CHAPTER I

INTRODUCTION
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1.1 Importance of the problem

The HIV/AIDS epidemic represents the most serious public health problem in India. There is no denial of the enormity of the problem. An estimated 38.6 million (33.4 million–46.0 million) people worldwide were living with HIV in 2005 among which around 4.1 million (3.4 million–6.2 million) became newly infected with HIV and an estimated 2.8 million (2.4 million–3.3 million) lost their lives to AIDS (2006 Report on the Global AIDS Epidemic, UNAIDS). At the end of 2010, an estimated 34 million people (31.6 million–35.2 million) were living with HIV worldwide, up by 17 percent from 2001. Globally, annual new HIV infections fell 21 percent between 1997 and 2010. In South and South-East Asia, the estimated 270 000 (230 000–340 000) new HIV infections in 2010 was 40 percent less than at the HIV prevalence peak in 1996. In India, the country with the largest number of People Living with HIV (PLHIV) in the region, new HIV infections fell by 56 percent (UNAIDS, World AIDS Day Report, 2011).

There are growing evidences that HIV/AIDS has transformed itself from merely an emerging health problem to a devastating developmental challenge for a number of developing countries today. People’s knowledge, beliefs and attitude to HIV/AIDS and intricacies of HIV/AIDS – related stigma have become better understood in recent years; however, stigma and discrimination remains a pervasive problem and occurs in a variety of contexts, including family, community, workplace and even health care settings (NFHS–3). Irrespective of the context, stigma and discrimination against
PLHIV may lead to various social consequences related to their rights, freedom of movements, self identity, and utilization of health care services and social interactions – which, in turn, may affect their overall quality of life. HIV/AIDS is associated with marginalized behaviours like indulged in multiple sexes, injected drug users; and People Living with HIV are stigmatized because they are assumed to be from marginalized and stigmatized behaviour groups which is not accepted in many societies and as a result already marginalized groups are further marginalized because they are assumed to have HIV/AIDS.

Stigma and discrimination is faced by PLHIV in many ways, inside the family and outside. They suffer physically, mentally, psychologically and even from economic criteria. Such persons are, most of the times, discriminated on the basis of stigma attached to the means of acquiring HIV and they may be ill treated and isolated from other family members which hurt PLHIV psychologically. They may also face discrimination by the society, at their workplace and while availing health services. This psychological burden is much more on women where she is only blamed for her and her husband’s HIV status and if husband passes away, she is abandoned by in-laws. She cannot approach her maternal home too and has to face burden of livelihood, educating children and other responsibilities. These are the main hindrances for People Living with HIV to access services as well as HIV prevention programs to carry out their programs effectively. PLHIV do not open up fearing the stigma and discrimination by society and hence, they cannot avail care and support services. This makes the HIV underground and being unable to address this, is a loophole in effective implementation of HIV prevention, care and support activities. PLHIV may be devoid of counseling, care and support, treatment to Opportunistic
Infections (OIs) and other services. This may increase the burden on PLHIV and also on their families.

1.2 Differences between stigma and discrimination

*Stigma is about beliefs & attitudes, whereas discrimination relates to action based on stigmatizing belief.*

The Code of Good Practice for NGOs responding to HIV/AIDS (the ‘code’) defines Stigma and Discrimination in the following ways:

“**Stigma** is a process of producing and reproducing inequitable power relations, where negative attitudes towards a group of people, on the basis of particular attributes such as their HIV status, gender, sexuality or behavior, are created and sustained to legitimatize dominant groups in society.”

“**Discrimination** is a manifestation of stigma. Discrimination is any form of arbitrary distinction, exclusion or restriction, whether by action or by omission, based on a stigmatized attribute.”

(www.hivcode.org)

AIDS related stigma refers to the prejudice and discrimination directed at PLHIV and the groups and communities that they are associated with. HIV/AIDS related stigma and discrimination is a ‘process of devaluation’ of people either living with or associated with HIV/AIDS (www.unaids.org). Discrimination follows stigma and is unfair and unjust treatment of an individual based on his or her real or perceived HIV
status. Discrimination occurs when a distinction is made about a person that results in him or her being treated unfairly on the basis of belonging or being perceived to belong to a particular group (UNAIDS, 2003). HIV/AIDS related stigma is mainly due to the fear as it is a life threatening disease and is more importantly associated with behaviors (such as homo sexuality, drug addiction, prostitution or promiscuity) that are already stigmatized in many societies. Moreover, religious or moral beliefs lead some people to believe that being infected with HIV is the result of moral fault (such as promiscuity or deviant sex) that deserves to be punished. Ever since the first case was detected in United States in 1981, people infected with HIV have been the targets of stigma. Press accounts and anecdotal reports from the early 1980s told stories of PLHIV — as well as those simply suspected of having the diseases — being evicted from their homes, fired from their jobs, and shunned by their family and friends (Altman 1986, Herek 1990).

Across the world, people infected with HIV have been rejected by their families, their loved ones and their communities, which have been reported to further intensify the fear the stigma that might result due to disclosure of HIV/AIDS status (Rankin & Brennan). As a result, stigma affects people’s willingness to disclose a positive test result to others, prohibiting them to avail Anti Retroviral Therapy (ART) services and early diagnosis of opportunistic infections. It is against this backdrop, the HIV prevention program in most developing countries, including India, has been paying increased attention to address the issues relating to stigma and discrimination. NACP–3 is focusing on undertaking advocacy, social mobilization and effective communication program to encourage social normative change by integrating HIV positive persons in the society to reduce stigma and discrimination. There will be
relatively more effective integration of the medical response to the epidemic through enhanced provision of ART services, STI services, and treatment to opportunistic infections through the National Rural Health Mission.

Stigma silences individuals and communities, saps their strength, increases their vulnerability, isolates people and deprives them of care and support. Responding to AIDS with blame, or abuse towards People Living with AIDS, simply forces the epidemic underground, creating the ideal conditions for HIV to spread. The most affected groups, often marginalized have little or no access to legal protection of their basic human rights. Stigma and denial undermine efforts to increase the coverage of effective intervention among high risk group such as men having sex with men, sex workers and injected drug users. Harassment by police and ostracism by family and community drives the epidemic underground and deprives the reach and effectiveness of prevention efforts.

1.3  **Psycho-social impact of HIV status disclosure**

HIV disease is not only a medical issue, but a psychosocial one as well. Infection and the subsequent progression of this disease present the patients with a broad range of personal experiences to negotiate. Persons Living with HIV develop new patterns of coping mechanism with the progression of the disease. At the same time, the person's condition may trigger a variety of reactions from others such as family members, significant others, employers, co-workers, and rehabilitation counselors and other helping professionals. People infected with HIV/AIDS must deal with strong emotional issues. Each of these stages can include a variety of emotional responses
such as fear, shame, loss, grief, anger, depression, feelings of dependency, and hope (HEART Project, San Francisco, 1997).

Infected persons are normally in fear because they have to adjust to a new lifestyle. It is not easy to accept that one is infected and thus shock and disbelief, leading to denial, is a frequent initial response. They commonly go through an initial stage of denial, in which they do not acknowledge having the disease or deny its likely consequences. HIV threatens a person’s life, goals, expectations, and significant relationships; no wonder that many people are reluctant to admit their diagnosis or their risk of infection. It is not uncommon for people who subject themselves to high-risk situations or behaviours to deny that they are at risk of HIV infection. They often avoid testing, and if they are tested, they avoid following up on results, as if avoiding a clinical diagnosis might prevent the disease. In order to battle HIV successfully, people having some level of acceptance can seek counselling, social support, and medical care with a better response.

Depression is common among people with HIV, especially as they adjust to the fact that they are no longer the healthy people they once thought they were. Adjustment to HIV is affected by the lack of hope that comes from a person’s inability to access or benefit from treatment and the anticipated rejection and need for secrecy because of HIV – associated stigma. Depression is increased by internalized shame regarding previous risk behaviours and by fear that others will come to know about their risk behaviours and HIV infection.
Psychosocial support is an important part of providing health care to PLHIV. Professional counsellors, social workers, health care workers, ambassadors of religion, trained volunteers, friends, and family play crucial roles in providing psychosocial support which is very essential to lead one’s life for those who are HIV positive (M.W Ross et al).

1.4 Utilization of care and support services

The care, support and treatment needs of HIV positive people vary with the stage of the infection. The HIV infected person remains asymptomatic for the initial few years; and it manifests by six to eight years. As immunity falls over time the person becomes susceptible to various opportunistic infections. At this stage, medical treatment and psycho–social support is very much needed. Access to prompt diagnosis and treatment of OIs ensures that PLHIV live longer and have a better quality of life.

Anti-retroviral therapy is the treatment provided to those who are infected with HIV/AIDS. This is not a cure, but it can stop people from becoming ill for many years. The treatment consists of drugs that have to be taken every day for the rest of a person’s life. NACO has recommended initiating ART depending upon the stage of infection. PLHIV with less than 200 CD4 (white blood cells/ mm$^3$) require treatment irrespective of the clinical stage. For PLHIV with 200-350 CD4, ART is offered to symptomatic patients. Among those with CD4 of more than 350, treatment is deferred for asymptomatic persons. The CD4 count needs regular monitoring and the question of drug resistance and change of anti–retroviral drugs is to be considered if the recovered CD4 count again starts falling. The aim of antiretroviral treatment is to
keep the extent of HIV in the body at a low level. This stops any weakening of the immune system and allows it to recover from any damage that HIV might have caused already. Opportunistic infections also occur when HIV has weakened the body’s defenses against disease. Common examples are tuberculosis (TB), herpes, pneumonia and candidacies. Providing prevention and treatment for these infections not only helps the sufferer, but also prevents further spread of the disease. Even in the best-resourced areas, treatment for opportunistic infections remain essential, especially for those who are yet to start, or have only recently started antiretroviral therapy. For young children and people with weak immune systems, drugs such as cotrimoxazole may be recommended to prevent occurrence of opportunistic infections (www.avert.org).

ART has played a significant role during the past few years by reducing the number of deaths due to HIV. The number of people dying of AIDS–related causes fell to 1.8 million (1.6 million–1.9 million) in 2010, down from a peak of 2.2 million (2.1 million–2.5 million) in the mid-2000s. A total of 2.5 million deaths have been averted in low– and middle–income countries since 1995 due to the introduction of antiretroviral therapy, according to new calculations by UNAIDS. Much of that success has come in the past two years when rapid scale–up of access to treatment occurred; in 2010 alone, 700 000 AIDS related deaths were averted. More people than ever are living with HIV, largely due to greater access to treatment. This reflects the continued large number of new HIV infections and a significant expansion of access to antiretroviral therapy, which has helped reduce AIDS–related deaths, especially in more recent years (UNAIDS World AIDS Day report 2011).
1.5 A broad review of Literature

1.5.1 Reviews related to stigma and discrimination to HIV/AIDS at familial and community level.

A study by ICRW during 2001 to 2004 in four countries Ethiopia, Tanzania, Vietnam and Zambia revealed stigma and discrimination to PLHIV inside as well as outside home. In the home, stigmas was expressed through the segregation of typically shared objects like eating, sharing utensils, clothes and bed linens and by making people with HIV/AIDS sleep and eat in isolation. Another study conducted in five African countries revealed that PLHIV experienced extensive verbal and physical abuse and neglect or negation (disallowing of access to services and opportunities) when their HIV status was disclosed to family, friends or community members (Dlamini et al, 2007). It was revealed in a study conducted in rural Jamaica that people of younger ages and secondary and higher educated people were less likely to stigmatize PLHIV and were more likely to shake hands, hug and dine with PLHIV (Mahdi et al, 2004).

Another study which was done in Baltimore depicted the most salient barriers to HIV-1 testing and serostatus disclosure described by women included fear of partner’s reaction, decision making and communication patterns between partners, and partner’s attitude towards HIV testing (Maman et al,2001). Findings based on sample of 145 men and women living with HIV in USA indicated that perceived HIV related stigma was associated with the endorsement of various reasons against disclosure to a friend and a parent including concerns about self-blame, fear of rejection, communication difficulties and a desire to protect the other person (Derlega et al., 2002).
In 2000, a study conducted on 7053 men and women aged 15–49 years in China revealed that those who had a lower level of education attainment and media exposure were more likely to hold stigmatizing attitude towards PLHIV. As expected, an individual misinformation about causal contacts for HIV transmission was positively associated with stigmatizing attitude towards PLHIV. However, an individual corrects knowledge about HIV transmission and prevention was not associated with reduced risk of HIV/AIDS related stigma (Chen et al, 2004). A cross-sectional survey was conducted to assess HIV-related stigma, HIV risk behaviors and preventive practices among 4208 rural–to–urban migrants (1699 women and 2509 men) aged 18–30 years in 2002 in Beijing and Nanjing cities of China. This study revealed that migrants who have a lower level of preventive practices perceived a higher level of HIV-related stigma. Perception of HIV related stigma were positively associated with having multiple sex partners (OR=1.81), selling sex (OR=2.11) and buying sex (OR=1.99) and negatively associated with condom use (OR=0.72) and willingness to access HIV testing (OR=0.59) (Liu et al, 2004).

Apart from studies conducted abroad, some Indian studies also revealed discrimination faced by people infected with HIV at different levels. A qualitative study was carried out among 53 PLHIV in Bangalore in a HIV counseling clinic and 79 PLHIV in Pune NGO counseling clinic, where, ART was available. This study revealed that women face more overt acts of stigma from their family; but women who contracted the infections from their husbands do not appear to stigmatize themselves. Men tend to have more guilt and self stigma (Ramakrishna et al, 2004).

A CASE STUDY from West Bengal: A primary school student in West Bengal was thrown out of his school after being allegedly humiliated by his teachers because
he was HIV positive, his mother said. The 11-year old boy, a resident of Baruipur on the eastern fringe of the city, was admitted to a school in the same locality 20 days ago. The mother alleged that initially the school authorities were reluctant to admit the boy. After the admission, he was made to sit on separate bench and his classmates were told to shun him. Later his mother was called and told by school officials to take him away as he could infect other students in the class (Times of India, Oct 13, 2007).

A clinic based study, conducted on 203 HIV infected individuals in Chennai, depicted that actual stigma experienced is much less (26 percent) as compared to the fear of being stigmatized or perceived stigma (97 percent). However individuals who did experience actual stigma seemed more determined to live and experience an above moderate quality of life (Thomas et al, 2005). Another study conducted to focus on the views of 187 teenage high school students regarding HIV to determine the prevalence and specific types of HIV-related stigma revealed that around 28.2 percent felt that those who have HIV deserve it. Next, 39.3 percent felt that HIV is a punishment by God to those who have multiple sexual partners. Finally, 47.5 percent said that due to stigma, they would never submit to an HIV test (Pramanik et al, 2002). A study which was conducted on 43 PLHIV attending the treatment and follow-up services by Vasai Regional AIDS Control Society, (VRACS), a home based care facility run by Kripa Rehabilitation Centre, Mumbai during 2003-2004. Majority of the patients seemed to have a supportive family and had not experienced discrimination within the family (92.3 percent).
1.5.2 Reviews related to stigma and discrimination to HIV/AIDS at workplace level

AIDS is a workplace issue because it affects workers and the families, enterprises and communities which depend on them. The stigma attached to AIDS has only accelerated by ignorance and fear causing discrimination at workplace. Several studies worldwide show that after disclosure of HIV status, the infected people have been barred from promotions, fired from jobs, cut their salaries etc.

The findings of global and regional surveys indicate the existence of high levels of employment discrimination based on HIV status worldwide, including forced disclosure of HIV status, exclusion in the workplace, refusals to hire or promote, and terminations of people known to be living with HIV. The survey findings show that employment discrimination based on HIV status is experienced in all African sub regions. Country-level surveys conducted in Kenya and Zambia indicated that PLHIV face marked barriers to employment, including discrimination in hiring, loss of promotions, and termination because of HIV status. Additionally, large numbers of variance were found in the degree of support versus discrimination that employees living with HIV in those two countries received following their disclosure (Sprague et al 2011).

Stigma and discrimination around HIV remain serious issues in China, particularly in employment and healthcare settings.

*In May 2010, a man named ‘Wu’ (pseudonym) applied for a teacher’s job at a school in Anhui province. After passing the written exam and interview he was found to be HIV positive who subsequently was denied of recruitment opportunity.* The Oct. 21,
2010 edition of the “South China Weekly” reported a similar case where 27-year-old Xiaojun (pseudonym) from Liangshan was denied employment at a local education bureau in Panzhihua after testing positive for HIV.

In both these cases, the health criteria for the civil service had been applied to employees within the education system. Another study found that 89.47 percent of respondents had lost their jobs at least once as a result of their HIV status (ILO China and Mongolia). This was highlighted by a recent case in China’s Guizhou province, where a young man, Xiao Hai, who had applied to work as a teacher, was rejected after being found to be HIV positive. Xiao Hai sought to take the local education authorities to court, but the case was rejected by the courts. This was the third such case in China. Other evidences suggest that discrimination is prevalent and in need of urgent attention. The China Stigma Index Report, a survey of over 2000 PLHIV carried out in 2009 found that 41.7 percent of respondents had experienced HIV–related discrimination; almost 15 percent said they had been refused employment based on their HIV status (Mr Guy Taylor, UNAIDS China, 2011). Another survey conducted by UNAIDS among people living with HIV in 2009 in China showed that nearly 15 percent of respondents had been refused employment because of their HIV status. Nearly 55 percent of those who were employed reported management reactions to their HIV status as discriminatory (ILO/AIDS).

One of the pilot studies conducted in Turkey finds 50 percent of the respondents who stated that it was right to request a HIV test whereas 36 percent of them declared that it was not right. The respondents' information level about the transmission of HIV was evaluated as medium or high. Respondents mostly think that HIV is not a punishment
to people for their misbehaviors, and that sufferers should not be ashamed of themselves; PLHIV are not guilty and do not have marginal life styles. They also showed sensitivity towards the right to treatment and protection of the human rights of PLHIV. The majority of respondents stated that they could work in the same workplace with PLHIV and also that they did not associate HIV with homosexuals (Olca Surgevil et al, 2011). A study by ICRW during 2001 to 2004 in four countries Ethiopia, Tanzania, Vietnam and Zambia revealed that people in formal employment found themselves being dismissed upon disclosure of their HIV status.

In India, a study by Kripa Rehabilitation Centre shows perceived stigma among HIV infected at their workplace. It was observed that 74.2 percent of the patients were unemployed due to illness and even among those employed 72 percent did not disclose their HIV status at work place. Another study conducted among kothi identified MSM reported stigma and discrimination across multiple social and institutional contexts (Chakrapani et al, 2007).

1.5.3 **Reviews related to stigma and discrimination to HIV/AIDS at health care facility level.**

Many reports reveal the extent to which people are stigmatized and discriminated against by health care systems. Many studies reveal the reality of withheld treatment, non-attendance of hospital staff, HIV testing and disclosure without consent, lack of confidentiality and denial of hospital facilities and medicines.

A study conducted in 2002, among some physicians, nurses and midwives in four Nigerian states revealed stigma and discrimination in access to health care facility.
One in 10 doctors and nurses admitted to have refused to provide care for an HIV/AIDS patient or to have denied HIV/AIDS patients admission to hospital. Around 40 percent thought a person’s disappearance betrayed his or her HIV positive status, and one–fifth of them felt that PLHIV had behaved immorally and deserved their feet (www.avert.org/aids-nigeria.htm).

A longitudinal study in Ethiopia, Tanzania and Zambia during April 2001 to Oct 2003 by ICRW among PLHIV explored various stigma perceived by them and its impact on health care settings. In Beijing, a study jointly carried out by the ILO and the National Center for STD and AIDS Prevention and Control (NCAIDS) among interviews with 103 People Living with HIV, and 23 hospital managers, healthcare workers and health administrators, provides insight into HIV–related discrimination in hospitals and clinics. The issues faced by individuals include difficulty in accessing medical services and discriminatory treatment by healthcare workers as well as denial of surgery and other forms of care.

A CASE STUDY: A 37-year-old HIV positive man from Shaanxi Province told the researchers what happened when he found a lump in his stomach. “Each hospital advised that I should be hospitalized immediately for surgery, but when they heard that I was HIV positive, none was willing to accept me. They asked me to go to the infectious disease hospital…” he said. “The hospital did not agree to let me use the operating theatre. They said if other patients knew that an HIV person had used the operating theatre, it would badly influence the hospital’s reputation” (Dr Richard Howard et al 2011).
Another study was conducted from August to September 2007 to investigate stigmatizing attitudes and acts of discrimination against HIV/AIDS patients among doctors and nurses working in public hospitals in Belize. A total of 230 respondents (81.0 percent) completed the survey which included 75 percent women; 61 percent nurses; 74 percent Belizean. It was found that stigmatization was greatest for “attitudes of blame/judgment”; disclosing a patient’s HIV/AIDS status to colleagues was the most frequent act of discrimination (29 percent). Doctors showed more stigmatization in “attitudes towards imposed measures,” which included HIV tests without consent and disclosed patient status to colleagues more frequently than nurses ($p \leq 0.05$) while nurses gave differential care to patients based on HIV status more frequently ($p \leq 0.01$) than doctors. Older age was associated with less frequent disclosure of patients’ HIV status ($p \leq 0.05$) (Aisha Andrewin et al 2008).

In India also, there had been some studies, which bring the underlying stigma and discrimination against PLHIV at various health care facilities level. A multi–centric study by CMC Vellore on 2200 health care providers, in 10 health care settings, depicts that many doctors (20 percent) had refused treatment to people with HIV/AIDS at some point of time in their professional career and about one–fourth of them isolated them in separate care areas and 13.3 percent had postponed or changed treatment based on the patient’s HIV Status (Kurien et al, 2007). Another study in three big hospitals in New Delhi by Mahendra et al, 2007 which included 884 hospital staffs as well as HIV patients revealed that health workers have mixed responses about supporting the rights of infected individuals. While over three quarters of health workers agreed that HIV infected people had the right to decide who should know their status, an equally large proportion endorsed the view that HIV infected women
should not get pregnant and give birth to children. Also a majority (60 percent) did not agree that PLHIV should be allowed to marry and two-fifths indicated that men with HIV deserved to be infected. The study done by Kripa Rehabilitation Centre, Mumbai during 2003-2004 depicts the various types of discriminations faced by HIV infected at health care settings. Maximum degree of discrimination was experienced in health care, namely accessing medical treatment (23.3 percent) and being segregated and isolated even in hospital settings (20.9 percent). Further, in one study, women participating in the Prevention of Parent To Child Transmission (PPTCT) programme reported refusal of treatment, moral judgment and abusive behavior by health care staff (Rahangdale et al, 2010) while in another study, half of the women respondents feared seeking care due to bad experiences at a maternity hospital such as breach of confidentiality, refusal to treat and humiliating statements made by health care staff (Thomas et al, 2009).

1.5.4 Reviews related to psycho-social impact of HIV status disclosure

Stigma to HIV has further led to loss of identity and role as community members; they are viewed as having no hope, no future, no longer productive, loss of status within the household and often lose decision-making power and respect. In a study in Zambia, PLHIV experiences different forms of primary and secondary stigma. It was revealed that as a result of facing constant pressures to deal with HIV and AIDS, alongside stigma, people with HIV often internalize stigma which can be explained as a complex process that involves internalizing the devaluation from people around them. This internal stigma led them to guilt and self deprecation, self isolation and abandonment of aspirations. The secondary stigma was experienced as mostly the same forms as primary stigma and its main forms were social exclusion and gossip.
Moreover, parents were held responsible for ‘misbehavior’ of children like “some people say that father never taught him good manners so he has ended up getting the disease” Rural women’s FGD participant, Zambia. It became a belief that HIV is transmitted in families and this kind of stigma further reduced livelihoods for whole family of PLHIV.

Stigmatized persons lose social status, they are discounted and discredited — reduced in the minds of others from being whole and acceptable individuals to those whose identities are spoiled and tainted. An HIV/AIDS infected person is looked at as “spoiled,” further contributing to a negative psychological impact of the disease. Being shunned from society has lead to self-loathing and self deprecation. It is common for HIV/AIDS infected persons to withdraw from society, relationships, and the work place. Self-esteem, isolation, and self-deprecation are all negative impacts of HIV/AIDS on people infected with the disease. However, one study found that general education minimized the psychological impact of the disease. In comparison to less educated patients, the infected persons feel more in control over their wellbeing and is able to maintain their health better (Fife and Wright).

Some studies revealed alcohol and drug use by HIV-infected patients as very common mode of coping strategies and are important determinants of secondary transmission risk and medication adherence. In U.S., as part of the Coping with HIV/AIDS in the Southeast (CHASE) Study, 611 HIV-infected patients were consecutively recruited from eight clinical care sites in five south-eastern U.S. states in 2001 – 2002. The study examined the distribution and predictors of alcohol and drug use in this sample with an emphasis on psychosocial predictors of use. It was found that in the prior 9
months, 27 percent of participants drank alcohol and 7 percent drank to intoxication at least weekly. The most common drugs consumed at least weekly were marijuana (12 percent) and crack (5 percent); 11 percent used a non-marijuana drug. Around 7 percent reported polysubstance use (use of multiple substances at one time) at least weekly. Injection drug use was rare (2 percent injected at least once in the past 9 months). The study further revealed that stronger adaptive coping strategies were the most consistent predictor of less frequent alcohol and drug use, in particular coping through action and coping through reliance on religion. Stronger maladaptive coping strategies predicted greater frequency of drinking to intoxication but not other measures of alcohol and drug use. Those with more lifetime traumatic experiences also reported higher substance use (Pence BW et al, 2008).

A few studies have examined the relation between race, social support, and coping, particularly among HIV-infected individuals. In one of the studies by David et al in 2006 brought out the relation of race and social support to coping with HIV infection in a sample of 121 gay and bisexual men (64 African American, 57 White). It was revealed that as compared to White participants, African Americans reported higher use of multiple coping strategies. High levels of perceived social support were related to greater use of positive coping and seeking support; lower levels of social support were related to greater use of self-destructive coping. It was also observed that there were no race-related differences in social support and no race by social support interactions.

One of the cross-sectional studies in United States by Vyavaharkar et al examined the relationships between social support, HIV disclosure, and depression among 340 rural
African American women with HIV disease living in the southern United States. Three aspects of social support (perceived availability of support, sources of available support, and satisfaction with available support) were measured along with HIV disclosure and depression. It was found that perceived availability of support (p < .0001), sources of support (p = .03), satisfaction with support (p = .003), and HIV disclosure (total and to children; p = .05 and .04, respectively) were significantly and inversely correlated with depression. It was also observed that perceived availability of support and satisfaction with support mediated the relationship between HIV disclosure and depression. If confirmed by longitudinal studies, these findings have implications for designing and implementing interventions supporting African American women with HIV disease in disclosing their HIV status appropriately, particularly to their children.

Eric W. Schrimshaw in United States found in one of his studies that HIV–infected adults aged 50 years and above are more socially isolated than younger HIV-infected individuals. This study examined the perceived barriers to obtaining emotional and practical social support from friends and family among 63 older adults (aged 50+) living with HIV/AIDS. Many reported that they did not receive enough emotional support (42 percent) or practical assistance (27 percent). It was found that barriers to obtaining support included nondisclosure of HIV status; others’ fear of HIV/AIDS; desire to be self-reliant and independent; not wanting to be a burden; unavailability of family; death of friends due to AIDS; and ageism. It was concluded from the study that these barriers may explain the greater social isolation of HIV-infected older adults and inform interventions targeted at reducing these barriers.
The study by Kripa Rehabilitation Centre brought out the feeling among HIV infected patients upon diagnosed as HIV+ person is indeed traumatic. Its natural corollaries reported by the infected people are anxiety, fear and tension (47 percent), sadness (14 percent), death anxiety (20 percent), despair (18 percent), sleeplessness and lack of appetite (11 percent) and denial (4 percent) (Research Unit, Kripa Rehabilitation center, 2003-04).

1.5.5 Reviews related to impact of stigma and discrimination on access to HIV testing and Antiretroviral Therapy services

Stigma had a profound impact on VCT, disclosure and prevention. Fear of experiencing stigma kept some people from using VCT services. And even if they did go for testing, the fear of what will happen if a partner, families, neighbors know they are HIV positive, kept people from disclosing their status – positive or negative. Stigma also showed an impact on preventive behaviors – such as using condoms, discussing safer sex with a partner, and the prevention of mother to child transmission. Care and support system was also undermined when accompanied by stigma in the form of judgmental attitudes and physical isolation, shunting HIV positive patient from provider to provider as none is willing to administer treatment. Care got reduced, over time, because of fatigue and diminishing resources may be experienced as stigma by PLHIV as they delayed care, travel farther or pay more in search of non-stigmatizing care (Laura Nyblade, 2003).

A qualitative sociological study conducted in Mexico consisted of 68 in-depth interviews with heterosexual, ambulatory male and female PLHIV who had known their diagnosis for at least 1 year. Informants were selected from social security
support groups (individuals with guaranteed free access to ART), hospitals for the
general population (individuals without guaranteed access to ART), and non-
governmental organizations (individuals with and without access to ART). Analysis
revealed that despite having access to ART and medical care, Mexican PLHIVs rarely
adhere correctly to ART. Some of the associated factors are: lack of training among a
majority of medical personnel, instances of discrimination, difficulties establishing
good physician-patient communication and a consequent lack of patients confidence
to speak openly about their behaviour, and PLHIV decision-making about adherence
based on previous experiences of sickness and health (Herrera et al, 2004).

Haiti is by far the most impoverished country in Latin America and, not
coincidentally, the region’s most HIV affected country, with an adult prevalence of
around 6 percent. Since 1998, in the framework of the HIV Equity Initiative, Partners
in Health (PIH) has purchased antiretroviral drugs to treat patients living with
HIV/AIDS, free of charge. Preliminary data from research in rural Haiti suggest that
the introduction of quality HIV care has lead to a rapid reduction in stigma, resulting
in increased uptake of VCT. It was found that antiretroviral has had a positive impact
on the demand for VCT. Improving clinical services had improved the quality of
prevention efforts, boost staff morale, and reduce AIDS-related stigma (Castro &
Farmer).

A qualitative study with three focus group discussions and 2 key informant interviews
conducted by Venkatesan Chakramani in 2007 explored the various factors that
hinder free ART access for female sex workers (FSWs) living with HIV in Chennai,
India. Findings revealed barriers at the individual, healthcare system, and
programmatic and social levels. At programmatic level, it was found that some ART
centers in Chennai recommend a two-week hospital admission for PLHIV who are initiating ART to monitor for serious side-effects (such as a life-threatening allergic reaction to nevirapine), which are more common during the first few weeks. Some FGD participants reported this admission to be a barrier to ART because they would not be able to explain a two-week admission to their family members, who do not know their HIV-positive status, and because they would not be able to engage in sex work or other work to earn money to feed their family during their hospital stay. Thus, some FSWs postpone initiating ART until they become symptomatic even though their current CD4 count may be less than 200 cells/micro litres, which makes them eligible for ART initiation.

A qualitative study was carried out on 53 PLHIV in Bangalore in a HIV counseling clinic and 79 PLHIV in Pune NGO counseling clinic where ART was available. This study revealed that increased access to care for management of opportunistic infections and ARV helped them to maintain a normal life while those who became ill inadvertently revealed their status (Ramakrishna et al, 2004). A study on providing ART in a community based care project; World Vision India's Chennai Integrated HIV/AIDS Care (CIHAC) Project which was started in 1999, focusing on HIV/AIDS prevention and the improvement of quality of life for marginalized HIV positive women and children. Anti-Retroviral Therapy (ART) was added after two years and 40 women and children were started on ART after consideration of various clinical and social parameters on a case-to-case basis. Drug regimens were decided with the government-run TB Research Centre. Complications were managed at a nearby NGO-run general hospital. Opportunistic infections requiring no hospitalization were managed by CIHAC's short-stay care facility; residents there are trained in various
skills and referred back to the community. It was found from the intervention that ART improves the quality of life of PLHIVs, thereby minimizes the number of orphans. It allowed PLHIVs to live longer, learn skills and stand on their own. It was feasible in primary care centers with appropriate networks even in resource-poor settings. ART availability resulted in increased VCT use and enhanced the effectiveness of behavior change communication. Support for ART could be mobilized when visible evidence of dramatic recovery was shown. It was further observed that community participation in PLHIV care, especially with ART, reduced fear, stigma and discrimination and enhanced positive living to a considerable extent (Punitha et al, 2004). Among FSW, stigma and discrimination was found to be a major barrier to ART access (Chakrapani, et al, 2009).

A gap is observed in the studies done for exploring stigma and discrimination faced by PLHIV and its overall impact on utilization of support system in terms of psychosocial impact, counseling, access to ART services and treatment to opportunistic infections. There are very limited studies done in India which covers these aspects all together as well as most of the studies are done at program level by various NGOs working for the prevention of HIV. So the proposed study is vital for exploring the stigma and discriminations faced by PLHIV as well as to assess the utilization of support system by them. This study is also important for academicians as there has not been much study done, which have covered all these aspects collectively.
1.6 Need for the study

Stigma is of urgent concern because it is both the cause and effect of secrecy and denial, which in turn are the primary preconditions for rapid HIV transmission. Stigma has a profound impact on the effectiveness of HIV/AIDS prevention, treatment and care program because people who are infected may be reluctant to use the services like HIV testing, Anti Retroviral Therapy and early diagnosis of opportunistic infections. AIDS stigma affects the well-being of PLHIV and influences their personal choices about disclosing their serostatus to others. It also affects loved ones of PLHIV and their caregivers, both volunteers and professionals. Stigma has hindered society's response to the epidemic, and may continue to have an impact as policies providing special protection to people with HIV face renewed scrutiny. To provide equality at workplace, Indian panel code has made a provision that PLHIV should not be fired from or discriminated at workplace in 2004, though effective implementation of the constitutional amendment is far below satisfaction. National AIDS control Program has committed at the universal access to ART services but this goal cannot be reached until and unless stigmas, shame, denial, discrimination, are eliminated on priority basis.

Therefore, this research study is vital in developing evidence based planning of addressing the issues pertaining to stigma and discrimination on the one hand and improving the quality of life of PLHIV on the other. Addressing the issues of human right violation and creating an enabling environment that increases knowledge and encourages behaviour change are thus extremely important to fight against AIDS. Despite significant increase in awareness level due to the efforts of government,
curbing the severity of stigma and discrimination at various contextual levels on the basis of seropositivity is vital to ensure HIV testing and disclosures - which are essential for controlling the opportunistic infections and effectiveness of ART services on the one hand and to strengthen the care and support program to improve the overall quality of life to PLHIV on the other.

1.7 The Conceptual framework

The conceptual framework of the study is presented in the following Figure.
1.8 Hypotheses:

The following are the hypotheses of the study:

1. Self-perceived stigma decreases with the duration of disclosure of HIV status.
2. Self-perceived stigma to HIV/AIDS reduces utilization of support system.
3. Familial support improves coping mechanism.

1.9 Objectives:

The broad objective is to study the impact of stigma and discrimination on care and support system including HIV testing and disclosure, access to ART services and management of other opportunistic infections.

The following are the specific objectives of the study:

1. To assess the perceived stigma and discrimination faced by PLHIV at different contextual levels.
2. To assess the psycho social impact of disclosure of HIV status.
3. To explore the barriers and opportunities for effective implementation of care and support services.
4. To assess the attitude of health care providers and community level stakeholders towards HIV positive people and the intensity of care and support provided by them in different settings.
1.10 Organization of the thesis

This research study is comprised of eight chapters as follows:

Chapter I: Introduction

This chapter includes the introduction to the research problem and broad review of literature. The literature review is done in the context of stigma and discrimination faced by PLHIV and its impact on overall quality of life. It has discussed systematically the issues such as how PLHIV were discriminated in their family and work places after their status disclosure, discrimination faced at health care settings on their visit after HIV test, psycho-social impact of HIV identification, and overall impact of stigma and discrimination on access to ART and treatment to opportunistic infections. Based on review of literatures and in order to understand the research problem in Indian context, a conceptual framework is developed. This chapter also consists of need for the study, hypothesis and objectives which were formulated on the basis of literature. Lastly this chapter also explains organization of the thesis.

Chapter II: Research design and methodology

This chapter comprises the study area, data and study design, duration of field work, ethical consideration and informed consent, methods of data collection, guidelines for qualitative data collection, process to make an entry to positive people. It also gives a brief description of weight calculation and tools and techniques of various quantitative analyses made in this study. This chapter also contains the computation of various indices used for the analysis.

Chapter III: Profile of People Living with HIV

This chapter looks at the socio-demographic and living conditions of the people infected with HIV/AIDS. Some of the socio-demographic characteristics of the people
infected with HIV/AIDS are age, sex, educational status, marital status, native place, current place of residence, and type of family.

**Chapter IV: HIV status, stigma and self-acceptance to HIV**

This chapter looks at information on symptoms, perceived stigma to HIV testing, immediate response of being positive, self acceptance of being PLHIV and duration of being identified as HIV positive.

**Chapter V: Status disclosure and experience of discrimination**

This chapter mainly focuses on information on immediate response of partner/parents/etc after being diagnosed as HIV positive, and discrimination faced at different contextual levels including familial, workplace and health care settings and variation in their behavior and attitude over time.

**Chapter VI: Psycho social impact of HIV identification**

This chapter deals with information on psycho social impact of HIV status disclosure will in terms of social support, coping mechanism and depression.

- Social support has covered the information on assistance provided by spouse, other family members and friends in terms of emotional support, financial support and advice or guidance on different issues.
- Coping mechanism has covered the strategies accepted at the stressful situation in terms of solving their problems and managing the emotional distress caused by problematic situation.
- Depression section has covered the self attitude about being PLHIV and how one feel oneself being different than others who are non-infected.
Chapter VII: Care and support services and quality of life of PLHIV

This chapter deals with perceived support from CBOs or NGOs attended, scope of attending care and support program from CBOs, NGOs and government and how these programs have brought changes in their life. This chapter also contains information on self interest or motivation factor to access ART centers, on any opportunistic infections acquired after the diagnosis of HIV will be taken along with their treatment seeking behavior for the OI. Moreover, this chapter also focuses on information on maintaining regularities in the doses of ART and medicare to opportunistic infections.

Chapter VIII: Summary, conclusion and recommendation

This chapter comprises the summary and conclusion of the study. It also contains emerging recommendations for government and non government organization. Lastly, this chapter includes the limitations of this research study.