from a similar perspective, forms the basis for defining social constructs. Social constructs, however, being created from societal perceptions, may lack scientific foundation. In fact, political and economic elites very often generate media images and other forms of discourse to influence social construction of meaning and reality. Social ideologies and also political interests, in essence, shape the construction of reality. Where HIV and AIDS are concerned, the social construct within which the pathological exists is built upon the politics of bodies and disease (ibid.).

Foucault (1980) argues that how ‘Power is Knowledge and Knowledge is Power’. People construct discourses which form the reality. According to Foucault, Discourse means, anything written or said or communicated using signs and marks. For instance, the discourse on madness produced by Psychiatrists, Psychologists, Social Workers and other experts define the roles of craziness and thus also the roles of normalcy. But Foucault doubted on Knowledge of absolute truth. He argues that if you take away the idea of absolute truth, what does knowledge means? May be Knowledge would be just what a group of people get together and decide is true (constructed truth). Foucault argues that in one case physical force and in the other mental force is exerted by a powerful minority who are thus able to impose their idea of the right of the true on the majority (Fillanham, 2003).

Foucault was concerned with the way in which discourses are shaped by social practices and the way they in turn shape social relationships and institutions. His theory of discourse begins with the assumption that all objects and actions are meaningful and that their meaning is a product of historically specific system of rules. It thus inquires the way in which social practitioner’s construct and contests the discourse that constitutes the social reality (Howarth, 2002). He further argues that, how some people get the rest of us to accept their ideas of who we are? That involves some power to create beliefs and these same people who decide what is knowledge in the first place can easily claim to be the most knowledgeable to know more about us than we do about ourselves (Fillanham, 2003).

Goffman (1959) in his famous writings ‘Presentation of Self in Everyday Life’ views human nature as predatory, inauthentic and manipulative. Goffman quotes Robert E. Park’s 1926 formulation: ‘we come into the world as individuals, achieve character and become persons’.
Goffman seems to endorse Park’s conception of the person as a role player with mask in place. He does not here deny that people have unique selves. But he persists with the sociological questions: how is that uniqueness publicly discernible? His answer is that uniqueness is marked by ‘identity pegs’ such as our knowledge of another’s appearance, or our knowledge of their placement in a kinship network and other life history matters (Smith, 2006).

Goffman also asserted that when we present ourselves in a certain way (e.g. as student), then we have a moral right to expect others (e.g. teachers) to treat us in that way. In other words, he said that moral obligations are built right into the detail of interaction. Morality is not something that is diffusely located in ‘society’ but is rather mediated and renewed in everyday social encounters. He also said that the individual spends a considerable amount of time bathing his wounds of fantasy, imagining the worse things that might befall him, day dreaming about sexual matters, monetary deals and so forth. Looking at all this, Goffman calls humans as vehicles of society, but overheated engines that are prone to keep firing even though the ignition is turned off (ibid.).

Alfred Schutz (c.f. Walsh and Lehnert, 1972) in his remarkable work Phenomenology of the Social World accepted the notion of Husserl that humans hold a ‘world of natural attitude’ to which he later calls as ‘life world’ is a taken-for-granted public world that shapes who we are and what we will do. In this interpreted or intersubjective world people perceive that they share the same life world and act as if they lived in a common world of experiences and thus, share the same stock of knowledge due to the reciprocity of perspectives. This is in no way a scientific world, but a world of commonsense, where we all have social relationships and carry on actions. He considered it the most important (paramount) social reality that is, the creation and maintenance of intersubjectivity that is, a common subjective world among pluralities of interacting individuals.

AIDS is a global pandemic and from the moment scientists identified HIV/AIDS, social responses of fear, denial, stigma and discrimination have accompanied the epidemic (Mann et al., 1992). The review of existing studies on the topic reveals various factors that are responsible for generating troubles in the alimony of People Living with HIV/AIDS (PLWHA). It has escalated the enigma of Denial, Stigma and Discrimination (DSD). The present study broadly aims at finding the way this disease is socially constructed and the way PLWHA are labelled by their family, community and society at large.
Construction of HIV/AIDS: Review of Literature

Barnett and Blaikie (1992) in their study conducted in Uganda revealed that, despite of all the efforts and the work of all those involved in HIV issue, it was evident in the early to mid 1990s that discrimination, stigma and denial were still very serious problems in the country. Particular negative effects have been identified in ‘culturally defined groups’, among whom HIV and AIDS related stigma has led to many of those infected and affected withdrawing from social contact with others altogether.

Denial

Several people find themselves reluctant to disclose their HIV positive status to others in fear of getting denial. Even when individuals suspect they are positive, they may not seek a test or treatment if it means going to a known AIDS clinic or a community doctor (Muyinda et al., 1997). Moreover, it may also depends on the way in which individual discover and disclose their HIV status to others, as well as how they cope with their HIV status, is influenced by cultural and community beliefs and values regarding causes of illness, learned pattern of responses to illness, social and economic contexts and social norms (Mechanic, 1995).

Malcolm et al. (1998) reported that, “HIV/AIDS pandemic has evoked a wide range of reactions from individuals, communities and even nations, from sympathy and caring to silence, denial, fear, anger and even violence. Stigma is an important factor in the type and magnitude of the reactions to this epidemic.” Cameron (2000) clarifies that, “Silence and denial may be the most pervasive reactions to stigma, as signified by the title of year 2000 International AIDS Conference: Breaking the Silence. For some individuals, not knowing one’s HIV sero status is far preferable to being tested.”

The study of Blumenfeld (2001) has revealed that the landlords have denied rentals to tenants, a number of airlines have been sued for refusing to allow people living with HIV/AIDS to fly and people have been denied services at many places. In prisons, sero positive prisoners are often segregated and denied access to appropriate medical and legal resources.”
Stigma

The term Stigma referred to a visible marking on the body that was usually made by a branding iron or pointed instrument that mark signified social ostracism, disgrace, share or condemnation. This term is well defined by Erving Goffman in his book Stigma: Notes on management of spoiled identity (1963). According to him, Stigma is an undesirable or discrediting attribute that an individual possesses, thus reducing that individual’s status in the eyes of society. Stigma can result from a particular characteristic, such as physical deformity or it can stem from negative attitudes towards the behaviour of a group, such as homosexual or prostitutes. Thus, in Goffman’s definition, stigmatization is the societal labelling of an individual group as different or deviant. A large number of studies have revealed that the stigma related to HIV/AIDS exist in a variety of ways.

In Brown et al. (2001) view that stigma is a common human reaction to disease. Throughout history many diseases have carried considerable stigma, including leprosy, tuberculosis, cancer, mental illness and many STDs. HIV/AIDS is only the latest disease to be stigmatized. HIV/AIDS Stigma refers to prejudice, discounting, discrediting and discrimination directed at people perceived to have HIV/AIDS and the individual groups and communities with which they are associated (Herek et al. 1990). UNAIDS (2008) made a statement that, AIDS stigma exists around the world in variety of ways, including ostracism, rejection, discrimination and avoidance of HIV infected people, compulsory HIV testing without prior consent or protection of confidentiality, violence against HIV infected individuals or people who are perceived to be infected with HIV and the quarantine of HIV infected individuals.

Like AIDS in itself, AIDS stigma is a global problem. It is manifested around the world through ostracism of people with HIV/AIDS, discrimination against them and in few countries, quarantines. Goldin (1994) pointed out that although AIDS stigma is effectively universal, it has different forms from one country to another and its specific targets vary considerably. This variation is shaped in each society by multiple factors, including the local epidemiology of HIV and pre-existing prejudices within the culture, with the stigma often expressed against unpopular groups disproportionally affected by the local epidemic.

Gerbert et al. (1991) has argued that AIDS stigma negatively affects prevention behaviour such as condom use, HIV test seeking behaviour, care seeking behaviour upon diagnosis, quality of care given to HIV positive patients and perception and treatment of
PLWHA by communities, families and partners. In view of Jayaraman (1998) stigmatization of an HIV positive is a dynamic process that arises from the perception that there has been a violation of a set of shared attitudes, beliefs and values. These can lead to prejudicial thoughts, behaviour and action on the part of governments, communities, employers, health care providers, co-workers, friends and family.

Meisenhelder and La Charite (1989) indicated that the sources of stigma include fear of illness, fear of contagion and fear of death. Fear of illness and fear of contagion is a common reaction among health workers, co-workers and caregivers, as well as the general population. Stigma is one means of coping with the fear that contact with a member of an HIV/AIDS affected group will result in contracting the disease. Rushing (1995) mentioned that, HIV stigma is often layered on top of many other stigmas associated with such specific groups as homosexuals and prostitutes and such behaviour as injecting drug use and casual sex. These layers of stigma have unfortunately helped to extend and deepen the AIDS stigma to many who are infected with or affected by the disease.

According to Raveis, Seigel and Gorey (1998), AIDS stigma can have a variety of negative effects on HIV test seeking behaviour, willingness to disclose HIV status, health care seeking behaviour, quality of health care received and social support solicited and received. In “AIDS and Its Metaphors”, Sontag (1988) eloquently described the emergence of HIV/AIDS as a new disease "whose charge of stigmatization, whose capacity to create spoiled identity" is far greater than any other disease in history. For centuries, persons at risk for or living with a communicable disease have been stigmatized, labelled as deviants, and shunned by society. Vincent (2006) mentioned that, where stigma is strong, people will not talk freely about HIV/AIDS and open up the space to find ways to address it together. Such an open discussion has been a key to tackling HIV in successful responses.

**Discrimination**

Discrimination, in its sociological meaning, involves highly complex social processes. The term derives from the Latin *discriminatio*, which means to perceive distinctions among phenomena or to be selective in one’s judgment (Borgatta *et al.*, 2000). Encyclopaedia of HIV/AIDS also defines Discrimination as, “Disadvantageous treatment, either overt or insidious, of individuals or groups that results in the unequal treatment of or the denial of opportunities to these people”
(Watstein et al., 2003). Discrimination as defined by UNAIDS (2000) in the *Protocol for Identification of Discrimination against People Living with HIV/AIDS* refers to any form of arbitrary distinction, exclusion or restriction affecting a person, usually but not only by virtue of an inherent personal characteristics or perceived belonging to a particular group – in the case of HIV/AIDS, a person’s confirmed or suspected HIV positive status irrespective of whether or not there is any justification for these measures. Family Health International (2004) mentioned that Discrimination occurs when a person is treated unfairly for a particular attribute. Discrimination towards people living with HIV/AIDS involves a wide range of practices from unconscious gestures or neglect to conscious decisions to reject a person and may take the form of harassment or hostility towards them.

A large and growing body of literature testifies to the occurrence of widespread discrimination based upon stereotypical qualities associated with HIV/AIDS. Globally, numerous studies have been conducted to apprehend the diverse issues associated with HIV/AIDS. Among them, studies on Discrimination made against people living with HIV/AIDS have been placed above by most of the national and international studies. Many Indian studies on the Discrimination against people living with HIV/AIDS have also been conducted over the years which have played a significant role in determining the impact of this disease on the sero positive people and well as their significant others. According to Perkins (2005), Discrimination is still an everyday experience for people living with HIV/AIDS and vulnerable population, yet their complexity and diversity in practice, coupled with the failure to develop a greater understanding of their social roots, means they are often not addressed effectively.

Harry and Das (1980) explain that discrimination has spread rapidly, fuelling anxiety and prejudice against the groups most affected, as well as those living with HIV/AIDS. It goes without saying that HIV/AIDS is as much about social phenomena as they are about biological and medical concerns. Persons with HIV/AIDS are discriminated throughout the world to varying degrees. AIDS discrimination around the world is expressed through social ostracism and personal rejection of people living with HIV/AIDS and violating the law which deprive them of basic human rights. Similarly, Panos (2001) argues that discrimination manifests itself as denial of services which also includes other practices like breach of confidentiality, isolation of HIV/AIDS patients or substandard and degrading treatment. Stutterheim *et al.* (2009) have brought out the prevalent discrimination in the health care system as well. In health care settings
people living with HIV can experience discrimination such as being refused medicines or access to facilities, receiving HIV testing without consent and lack of confidentiality. Such responses are often fuelled by ignorance of HIV transmission routes amongst doctors, midwives, nurses and hospital staff.

**Issues Related to People Living with HIV/AIDS: Review of Literature**

**Gender**

Unequal gender relations are a key factor under-pinning women's inability to protect themselves from sexually transmitted infections, including HIV/AIDS, as well as the influence of HIV/AIDS on the lives of women. Women receive harsher forms of stigma. They are seen as the “carriers” or “vectors” of HIV/AIDS and are assumed to have brought AIDS into the family because they are most often the first to be diagnosed HIV positive either through antenatal screening or the birth of a sick child. Daniel (2002) stated that, more than 20 years into the human immunodeficiency virus epidemic, women account for nearly half of the 40 million people living with HIV worldwide, with an even higher proportion existing in developing countries. Social determinants of female vulnerability to HIV include gender disparities, poverty, cultural and sexual norms, lack of education, and violence.

Gender specific roles combined with poverty and social and cultural attitudes toward women mean that women bear the burden of caring for people who are sick. This burden of care also falls disproportionately on girls. A Zimbabwean study (c.f. www.unaids.org) found that 76 percent of children who left school to take care for sick people were girls. This study also found that when women are HIV-positive they face discrimination in health care, education, and legal rights. They are also more likely to be blamed, stigmatized, and even abandoned by their families. Rural women are particularly at risk. Many cultural and social attitudes and practices undermine and negate women’s equality, and directly or indirectly increase women’s vulnerability to HIV/AIDS. These vary between different countries. Many times destitute women form sexual relationships to ensure food and maintenance for themselves and their families. Thus, in many societies men provide women with desired goods in return for sexual access. Sex may also be traded for a job, permit, or promotion in the employment sphere, and for marks or
fees in the educational sphere. Most of this sex is unsafe because women risk loss of economic support from men by insisting on safer sex.

Amoakohene (2004) revealed that, both women and girls report increased violence at the hands of their partners for requesting condom use, accessing voluntary testing and counselling, refusing sex within or outside marriage or for testing HIV positive. Physical violence, the threat of physical violence, and sexual violence and coercion are all likely to be important factors associated with HIV transmission for women of all ages across the space (Moreno, 2000). They are often subject to emotional harassment and many times are thrown out of their jobs. Violence against women and girls plays a major role in the spread of HIV. According to World Health Organization (2001), “Violence and the fear of violence are emerging as an important risk factor contributing to the vulnerability to HIV infection for women. The extent to which individuals who are HIV infected, particularly women, are vulnerable to violence is also an issue of concern.”

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Bharat (1996) mentioned that, forms of Discrimination against women with HIV included being refused shelter, being denied to share household property, being denied access to treatment and care and being blamed for husband’s HIV diagnosis, especially when the diagnosis was made soon after marriage. Ramasubban (1998) stated that, there is wide range of biological and social factors at work here. Men therefore can infect women more effectively than vice versa.

UNAIDS (2007) acknowledged that, “Women tend to experience greater stigma and discrimination than men, are more likely to experience its harshest and most damaging forms, and have fewer resources for coping with it. Violence is as severe consequence of stigma faced principally by women.” A study conducted by Asia Pacific Network of People Living with HIV/AIDS (2004) elucidated that, “There are remarkable similarities in the extent of discrimination between countries, particularly in the lack of information provided to people before and after they are tested for HIV and the extent of discrimination against women. The most important factor influencing whether people experience AIDS related discrimination with the family and the community is not age or country but the sex of the respondents.”
There are countless issues that have bent the problems in the life of People Living with HIV/AIDS. Negative recrudesce from the family and community members, friends and colleagues and from the society at large are the foremost factors held responsible for accelerating discrimination and Stigma. But discrimination and stigma was seen with different vision in Asia countries as compared to the western nations. Further, studies have been presented to show the additional reasons accountable for creating the troubles in the social life of those who are either infected or affected with HIV/AIDS in Asia with particular emphasis on India.

According to UNAIDS technical update (1998), “An important biological difference between men and women that leads to additional social and cultural consequences with regard to HIV/AIDS is that women with HIV can transmit the virus to their babies before or during birth or through breastfeeding. This reality raises many complex issues surrounding pregnant women’s right to freely choose whether to be tested for HIV, and the right of those who know they are infected to make independent, informed choices about childbearing and breastfeeding.”

**Marriage**

Gender inequities within marriage, cultural norms and limited economic and social autonomy leave women with poor or no control over decisions related to sexual activities. These factors propel the risk for HIV transmission from men to women. A woman’s limited or lack of control over her sexual life is exacerbated by intimate partner violence that includes coercive sex (Silverman et al., 2008). In India, gender inequalities and the construction of masculinity limits women’s control over decisions related to sexuality both for her husband and herself (Maman et al., 2002).

Women’s lack of control is fuelled by intimate partner violence that involves sexual coercion and increased HIV risk. Domestic violence is more common in relationships where men and women have extramarital sex and/or STI like symptoms (Verma and Collumbein, 2003). Very few attempts have been made to examine the marital relations of sero-discordant and sero-concordant couples living with HIV/AIDS. Most of the existing literature highlights the trend of violence among the intimate partner relationship with regard to either or both having positive status.

According to AIDS Alliance, there are several ways in which HIV and violence among the intimate partners relationship overlaps in the context of women’s lives. Coercive sexual
intercourse by HIV positive male partner may directly increase women’s risk for HIV through physiological trauma. Violence and threats of violence may limit women’s ability to negotiate safe sexual behaviour.” Castor et al. (2010) reveals that having a partner who has a concurrent status has been shown to be a risk factor for HIV infection. It is plausible that having an unfaithful male partner is a risk factor for intimate partner violence too, because so much of the fighting between men and women has to do with accusations of infidelity.

Cichocki (2007) argues that in couples where both partners are HIV negative, the concern of both partners is the same, to stay HIV negative. However, in couples that have one partner negative and one partner positive, different issues are at hand. The positive partner is concerned about transmitting the virus to the negative partner. The negative partner commonly devotes his or her attention to the positive partner’s health, becoming the caregivers in the relationship. The most common problem among the couples with HIV included fear of abandonment, rejection, discrimination, violence, upsetting family members, and accusations of infidelity. Women’s fear of abandonment is closely tied to fear of loss of economic support from a partner. In those settings where resources are extremely scarce and women’s access to resources independent of their partner is uncommon there the fear of losing this instrumental support from a partner is a major consideration when deciding whether to share HIV test results or not (Medley et al., 2004). Many times when married couples test for HIV and find themselves discordant, the negative partner accuses the other of infidelity. That person thinks the partner wanted to spread the virus intentionally and attempts to ‘kill’ them by spreading the virus (Abaho, 2009).

Health Care

While talking of HIV/AIDS, one institution that comes to our mind is the health care system as it becomes a shrine for all those who are trapped into the vicious circle of HIV/AIDS. Although the things are not similar as it seems to be since the PLWHA who are admitted within the hospitals are mistreated by the doctors, nursing and paramedical staff members. With the help of certain studies, an effort has been laid down to understand the attitude of health care system towards PLWHA.

A study conducted by Nguyen TL, Nguyen AT, Huyen HT (2004) in Vietnam reveals that almost all PLWHA had negative experiences from health providers. Nursing staff reported the fear of transmission of the diseases such as AIDS and tuberculosis. They either did not
provide adequate care or refused to provide services such as fluid transfusions and assistance for child birth. Health staff informed the patient’s relatives about HIV status without informed consent. Women experienced more stigma and discrimination than men. During childbirth, they were poorly treated or turned away from public health facilities. Some health workers stated that HIV/AIDS infected women should abort their babies and communicated this to pregnant women and their families. Many poor PLWHA were turned away by hospital staff because of the high cost of care for PLWHA.

Ogden et al. (2005) elucidated that the health care setting is a particularly conspicuous context for HIV/AIDS related stigma and discrimination. In this context people living with HIV or AIDS (PLWHA) often discover their status, and it is where people living with HIV have the potential to gather information about how to care for them and prevent transmission to others, as well as get treatment and care. Because of stigma, there have been various reports of HIV positive people receiving inferior care or being denied care altogether. In view of Miller (2001), HIV/AIDS stigma that results in breach of confidentiality within the health care system is sometimes layered upon pre-existing stigma concerning socially marginalized and vulnerable groups: IDU, MSM and CSW, women, children and migrant workers.

Paxton (2004) comments that health workers mirror the attitudes within a society and can also have a role in reinforcing those attitudes’ given that Paxton found a significant number of breaches of confidentiality to be the result of an action of a health worker, this distinct pattern may be sending messages to the community that it is appropriate and sometimes necessary to discuss the health status of HIV positive people without their consent.

Sharma (1994) mentioned that no doubt, death ends the social psychological sufferings, but social death perhaps is crueller to the patients than the physical death. The reason being that a patient with HIV positive status is totally dejected ostracized and is helpless. In view of Tirelli et al. (1991), the most commonly reported response in the health care system is a refusal to admit or treat HIV positive patients. According to Family Health International (2004), Responses to PLWHA in health care settings may be supportive and informative or restrictive and hurtful. Forms of discrimination reflect fears of infection and assumptions that those afflicted with HIV have been involved in socially disapproved sex or drug use. Discrimination from health care settings may be in forms of reduction in denial of care, breaches of confidentiality, withholding information and mistreating and talking to patients disparagingly.
Workplace

Workplace of an individual is a place where a person lays down his/her efforts for the appraisals of the institution. However, at some workplace discrimination towards PLWHA does persist but such vilification is not often reported by the victim due to the threat of revealing their status to rest of their colleagues. With the help of certain studies on the issue of HIV/AIDS discrimination at workplace, effort has been made to understand the present scenario of HIV/AIDS at workplace of PLWHA.

According to International Labour Organization the HIV epidemic is a global crisis, and constitutes one of the most formidable challenges to social and economic progress. It is devastating the lives of individuals, their families and communities; it is touching all levels of society, the young and the old. In the most affected countries, the epidemic is undermining decades of development gains. It is a real threat to social and economic progress.

ILO (2001) further states that HIV/AIDS has an enormous impact on infected individuals and their families, as well as on the community at large. The implications are serious for the old and young dependants of infected family members. The impact at the individual and household level is mirrored at the enterprise level and, increasingly, in the national economy. The epidemic manifests itself in the world of work in many ways: disruption of production, discrimination in employment, the worsening of gender inequalities, and increased incidence of child labour; other manifestations are depleted human capital, pressure on health and social security systems, and threatened occupational safety and health.

ILO Code of Practice on HIV/AIDS (2001) acknowledged that, beyond the suffering it imposes on individuals and their families, the epidemic is profoundly affecting the social and economic fabric of societies. HIV/AIDS is a major threat to the world of work: it is affecting the most productive segment of the labor force and reducing earnings, and it is imposing huge costs on enterprises in all sectors through declining productivity, increasing labour costs and loss of skills and experience. In addition, HIV/AIDS is affecting fundamental rights at work, particularly with respect to discrimination and stigmatization aimed at workers and people living with and affected by HIV/AIDS.

Juan Somavia (2002), the Director General of ILO once stated that the HIV/AIDS is not just a public health issue; it is a workplace issue, a development challenge and the source of
widespread insecurity. Hard won gains in employment and social protection are being reversed because of the epidemic. At the enterprise level, the effects of AIDS include loss of earnings, loss of skills, reduced productivity and the loss of markets as the consumer base is whittled away. The household income and assets become an employment issue as money is spent on medical care instead of food, clothing, household goods and other commodities. Multiplied many times over, fewer purchases translate into fewer sales for retail outlets, and thus in decreased production. Lessened demand at the retail and production levels in turn affects levels of employment (Rau, 2002).

The National Policy on HIV/AIDS and the World of Work (c.f. www.ilo.org) stated that, HIV/AIDS is a major threat to the world of work. It has shown maximum impact on the most productive segment of the labour force. In countries with high HIV prevalence rates, it has cut the supply of labour and slashed income of workers, adversely affected enterprise performance and national income. HIV/AIDS affects fundamental rights at work, particularly with respect to discrimination and stigmatization of workers and people living with HIV/AIDS. Stigma and discrimination at the workplace gets reflected in the form of loss of employment and livelihood opportunities in addition to ostracism and seclusion faced by workers either due to known or presumed HIV status.

According to Park (2001), an infected person’s right to privacy in the workplace has been covered by laws prohibiting employers from asking about HIV status and prohibiting HIV tests prior to or during employment, unless an employer can show a clear link between test results and job qualification. Despite the laws covering AIDS discrimination in the workplace, incidents still have occurred; policies and laws are abstract and their enactments cannot guarantee that in practice they will be followed.

Blumenfeld (2001) mentioned that Workplace discrimination also runs high, stemming in part from employers irrational fear of HIV transmission or from their fear of losses in productivity of possibility of higher insurance costs or that the entire business will become stigmatized by association. Employers often fire, reassign, or do not hire employees based solely on HIV status. According to UNAIDS (2001) in the workplace, people living with HIV/AIDS may suffer stigma from their co-workers and employers, such as social isolation and ridicule or experience, discriminatory practice such as termination or refusal of employment.
Family, Community and Society

Family, Community and Society are said to be the moral fibre for the efficacious and smooth running of its members. Nevertheless, with the rising debate of HIV/AIDS, these associations have taken a different shape which has diverted the mind of its members. They act as a facilitator and simultaneously as an inhibitor for its associates. The following studies examine the multifarious standpoint of relationship pertaining to PLWHA with Family, Community and Society.

Families are the primary source of care giving and illness management. But they are also an important site for stigma and discrimination in the lives of PLWHA. This may include physical and social restrictions, fear of losing honour and social standing and separation and loss of contact with family (Family Health International, 2004). Bor (1993) argues that the impact of HIV/AIDS on the family is discussed in terms of social stigma, isolation and secrecy, stress and coping, social support, communication and disclosure, responses to illness and changing structure and roles in families. The fear of being stigmatised had a number of negative spin-offs, especially regarding lifestyle choices for PLWHA. For instance, most of the PLWHA were reported as being very reluctant to disclose their HIV-positive status to their family members, partners, friends or associates (Strebel et al. 2009).

Panda (2002) mentioned that the disease has serious economic repercussion on the family budget, family welfare and care. Many resources indicate that the HIV epidemic has now become impact on resource utilization and deprivation at the levels of institutions, communities as well as on the households and family.

According to McGrath et al. (1993), family responses to infected relatives are heavily influenced by community perceptions of the disease. Families that include an individual with HIV may fear isolation and ostracism within the community. Cloete et al. (2009) acknowledged that PLWHA also are often refused to access services for fear of their community discovering that they were HIV-positive. Many were also reluctant to visit Voluntary Counselling and Testing (VCT) centres, or to attend support groups, as members of the community would assume that they were HIV-positive. Community level stigma and discrimination towards people living with HIV/AIDS is found all over the world. A community’s reaction to somebody living with HIV/AIDS can have a huge effect on that person’s life. If the reaction is hostile a person may be
ostracised and discriminated against and may be forced to leave his home or change his daily activities such as shopping, socializing or schooling.

According to Family Health International (2004), Communities are critical areas of stigma and discrimination for HIV infected individuals. Individuals and families are heavily dependent on community relations for their social and economic functioning. Community member’s fears of physical contact and infection and subsequent social restrictions of PLWHA, may lead to their social isolation and loss of access to resources. This may include physical and social restrictions in the community, loss of honour and standing, social restrictions, separations and illness beliefs in the community.

United Nations (2007) states that HIV related stigma and discrimination are widespread and have proven remarkably enduring in almost every society, regardless of characteristics of the local epidemic. Stigma is driven and exacerbated by fear and ignorance. Until relatively recently, HIV infection often resulted in quite rapid progression to serious illness and death no matter where one lived. Not only is death a fearful prospect to many, it is also a taboo subject in many cultures as is sex, the most common mode of HIV transmission globally. Reluctance to speak about sex inhibits dissemination of accurate information about HIV and allows stigma and discrimination to flourish.

**The Scenario of HIV/AIDS in Punjab and Amritsar**

The epidemic of HIV/AIDS after capturing India did not take long to reach different parts of the country. In the northern states of India, Punjab records large concentration of HIV positives. According to Sehgal (1998), the first AIDS patient in the northern state of Punjab was reported in May 1987. Though it was not clear how that patient contracted HIV/AIDS but presently, the rapid spread of HIV/AIDS in Punjab is due to the large scale of Intravenous Drug Users (IDUs) as well as the Heterosexual activities among the population are the major reasons. Truckers in particular are held responsible for the massive spread of HIV/AIDS in Punjab as they remain away from their families, at times for months. This fosters their casual sexual relations with roadside prostitutes.

Singhal *et al.* (2003) argue that several consequences of the rapid development, such as truck transportation, industrialization and urbanization have contributed to AIDS epidemic. India being a huge country has a network of national highways and an extensive system of truck
transportation. For instance, some 200,000 trucks arrive in Mumbai every evening. There are approximately 3.5 million truck drivers in India and they are the key means of HIV transmission. Truck drivers come mainly from Punjab and other northern Indian states and are away from their families for lengthy periods. Commercial sex workers are found at dhaba’s on the highways where the truck stops. Often, providing female sex worker is a regular service offered by the truck stop as providing food, alcohol, gas, oil, and truck repairs.

Use of drugs can be another reason for the rapid spread of HIV/AIDS in Punjab. In an interview with PTC news channel, Vinayak Ramesh, Bureau chief of India Today (Punjab zone) mentioned that at present a sixth river of drugs is flowing in Punjab. He also said that 90 percent of all the drugs come from Afghanistan and Pakistan and being the bordering belt, Punjab receives the highest number of drugs. Modi (1997: 25) has defined this drugs trafficking route as ‘Golden Crescent’, which includes trafficking of drugs from North Western Province of Pakistan, Afghanistan and Iran.

In the villages of Punjab, be it a wedding or any small function, all the occasions are incomplete without desi daru (homemade alcohol). According to Sandhu (2009: 71), “Use of alcohol and other drugs is a part of Punjabi culture. No wedding or a happy occasion is complete until liquor is served in plenty.” However, in the last two decades the pattern of drug use in the state has undergone change in favour of new and modern synthetic drugs or the non pharmaceutical drugs like opium and its substitutes, cannabis, poppy husk etc. Among the pharmaceutical drugs tablets like Bruffin, Proxyvon, Dazapam, Combiflamin, Compose, Cough syrups and Injections of Morphine and Norphine are included.

Apart from the above stated sources, sharing of injections or Intravenous Drug Users (IDUs) is the major reason for promoting HIV/AIDS in Punjab. It refers to the sharing of needles or syringes among the group members who actively participate in the IDU activities. Here, a hypothesis can be generated that if any single member within the group is HIV positive, he may become a source of spreading HIV/AIDS to other partners. Further, they may have a chance of spreading the virus to the spouse within the family or any partner outside the family including prostitutes. In this way, a cycle of HIV/AIDS transmission may embark on and countless innocent individuals become victim of this contagious illness.

The holy city of Amritsar is also at the brink of HIV pandemic. With growing number of people living with HIV/AIDS in the city, it is becoming a major problem for the health
authorities to hamper the growth of this deadly infection. HIV in Amritsar is largely the result of injecting drug users (IDUs) who share single syringe and later on become an agent of transmitting the same virus to their family members. Moreover, Amritsar being a tourist destination receives large number of visitors from various regions of India and from other parts of the globe. Among the tourists who are not accompanied by their family members come across with their sex needs. It can also be considered as another reason for growing number of sex workers and HIV cases in Amritsar.

As per the National AIDS Control Organization (2008), the total number of AIDS patients in Punjab who are receiving the ART are 3175. Among them, 2982 are adults and 193 are children. To cater the needs of PLWHA in Punjab, the setup of ART centres are made in government hospitals in Amritsar, Jalandhar and Patiala. Among these three districts, Amritsar yields the highest number of PLWHA. Moreover, considering the poor health status of PLWHA and non availability of transportation, National AIDS Control Organization (NACO) has started the scheme of Link ART centres in Punjab and elsewhere. In Punjab they are situated at Ferozpur, Hoshiarpur, Bathinda and Faridkot. Gurdaspur and Moga are also likely to get Link ART centres.

In Amritsar, ICTCs are located at seven different sites namely, Government Medical College, Civil Hospital, Civil Hospital Ajnala, Civil Hospital Baba Bakala, Shri Guru Teg Bahadur Hospital – Department of Gynaecology, ESI Hospital and Shri Guru Ram Das Hospital Valla. Beside Government Hospitals, ICTCs are also initiated at PHC and CHC level to promote awareness among the rural population. These are located at Mannawala, Jandiala Guru, Majitha, Thrawal, Tarsikka, Lopoke and Verka.

Integrated Counselling and Testing Centre (ICTC) in Amritsar was commenced in the year 1993. During that time, it was among few ICTCs in the Northern zone to start HIV testing. During that period of time it was named as Voluntary Counselling and Testing Centre (VCTC). Below is the year wise distribution of the people including voluntary and High Risk Groups (HRGs) who came for the HIV testing in Government Medical College, Amritsar as well as the people who were diagnosed with HIV/AIDS.
<table>
<thead>
<tr>
<th>Year</th>
<th>Total number of people coming for HIV testing</th>
<th>Total number of people diagnosed as HIV positive</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>1993</td>
<td>175</td>
<td>6</td>
<td>3.42</td>
</tr>
<tr>
<td>1994</td>
<td>238</td>
<td>12</td>
<td>5.04</td>
</tr>
<tr>
<td>1995</td>
<td>53</td>
<td>4</td>
<td>7.54</td>
</tr>
<tr>
<td>1996</td>
<td>1086</td>
<td>45</td>
<td>4.14</td>
</tr>
<tr>
<td>1997</td>
<td>344</td>
<td>13</td>
<td>3.77</td>
</tr>
<tr>
<td>1998</td>
<td>225</td>
<td>3</td>
<td>1.33</td>
</tr>
<tr>
<td>1999</td>
<td>855</td>
<td>52</td>
<td>6.08</td>
</tr>
<tr>
<td>2000</td>
<td>1058</td>
<td>70</td>
<td>6.61</td>
</tr>
<tr>
<td>2001</td>
<td>1917</td>
<td>123</td>
<td>6.41</td>
</tr>
<tr>
<td>2002</td>
<td>2533</td>
<td>152</td>
<td>6.00</td>
</tr>
<tr>
<td>2003</td>
<td>3174</td>
<td>186</td>
<td>5.86</td>
</tr>
<tr>
<td>2004</td>
<td>3015</td>
<td>242</td>
<td>8.02</td>
</tr>
<tr>
<td>2005</td>
<td>2751</td>
<td>195</td>
<td>7.08</td>
</tr>
<tr>
<td>2006</td>
<td>4273</td>
<td>492</td>
<td>8.68</td>
</tr>
<tr>
<td>2007</td>
<td>5506</td>
<td>1315</td>
<td>23.9</td>
</tr>
<tr>
<td>2008</td>
<td>5854</td>
<td>1085</td>
<td>18.53</td>
</tr>
</tbody>
</table>
Table 1.2 depicts that in 1993 limited number of people came for HIV testing and the rate of people diagnosed as HIV positive was also very low. With the beginning of year 1999, the rate of people coming for HIV testing and the rate of people diagnosed as HIV positive increased. Figure 1.2 also illustrates the similar facts with the help of curve which started mounting from year 1999 and sudden climb is also visible from year 2005 onwards.

From the above figure, it is clear that HIV/AIDS is rising at the alarming rate. From 1993 to 2010, there has been a rapid increase in the magnitude of HIV positive clients in Government Medical College, Amritsar. As compared to other districts of Punjab, it has been found that prevalence rate is higher in Amritsar. It was revealed by The Tribune survey (1st December 2009) that Amritsar has the highest concentration of HIV positive in the state. Earlier it was Ludhiana city with maximum number of HIV positive within the state but presently it has been surpassed by the Amritsar.
The Methods

This study is an attempt to gain sociological insight in the area of health and disease. HIV/AIDS has become a social problem worldwide. Though, it emerged as a health problem, but due to the complexity involved around various issues, it has affected the social life of the people with HIV/AIDS. It has raised the questions on the integrity and alliance between the families, communities and society which further has directed to the chaotic milieu in safeguarding the fraternity and solidarity within the marital union of the couples infected or affected with HIV/AIDS. The knowledge and awareness associated with this issue seems to be inadequate among the general population. As a result, they came out with prejudiced notion of HIV/AIDS transmission which leads to social construction of this disease. In other words, it can be said that people construct the reality of HIV/AIDS in their own way. The study is an attempt to know how a disease is socially constructed.

Objectives of the Study

1. To know the socio-economic background of the people living with HIV/AIDS.
2. To identify the ways HIV/AIDS is constructed in the family, community and society.
3. To analyze the relation between people living with HIV/AIDS and their family, community and colleagues at workplace.
4. To examine how HIV/AIDS is affecting the marital life of couples.
5. To understand how People Living with HIV/AIDS are discriminated by the personnel in the health care system.

Selection of the Universe

It was decided to study the problem in the state of Punjab as it has been reported that Punjab is the worst affected state due to the rising trend of Injecting Drug Users (IDUs). The other factors like unprotected sex, blood transfusion and mother to child transmission cannot be excluded. All these reasons make Punjab more vulnerable to HIV/AIDS. National AIDS Control Organization (NACO) has mentioned in their guidelines that all the voluntary tests should be done within Integrated Counseling and Testing Centers located in all the districts of India. Any tests done outside the ICTCs are considered illegal as they don’t provide any counselling regarding
HIV/AIDS. So it was decided to visit the ICTCs to get the overview of HIV positives in Punjab. According to Punjab State AIDS Control Society (PSACS), Ludhiana and Amritsar have reported the highest number of HIV positive cases. To get the picture, ICTCs in Ludhiana was visited which are located at District Medical College (DMC), Christian Medical College (CMC) and Civil Hospital. Furthermore, it was also observed that no Anti Retroviral Therapy (ART) centre was located within Ludhiana and as a result all the clients after getting diagnosed as HIV positive were referred to Post Graduate Institute of Medical Education and Research (PGIMER), Chandigarh for the purpose of getting their free ART.

All the HIV positive patients after getting their monthly ART are supposed to return to the concerned ICTCs for their follow up counselling. It was found that most of the patients after getting their ART do not report to the concerned ICTCs for follow up rather visits were made to PGIMER which results in the absenteeism of the patients in ICTCs. After visiting Ludhiana, ICTCs in Amritsar were visited which were located at four different sites namely, Government Medical College, Civil Hospital, Shri Guru Ram Das Hospital and Shri Guru Teg Bahadur Hospital. It was found that Anti Retroviral Treatment Centre was running in Guru Nanak Dev Hospital (GNDH) and the patients who after getting diagnosed as HIV positive were referred to GNDH for the purpose of getting their free ART.

According to World Health Organization (WHO), not all the patients are liable to get ART as it is only preferred for those who are having AIDS. Due to this reason, CD4 (Cluster Differentiation 4) tests were conducted so that the patients can be differentiated and only those were provided free ART whose CD4 were found 200 or below. For this purpose, all those who wanted to get their CD4 tests done were asked to give their blood sample in ICTC, Government Medical College, Amritsar. All the other ICTCs were also supposed to direct their HIV positive patients to this centre.

For the purpose of this study, Integrated Counselling and Testing Centre, Department of Microbiology, Government Medical College, Amritsar was selected. The reason for selecting Government Medical College, Amritsar was because of the high concentration of people who come for HIV tests in routine. Moreover, on the average 10 to 12 patients are diagnosed with HIV positive antibodies every day. Another reason why people come to Amritsar for HIV/AIDS testing is because of the Anti Retroviral Treatment centre available in Guru Nanak Dev Hospital, Amritsar.
Selection of the Sample

The Sample was selected from Integrated Counseling and Testing Centre, Department of Microbiology, Government Medical College, Amritsar. The patients who come for their follow up counseling were taken as the samples. A sample of 300 respondents was randomly selected for the study and among them only those patients were interviewed who knew their HIV positive status for at least 20 to 25 days from the time of their HIV tests. It was assumed that these respondents must have interfaced several tribulations over the issue of HIV/AIDS subsequent to their diagnoses as Sero positive. Moreover, change in the outlook and conduct of the family members, community, society, friends and colleagues after knowing the sero status of the respondent was the subject of concern.

Methods of Data Collection

Collection of data was one of the most complicated tasks for me. Because of the sensitive nature of the topic, most of the respondents were reluctant to talk about their illness. The respondents were more worried about their social status pertaining to this health issue. Most of them were suspicious about their confidentiality. Later on, their doubts were cleared regarding the nature of the study. Assurance was given as far as the confidentiality of their HIV positive status is concerned. Many respondents were uncertain about the nature of the study and perceived it as a modus operandi of government to assassinate the HIV positive people. But their misconceptions were cleared before interviewing. They were fully assured that their responses would be kept confidential and the study was purely for academic purpose and not for any other motives.

For the purpose of collecting the data, Interview Schedule was used. The interview schedule was prepared after knowing the problems of people living with HIV/AIDS during the early visits. After the preparation of interview schedule, pre testing was done on ten HIV positive respondents. Later on, certain questions were dropped and some more were added to it. After pre testing, the final interview schedule was prepared. Data were collected through interview method. In order to keep uniformity of the data collection, all the interviews were conducted personally with the respondents so that the confidentiality of the respondent can be maintained. In addition to that, observations were also made on various aspects of their life including their life style, condition of their children and family members. During the interviews, few hurdles
were faced as the majority of respondents were emotionally shattered owing to their ill health. It was really a complex job to hold the respondents during the time of interview whereas the most exigent question was to inquire about their route of transmission. Furthermore, most of the questions were largely based on the factual life of the respondents. Each and every question was found to be significant after getting the responses from them.

To facilitate the respondents, each question was read out patiently in Punjabi language to obtain the correct information. Each interview took at least 30 to 45 minutes. Few interviews took more than 1 hour because of the fact that most of the respondents during the interview were in tears as the questions were based on their personal life. The majority of respondents with few exceptions showed a keen interest in the interviews. In all 300 respondents were interviewed.

Apart from that, comprehensive electronic search of academic journal websites, websites of international agencies like United Nations and standard internet search engine like ‘Google Scholar’ were used for obtaining information related to the study. The gathered data were scrutinized and was incorporated within the study according to the needs and requirements.

In order to have an in depth knowledge and understanding of the issue, the case study method was adopted for those cases that were willing to share the information in detail and was also a suggestive device for improvement in various dimensions of the cases under examination. A total 20 case studies were selected for the study.

Coding

The purpose of coding in surveys is to classify the answers to a question into meaningful categories, so as to bring out their essential pattern. The process involves two distinct steps. The first is to decide on the categories to be used and the second is to allocate individual answers to them. So, after the collection of data, all the schedules were edited to check the completeness. All the information was compressed into meaningful and manageable categories and the categories were assigned codes systematically. Thus a clear and comprehensive code design was prepared after going through responses. All the interview schedules were coded according to the code numbers assigned to different responses. These were then transferred to the coding cards.
Analysis of Data

After editing and coding, the data were tabulated to make the analysis more easy and accurate. Simple and crossed tables, besides the figures and graphs were prepared for the presentation of data. The interpretations of the data are presented in the following five chapters and few generalizations have been drawn in the last chapter of the thesis.

Scope and Significance of the Study

From the origin of HIV/AIDS, the studies started making their way out in the academics. From the social science perspective, HIV/AIDS has been defined in the terms of stigma and discrimination but very few studies have been done on the way the disease is constructed. The present study is of immense value to get a vivid picture of the people living with HIV/AIDS and the kind of problems they are facing. Moreover, this study is an attempt to reveal that stigma and discrimination are simply the reaction or the response to HIV/AIDS. It tends to focus on the process of social construction of a disease, therefore, it can be considered as a new study of its own kind.

Apart from this, it has its significance as it could be a source of information for the individuals from various occupations to understand the present situation of PLWHA. Furthermore, very few studies have been conducted in social sciences because of the sensitive nature of the issue. The findings of this study will inspire more and more researchers to conduct studies on the social dimension of a disease in future.