COPING WITH HIV/AIDS AND SOCIAL SUPPORT: A STUDY OF WOMEN IN HYDERABAD

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Certificate

This is certify that the thesis, entitled ***"Coping with HIV/AIDS and Social support: A study of Women in Hyderabad",*** submitted by Ms. Kusum Bharati in partial fulfillment of the requirements for the award of Doctor of Philosophy in Anthropology, is an original research work carried out under my supervision and guidance.

We declare that to the best of our knowledge no part of this thesis has been submitted previously in part or in full to this or any other university or institution for the award of any degree or diploma.

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I, hereby, declare that this Thesis entitled ***"Coping with HIV/AIDS and Social support: A study of Women in Hyderabad",*** submitted by me under the guidance and supervision of Prof. N. Sudhakar Rao, is an original research work.

I also declare that it has not been submitted previously in part or in full to this university or any other university or institution for the award of any degree or diploma.

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Kusum Bharati

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ABBEREVIATIONS

ASHA	Awareness sustained and Holistic Action
AIDS	Acquired Immune Deficiency Syndrome
ANC	Antenatal Care
AP	Andhra Pradesh
APSACS	Andhra Pradesh State AIDS Control Society
APSRTC	Andhra Pradesh State Road Transport Corporation
ART	Anti-Retroviral Treatment/Therapy
ARV	Anti-Retroviral Treatment
BMGF	Bill and Melinda Gates foundation
CBO	Community Based Organization
CDC	Centers for Disease Control
CCF	Christian Children's Fund
CHORE	Center and Housing Rights and Eviction Report
CMM	Chatinaya Mahila Mandali
CSW	Commercial Sex Workers
DARE	Development Action for Rural Development
DFID	Department for International Development
GIPA	Greater Involvement of People with HIV/AIDS
HAART	Highly Active Anti-Retroviral Therapy
HIV	Human Immono-Deficiency Virus
ELISA	Enzyme Linked Immuno-Sorbent Assay

FHI	Family Health International
ICTC	Integrated Counseling and testing Centre's
IDU	Injecting Drug User or Intra Venus Drug User
IEC	Information, Education and Communication
IRDS	Integrated Rural Development Service
IVDU	Intra Venus Drug User
INP+	Indian Network of People Living with HIV/AIDS
MSM	Man Having Sex with Men
MTCT	Mother to Child Transmission
NACO	National AIDS control Society
NACP	National AIDS control Programme
NAPCP	National AIDS Prevention and Control Policy
NGO	Non-Government Organization
NH	National Highway
NHP+	Network of People with HIV/AIDS
PLHAs	People Living with HIV/AIDS
PPCT	Prevention of Parent to Child Transmission
RTI	Reproductive Tract Infection
SFV	Simian Foamy Virus
SC	Scheduled Caste
ST	Scheduled Tribe
STD	Sexually Transmitted Disease
STI	Sexually Transmitted Infection

TB	Tuberculosis
TNP+	Telugu Network of People with HIV/AIDS
UNAIDS	Joint United Nations Programme on HIV/AIDS
UNDP	United Nations Development Programme
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children's Emergency Funds
USAID	United States Agency for International Development
ILO	International Labor Organization
USA	United States of America
VCTCT	Voluntary Counseling and Testing Centre's
VSSA	Venkateshwara Social Service Association
WLHAs	Women Living with HIV/AIDS

CHAPTER-1

INTRODUCTION

Two decades have gone by and humanity is still struggling to find ways to face the challenge posed by Human Immuno-deficiency Virus (HIV) and Acquired Immune Deficiency Syndrome (AIDS). The HIV/AIDS pandemic is now in its third decade and has progressively exhibited its impact both on science, as well as society. Today, it is both a medical enigma, as well as social problem. Beginning from its first reported case in 1980-81 in the United States of America (U.S.A), AIDS has been found all over the world and is reported from more than 193 countries (Herdt 1992). AIDS has become the most devastating disease that humankind has ever faced.

Though HIV/AIDS is more than a physical illness- it affects the psychological, as well as social, wellbeing of human beings. The epidemic also carries stigma, both for the infected individuals and their families who suffer from a great deal of psychological trauma, shame and even ostracism. They have to develop strategies and cope with the disease with reference to the experiences of stigma, discrimination and denial that they face. Due to the social stigma associated with HIV/AIDS, developing and maintaining relationships can be difficult.

If a person is confronted with HIV/AIDS, diseases such as tuberculosis, cancer, leprosy and so on inevitably follow and the individual has to struggle with the burden of treatments. Thus, one has to deal and cope with these diseases besides the social stigma and discrimination. The human adaptive mechanisms need to be operated within the social milieu, which may accept or reject the individual suffering from this serious illness. In this context, the social support, the positive experiences that result from social interaction, is important for this adaptation.

Social support is vital in terms of the role-played by family members, friends, neighbours, etc. Similarly, government agencies and Non-GovernmentOrganisations (NGOs), who are sympathetic to the HIV/AIDS victims are also playing a significant role in support of HIV/AIDS victims to cope with bear with the situation.

Social support can be defined as the degree to which the social needs of an individual are met by interactions with others. Social support network can help a person find solutions to problems, validate an individual's identity, direct the individual to helpful information and provide comfort to him/her. So, social support has been identified as one of the determinants of health which is believed to contribute to overall health. Social support is a general term that refers to any resource that aids a person at times of crises and helps copeup with life. Social support is one source of empowerment to an individual. Such individuals are considered as valued, esteemed and cared for. The agency that extends social support enters into a network of mutual obligations and makes them feel part of a larger social order. The social support networks often provide useful information and material resources such as financial aid as well as other help and even help recovery from the illness (Levin and Idler 1981).

The information on HIV/AIDS in India as well as in other parts of the world shows that women are most vulnerable to the AIDS virus.The low economic position, limited access to reproductive health services, ignorance of the ways the HIV spreads and lack of prevention option make women come under major risk groups. It is in this context that the present study has been undertaken for gaining a fair understanding about coping mechanisms and social support networks among HIV/AIDS women in Hyderabad, one of the major cities of India.

Statement of the Problem

It is always a psychological shock for a woman victim to learn that she is infected by the HIV/AIDS virus as the presence of the virus is going to radically change

her life in all spheres, leading to social isolation and psychological stress and strain. Thus, in such a scenario, HIV infected people need assistance in terms of emotional and physical support from healthcare professionals, social activities, their family members and friends.

In this background, it is felt necessary to ask what are the coping mechanisms which may be individual specific and cultural specific for women victims of HIV/AIDS? The coping strategies are most likely based on the set of beliefs about health, illness, social resources, community norms, systems and stigma that the victims face. It will also be necessary to ask what experiences of stigma, discrimination, denial and social reactions that are faced? Moreover, what is more important is the necessity to find out how HIV/AIDS is interpreted in the background of the various, beliefs and the type of support provided to the victims by the families, communities and the government and non-government agencies? And what alternative support strategies might be necessary to make life worth living for HIV positive and AIDS women.

Keeping in view the above, a brief account on the origin, meaning of HIV/AIDS and vulnerability of women with HIV/AIDS are given to contextualize the present study. Further, the scenario of HIV/AIDS in the world and in India, the context in which the HIV/AIDS assumed significance, i.e., the Human Rights concerns and the response of the governments in India in this regard are also discussed in order to show how the issue at hand is approached.

Origin of HIV/AIDS

There are various theories about the origin of HIV, but nothing has been established so far, and therefore, they remain as myths only. One theory is related to 'hunters'. In this theory, Simian Immunodeficiency Virus (SIV) was transferred to humans as a result of chimps being killed and eaten or their blood getting into cuts or wounds on the hunters. 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.

There are some more theories and among them, one theory states that the virus was transmitted via medical experiments (iatrogenically) especially through the polio vaccines. The oral polio vaccine called Chat was given to millions of people in Belgian Congo, Ruanda and Urundi in the late 1950s. Then it was cultivated on kidney cells taken from the chimps infected with SIV in order to reproduce the vaccine. This is the main source of contamination, which later infected a large number of people with HIV.

Meaning of HIV/AIDS

The HIV/AIDS is a silent, symptomless infection caused by a virus, the Human Immuno-deficiency Virus (HIV) that could enter the body during unprotected sexual encounters, through blood transfusion, infected needles or from mother to child. HIV positive denotes the presence of the HIV virus in the infected person's body, the production of the specific antibodies as the immediate response of the body to the virus. Further, it confirms that the body is harbouring that particular pathogen.

Since HIV has no specific symptoms of its own until very late, but only it decreases the person's immunity.There isn't any way to tell just by looking if someone has been infected by HIV. In fact, a person infected with HIV may look and feel perfectly well for many years and may not know that he/she is infected. But as the person's immune system weakens, he/she becomes increasingly vulnerable to illnesses, many of which he/she would previously have fought off easily. The person has no clue that he/she contracted the infection until opportunistic infections start occurring. The only reliable way to tell whether someone has HIV is to take a blood test, which can detect infection from a few weeks after the virus first entered the body. After that only an HIV test, i.e., ELISA test and a further confirmatory test, that is Western blot test, can identify

the antibodies, and thus establish the HIV status of a person, i.e., whether he or she is positive or not. Since the antibodies first appear in the blood only between six weeks and six months after the entry of the virus, any test that is conducted during this period is called “Window period”, i.e., when the seroconversion is still taking place it will not show reliable results. Even the test done already before the test must be repeated after the window period is over.

The uniqueness of the HIV virus is that it attacks the immune system itself, making the body steadily incapable of fighting common infections. In course of time, the person becomes “immune-deficient” and susceptible to what are called “opportunistic infections”; well-known communicable illnesses such as tuberculosis, bacterial pneumonia, herpes zoster, mouth ulcers, skin diseases, etc. What makes HIV so dangerous is that it particularly attacks a special type of immune system cell known as a CD4 lymphocyte. A damaged immune system is not only more vulnerable to HIV, but also to the attacks of other infections. It won't always have the strength to fight off things that wouldn't have bothered it before.

As time goes by, a person who has been infected with HIV is likely to become ill more and more often until, usually several years after infection. He/she becomes ill with one of a number of particularly severe illnesses. It is at this point in the stages of HIV infection that they are said to have AIDS - when they first become seriously ill, or when the number of immune system cells left in their body drops below a particular point. Different countries have slightly different ways of defining the point at which a person is said to have AIDS rather than HIV. AIDS is an extremely serious condition, and at this stage, the body has very littledefence against any sort of infection.

There is no cure or effective vaccine for HIV infection till date. Efforts at prevention have focused primarily on changes in sexual behaviour by promoting abstinence and increasing the availability and use of condoms. Attempts to reduce intravenous drug use and to discourage needle reuse have also led to a

reduction in infection rates in some areas where HIV infected mainly through injecting drug users. Currently, a person infected with HIV/AIDS has been prescribed to intake three classes of antiretroviral medications (ART).

Each drug has unique side effects, and, in addition, treatment with combinations of these drugs leads to additional side effects including a fat-redistribution condition called lipodystrophy. Since HIV rapidly builds resistance to any single anti-retroviral treatment, combination treatment is necessary for effective viral suppression. Highly Active Anti-retroviral Therapy (HAART), a combination of three or more ART and protease inhibitors, has resulted in a marked drop in the mortality rate from HIV infection in the United States and other industrialised states since its introduction in 1996. Due to its high cost, HAART is generally not available in regions of the world hit hardest by the AIDS epidemic. Although HAART does not appear to eradicate HIV, it largely halts viral replication, thereby allowing the immune system to reconstitute itself. Levels of free virus in the blood become undetectable.

However, the virus is still present in reservoirs, the best-known of which is a latent reservoir in a subset of helper T cells called resting memory T cells. The virus can persist in a latent state in these cells, which have a long life span due to their role as immune memory cells to respond readily to previously encountered infections. These latently infected cells represent a major barrier to curing the infection. Patients successfully treated with HAART no longer suffer from the AIDS-associated conditions mentioned above, although severe side effects may accompany the treatment. Patients must continue to take all of the drugs without missing doses in the prescribed combination or risk developing a drug-resistant virus. Viral replication resumes if HAART is discontinued (Barnett and Whiteside 2002, Janeway and Travers 1997, UNAIDS 2002).

Having explained the meaning of HIV/AIDS, we shall examine the situation of women in general across the world. The socio-economic and political powerlessness has made them more vulnerable than men.

Women and HIV/AIDS

The effect of the HIV/AIDS epidemic on women has changed considerably over the past decade (WHO 1994). Currently, women are at the centre of concern. WHO estimates that women account for almost half of all newly infected adults and, worldwide, there are 15.7 million women living with the HIV infection and it has become the leading cause of deaths in women of reproductive age in the Americas, Western Europe and sub-Saharan Africa. Women become infected with HIV through all the known routes of transmission. They are most at risk through unprotected sexual intercourse with an infected partner. In addition, sharing of unsterilized injecting needles by drug users, as well as infected blood and blood product transfusions put many women at risk (Vimala, et al 1999). Given the predicament of women, it is necessary to examine the vulnerability of women.

Gender inequality and molded notions of what is to be a 'man as a sexual being' and man's legitimate sexual expectations from his wife, result in woman's unquestioning subordination to man's sexual desires, and they rob of woman's autonomy in relation to her own body. This may be more acutely manifested condition of dire poverty. Poverty acts to worsen the effects of the social and cultural influences. Widespread poverty keeps people from school and leaves them too illiterate to correctly absorb and retain protective health information. They generally get information from peers, acquaintances random public places, like pamphlets or hoardings or TV advertisements. Poverty forces men to migrate in search of work and endure long periods of separation from their wives. This makes them vulnerable to seeking out paid sex. When poverty combines with the fact of being a woman in a society, where girl children are at a discount, the consequences could become even worse. When women test positive usually when they go to health centre's for pregnancy test, they are castigated by their

families as immoral and even thrown out of the houses. When their babies are born with HIV positive and die, they are seen as total failures in their roles as mothers. When the positive husband dies, the wife may be thrown out of the home or denied a share in his property. Without education or skills, women, who become destitute and or deserted by their husbands, may be forced into prostitution for their survival. The chain of HIV transmission and human tragedy could thus go on.

The gender-based socialization of boys and girls continues to create power dynamics in sexual relationships that put women at a disadvantage (Population Council 2001). Girls usually enter relationships with the opposite sex as unequal partners. As such, they are often unable to negotiate safe sex or to avoid sexual abuse and exploitation. They also have less access to condoms, even if they are available, and are, therefore, likely to leave decisions about their use to their male partners. Girls in Africa, looking for ways out of poverty, or more precisely, a means of paying their school fees, acquiring clothes, jewellry and makeup, or travel, are often courted by older men or "sugar daddies" who give them such gifts in exchange for sex. Such "transactional sex" is very common in many countries and is a prime reason for the spread of HIV in young women. In parts of Africa and Asia, some men falsely believe that having sex with a virgin or younger "Clean" girl can act as a cure for HIV/AIDS. Many young girls have been infected as a result of such misinformed and desperate searches for a cure.

Migration also increases the woman's vulnerability to HIV infection if she is isolated from community structures and support, and cannot speak or read the local language. Female migrant workers, refugees or returnees are often more vulnerable than other women to some kind of sexual barter as they try to negotiate employment necessary documentation or a place to live (WHO 1995).

The cultural practices such as female genital mutilation may also increase the risk of HIV transmission. Many women worldwide are living with the consequences of this practice. An estimated two million young girls each year are at the risk of

being subjected to it. In addition, a large number of studies conducted in many countries and in all continents of the world suggest that between one-third to one half of all married women have been beaten or otherwise physically or sexually abused (Sowell, et al 1999). The most powerless and vulnerable are children and women who are coerced into sex trade by traffickers. An estimated two million girls are coerced into the trade each year. Unfortunately, prostitution is often the only means of financial security for women, but they rarely have the power to negotiate condom use. Social and cultural determinants relating to women's position in Indian society directly affect their ability to care for their health. This is especially so in regard to HIV/AIDS. Dependency of women on men, their lower level of education, limited access to resources, and lower economic status have enhanced their vulnerability in the area of health care, particularly in their incapacity to protect themselves from sexually transmitted infection. Increasingly, it is being recognized that cultural values and status of girls and women in society are important aspects of the AIDS problem. AIDS is a development and gender issue (Seidel 1993). Social inequality between men's and women's roles and positions is cited as being most responsible for the spread of HIV/AIDs in India.

Women's helplessness is visible in large sections of the Indian society right from her childhood even if it has to cost her life. Here, a woman is suppressed and not allowed to speak out or raise voice against any abuse. She is subjected to the subordination for everything at every time. The subordination affects her life's choices, her autonomy, her health and her life itself. Given the prevailing gender norms in Indian society, such as low status of women in all spheres compared to their male counterparts that the majority of women infected are married women whose husbands or primary sexual partners are engaged in high risk sexual behaviour outside marriage and are, in effect, "bringing home" the virus. Moreover research has shown that women are more vulnerable epidemiologically, biologically and socially to contracting HIV/AIDS, and young women are particularly at risk. Indeed, it is estimated that women are nearly 2.5 times more likely to contract HIV than their male counterparts. In a society where discussion

of sex is largely taboo, there are currently few avenues for women to get reliable information about HIV/AIDS. About their knowledge on HIV/AIDS, Irfan Khan of Naz Foundation states "far too many women do not know how AIDS is spread." He further adds, there need to be more spaces where women and girls can access information about HIV/AIDS, and also engage in open discussions on sexual health and sexuality."(Smita Jain 2005). So the rate at which AIDS is spreading among women in the general population is alarming.

The Biological Context

Biology makes women anatomically more vulnerable to contract HIV/AIDS than men. Research shows that the risk of becoming infected with HIV during unprotected vaginal intercourse is as much as 2-4 times higher for women than men (WHO 2000). Male to female transmission is more likely because during vaginal intercourse. A woman has a larger surface area of her genital tract exposed to her partner's sexual secretions than does a man, which has a higher concentration of HIV than a woman's vaginal secretion.

Women are more likely to bleed or bruise during violent or rough sex, which makes them more likely to become infected not only with HIV, but with other sexually transmitted disease as well. Gupta asserts that menstruations make women more vulnerable to contracting HIV. Sexual Transmission Infections (STIs) are readily acquired during this time. However, according to Sterbel (1995), these remain undetectable resulting in inefficient treatment that, in turn, increases the risk of HIV infection. Accessing services for STI's is perceived as being highly stigmatizing. Consequently, many women do not seek treatment. In the presence of STI's, the risk of contracting HIV is greatly increased (Gupta 2000).

The above account makes it clear that the HIV/AIDS has a devastating effect on women as there is inherent gender bias in the spread of the disease. The magnitude of the problem can be accessed from its prevalence across the globe.

The problem is quite serious in India as it places the country in one of the top positions, leading to irreparable human and economic loss.

Overview of HIV/AIDS Epidemic: Global and Indian scenario

The first AIDS case was reported on 5th June 1981 in the city of Los Angeles, U.S.A. However, by the end of 2007, the Global estimates of the HIV/AIDS pandemic have brought out that more than 60 million people worldwide have lived in HIV/AIDS and 20 million have died of the disease. The global and HIV and AIDS statistics, published in UNAIDS in 2008, reported that 33 million people were living with HIV/AIDS in 2007 and the number is still growing. Around 67 percent people living with HIV are in sub-Saharan Africa. At the end of 2007, women accounted for 50% of all adults living with HIV worldwide and for 59 percent in sub-Saharan Africa. Young people under 25 years of age account for half of all new HIV infections worldwide (UNAIDS 2008). However by the end of December 2004, an estimated 34 to 46 million people are living with HIV/AIDS apart from 279 million deaths (UNAIDS 2004). Nearly 14,000 new infections and 8000 deaths are occurring ever day. It was estimated that another 4.54 million infections were likely to occur by 2010.

As far as India is concerned, the first case of AIDS was reported in Chennai in 1986, and later it was found in almost all parts of the country, and now affects a vast cross section of the society. The first HIV/AIDS patient in India was diagnosed by Dr. Suniti Solomon, a microbiology Professor at the Madras Medical College in India, in 1986. This discovery should have served as a wakeup call for immediately launching an effective preventive campaign in India. But Indian government officials smugly and monastically proclaimed that AIDS was a foreign disease and that the epidemic could never spread in a family centred society like India. They were decidedly wrong and in 1999 about 1,400 Indian citizens were being infected each day (Dube 2000).

In 2006, UNAIDS estimated that there were 5.6 million people living with HIV in India, which indicated that there were more people with HIV in India than in any other country in the world (UNAIDS 2008). However, the National AIDS control and preventive organisation (NACO) disputed this estimate, and claimed that the actual figure was lower (NACO 2006). In 2007, following the first survey of HIV among the general population, UNAIDS and NACO agreed on a new estimate – between 2 million and 3.6 million people living with HIV. The figure was confirmed to be 2.4 million in 2008. This puts India behind South Africa and Nigeria in numbers living with HIV/AIDS (UNAIDS 2008).

India's highly heterogeneous epidemic is largely concentrated in six states. On an average, HIV prevalence in those states is 4–5 times higher than in the other Indian states. HIV prevalence is highest in the Mumbai-Karnataka corridor, the Nagpur area of Maharashtra, the Nammakkal district of Tamil Nadu, coastal Andhra Pradesh, and parts of Manipur and Nagaland.Populations of nearly 50 percent of the new HIV infections are occurring among young people between 15 to 24 years old. This is partly because a large part of the world population is young between 10 to 19 years of age (NACO 2003). HIV/AIDS epidemic in India shows warning sign, it is the young, especially women who are most vulnerable. So, the HIV/AIDS epidemic represents the most serious public health problem in India

According to the medical understanding, the predominant mode of transmission of infection is through heterosexual contact (80.86 percent), followed by blood product infusion (5.30 percent), prenatal transmission (0.72 percent) and others (7.60 percent) *(The Hindu, Nov 17 2002).* As the main mode of transmission of HIV is through heterosexual contact, the heterosexual transmission assumes importance in the Indian cultural context primarily due to the large size of the population and the frequency of exposure. The prevailing cultural norms of universal marriage, early age at marriage are some of the reasons where women's vulnerability towards HIV/AIDS is observed. Ramasubban (1995) explains that

early onset of coital activity and child bearing, as well as the prevailing demographic structures, imply that an overwhelmingly high proportion of the population comes within the sexually active group. NACO estimates that 89 percent of the reported cases occur in the sexually active and economically productive age group of 15 to 44 years and in every four cases reported one is a woman (*The Hindu, 17 Nov 2002).*

Studies in India show that the spread of HIV within the country is as diverse as the societal patterns in its different regions, metropolitan areas and states. It is largely concentrated in risk population such as commercial sex workers, intravenous drug users and truck drivers. The surveillance data suggest that the epidemic is moving beyond these groups in some regions into the general population and is moving from urban to rural areas. Migration of labour, low literacy levels, low awareness, gender disparities, prevalence of sexually transmitted disease and reproductive tract infections are some of the factors attributed to the spread of the HIV/AIDS. Thus, it can be said that, in India, HIV/AIDS epidemic is a major problem increasingly everyday in its effect and hence represents a serious public problem to the country and to the society at large.

The problem of HIV/AIDS is not confined to the individual sufferer alone, or the society, but it is a problem of national and global dimensions. At the global level, the issue is seen as an incursion into the Human Rights according to the United Nations Organisations (UNO). In agreement with this, different countries have taken steps to effectively alleviate the situation. The same are examined in the following pages.

Human Rights and HIV/AIDS

HIV/AIDS is a Human Rights catastrophe, at it deprives people of universal entitlements given to individuals who can enjoy freedom irrespective of sex, nationality, religion, culture or other status that are inherent to human beings and

that are proclaimed and protected by international law. The principle of non-discrimination is fundamental to Human Rights law and is of particular significance to those living with HIV/AIDS who frequently suffer from high levels of stigma and discrimination. The epidemic has emerged as the single greatest threat to the fulfillment of the Rights of children and women all over the world. Those affected are routinely denied their Rights to education, economic opportunity and health care and to protection from exploitation and harm. They are discriminated against and left powerless to resist the danger they face (Ramamuthy 2004).

In this regard, the key international Human Rights document is the Universal Declaration of Human Rights (UDHR) 1948 under the UNO. It is a common inspirational document, by and for government, about what Rights should exist for all people everywhere. Apart from this, a number of international Human Rights treaties exist that further elaborate the Rights set out in the UDHR. These include the International Covenant on Civil and Political Rights (1966); the Convention on the Elimination of all forms of Racial Discrimination (1965); the Convention on the Elimination of all forms of Discrimination Against Women (1979); and Convention on the Rights of the Child (1989). Each of these documents lays out legally binding obligations for the government for health in the context of the HIV/AIDS epidemic. For HIV/AIDS infected people, the Human Rights concerns included stigma and discrimination, mandatory testing, barriers to employment and housing, access to education, medical care/health insurance, and the issues relating to confidentiality. Seized of the magnitude and intensity of HIV/AIDS in India, the government has adopted a policy called the National AIDS Prevention and Control Policy (NACA), in 2002 to control the HIV/AIDS.

The National AIDS Prevention and Control Policy (NACP), 2002

The NAPCP articulates understanding of the HIV/AIDS epidemic in India. It states that for an effective response, development and Human Rights need to be

addressed through a multi-sectoral collaboration. The NAPCP priorities are Human Rights protection as an objective, and not merely a strategy. Other objectives include reduction of the impact of the epidemic, bringing about a zero transmission rate by 2007, bringing about an enabling socio-economic environment for prevention and control, decentralization of the programme and working towards a horizontal integration of the HIV/AIDS response with other national programmes relating to health. The implementation of the policy is through the involvement of different departments of the government, decentralization and collaboration with NGOs, especially for the purpose of targeted interventions. Apart from this,the Lawyers Collective (HIV/AIDS Unit), an NGO in India, with the help of European Commission, has set up this unit to provide legal aid and allied services for people affected by HIV/AIDS and people working in the area of control of HIV/AIDS. The Lawyers' Collective is one of the most prominent Organisations that has been fighting for the Rights of People Living with HIV/AIDS (PLWHA) and has been successful in its legal battles to enforce the same. They have also made valuable contributions in ensuring that people have access to accurate information about HIV to protect themselves. Under the NACP, the government of India established the National AIDS Control Organisation (NACO).

Government and Non-Government Response to HIV/AIDS in India

The NACO, established by the Ministry of Health and Family Welfare, is a comprehensive structure at the national level which forges alliances with various ministries and NGOs, coordinates and monitors the programme activities in various states, strengthens the technical and research capabilities, and has a system of monitoring and evaluation. NACO also collaborated with various sponsoring agencies and NGOs which provide it with an established community base for operation. NACO launched its National AIDS control Programme (NACP) in 1987, but the strategic plan for the prevention and control of AIDS was put into operation for country wide implementation only in 1992. The main strategies of the NACP are to:

- Prevent HIV transmission,
- Decrease the morbidity and mortality associated with HIV infection, and
- Minimize the socio-economic impact resulting from HIV infection.

Besides NACO, the country also has a National AIDS Control Board (NACB), which is chaired by the Union Health Secretary. The Board reviews NACO's policies, expedites sanctions, approves procurement and undertakes and awards contracts to private agencies. The other major functions of the Board are: approval of annual operational plan budget, reallocation of funds between programme components, formation of the programme managerial teams and appointment of senior programme staff.

There are numerous NGOs and Community Based Organisations (CBOs) which are working on HIV/AIDS issues in India at the local, state, and national levels. Projects include: targeted interventions with high risk groups; direct care of people living with HIV; general awareness campaigns; and care for children orphaned by AIDS. Funding for non-government and community-based groups comes from a variety of sources: the federal or state governments of India, international donors, and local contributions. (World Bank 2009).

Response of the Government of Andhra Pradesh.

Similar to the NACO, the State Government established the Andhra Pradesh State AIDS Control Society (APSACS) in 1998**.** This was considered necessary since Andhra Pradesh is currently one of the six "hard hit" states. Andhra Pradesh has 5.5 lakh HIV infections in the country *(The Hindu 2nd December 2008)*. The state has the highest proportion of those with sexually transmitted disease (STD), who have tested positive for HIV/AIDS. People suffering from STD are more vulnerable to HIV infection. But HIV/AIDS is no longer confined to those with risky sexual behaviour. The NACO classifies the HIV/AIDS epidemic in Andhra Pradesh as high prevalence with five percent or more of high risk groups and one

percent or more of women in antenatal clinics testing positive. Rates for women in some clinics have now risen as high as four percent. That is very high rate for women in the general population behaviour and whose chances of contracting HIV are considered low.

The NACO's Director General noticed that the high prevalence of HIV in Andhra Pradesh is because 'one in every five men in Andhra Pradesh has multi partner sex' and of them only 25 percent use condoms. She also said that the surveys conducted by APSACS showed that of the youngsters who have been surveyed, 20-30 percent had premarital sex (APSACS 2009).

The following are the some of the facts which explain the reasons for high prevalence of HIV in Andhra Pradesh.

1. Andhra Pradesh records high prevalence of sex with non- regular partners and it is 19 percent (12 percent) in men and 7 percent (2 percent) in women.[1]
2. Traditional and strong sexual networks; some castes such as Dommara, Kalavantulu, Erukala, Bhogam and the like are traditionally in commercial sex in places like Chilakaluripeta and Peddapuram, which are historically commercial sex centres.
3. High trafficking of women and girls; major suppliers of commercial sex workers to all sex networkers including Goa, Mumbai, Delhi, and Kolkata.
4. Highway prostitution of native sex workers and widely traveling truck drivers. The long stretch of NH-5 particularly runs through the coastal districts of the state. NH-5 is notoriously known for highway prostitution.

[1]Percentages in the parenthesis are national figures. The Guntur district has an infamous record of 38 percent of men and 10 percent of married women engaging in sex with non- regular partners. Sex with non- regular partner is an extreme risk behaviour. Andhra Pradesh also records low condom use of 25 percent in sex with non- regular partners.

5. High prevalence of Sexually Transmitted Infections among men and women (The STI increases the chances HIV infection tenfold.
6. Large number of migrant population.

The APSACS is the nodal agency in the State in implementing various schemes through government departments and NGOs. It monitors the programmes implemented, organises surveillances, and advices the government about various steps to be taken for control of AIDS in the state. In the light of the above discussion, the research work done already particularly in the social science discipline is examined in the succeeding paragraphs.

REVIEW OF LITERATURE

Psychology has been the dominant field of the social sciences to study the HIV/AIDS issues (Mann and Torantola 1996). It has used the approach that focus on individuals and their behaviour to understand how HIV is transmitted in different populations, how it affects the wellbeing of the individuals and families. However, a few researchers like Nelkin (1991) pointed out that AIDS will also reshape many aspects of society, its institutions, its norms and values, its interpersonal relationships and cultural representation.

STUDIES OUTSIDE INDIA

Richard Parker (2001) provides an excellent review of anthropological research carried out till the turn of the century and points out that the fact that anthropological institutional response to HIV/AIDS was late compared to other disciplines, though individual scholars have contributed irregularly. They have pursued vigorously from late 1980s. Starting from the studies into behavioural risks, they moved to cultural meanings. Later from cultural meanings, they shifted to structural violence. In the structural violence, there has been more focus on the gender disparity in cultural settings. The present study locates itself in this type of research. However, here a brief review is made on various issues related to

HIV/AIDS that are considered by social scientists, in general, including anthropologists.

Experiencing fear of violence, abuse, abandonment and stigma

There are many studies conducted about the experiences of the people living with HIV/AIDS. In the study of Baltimore, MD, USA (Rothen Berg K.H, et al 1995), researchers interviewed care providers who counseled HIV infected women. It has been found that forty five percent of the providers reported having had female patients expressed fear of physical violence as a result of disclosure to their partners, while 56 percent had patients who expressed fear of emotional abuse, and 66 percent had patients who feared abandonment. While talking to women about disclosure of their HIV status to their family members, Moneyham, et al (1996) found that women did not tell their children or anyone else about being HIV positive because they feared that their children would be stigmatised and isolated by their classmates and neighbours.

Temmerman, et al (1995) in Nairobi, Kenya found that less than one third of women living with HIV had informed their partners of their HIV status, and violence against HIV positive women was common. Such violence included being chased away from their homes or being replaced by another wife and beatings, one woman was driven to suicide. In a similar study in Rawand, Van der Dtarten, et al (1997) found that woman had suffered beatings and break up of relationships.

In reviewing the literature on stigma and HIV/AIDS, it is found that most people living with HIV and AIDS suffer or fear from stigmatisation (UNAIDS 2004, Exner T.M, et al 1997, Bunting S.M 1996). Studies from Africa suggest that AIDS stigma is linked to people's sense of sexuality, morality and their fear of breaking taboos (Swantz 1990). So, it is thought that the fear of stigma adversely influences women's health seeking practices (Chesney M.A, et al 1999, Lester

Petal 1995). Conspiracy of silence in HIV/AIDS is seldom openly discussed, even in heavily affected areas.

Disclosure of HIV identity

Sowell, et al (1997) studied women's disclosure patterns in Georgia, USA and found that 90 percent of women disclosed their HIV status to Health care providers, while only 69 percent reported disclosing it to the sexual partners. According to Seigel and Krauss (1991), deciding to tell about one's HIV status entails trying to protect oneself from discrimination, assessing one's fear of rejection and avoiding people who might inflict pain or pity. In an evaluation study in Uganda, Kaleeba, et al (1997) found that 90 percent of people sampled had revealed their HIV status a rare high figure. However, this study also reported that only 36 percent of the sample revealed their sero-status to a spouse or sexual partner. It should also be noted that in this evaluation study, 41 percent of the respondents had been widowed. A Tanzanian study reported that people often chose to postpone the disclosure of their HIV status because they felt that they did not want to receive the blame associated with the disease, or that the family burden of the stigma should be avoided. This study also found that people mostly chose a confident of the same gender and generation. Reasons for these decisions include the desire to reduce the impact of moral adjustment, and the near prohibition of discussing sexuality across generations. In a Thai study (Bennetts, et al 1999), it was found that women who did not disclose their HIV status had higher levels of worry and feared family shame.

The study byWoudenberg (1993) in Harare in Zimbabwe, found that most women rarely shared their diagnosis for fear of discrimination and stigmatisation. If they told anyone, they told their mother or sister. They felt reluctant to tell others in the community or even to allow women outside the cooperative. This fear was deeply ingrained that the majority kept their status secret and continued to feel and unsupported by the community and, at the same time, they were some open

women who participated in a national AIDS awareness, video campaign reminiscent of courageous advocates worldwide who lived to make a better environment for themselves and others by sharing their diagnosis and breaking the stigma.

Although the emotional and physical amplifications of disclosure can be profound, Gielen, et al (1997) found that women's fear of disclosure did not necessarily reflect their experience when disclosure was made. The woman in this study feared rejection, discrimination, public ignorance and violence, but reported somewhat different experiences when disclosure was made, i.e., emotional trauma, acceptance and support, rejection and violence. Therefore, some of the women's fears were actualised in this study, while others were not. All the women in this study felt that it was better to limit the number of people who knew their status, in order to protect their own privacy and that of the family.

Stigma

With respect to stigma, the single most important social- psychological issue for perception with HIV/AIDS is its association with homosexuality and IV drug use (Weitz 1991, Crandall and Coleman 1992, Conrad 1986, Stine 1998). It is identified with behaviour considered to be deviant; is classified as a sexually transmitted disease; is viewed as the responsibility of the individual; is thought to be acquired by way of immoral behaviour; and is perceived as contagious and dangerous to the community (Herek and Glunt 1988, Sontag 1988, Freund and McGuire 1991, Sacks 1996). Furthermore, HIV/AIDS is associated with "blame the victim" ideology as well as with all three types of Goffman's (1963) stigmatised statuses; physical imperfection, character flaws and membership in a negatively regarded social group (Siegel and Krauss 1991). Therefore, we would expect that due to the social onus of their illnesses, persons living with HIV/AIDS experience greater stigmatisation, in the forms of social rejection, economic discrimination, internalised shame, and social isolation.

In 1987, Jonathan Mann, the Director of the WHO global programmes on AIDS identified three phases of HIV/AIDS epidemic- the epidemic of HIV, the

epidemic of AIDS, and the epidemic of stigma, discrimination and denial. He noted that the third phase is "as central to the global AIDS challenge as the disease itself". Stigma and discrimination relation to HIV/AIDS undermine public efforts to combat the epidemic, AIDS related stigma negatively affects preventive behaviours such as condom use, HIV test seeking behaviours, care-seeking behaviour upon diagnosis, and quality of care given to HIV positive patients and perception of People Living with HIV/AIDS (PLHA) by communities, families and partners. One of the most surprising elements of AIDS stigma is the ubiquitous nature even where the epidemic is widespread and affecting so many people such as on sub-Saharan Africa.

AIDS also brings to the fore issues of stigma and marginality. The entire high-risk population-homosexual, hemophiliacs, drug users intravenous and other-suffers from societal ostracism. Stigma plays a devastating role in the life of PLHA and the barrier it presents to prevention. Stigma results from the devaluation of individuals or groups of people who are perceived to be HIV-positive or living with AIDS (whether or not they manifest symptoms of AIDS). Stigma leads to acts of discrimination, which occur when "distinction is made against a person that results in his or her being treated unfairly and unjustly on the basis of their belonging, or being perceived to belong, to a particular group" (UNAIDS 2002). Perceived stigma can have powerful psychological consequences for the victim, leading to depression and feelings of lack of self worth, which further impacts the health status of PLHA (UNAIDS 2002).

Care and support for PLHA often coexists with stigmatising attitudes and acts of discrimination in the same community (ICRW Research Update 2002). Fear of stigmatisation prevents PLHA from disclosing their status, protecting their sexual partners, asking friends of family for support, and making long term plans for their dependents. Various scare messages such as "AIDS kills," as well as stereotypes associated with PLHA, have clearly contributed to the perception that AIDS only affects "others" especially those who are already marginalised, such as

sex workers and MSM. People may not be willing to get tested or disclose their status for fear of being associated with such groups. Stigma limits the effectiveness of prevention efforts. Because of the stigma attached to HIV and AIDS, people may deny that they are at risk, avoid getting tested and may also avoid protective behaviours or discussions of HIV/AIDS altogether. Those who learn they are HIV positive may continue former risky behaviour or reject healthy practices to avoid arousing suspicion. Stigma has also led political leaders in many countries to deny that HIV and AIDS are problems that need urgent action (UNAIDS 2000).

Stigma and discrimination can be manifested at different levels and in different contexts: policy and legal, institutional (schools, healthcare facilities, and workplace) community, family and individual. Stigma is the consequence of the association people make between HIV/AIDS and pre-existing prejudices, shame, blame and fear related to sexuality, gender, race/ethnicity, and class (Kidd and Clay 2003, Parker, et al 2002).

Counseling

In contrast, in a West African study (Sibindi 1995 and Moneygham, et al 1996), more than half of the women undergoing HIV testing stated that they wished to receive their test result in the presence of another person, namely their regular partners. A study in Zimbabwe (Sibindi 1995) found that with enhanced counseling, 75 percent were able to disclose their HIV status to their partners. A Thai study found that 84 percent of the study participants had disclosed their HIV status to their family or friends and reported a feeling of shame and fear of rejection and discrimination (Bennette, et al 1999).

Problem with prolonged infection

From different studies on HIV/AIDS, it has been found that as people live longer with HIV infection they become increasingly vulnerable to multiple emotional and social problems. Progressive immune system deterioration, the onset of

symptomatic illnesses as well as other HIV related events, precipitate psychological distress (Kalichman 1998). Physical limitations, resulting from both disease and treatments, threaten the quality of life and daily functioning of people living with HIV infection, including AIDS stigmatisation (Herck 1990), relationship conflicts (Turner 1993), discrimination, and multiple losses (Martin and Dean 1992). Even the study of Smith and Rampkin (1995) pointed out that more than one third of people living with HIV have unmet social needs.

Coping

There is considerable interest in how people cope with the disease and AIDS. The importance of coping as a buffer life event is well recognized. Lazarus and Folkman (1984) contend that stress consists of three processes: primary appraisal that attends how the threat is appraised by the person. Second appraisal involves bringing to mind a potential response and decision about how to cope with the threat and the third, coping process of responding to the treatment. In a review of the coping literature (Bennelts, et al 1999), it appears that people generally choose two different types of coping: active (problem focused) or passive (emotion focused). The former is aimed at problem solving or doing something to alter the stressful situation or the stress itself, while the latter is aimed at managing the emotional stress caused by the situation. It is generally believed that each type of coping is helpful, and that neither is considered superior to the other. Judgment lies in how well the type of coping used helps with a specific situation (Moneyham, et al 1996).

In a study in the United States of America, Moneyham, et al (1996) found that the emotion focused coping strategy of avoidance was associated with emotional distress and physical symptoms. In contrast, Rose and Clarke Alexender (1996) found emotional focused coping to be associated with increased psychological well-being and improved quality of life. Studies have also found problem focused coping to be positively associated with the psychological well-being of HIV infected women (Clark Alexander 1996). In an evaluation study, Kaleeba, et al

(1997) found that counseling had a positive effect on people's ability to cope. There is a qualitative study by Abetz L, et al (1998) who collected information from 150 respondents in three countries (US, UK and France) on the most useful strategies that people with HIV/AIDS use to cope with the disease and its effects. In their study sample, every person believed that a positive attitude helped to keep them healthy. Sustaining a positive attitude was, at times, quite difficult and was aided by: social support from friends, family and support groups, spiritual beliefs, taking control of one's treatment regimen, making drastic lifestyle changes (such as diet, exercise, eliminating addictive habits and stress), and using alternative therapies (such as tai chi, massage, Chinese herbs). Many respondents were convinced that these coping methods have extended their lives. Those with more passive coping styles still believed in the power of positive thinking but tended to be bolstered by new treatment developments.

In the study of the Sikuluchwa in Zimbabwe,Wodendberg (1993) found that the women used different coping strategies, often in combination and at different stages of their illness planning. According to them, the coping especially for their children's future can be used in problem based coping and, most often, religious and emotional support and distraction at the cooperative were used.

It is found from the studies of David and Godwin (1997) and Kongsin, et al (2000), that to cope up with the financial situation, households used various strategies which included reduction of household composition, reallocation of labour, withdrawal of children from school, dependence on extended family system and the community to support and help them to cope.

Social support

The theories of social support state that needs are met through much more than mere interpersonal contact (Cohen and wills 1985). Support for people living with HIV infection can come from multiple sources, including family, friends, relationship partners, professional care givers, and others (Johnston 1995). More specifically, the link between social support and greater psychological well-being

and lower incidence of physical illness has been well documented since the 1970s (Cobb 1982, Cohen and Wills 1985, Schaefer 1981). Furthermore, the relationship between social support, depression and coping has shown to be especially important for HIV- positive individuals. Zich and Temoshok (1987), in their sample of 103 gay and bisexual men with AIDS or ARC, found evidence that HIV-positive persons with low levels of social support experienced more physical symptoms, more hopelessness and depression than those with high levels of social support.

Most of the researchers incorporating specific providers of social support have suggested family members are not viewed as particularly helpful to HIV- positive persons. In fact, although results are somewhat equivocal (Hudson and Morris 1994, Kimberely and Serovich 1996), the majority of studies suggest that friends provide more support than family to HIV infected individuals (Friedland 1996, Hays 1990, 1994, Johnston 1995, Namir 1989, Schwarzer and DunkelSchetter 1994, Stowe 1993). One explanation offered for friends being viewed as more supportive than family has been associated with the mode of contraction. That is individuals who contact HIV via homosexual sex or injection drug use are less likely to receive support from family than friends.

Of the few studies that have found family members to be more supportive than friends, the sample tends to be heterogeneous with regard to mode of contraction. For example, in their study of 219 HIV positive men and women, Smith and Rapkin (1996) divided their sample into four groups based on gender and mode of contraction. These include women, men who had sex with men, male intravenous drug users and heterosexual men. They found that women, male IDUs and heterosexual men perceived family members as more supportive than friends. Only those who reported that friends as more supportive than family were men who had sex with men.

Intervention

A few studies have discussed certain proposals/ interventions related to HIV/AIDS, which include enforced quarantine, mandatory screening constraints on marriage and child bearing and exclusion of infected person from work, restaurants and schools, a salacious gaze in law, legal analysis. In the health sector, studies have shown that despite strong scientific arguments AIDS is not transmitted through casual contact (Gangoli 2002, Nelkin 1991, Robinson 1998, Susan Sontag 1989, Waldley 1990).

STUDIES IN INDIA

Similar to the delayed response of anthropologists in the United States of America, the efforts of Indian anthropologists to address the HIV/AIDS entered the scene late and the studies were largely confined to individual scholars. The social sciences, particularly social workers, health activists, responded to the epidemic spontaneously and their efforts have been to bring pressure on the government for tackling the precarious situation and offering social services to the victims. It may be said that anthropologists with their academic credentials mainly appeared as researchers after 1990s though the virus was discovered in 1986 in Chennai. Their focus has been to explore the social and cultural issues of HIV/AIDS and sometimes to give advise to various agencies.

A conference was held in New Delhi in 1998 on HIV/AIDS - An Interdisciplinary Approach to Prevention and Management. The papers presented at the conference dealt with the issues such as how to manage HIV/AIDS and underlined the need to provide holistic care and support to HIV/AIDS patients. While clinical care provides symptomatic relief to patients, there is a great need for treatment that would help also include counseling and social support directed at helping patients to improve the quality of their lives, and enable them to live longer and that too productively. The role of counseling was highly emphasized as it plays a major part in providing information, removing fears, and giving support to those infected and their families. The counseling programmes generally

focus on building skills, character, and personnel capacities of HIV patients, as well as helping them to take personnel decisions. Despite the best of work, there is still a great need for streamlining and strengthening counseling services which have to be highly professional, and for following ethical norms and standards.

Discrimination of women victims against men victims

It has been noted that household dynamics played a crucial role in the nature and quality of care received. Men received more supportive care than their wives, even when their female partner was also sick. In-laws often showed little compassion or sympathy toward widowed, infected daughters-in-law (UNIFEM 2000). Individuals without open sores or lesions were better accepted by family members and perceived as less likely to transmit the virus (Bharat 1996, Subramanian, et al 2009). The HIV+ people in Mumbai experienced acute distress and their effective response was essentially due to the terminal and stigmatising nature of the infection. The terminal nature of the infection deeply affected the spousal relations, tempering wives anger towards their husband for being responsible for the present problems and misfortune (D'cruz 2003). In the role of mother, women judged themselves for being unable to properly care for their own children (Lisa Rahangdale, et al 2007).

Women and their husbands were poorly informed about HIV and had limited awareness of how HIV is transmitted, how to live with the disease and its links with risky sexual behaviours. Women are discriminated against in their marital family and are refused a share of the property and even financial or emotional support. Providing financial security for their children is the major concern of the HIV + women(UNIFEM 2000, D' Cruz 2004, Kausahlya and Gaunj 2004). Women need financial, medical and social support (Nyamathi, et al 2010).

Hospital/treatment

Studies reveal lack of facilities, delivery service,experiences of refusal for treatment, abusive behaviour, moral judgment, and lack of confidentiality by staff. There has been denial of personal contact or hospitality (Kaushalya and Gaunj 2004, Lisa Rahangdale, et al 2007, SudhirVerma 2005, UNIFEM 2000).

Disclosure of HIV status and Stigma

SudhirVerma (2005) found that most of the women did not tell it to others for fear of boycott, discrimination, getting defamed, loss of job, etc. The attitude of people changed overnight towards HIV+ and discrimination ultimately followed. The whole scenario changed and ultimately a woman is put to the sword. D' Cruz (2003) found in Mumbai that victims do not like to disclose their health status to the children. Even sharing their status with the social network was a major issue. The social stigma forced the couples to maintain secrecy over the HIV diagnosis with the extended family, close relatives and friends. The breach of confidentiality by the health care system, however, interfered with the process in a few cases, affecting the couple's autonomy over the process of disclosure.

The sero-positive people and their families cut themselves off from their social networks for fear of stigma.As a result, they experience acute loneliness and isolation at the most trying and painful time of their lives. The stress, suffering and the effects of support are amply documented (Ankrah 1994, McGrath, et al 1994, Poindexter and Link 1998, 1999). But it has been pointed out in some other studies that for seeking economic support from the relatives, the sero-positive status was an important factor. When the family was unable to manage its basic needs independently and its survival was at stake, it concludes that there was no other option but to disclose the sero-positive status and solicit help (D' Cruz 2004).

Economic burden

A lot of money is being spent on medicines by the victims. The family is now focused on bare survival. The access to medical facilities is meager and it takes a

heavy toll of earned money. No government and NGO support is available at remote places. The women wanted free education for children, free food, free medicines, employment opportunities, free travel in rail/buses, rehabilitation, care and support in the form of some policy framework to ameliorate the condition of women already infected. For combating AIDS, one has to become economically independent by engaging in occupations running STD booths, dhabas, grocery shops, garland making, tailoring, papad making, small scale industry, vegetable shops, embroidery work, running of schools and mehndi work, etc. (SudhirVerma 2005, Singh and Sathyanaryana 2006). People sold away and mortgaged properties for meeting the expenditure in Maharashtra villages (Pallikadavath, et al 2005). A similar situation has been noted among the HIV+ victims in Mumbai and Thane also (Committed Community Development Trust 2004). Various studies have indicated that economic status and HIV/AIDS are strongly correlated (Dilip and Duggal 2002, Mukhapadhyay,et al 2001).

Lack of Education and dependency of Women

It has been found in four regions such as Delhi, Pune, Chennai, and Assam, women lacked elementary knowledge of reproduction, health issues, and safe sex practices. There were gender differentials in levels of awareness about HIV/AIDS - low among women and girls compared to boys and men. In most cases, positive women were dependent on their spouses due to lack of education and insufficient skills (UNIFEM 2000). On the other hand, another study conducted in Bangalore shows that majority of the women were aware of HIV/AIDS, but there were important misconceptions about the mode of transmission. Women acknowledged the potential risk for HIV associated with their spouse's drinking, as well as their extramarital sexual activities, but expressed an inability to negotiate safer sex behaviours, such as condom use, within the context of marriage. This was often expressed as fear of being physically abused for attempting such negotiations (Deepthi, et al 2010).

Hindu and Muslim differences on awareness of HIV/AIDS

In Sonitpur district of Assam, it has been found that only 49.6 per cent of Muslim women have heard about the disease, as compared to 71.4 per cent of Hindu women. With regard to their social background, 61.5 percent and 38.8 per cent respectively are rural Hindu and Muslim women, and 81.3 percent and 67.5 percent are urban Hindu and Muslim women. Knowledge about HIV/AIDS was found to have a direct correlation with the educational levels of both men and women in both communities, and also with levels of media exposure and family types (Rajput 2007).

Psychological problems of the victims

Psychological problems of the victims in Bangalore are rooted in increased financial difficulties; problems in child care and support; compromised help-seeking due to stigma; problems in sexual interactions and communication in their marital relationship; role strain in care-giving; gender discrimination and inadequate care; and increased concerns about parenting efficacy, post HIV infection. Escape and avoidance was the most preferred coping strategy adopted by them. Situating the illness in a socio-familial context is indicated, and implications for social work and mental health practice follow from the findings (E.B. Joseph and R.S. Bhatti 2004).

In Delhi, it has been found that the victims have developed negative thoughts about body image and appearance, negative feelings, positive feelings, self-esteem and personal beliefs. Education, income and clinical categories of patients were found to significantly affect the psychological domain of quality of life. There is a significant difference in the psychological domain in relation to the educational level of more than high school possibly suggests better coping attitudes towards the disease. Similarly, higher income of the individual may point towards higher coping capability. Lower psychological domain scores in advanced disease possibly are the reflection of increased morbidity and negative attitude toward life (Naveet Wig, et al 2006). The psycho-social impact of HIV on

quality of life in Tamil Naidu has shown problems in parenting their children after acquiring the infection, seeking help from their family members, relatives or close friends at the time of their illness, in their physical domain, in psychological domain and environmental domain (Subramanian, et al 2009).

From the above review of literature on HIV/AIDS, it is clear that studies especially by western scholars have been carried about the people living with HIV/AIDS. But there are very few studies by Indian scholars. But there are very few substantive studies on coping mechanisms and social support aspects of HIV/AIDS patients. In India perhaps there is no any detailed study so far on these issues. So the present study attempts to understand the coping strategies and social support in India among the women living with HIV/AIDS.

Keeping the above in view, the present study has formulated the following objectives.

OBJECTIVES OF THE STUDY

1. To understand the society's knowledge and response towards the HIV/AIDS persons.
2. To study stigmatisation, problems and challenges of women with HIV/AIDS.
3. To study coping strategies of women in response to their HIV status.
4. To study the kind of social support and care available to them.

RESEARCH METHODOLOGY

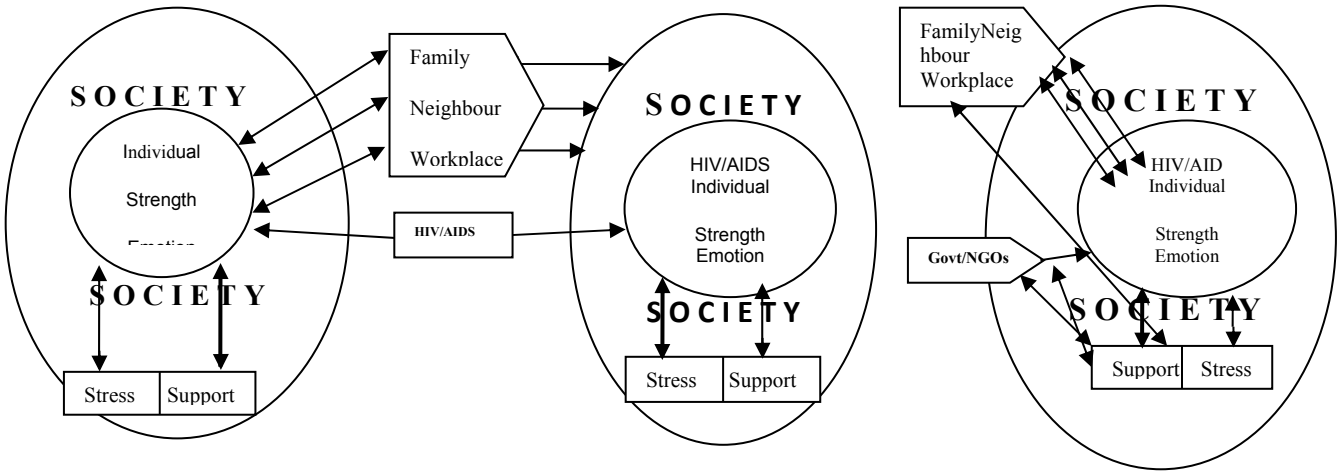
Conceptual framework

The present study uses structural-functional framework to understand the mechanisms of coping up with the HIV/AIDS status and social support to the HIV/AIDS person. Though most of the HIV/AIDS persons live incognito in their localities, they constitute a sub-group for the support agency, and for the wider society. The experiences of the individual rooted in social and cultural context

impinge upon the individual's, psychological and social behaviour. Therefore, the individuals, on one hand, develop adaptive mechanisms to the situation that they encounter or in which they are pushed. On the other hand, they also have to adapt to the society live that discriminates and stigmatises them. The society also adapts to the new situations developed within itself in order to maintain equilibrium status, while incorporating the resultant changes with little modifications in its structures and functions.

The theoretical framework of the study of stress and social support can be shown in Figure 1.1

Figure: 1.1, Individual – HIV/AIDS – Society – Support Agencies



Caplan (1974) describes support systems as health promoting forces at the person-to- person and social levels that enable people to master the challenge and strains of their lives. Caplan's research on how individuals respond to crises in their lives led him to the conclusion that response to a crisis by an individual is dependent on three factors: (1) the nature and vicissitudes of stress, (2) the current ego's strength of the individual, and (3) the quality of emotional support and task-oriented assistance provided by the individual's social network. Of these three factors, Caplan found that the role of social network to be most significant. In a pluralistic society, people seek help, solve problems, and meet needs in different ways. Family; friends; neighbours; mutual helpers; community gatekeepers; coworkers; and religious institutions; neighbourhood, fraternal, or social organisations; and mutual aid groups can all provide meaningful assistance in

times of need and are encompassed in the term "community support systems." Community support systems can serve preventive, treatment, and rehabilitative functions. On a preventive level, any one or multiple of above components of community support can contribute to an individual's sense of well-being and competent functioning. They can assist in reducing the negative consequences of stressful life events.

There are further developments in the field of coping with stress and trauma. Lazarus and his coworkers (Lazarus 1993, Lazarus and Folkman 1984 have viewed the process of coping as comprising of two distinct phases: (a) primary appraisal, which refers to a set of cognitions concerning the significance or impact of the stressful event for the individual, and (b) secondary appraisal, which refers to a set of cognitions regarding the availability of resources or options (e.g., coping skills) for dealing with the stressful situation. These and other (Billings and Moos 1981 and Pearlin and Schooler 1978) first generation coping theoreticians and researchers often viewed coping dimensions as comprising of two separate classes, namely, emotion-focused, efforts directed at affect regulation, and problem-focused strategies directed at minimizing or solving the impact of the stressful event. More recent efforts on conceptualizing coping include the addition of a third dimension, that is, avoidance-orientated coping (Parker and Endler 1992), as well as other two-dimensional configurations, e.g., approach vs. avoidance, engagement vs. disengagement coping (Krohne 1996, Parker and Endler 1996). Thus, coping should be considered as the more important analytical focus for predicting health outcomes to certain behaviour (Lazarus 1993).

The above theoretical points on coping with stress are shown in Table 1.1:

Table: 1.1, Coping Strategies of Stress

S.No	Researcher	Strategy	Mechanisms
1	Caplan	By individual	1.Experience of Stress 2.Ego's own strength 3.Own emotional support and social network
2	Lazarus, Folkman etc.	By individual	1.Primary appraisal- cognition of stress 2.Secondary appraisal- cognition of resource availability
3	Billing and Moss Parker and Endler	By Individual	1.Emotion focused strategies 2.Problem focused strategies 3.Approach vs avoidance 4.Engagment vs disengagement

The design for the study

The conventional ethnographic method used by anthropologists living in a locality which may be village or small community or locality of a town/city, employing participant observation technique has not been found suitable for the present study. It is so because the HIV/AIDS women are not confined to any particular geographical area. Moreover, these victims are not known to people as their identity is undisclosed in several cases. Therefore, it required a different kind of research design. In this design, three components have been included. First, an understanding of the knowledge and attitude of the general public about the HIV/AIDS through a survey. This has provided the scenario in which the victim have been living; they throw light on social conditions which point out stress, strain, control and stigma that shattered the lives of the victims. The second is a collection of detailed cases of the victims using in-depth interviews for more than one sitting at a place convenient for the respondent. These covered the aspects of family, marriage, sexual behaviour, and knowledge of HIV/AIDS stigma, discrimination, and social support available from the family, friends, coworkers and support agencies, socio economic problems, issues of children and so on. The third component is the information from the social support agencies with regard to the services that they have been providing to the victims (see annexure-3). The fieldwork for the study began in May 2007 with the attempt of finding out the

HIV/AIDS women victims through NGOs in the field and simultaneously planning for the survey of general public. This was followed by detailed discussions with the executives and functionaries of NGOs.

Survey

While frequently meeting the HIV/AIDS affected women, a short survey was organised for eliciting information from the general public about their awareness and beliefs about HIV/AIDS, the modes of transmission of the virus, and the knowledge about prevention and attitudes towards the HIV/AIDS victims. For this purpose,Likert's five point scale was developed. This scale had initially 75 items. In order to standardize the scale, three medical doctors of the University of Hyderabad and four experts of different organisations working for the welfare of the HIV/AIDS victims were contacted. Each of them separately identified relevant items and also, they offered extra items. On this basis, the items which are commonly identified as relevant items were kept and others were deleted. Thus in the final scale, only 50 items were included and they were distributed under five categories: basic awareness of HIV/AIDS, transmission, prevention and attitudes towards the AIDS victims. There were about 13 items about awareness; eight items on transmission. There were Nine items under prevention; finally 20 under the category of attitudes towards HIV/AIDS (Annexure-I).

Based on the information supplied by NGOs working for the HIV/AIDS victims, the following areas were identified where HIV/AIDS victims are living: Rasoolpoora a slum situated in Secunderabad, Uppaguda another slum located in old city in Hyderabad and a village called Gagilapur located in the outskirts of Hyderabad city. In each area, a sample of 25 males and 25 females above 16 years of age were selected randomly for the purpose of administering the schedule. Altogether 150 samples were drawn from these three areas.

Further, it was thought appropriate to draw some sample from the three main government hospitals: Gandhi hospital which is located in Secunderabad, Fever hospital in Hyderabad and Osmania Hospital in Hyderabad. In each of these

hospitals the patients and their attendants were randomly selected for the purpose of administering the schedule: Fifty samples from Gandhi hospital and 25 each from both the other two hospitals i.e., Fever hospital and Osmania hospital were collected.

The primary data thus collected are believed to have reflected the knowledge about AIDS with reference to the four aspects prevalent among the general population of Hyderabad. In order to analyze the data for each scale, weightage ranging from 1 to 5 are assigned, the highest weight has been assigned to correct answer/statement. In this regard, if the correct statements indicated with strongly agree, it has been assigned the weight of five. In this manner for the category of the items under awareness, if someone stated the item correctly, that person would get the score of 65. Similarly for others the scores would be 52, 39 and 26 and 13. For the purpose of analysis, the five point scale has been reduced to three levels of knowledge, i.e., adequate knowledge with range of score between 65-52, some knowledge with the score ranging between 51- 26 and poor knowledge with the score of 25 to 13. In this way, the analysis was carried out for other aspects of knowledge. For transmission knowledge, the score of adequate knowledge included 40-32, some knowledge 31-24, poor knowledge 23-8. For prevention, the scores of adequate knowledge include 45-36, 35-27 for some knowledge and the individual who scored less than 26 is having poor knowledge about the preventive methods of HIV/AIDS. Similarly for the attitudes category there are 20 items and for this, three levels of knowledge constructed as better attitude with range of score 100-80, good attitude score ranging between 79-60 and bad attitude with score of 59-20. Finally the data collected was analyzed using SPSS software version 12.

Case studies

As it was difficult to identify the HIV/AIDS women for the study because of the nature of the disease, the researcher approached a hospital where the treatment is provided to the HIV patients, but the authorities demanded Rs 5,000 to proceed

with the work in that hospital. The researcher then approached some of the NGOs who are working for the HIV people but there also the authorities asked to give them a questionnaire which would be filled by them and return to the researcher. So they didn't allow the respondents for the study. Finally,the researcher had taken help from the Andhra Pradesh State AIDS Control Society (APSACS). It supplied a list of NGO's which are in this field and which are also receiving help from APSACS and directed them to arrange respondents for the study.

The Following NGOs were approached to identify and introduce to HIV/AIDS women:

1) Shivananda Rehabilitation, Kukatpally. Secunderabad.
2) Telugu Network People Positive, Erragadda, Secunderabad.
3) Nrityanjali, West Mareredpally.
4) DARE, Gandhinagar, Hyderabad

The above NGOs were chosen for the study because all these are to some extent different in their nature and support provided to the victims. Shivnanda is an organisation which provides only medical treatment to the HIV/AIDS infected persons. The patient visits this organisation after being referred by another NGO or doctors from different hospitals in the city for treatment. In these particular organisations, the infected persons receive medical support and nutritional support only during the stay in the centre.

Secondly, the Nrityanjali and DARE organisations were also chosen as they are working on the issues like environment, illiteracy, drug de- addiction and health to the population below poverty line. These NGOs are providing medical and counseling services, health, nutrition, education and social economic support to the People Living with HIV/AIDS.

Finally the researcher had chosen the Telugu Network of HIV Positive people for the study. The people who are working in this organisation are themselves

infected with the HIV/AIDS and their main task is to provide quality of life for other PLHA in society through knowledge in health care, employment opportunities to the victims and legal supports to the victim who receives ill treatment from the community or in their office premises.

Thus the above mentioned organisations were chosen for the study. In keeping ethical guidelines in research on HIV/AIDS, the researcher did not approach the potential respondents directly, but the staff of the agencies introduced the idea, and explained the purpose of the research to the infected women and their families, who came to their organisations.

Thus, after being introduced to them the HIV/AIDS women were interviewed for the study while they were visiting the organisation for treatment or attending the monthly meetings organised by the organisation. The researcher also visited some of the houses of the victims along with the outreach workers. These outreach workers were the employees of the organisation who visited often to the victim's house for the follow up and counseling's. Hence, there was no problem to talk to these housewives. There were some other women who said directly that they do not want to give information in their houses as their identity had to be kept secret. Thus, for such cases, the interviews were held in the organisation premises itself. Being a woman, there was an advantage to interact with women who could share their personal information with the researcher

Altogether 40 case studies were collected to get the detailed experiences of the women as being HIV/AIDS women. Case studies helped in understanding their socio and economic status and also provided the information on different coping mechanisms developed by them to adapt themselves with the infection and the opportunistic diseases (see Anneure-3).

Ethical consideration

In line with the code of ethics, respondents were informed about the objectives of the study. It was made clear to them to provide information purely on voluntary

basis and they were also ensured that no harm would come to the participants during the research process. The researcher also maintained the rights and dignity of the participants. The researcher also clarified to the respondents that the information provided by them for research purpose would, therefore, be strictly anonymous and dealt with confidentiality.

Limitation of the study

The present study mainly used purposive sampling to collect the information related to the objectives. Secondly most of the interviews were conducted in the premises of the organisation particularly at the times of the meetings organised by the NGOs. The researcher interacted with the respondents only 3 to 4 times during the tenure of the study and the reason behind is that the respondents stopped visiting the NGOs. The researcher could not interact with all families of all the 40 respondents. Only the families of the 14 infected women respondents were contacted. The other infected respondents did not allow the researcher to interview their families because they are not getting any support from their families and also some have broken relationships with the families. A few respondents did not disclose their status to the family members because of the fear of stigmatisation and discrimination. Given these limitations, the study cannot claim to have covered every aspect, but it is certainly indicative of the situation.

At this stage it is also be necessary to clarify certain terminology used in this dissertation. The term “victims” has been consistently used throughout the dissertation. The HIV/AIDS affected persons are in fact patients taking medicines but this is also a fact some are not considering themselves as patients and for that reason they have also not taking medicines. In order to cover both the categories of people the term Victim” is used. Further, are using “victims” there is also a moral stand taken. All women except a very few are only victims as a researcher is convinced because they contracted the HIV through their husbands. Therefore,

a large majority of women are considered victims of innocence and widow victims of unfaithful behaviour of their husbands. The study has been based on the information provided by the patients as well as victims of HIV/AIDS.

Outlines of the thesis

Keeping in view the main purpose and objectives, the present study is divided into seven chapters. The first chapter is introductory in nature. It provides the general overview of the HIV situation in India, as well as other countries, statement of the problem and vulnerability of women to the HIV/AIDS. This chapter also deals with review of literature on HIV/AIDS, objectives of the study and finally the conceptual framework for the study and the general background of HIV/AIDS in Andhra Pradesh. It also covers the procedure of data collection and data analysis.

The Second chapter deals with the background of Hyderabad city. This chapter provides the socio demographic profile of Hyderabad and also the survey results of the general public in Hyderabad about their awareness, beliefs and prevention knowledge of the HIV/AIDS. It also covers the attitudes of the general public towards the HIV/AIDS victims

The Third chapter focuses on the socio-economic profile of the 40 infected women, their experiences of childhood, views about the marriage, sex and decision making powers. An attempt has been made here to provide the women's life prior to the HIV/AIDS diagnosis.

The Fourth chapter is about the stigmatisation, problem and challenges faced by the HIV/AIDS women in their day to day life. It deals with the reaction of the respondents towards the illness and the reaction of the other family members. Different issues and problems that women are facing due to HIV/AIDS in their

life are also discussed in this chapter.

The Fifth chapter is concerned with the coping strategies developed by the women in response to their HIV/AIDS status. It includes the information on different coping mechanisms followed by the families of the infected women.

The Sixth chapter deals with the nature of support that the different agencies are providing to the HIV/AIDS patients in Andhra Pradesh. This support include supply of rations, old clothes, jobs and training, etc., in addition to supply of medicines and giving counsel at various stages of the experience.

Finally, the Seventh chapter summarises finding of the study, drawing conclusion of the study in relation with the coping mechanisms of other stigmatised diseases and other earlier studies on HIV/AIDS.

CHAPTER-2
HYDERABAD AND THE BACKGROUND OF THE RESPONDENTS

The present study has been carried out in the twin cities of Hyderabad and Secunderabad in Andhra Pradesh, hereafter referred as Hyderabad only. The city is considered one of the high vulnerable metropolises with HIV prevalence rate of 1.75, according to APSACS report of 2008. The present chapter will provide a brief account on the demography and socio- cultural background of the people of Hyderabad city. This is necessary as the HIV women victims who responded for the study come from different parts of the city. It also gives the background profile of these respondents, besides the awareness about the HIV/AIDS of the general public.

Historical Background

Hyderabad is the capital of Andhra Pradesh, and it is the fifth biggest city in India with a population of more than 6 million. Males and females constitute 52 and 48 percent of the total population and the sex ratio stands at 947: 1000.

Hyderabad city, with a history of four centuries has experienced many political, economic and cultural upheavals. As it is known at present, did not exist 400 years ago. The areas have been largely covered by undulating rocky ground with jungle growth and some old villages located here and there around which were some green fields and archeds. It was one of the local governors of the Bahamani rulers, Sultan QuliQutub Shah, who established his headquarters at Golconda. With the breaking up of Bahamani rule, with his own independent kingdom of Golconda in 1518,Qutab Shah improved the Golconda fort.

As the fort became congested, on a representation of nobles, it is believed that the fifth ruler of Golconda, MohmadQuliQutab Shah, founded the city in AD1591 known as Bhagyanagar on the southern bank of river Musi, at the place where the present old city of Hyderabad is located. There existed a village called

Chinchalem now known as Shal-Ali-Banda or Shalibanda. The romantic story goes that the king chose this spot for the establishment of the new capital on account of his love for a local Hindu girl called Bhagayamati, after whom the city was named Bhagayanagar. In due course, the city acquired the name of Hyderabad as her name was changed to Hyder Begum after her marriage with the sultan.

Hyderabad could be claimed as a well planned city primarily intended for the nobles to live in. It was laid on a grid iron patterns, the Charminar (four Minarets) forming the center piece, for its five portals. Many Indian and foreign architects, artists and scholars were responsible for making the new city. Mir MohmmedMomin the spatial advisor and the prime minister of the Sultan Mohammed Quli played a vital role in laying out the beautiful city. But with the conquest of Deccan by the Mugal emperor Aurengzeb in 1687, Hyderabad lost its importance and the headquarter was shifted to Aurangabad. It was Nizam Ali Khan AsifJah II who restored the capital of Hyderabad in 1763 and since then Hyderabad has shown a steady growth.

The city developed into a multi - nucleated centre of the region under different political, economic and socio cultural conditions which added new ingredients into the modern urban complex. The people of Hyderabad are an epitome of the diverse cultures of India. We find the real confluence of northern and southern cultures of India in this city. The twin cities of Hyderabad and Secunderabad each have different historical backgrounds. Secunderabadwas formerly known as Lashkarto many old generation people in the city. Lashkar meaning 'cantonment' was renamed as Secunderabad after SikanderJahBahadurNizam III in 1806. Secunderabad was also called the Residency Bazaar at the end of the 19th century. It was also developed to house British soldiers. In the early decade of the 19th century, the East India Company had declared Secunderabad as an important military base and a trading centre. Now Secunderabad is the abode for Secunderabad Railway Station, Headquarters for South Central Railways, Parade Grounds and many churches. Kings Way, now known as Rashtrapathi Road (laid

out in 1936 to relieve congestion), James Street (only existing thoroughfare before 1936 AD, now called the Mahatma Gandhi Road are parts of this great locality.

Hyderabad, with a medieval origin, grew mostly under Muslim feudal rule, while Secunderabad developed mainly under British influence. The growth of the twin cities of Hyderabad and Secunderabad has thus been influenced by differing historical social and economic factors.

Geography of the Hyderabad

Hyderabad is situated on the Deccan Plateau; it has an average elevation of about 489 metres above sea level (1,607 ft). Most of the area has a rocky terrain and some areas are hilly. Crops are commonly grown in the surrounding paddy fields. Hyderabad has a tropical savanna climate with hot summers from late February to early June, the monsoon season from late June to early October, and a pleasant winter from late October to early February. In the evenings and mornings the climate is generally cooler because of the city's good elevation. Hyderabad gets about 32 inches (about 810 mm) of rain every year, almost all of it is concentrated in the monsoon months. The highest temperature ever recorded was 45.5 º C (113.9 °F) on 2 June 1966, while the lowest recorded temperature was 6.1º C (43 °F) on 8 January 1946.

Hyderabad has been the meeting place of many different cultures and traditions. The groups arriving over the centuries differed in ethnicity, religion, language and caste. A number of those differing cultural groups continued to cultivate their specific collective identities, partly until today.

Demography of Hyderabad

The city's population in 2001 was 3.6 million and it reached over 4.0 million by 2009- making it among the most populated cities in India, while the population of the metropolitan area was estimated above 6.3 million.Muslims constitute about 40 percent of the population, making Hyderabad's Muslim community the largest in Andhra Pradesh. Muslims have substantial presence across the city and are

predominant in and around the Old City. Christians constitute a small percent of the city's population.

Literacy

The percentage of literacy in the city as per 2001 Census is 66.21 percent out of which 75.02 percent is male and 54.4 percent is female. A decadal increment of 25.97 percent is recorded from 1991 to 2001. The details of literacy are shown in Table 2.1.

Table: 2.1, literacy percentage in Hyderabad

S.No	Category	Male	Female	Total
1	All	75	54.4	66.2
2	Scheduled Castes	57.4	34.48	45.9
3	Scheduled Tribes	50.7	27.68	39.2

Source: Census Report 2001

Table 2.1 shows clearly that the literacy levels of Scheduled Castes and Tribes are much lower than that of the general population; women in general are less literate than men, but in case of SCs and STs the figure is far below.

Migration in Hyderabad

As the city is connected to the rest of the country by National highways, NH-7, NH-8 and NH-208 and also remaining parts of the state, Hyderabad has been the meeting place of many different cultures and traditions. The groups arriving over the centuries differed in ethnicity, religion, language and caste. However, it experienced a tremendous growth after the formation of Andhra Pradesh in 1956. After independence Hyderabad thus emerged not only as an administrative centre, but it has developed into a major industrial centre also. Many private and public sector industrial units are located here. With this, the city attracted many people and it caused a large influx of immigrants. The numbers of suburban settlements or agglomeration units have been increasing as a consequence of tremendous population growth. It resulted in not only peripheral growth, but there has been an intensification of residence and commercial activities in the city core also.

Hyderabad, a city branded by the present boom of the information technology, is one of the fast growing hot spots in India, along with the current economic growth, there is an enormous increase in population: Between 1975 and 2000, the United Nations Population Division calculated an annual population growth of 3.84 percent in the agglomeration Hyderabad(United Nations 2001). Since the formation of the Greater Municipal Corporation Hyderabad (GHMC) in April2007, the area of Hyderabad is as large as 650 square kilometres with more than 6 Million inhabitants (GHMC 2007).The population increase is mainly due to immigrants: in 2001, 8.7 percent of the population of Hyderabad having moved in during the last decade (Census 2001).

The phenomenon of immigration is,however, not a new one in the city: Founded in 1591 by the fifth Sultan of the Muslim Qutb Shahi Dynasty as capital of the Deccan Empire, Hyderabad has been staging a continuous stream of immigrants during its 400 year history. Besides the then established Deccani population of Hindus and Muslims, the early prospering city attracted traders, such as Marwaris, Bawahirs and Gujaratis(Census 1989). They did not only bring different customs and skills, but also specifications in religion and further languages (besides the then established Urdu, language of the Muslim population,and Telugu, language of the Hindu population). The third major immigration wave was set off at the end of the 18th century, when the ruling Nizamsigned a contract, allowing the permanent residency of British armed forces. The British established amilitary base and founded the new town Secunderabad north of Hyderabad. The coexistence of theChristian (British) town and the predominantly Muslim old town formed a very special setting for thefurther development of Hyderabad. During the last century, the initially spatially separated cities grewinto each other and thus form the contemporary city of Hyderabad.Since the foundation of the State Andhra Pradesh in 1956 following Indian Independence andespecially since the blossom of the new economy in the early 1990s, the current stream of migrants, mainly formed by Hindus from Telangana and the coastal regions of Andhra Pradesh, is moving to the state’s capital.

Andhra Pradesh figures prominently among Indian states with high rates of rural labour migration. Other states with relatively high levels of migration include Bihar, Orissa, Madhya Pradesh, Jharkhand and Chhattisgarh. The National Sample Survey estimates show that AP has the highest incidence of short-term or seasonal migration in south India. Among those who migrate to urban areas, the reasons underlying their migration vary. One of the primary reasons identified and discussed in the literature on urbanization and migration is economic. Simply put, individuals often come to urban areas in search of jobs and the opportunity to earn more income than they can earn in rural areas.

Migrants to urban areas may come from other cities or the countryside.[2] Those migrating from rural areas often seek to increase or supplement their income from agricultural activities. Income from agriculture is notoriously unstable, and in an era of global warming, even more precarious. Agriculture is a seasonal activity, and thus rural residents may find themselves without adequate food or cash in the off-season.

[2]According to Center and Housing Rights and Evictions report (CHORE) 2008, women are also migrating in cities. It is said that women are sometimes said to be newer entrants in the global migration trend. Today, about half of international and national migrants globally are women. Women migrating to the cities are gender specific in most of the cases. While previous studies revealed that most women accompany or join family members – most often their husbands – in the city, but this trend appears to be changing. New trends show an increasing number of female migrants migrating on their own, as an increasing number of women are now the principal wage earners for themselves and their families. Women move to urban areas for a number of different reasons, ranging from seeking income opportunities to fleeing conflict, environmental degradation, or family problems (especially those resulting from discrimination), to coping with health related problems like HIV/AIDS and other factors that too often leave women isolated and financially destitute.

Migration is widely recognized as one of the main reasons for HIV transmission[3]. When it comes to migration, it is generally men who first migrate. This is followed with migration of spouse and other family members. Migration makes people redefine their identities as they move from one place to another in search of work. Increased migration to urban centres in many developing countries has resulted in changes in the traditional family structure. Temporary labour migration results in men having to leave behind families and their social groups and redefines their identities. They have to abstain from sex or look for other alternatives to satisfy their sexual needs. HIV/AIDS and migration do not have a linear, cause-effect link but they are linked laterally. HIV prevalence in migrant groups is then a manifestation of economic and social inequalities (UNDP 2004). Being a migrant is not a risk factor in itself, but the process of migration and integration into local communities can expose the migrant to the risk of acquiring infectious disease (Bailey 2008).

It is also observed from the present study that out of forty women thirteen women came to city mainly in search of employment along with their husbands after they got married in the villages. Among them eight women came to city after the death of their husbands as their families were not supported by their husband's families. They had decided to move to the city to stay with the relatives who are already living the Hyderabad city for some time. They felt that their lives would be better in city. After sometime they left their relatives in the city and moved to different locations of the city along with their children. While seven women were born and married in the Hyderabad city but in a few cases (3) their parents married them off to other districts and villages in the Andhra Pradesh. But after the death of their husbands, they again rejoined their natal homes in the city to start a new life. In case of other nine women, their husbands shifted to the city due to transfer of

[3] An understanding of the linkages between migration and HIV risk factors is critical to control further spread of AIDS. It is well known that vulnerability to HIV is often greatest when people find themselves living and working in conditions of poverty, powerlessness and social instability, conditions which apply to many migrants (UNAIDS 1998).

their jobs. Among them, three are from the other states (two from Rajasthan and one from Tamil Naidu) and the rest of the victims belong to the same state only.

It is clear that the majority of women migrated to the city because of the livelihoods and a few came because of the impact of the HIV/AIDS in their life. Women, whose husbands died of AIDS related disease in the village, came to the city fearing that they will infect other members of communities. Their in- laws have sent them away or thrown them out of home because of fear that they will infect more people in the family and spread the disease to the entire community. In some cases, the women along with infected children came to the city because they were denied a share in the husband/father's property on the grounds that they will die soon. Thus women mainly migrated to the Hyderabad city in hope of a better life in terms of opportunities, living conditions, access to services, and for their autonomy and dignity. They seem to be somehow happy here because they are now free from the discrimination that they have faced at their conjugal homes and villages. The relocation into the city also benefitted most of the women in terms of being able to access treatment and other services, which they were otherwise not getting in their origin villages.

Slums in the City

Slums are scattered across the city and surrounding municipalities, with high population densities and the number of people inhabiting them estimated to be around two million. It is estimated that more than half of these slums are on private land, and the rest on lands belonging to various public entities.

According to the latest information available from GHMC, there are 815 notified slums in the city and 203 non-notified slums. The non-notified slums are slums that were not notified by the MCH but their existence within the city limits is recognized. Thus, a total of 1018 slums exist in the MCH area. In addition, in the municipalities around the MCH constituting the Hyderabad Urban Agglomeration (HUA), there are around 500 slums.

The city provides a wide range of employment opportunities to people from

all walks of life from the highly skilled professionals to unskilled wage labourers. This abundance in the availability of jobs is attracting people from the rural areas to migrate to the city. People migrating from the rural areas do not have a place to live and end up living in houses in slums. Hence the number of people keeps on increasing and the space remains the same, resulting in over-crowding of any slum. This over-crowding makes the slum condition deteriorate. Already the area is deprived of all kinds of amenities, and this extra population makes the standard of living still lower and inimical for human survival. According to Ali and Toran (2003), the population which flows to Hyderabad is mostly from Telangana, because of its nearness. Migration from other parts of the state/country also occurs but when compared with that of Telangana it is negligible. Once the migrants occupy the slum, the real problem starts. Over-crowding itself is the significant one that leads to other problems like sanitation, food and nutrition, garbage, pollution, etc., it may be noted here that majority of the HIV women respondents for the study live in slums of Hyderabad.

Brief- Socio-economic Characteristics of slum population

Communities: Slum population in Hyderabad is heterogeneous in character - with Hindus, Muslims and Christians. Languages predominantly spoken in slums in Hyderabad and Secunderabad are Telugu and Urdu, followed by a smattering of Marathi and Kannada.

Environmental Conditions and Health Status

According to Hyderabad city development plan report (2001), the environmental conditions in slums are very poor and lack of basic civic amenities like dust proof roads, drainage, protected water supply, street lights and adequate number of community toilets. Earlier studies have recorded that the common diseases prevalent in slums in Hyderabad are gastro-enteritis, dysentery, liver enlargement, malnutrition, ringworm, scabies and other skin diseases. To overcome these hazards, health infrastructure was developed and 64 urban primary health

centreswere established under India Population Project VIII. Most of the slum communities and the poor access the services from these centres.

Life in the Slums

Over-crowding itself is the significant one that leads to other problems like sanitation, food and nutrition, garbage, pollution and so on. The slum dwellers have certain common habits of 1.chewing paan, 2. tobacco chewing. 3. smoking, 4. drinking liquor, 5. matka (gambling) and the like[4](Ali and Toran 2003).

HIV/AIDS and Risk population in Hyderabad

As labor migration is emerging as an important livelihood option for millions of people, and one of the contributing factors to the spread of HIV in Andhra Pradesh is migration of people from one place to another (APSACS 2006). According to National AIDS Control Policy III bridge population comprises of migrants, who, through close proximity to high risk groups, are at higher risk of contracting HIV. The other high-risk groups which are vulnerable to HIV include commercial sex workers (CSWs), Men having sex with men (MSM), and injecting drug users (IDUs). According to APSACS's report on HIV and AIDS

[4]It does not mean that these habits are not found in the rest of the community but most of the families living in the slum areas are addicted to these habits which not only affect their health, but also families and ultimately the environment. Drinking liquor and smoking are the most common habits of slum dwellers. Most of the habits are formed between ten to twenty years. This probably confirms the view that most of the habits are formed during the adolescent period. In most of the slums there is lacking of proper community and facilities. Washing of clothes and vessels is done in open places, unhygienic conditions because of non-availability of pure water, going for toilets in an open place, lack of cooking gas, etc., make the surroundings totally unsuitable for living. In contrast, the rural society in Andhra Pradesh mostly depends on natural environment, agriculture and allied activities. These societies have a low density of population, intimate group relationships and have oral traditions. Rural societies are rich in culture and tradition. However, from the development point of view, they are considered to be socially and economically less developed. In rural society, people mostly live in join families. Their social structures are based on kinship and family relationships, and the role of lineage is very important.

Situation and Response, several other factors are responsible for the consistent high-prevalence rate of HIV in the state (APSACS 2005).

In Hyderabad city, it is also found that there is a high prevalence of sex with non-regular partners and STI among both men and women and low condom use with non-regular partners. There is also a high level of trafficking of girls and women. According to the estimates of mapping of population groups that are vulnerable to HIV and AIDS in the state, the number of female sex workers is likely to be around as many as 24000. The infection is being spread along the vast network of national highways (4,472 kilometres) and other roads (1, 79,980 kilometres) and by the large number of migrant population like migrant labourers, truckers, construction workers and street children in all districts of the state. These groups are characterized as "bridges" of the general population because they are mobile and away from home for extended periods of time and may be more likely to visit sex workers, have multiple partners, or use IV drugs and share needles. In 2002, APSACS carried out a mapping exercise to locate these groups in order to effectively reach them with prevention, care, and treatment programmes. Additional studies of Comercial Sex Workers (CSW) and Men having Sex with Men (MSM) populations were conducted in 2003 and 2004 by the AVAHAN programme of the Bill and Melinda Gates Foundation (BMGF) and it was estimated that in Hyderabad the population of commercial sex worker present in Hyderabad is 7,496 and MSM is 5, 400. The population of truckers who also come under the high risk was estimated is 7500 whereas migrants laborer which constitute very high in Hyderabad the population is 41, 275. Street children who also come under the high risk population are established to be 1,008. There is other group which is also a high risk and come under the bridge group is the construction laborers and the population estimated for this group in Hyderabad is 10,379.

This HIV/AIDS high risk populations are found in large numbers in the slums of Hyderabad. Further it may be mentioned here that the majority of the women

victims that from the present study also living in the slums. In this historical, socio-economic scenario of Hyderabad the awareness about HIV/AIDS among the general population particularly those living in the slums of Hyderabad or with poor economic background has been carried out by conducting a survey as stated in the previous chapter. The findings of the survey are the following:

General awareness about HIV/AIDS

One of the objectives of the Andhra Pradesh State AIDS Control Society (APSACS) is to bring awareness among the general public about HIV/AIDS. This Society has involved NGOs, volunteer organisations, media channels including posters, hoards, bill boards, slogans and so on. For this purpose the NGOs are engaged in campaigns in bringing awareness among the general public through personal contacts. Therefore, it is believed that the efforts of various agencies would have brought some bearing upon the general public about the HIV/AIDS. The survey has aimed mainly to understand the awareness and knowledge scenario of HIV/AIDS among the public. In this background, the awareness levels of which the women victims of HIV/AIDS under the present study are examined. Without this background the picture that is likely to emerge from the study of women victims would be inaccurate. As such the findings may lead to wrong conclusions; for instance, one may say that the victims are too ignorant of things or it is only due to their foolishness that they became prey to the dreaded disease. Ideally the scenario of the survey and the picture of women victims under examination should match, and in fact it is almost the same.

The knowledge of HIV/AIDS of a doctor or physician, pathologist, virologist or scientist is quite different from that of a common person. For the latter it is basically to protect oneself from the dreadful disease and develop certain positive attitudes towards the victims. The present survey focuses on the awareness of common person only. The following section of analysis represents the socio - demographic profile of the respondents. It is followed by the findings and results of the survey.

SOCIO-DEMOGRAPHIC PROFILE OF THE RESPONDENTS

Age and Sex of the Respondents

A sample of 250 respondents equally distributed among both sexes has been drawn. The respondents are in the age between 16 and 45 and above. Since the girls are usually married around 16 years after their puberty, the women respondents who are 16 years and above are selected for the study. The sample clearly shows that majority of them are in the age group of 16 to 35. This is the group which is sexually active and also has the tendency of moving from place to place in search of work as individuals. This is true particularly in case of males. After 35 years generally the males are settled down in particular occupations. However, the sample has been drawn from the respondents who are beyond 36 years also, with a view that they had the marital experiences and also encountered the problem of HIV/AIDS either personally or through friends and relatives. Table: 2.2, shows the details of sex and age of the respondents of the survey.

Table: 2.2, Sex and Age of the Respondents

S.No	Age of the Respondents	Men	Women	Total
1	16-25	38(46.9%)	43(53.1%)	81(100%)
2	26-35	57(54.8%)	47(45.2%)	104(100%)
3	36-45	25(52.1%)	23(47.9%)	48(100%)
4	45 and above	5(29.4%)	12(70.6%)	17(100%)
5	Total	125(50.0%)	125(50.0%)	250(100%)

Marital Status

The respondents are selected randomly-not systematically-in such a way that both married and unmarried are covered. The marital status of the respondents shows that the married are more in number than the unmarried. While the married women outnumber the married and unmarried men, the unmarried men outnumber the unmarried women.

Table: 2.3, provides the details of marital status of the respondents. The married men and women are in the ratio 41.9 and 58.1. Whereas the unmarried men and

women are in the ratio of 64.4 and 35.6, while the total of men and women in respective sex are same. The total married and unmarried are in the ratio of 64 and 36.

Table: 2.3, Marital Status of the Respondents

S.No	Marital Status	Men	Women	Total
1	Married	67(41.9%)	93(58.1%)	160(100%)
2	Unmarried	58(64.4%)	32(35.6%)	90(100%)
3	Total	125(50.0%)	125(50.0%)	250(100%)

Education

Only 40 respondents (16 percent) out of 250 are illiterate. Among the literates, majority of them are graduates followed by those who studied up to tenth class and then intermediate. The representation is least from those who had only primary education. The Table: 2.4, clearly shows that the numbers of female respondents in the illiterate category are much higher than the male respondents. However, except among the graduates in the other categories the women respondents are more compared to the male respondents. This representation appears to be the general scenario of the Hyderabad city which has been described earlier. The girls are getting educated at least till intermediate. However, the poor families are not able to send their girl child to school either because of the girl child is required to attend the domestic works or the child does not show any interest in education. In any case, the parents think that the girls are to be trained to look after home and their family members primarily, and earning a livelihood is secondary for them.

Table: 2.4, Educational Status of the Respondents

S.No	Educational Status	Men	Women	Total
1	Illiterate	14(35.0%)	26(65.0%)	40(100%)
2	Primary Education	13(38.2%)	21(61.8%)	34(100%)
3	Secondary Education	25(43.9%)	32(56.1%)	57(100%)
4	Intermediate	22(46.8%)	25(53.2%)	47(100%)
5	Graduation and Above	51(70.8%)	21(29.2%)	72(100%)
6	Total	125(100.0%)	125(100.0%)	250(100%)

Age and Education

The sample drawn shows that the older generation, i.e., 36-45 and above is less educated than the younger generation[5]. The percentage of illiterates is less in the age groups of 16-25 and 26-35. Further, the percentage of respondents in the younger generation who have studied intermediate and above is higher compared to the older generation. Therefore, the younger generation is better educated than the older generation (See Table: 2.5).

Table: 2.5, Age and Education of Respondents

S.No	Educational Status	Age				Total
		16-25	26-35	36-45	45 & above	
1	Illiterate	14(17.3)	13(12.5%)	11(22.9%)	2(11.8%)	40(100%)
2	Primary Education	6(7.4%)	14(13.5%)	8(16.7%)	6(35.3%)	34(100%)
3	Secondary Education	13(16.0)	29(27.9%)	10(20.8%)	5(29.4%)	57(100%)
4	Intermediate	16(19.8)	19(18.3%)	10(20.8%)	2(11.8%)	47(100%)
5	Graduation and Above	32(44.5)	29(40.2%)	9(12.6%)	2(2.7%)	72(100%)
6	Total	81(100.0%)	104(100.0%)	48(100.0%)	17(100.0%)	250(100%)

[5]Even if the age groups 36-45 and 45 above are considered, the illiterates would constitute 20 percent, which is higher compared to the other age groups.

Age and Marital Status

The percentage of unmarried respondents are more in younger generation, in the age group of 16 to 25. Similarly, the married respondents are more in the older generation.

Table: 2.6,Age and Marital status of Respondents

S.No	Age of the Respondents	Marital Status		Total
		Married	Unmarried	
1	16-25	27(33.3%)	54(66.7%)	81(100%)
2	26-35	69(66.3%)	35(33.7%)	104(100%)
3	36-45	47(97.9%)	1 (2.1%)	48(100%)
4	45 above	17(100.0%)	0(0.0%)	17(100%)
5	Total	160(64.0%)	90 (36.0%)	250(100%)

Occupation

The 250 respondents are pursuing a variety of occupations. However, the sample represents 29 respondents who are students. Among them the number of men is almost double to that of women. Among the women 65 of them are housewives. In rest of the cases they are either employed in government institutions or private institutions or self-employed. There are only six unemployed among the respondents. Those who are in service are more than the self-employed. In all the cases there are more men than women who are employed. This suggests the general scenario of men that form the main bread earners. Table: 2.7, provides the details of occupation of the respondents.

Table: 2.7,Occupation of the Respondents

S.No	Occupation	Men	Women	Total
1	Students	19(65.5%)	10 (34.5%)	29(100%)
2	Housewives	0(0.0%)	65(100.0%)	65(100%)
3	Private employees	42(66.6%)	21(33.4%)	63(100%)
4	Government employees	20(87.0%)	3(13.0%)	23(100%)
5	Self employed	39 (60.0%)	26(40.0%)	65(100%)
6	Unemployment	5(83.3%)	1(16.7%)	6(100%)
7	Total	125(50.0%)	125(50.0%)	250(100%)

MISCONCEPTIONS AND MYTHS

There are many myths and misconceptions around the HIV/AIDS that people carry with them. Therefore, it is necessary to find out the levels of correct information that the respondents hold with reference to HIV/AIDS. It is observed that an overwhelming number of respondents (83.2 percent) are having adequate knowledge about the infection. Only 16.8 percent of the respondents are having some knowledge about the infection with few misconceptions (see Table: 2.8). No doubt that most of the people (83.2 percent) have adequate knowledge about HIV/AIDS, it is well observed that among the 40 detailed cases of the present study the PLHA are discriminated by their dear and near once. The fact is that as the general public got information through media and other channels about the true knowledge of transmission of infection still they are not sure about the information that they received. They are not willing to share the things which are used by the HIV/AIDS person. It is considered safe for self and the other non-infected family members not to touch the things or belongings of the HIV/AIDS victims.

Age wise overall knowledge

The younger generations in the age group of 16 to 25 are having adequate knowledge (90.1 percent) about the infection followed by the age group of 26 to 35 years (82.7 percent). A few people who are above 36 years do have adequate knowledge (Table: 2.8). So here the age is a significant factor as the younger generations are more aware of the basic issues about the infection compared to the people who are above 36 years. The reason for the accurate information among the young generation could be due to their exposure to media (See Table 2.4). Not only that, this is the age group which is targeted for providing the correct overall knowledge about the HIV/AIDS by the government and non government agencies.

Table: 2.8, Age Wise Awareness about Overall HIV/AIDS

S.No	Age of the Respondents	Some Knowledge	Adequate Knowledge	Total
1	16-25	8(9.9 %)	73(90.1 %)	80(100 %)
2	26-35	18(17.3 %)	87(82.7 %)	104(100 %)
3	36-45	13(27.1 %)	35(72.9 %)	48(100%)
4	Above 45	3(17.6 %)	14(82.4 %)	17(100 %)
5	Total	209(16.8%)	41(83.2%)	250(100%)

Overall Knowledge of HIV/AIDS and Sex

Among the men and women, the men have adequate knowledge (87.2 percent) about the overall knowledge, compared to the women (79.2 percent) (see Table: 2.9). This may be due to the fact that they are better educated and are also more exposed to the information, compared to the women.

Table: 2.9, Knowledge of HIV/AIDS by Sex

S.No	Sex of the Respondents	Some Knowledge	Adequate Knowledge	Total
1	Male	16(12.8 %)	109(87.2%)	125(100%)
2	Female	26(20.8 %)	99(79.2%)	125(100%)
3	Total	42(16.8%)	208(83.2%)	250(100%)

Overall Knowledge of HIV/AIDS and Marital Status

As far as relationship between the knowledge and marital status is concerned, more than 90 percent of the unmarried have adequate knowledge about the disease compared to married respondents (Table: 2.10). The higher knowledge level among the unmarried may be due to the fact that this group is young and educated and is also more targeted by the many government and non agencies for providing correct information about the infection through media.

Table: 2.10, Overall Knowledge of HIV/AIDS by Marital Status

S.No	Marital status	Some Knowledge	Adequate Knowledge	Total
1	Married	34(21.3%)	126(78.7%)	160(100%)
2	Unmarried	8(8.9%)	82(91.1%)	90(100%)
3	Total	42(16.8%)	208(83.2%)	250(100%)

Overall Knowledge of HIV/AIDS and Education

In terms of educational status of respondents, the data suggest that it is likely that the adequate knowledge increases along with educational status. As it is seen in the Table: 2.11, majority of those who have done graduation has better knowledge (94.4 percent) compared to semi-literates (73.5 percent) and the illiterates (62.5 percent). So increase in the knowledge about HIV/AIDS corresponds to the increased educational level of respondents. Thus, education is an important tool for providing awareness among the people.

Table: 2.11,Overall Knowledge of HIV/AIDs by Education

S.No	Occupation of the Respondents	Some Knowledge	Adequate Knowledge	Total
1	Illiterate	15(37.5%)	25(62.5%)	40(100%)
2	Primary Education	9(26.5%)	25(73.5%)	34(100%)
3	Secondary Education	7(12.3%)	50(87.7)	57(100%)
4	Intermediate	7(14.9 %)	40(85.1%)	47(100%)
5	Graduation above	4 (5.5%)	68(94.4%)	72(100%)
6	Total	42(16.8%)	208(83.2%)	250(100%)

Overall Knowledge of HIV/AIDS and Occupation

The sample drawn shows that among occupational groups the government employees have an adequate knowledge (95.7 percent), followed by the students (89.7 percent) and the private employees (85.5 percent). Only 80 percent of respondents who are self-employed have adequate knowledge. Among housewives, only 76.9 percent are having adequate knowledge about the basic awareness about HIV/AIDS (see Table: 2.12).

Table: 2.11, Overall knowledge of HIV/AIDS by occupation

S.No	Occupation of the Respondents	Some Knowledge	Adequate Knowledge	Total
1	Students	3(10.3%)	26(89.7%)	29(100%)
2	Housewives	15(23.1%)	50(76.9%)	65(100%)
3	Private employees	9(14.5%)	53(85.5%)	62(100%)
4	Govt employees	1(4.3%)	22(95.7%)	23(100%)
5	Self employed	13(20.0%)	52(80.0%)	6(100%)
6	Unemployed	1(16.7%)	5(83.3%)	6(100%)
7	Total	42 (16.8%)	208 (83.2%)	250(100%)

KNOWLEDGE ABOUT TRANSMISSION

There are various modes of transmission which are propagated by the health practitioners through the media. Some of them are: a pregnant mother passing HIV to her child, usage of un-sterilized needles, unsafe sexual practices, injecting needles, etc.

In order to know about the knowledge of modes of transmission among the people, eight questions related to the awareness about the HIV/AIDS and their transmissions are included in the schedule. The responses of the people as analyzed are as follows. Majority of the people are only having some knowledge about the correct modes of HIV/AIDS transmission.

It is very important that only 28 percent of the respondents have adequate knowledge about transmission of HIV/AIDS. A majority of them have some knowledge about it (66.4 percent) (see Table: 2.13). The correct knowledge about the transmission is essential for preventing the spread of the HIV. But the reality shows a very grim situation.

Knowledge about transmission of HIV/AIDS and Age

Looking at the relation between knowledge about the transmission and age group of the people, it is found that only 28.8 percent respondents have adequate

knowledge about the HIV/AIDS in the age group of 25 to 35 years, followed by the age group of 16-25 (27.2 percent). Not even 30 percent of the respondents have adequate knowledge about the transmission of HIV/AIDS. How people are having some knowledge is only due to the efforts of media such as television, radio, posters, magazines or through the doctors, NGOs personnel and other peer. Table: 2.13, clearly shows that those of 35 years are having less knowledge about the correct modes of transmission. The lack of knowledge may be due to the fact that these are engaged in work for most of the time and as such do not have time to watch television and listen to the radio, and so on. It suggests that more efforts have to be made to reach this group. In fact, the knowledge levels of the youth in the age group of 15 to 35 years has to be improved greatly as these are sexually more active and if they have negative attitude toward safe sex, then they will be more prone to get HIV/AIDS themselves and, in turn, pass on to their wives and sex partners. An equally important aspect is to divert and broaden the target group for providing the correct information about HIV/AIDS transmission. The knowledge levels of those above 45 years are higher than others, but it cannot be considered correct as the sample size is very small.

Table: 2.13, Knowledge of transmission of HIV/AIDS by Age

S.No	Age of the Respondents	Poor Knowledge	Some Knowledge	Adequate Knowledge	Total
1	16-25	8(9.9 %)	51(63.0%)	22(27.2 %)	81(100 %)
2	26-35	4(3.8 %)	70(67.3 %)	30(28.8 %)	105(100%)
3	36-45	3(6.3 %)	34(70.8 %)	11(22.9 %)	48(100%)
4	Above 45	0(0.0%)	10(58.8 %)	7(41.2 %)	17(100%)
5	Total	15(6.0%)	165(66.4%)	70 (28.0%)	250(100%)

Knowledge of Transmission of HIV/AIDS and Sex

About the knowledge of transmission among the men, Table: 2.14, reveals that 60.8 percent of women respondents out of 125 are having some knowledge. Only 31.2 percent of women (39) are having adequate knowledge about the modes of transmission. As far as men are concerned, similar to women 71.2 percent of them are having some awareness about the transmission ways. But, this percentage is

higher than that of the women respondents (68.8 percent). It is only 24.8 percent of male respondents who have adequate knowledge, and in this respect women are better as 31.2 percent of them are having adequate knowledge. However, this shows that, both groups are lacking proper knowledge about transmission. Therefore, efforts have to be made vigorously in this regard to enhance the knowledge levels of the public. It may be noticed here that compared to men women are having more knowledge about the HIV issues and one of the reasons for this is that as most of these women are housewives they are as exposed to media like T.V and radio which keep disseminating information about the HIV/AIDS. Thus, due to regular listening/viewing such information, unlike men who spend time mostly outside the house, they have better knowledge about the issue.

Table: 2.14, Knowledge of Transmission of HIV/AIDS by Sex

S.No	Sex	Poor Knowledge	Some Knowledge	Adequate Knowledge	Total
1	Male	5(4.0 %)	89(71.2%)	31(24.8%)	125(100%)
2	Female	10(8.0%)	76(60.8%)	39(31.2%)	125(100%)
3	Total	15(6.0%)	165(66.0%)	70(28.0%)	250(100%)

Knowledge About Transmission of HIV/AIDS and Marital Status

The relation between the marital status of the respondents and knowledge about transmission shows that among those who are married, majority (68.8 percent) has some knowledge and only 25.6 percent of those have adequate knowledge. Similarly, among the unmarried respondents only (61.1 percent) of them has some knowledge and here also only 32.2 percent are having adequate knowledge about the modes of transmission. If we compare the knowledge levels among the married and the unmarried, it is clearly seen that more unmarried respondents have adequate knowledgeable (Table: 2.15). Such difference among the two groups could be due to the fact the young group is more exposed to media and also better educated.

Table: 2.15, Knowledge about HIV/AIDS by marital status

S.No	Marital status	Poor Knowledge	Some Knowledge	Adequate Knowledge	Total
1	Married	9(5.6%)	110(68.8%)	41(25.6%)	160(100%)
2	Unmarried	6(6.7 %)	55(61.1%)	29(32.2%)	90(100%)
4	Total	15(6.0)%	165(66.0%)	70(28.0%)	250(100%)

Knowledge about Transmission of HIV/AIDS and Education

As regards to education and modes of transmission, as discussed earlier, here also it may be observed from Table: 2.16 increase of education level increases the knowledge. Adequate knowledge is found among the respondents who have completed their graduation (36.2 percent), followed by the people who have done their senior intermediate (31.9 percent). Only 21.1 percent and 26.5 percent of people who have completed secondary education and primary education respectively have the adequate knowledge about the disease. Only 20 percent among illiterates have a fair knowledge about the modes of transmission. Thus, education is playing an important role in acquiring accurate information with regard to HIV/AIDS.

Table: 2.16, Knowledge about Transmission by Education

S.No	Education of the Respondents	Poor Knowledge	Some Knowledge	Adequate Knowledge	Total
1	Illiterate	5(12.5%)	27(67.5. %)	8(20.0 %)	40(100%)
2	Primary education	0(0.0%)	25(73.5 %)	9(26.5 %)	34(100%)
3	Secondary education	4(7.0%)	41(71.9%)	12(21.1 %)	57(100%)
4	Intermediate	2(4.3 %)	30(63.8 %)	15(31.9 %)	47(100%)
5	Graduation and above	4(5.5 %)	42(58.3 %)	26(36.2%)	72(100%)
6	Total	15(6.0%)	165(66.0%)	70(28.0%)	250(100%)

Knowledge about Transmission of HIV/AIDS by Occupation

As far as the occupation of respondents and its relation with the awareness is concerned, the students more than half have some knowledge (55.2 percent),whereas only 41.4 percent of them have adequate knowledge about the correct modes of transmission. It may be due to the fact that as the HIV/AIDS topics is incorporated or discussed now days in schools and colleges.Hence, education has given correct knowledge on modes of transmission. Among the housewives, the majority has some knowledge (60.0 percent) and 27.7 percent are having adequate knowledge, and the reason has been mentioned above. Similarly, in the case of private employees, the majority (56.5 percent) has some knowledge compared to the people who have adequate knowledge (38.7 percent). However, it may be noted that more private employees have better knowledge than the government employees (Table: 2.17). It is has to be ascertained why more number of private employees have adequate knowledge.

Table: 2.17, Knowledge about Transmission of HIV/AIDS by Occupation

S.No	Occupation of the Respondents	Poor Knowledge	Some Knowledge	Adequate Knowledge	Total
1	Students	1(3.4%)	16(55.2%)	12(41.4%)	29(100%)
2	Housewives	8(12.3%)	39(60.0%)	1 (27.7%)	65(100%)
3	Private employees	3(4.8%)	35(56.5%)	24(38.7%)	62(100%)
4	Government employees	0(0.0%)	19(82.6%)	4(17.4%)	23(100%)
5	Self employed	3(4.6%)	51(78.5%)	1(16.9%)	65(100%)
6	Unemployed	0(0.0%)	5 (83.3%)	19(16.7 %)	6(100%)
7	Total	15(6.0%)	165(66.0%)	70(28.0%)	250(100%)

PREVENTIVE KNOWLEDGE

Awareness about preventive measures of the HIV/AIDS by age

Though the proverb says prevention is better than cure, it is truer in case of HIV/AIDS as till date there is no curative medicine available for the HIV/AIDS infection.Prevention is therefore, considered the most important element in

handling the HIV/AIDS problem. A few sets of questions on preventive knowledge were asked; having commitment with only one faithful partner, using disposable needles, protected sex, avoiding homosexuality, and screening of blood before transfusion and so on.

Adequate or Very good preventive knowledge of HIV/AIDs is found only among 51.2 percent of the respondents. About 46.0 percent is having some knowledge. Those having adequate preventive knowledge are in the age groups of 16 - 25 (55.5 percent) and 26 - 35 (56.7 percent) respectively.

Table: 2.18, Preventive Knowledge about the HIV/AIDS by age

S.No	Age of the Respondents	Poor Knowledge	Some Knowledge	Adequate Knowledge	Total
1	16-25	6(7.5 %)	30(37.0%)	45(55.5 %)	81(100%)
2	26-35	1(1.0 %)	44(42.3 %)	59 56.7 %)	104(100%)
3	36-45	0(0.0 %)	31(64.5 %)	17(35.4 %)	48(100%)
4	Above 45	0(0.0%)	10(58.8 %)	7(41.2 %)	17(100%)
5	Total	7(2.8%)	115(46.0%)	128(51.2%)	250(100%)

Awareness about Prevention of HIV/AIDS and Sex

Regarding the knowledge about preventing methods of HIV/AIDS among men and women it has been found that the majority of male respondents (53.6 percent) have adequate knowledge of preventing and 44.0 percent of men have some knowledge about the HIV/AIDS prevention. In case of women respondents only 48.8 percent is having adequate knowledge and almost equal number, that is, 48.0 percent is having some knowledge about the preventing mechanisms. Thus the comparison of knowledge about preventive mechanisms shows that more men have accurate knowledge compared to the women respondents (Table: 2.19). The reason could be that the men are more mobile and also targeted by the intervention programme for providing knowledge of the HIV/AIDS. Though women have some knowledge of modes and transmission and prevention of disease, but still they are unable to protect themselves from the HIV and the reasons could be many. One is vulnerability of women to HIV/AIDS. It is directly

linked to gender inequality and a low economic and social status. Though the women have good knowledge about using condoms to protect themselves from HIV/AIDS, they are unable to go for safe sex practices with partner or husbands because of violence or threat of violence from their intimate partner.[6]

Table: 2.19, Awareness Knowledge of Prevention by Sex

S.No	Sex	Poor Knowledge	Some Knowledge	Accurate Knowledge	Total
1	Male	3 (2.4%)	55 (44.0%)	67(53.6%)	125 (100%)
2	Female	4 (3.2%)	60 (48.0%)	61(48.8%)	125 (100%)
3	Total	7 (2.8%)	115 (46.0%)	128 (51.2%	250 (100%)

Awareness about Prevention of HIV/AIDS and Marital Status

Knowledge about preventive measures of HIV/AIDS and its relation with the marital status of the respondents reveals that unmarried respondents (53.3 percent) are having the accurate knowledge, whereas 50.0 percent of married respondents have the similar knowledge (Table: 2.15). So here, also one can say that the unmarried people are having a very good knowledge of preventive measures of HIV/AIDS than the married respondents. The reasons may be the same; unmarried are young and educated, who are more exposed to different media channels.

[66]Research studies in Africa and the United States reveal a strong and consistent association between the history of domestic violence and HIV infection. Domestic violence in India is pervasive and very common. National surveys report that 40 percent of married women in India experience physical abuse. Fifteen percent of these women have also reported being coerced into sex by their husbands. Research has shown that women have very little power to negotiate sexual relationships and that the taboo on even discussing about sex put them at high risk of contracting STIs and HIV. Social norms around masculinity endorse the use of force during sex. A recently conducted research study showed that 60 percent of youth and middle class men use of force against wife/partner for sexual satisfaction (cited from AIDS Alliance 2008).

Table: 2.20, Preventive Knowledge of HIV/AIDS by Marital Status

S.No	Marital status	Poor Knowledge	Some Knowledge	Adequate Knowledge	Total
1	Married	3 (1.9%)	77 (48.1%)	80(50.0%)	155(100%)
2	Unmarried	4 (4.4 %)	38 (42.2%)	48 (53.3%)	9(100%)
3	Widows	0 (0.0%)	2 (40.0%)	3 (60.0 %)	5(100%)
4	Total	7 (2.8%)	115(46.0%)	128(51.2%)	250(100%)

Awareness of Prevention of HIV/AIDS by Education

Table: 2.21 shows that 51.2 percent of respondents are having the adequate knowledge about the prevention of HIV/AIDS followed by the 46.0 percent of the respondents having some knowledge about the preventing measures. As stated earlier, here also it can be found that as the education increases knowledge about prevention of HIV/AIDs also increases. The respondents of higher education seem to have accurate knowledge about the prevention HIV/AIDS than the other educational groups. Interestingly enough, the illiterate and those who studied up to intermediate have the same knowledge levels which cannot explained. Similarly, there is very little difference between the people of primary and secondary education. More or less similar trend can be noted among the ones who have some knowledge. Thus, it can be stated that people have fair awareness about the modes to prevent the disease, but even then it is necessary to educate people more effectively about preventive measures of HIV/AIDS transmission, as only half of them have adequate knowledge.

Table: 2.21, Knowledge of Prevention of HIV/AIDS by Education

S.No	Education of the Respondents	Poor Knowledge	Some Knowledge	Adequate Knowledge	Total
1	Illiterate	1(2.5%)	24(60.0 %)	15(37.5 %)	40(100%)
2	Primary education	0(0.0%)	15(44.1 %)	19(55.9 %)	34(100%)
3	Secondary education	1(1.8%)	26(45.6%)	30(52.6 %)	57(100%)
4	Intermediate	4(8.5 %)	25(53.2 %)	18(38.3 %)	47(100%)
5	Graduation and above	1(1.4 %)	25(34.8 %)	46(63.8%)	72(100%)
6	Total	7(2.8%)	115(46.0%)	128(51.2%)	250(100%)

Awareness of Prevention and Occupation

The respondents who have adequate knowledge about the prevention of HIV/AIDS are more among the private (56.5 percent) and government employees (56.5 percent). This knowledge among the housewives is 52.3 percent, followed by the respondents who are students (44.8 percent). So people who are having comprehensive good knowledge about the issue are mainly from the people who are in service either private or government. Among those who have some knowledge, half of the respondents are in the category of self-employed.

Table: 2.22, Awareness of Prevention Knowledge by Occupation

S.No	Occupation of the Respondents	Poor Knowledge	Some Knowledge	Adequate Knowledge	Total
1	Students	2(6.9%)	14(48.3%)	13(44.8%)	29(100%)
2	Housewives	1(1.5%)	30(46.2%)	34(52.3%)	65(100%)
3	Private employees	1(1.6%)	26(41.9%)	35(56.5%)	62(100%)
4	Govt employees	0(0.0%)	10(43.5%)	13(56.5%)	23(100%)
5	Self employed	2(3.1%)	33(50.8%)	30(46.2%)	65(100%)
6	Unemployment	1(16.7%)	2(33.3%)	3(50.0%)	6(100%)
7	Total	7(2.8%)	115 (46.0%)	128(51.2%)	250(100%)

ATTITUDES

Attitudes towards HIV/AIDS victims

Right attitude towards HIV/AIDS victim is very important for extending support to the victim to cope with the disease. In general, the non-infected persons fear that if they mingle with HIV/AIDS people, they will also get the disease. Actually this is not the case. In this regard, some 20 questions were included in the schedule to know the attitudes of respondents towards the HIV patients such as, whether they will take care of the HIV affected person in their family or will accept patients from other family members, would allow them to visit their houses, whether handle those utensils used by the victim, take food cooked by

them, will allow AIDS person to live in their locality, will allow their children to play with the infected children or with infected persons, will feel that the HIV person should be allowed to continue jobs and so on.

Table: 2.23 shows a majority (83.6 percent) of the respondents are showing good attitudes than showing better attitudes (16.4 percent) towards the HIV/AIDS people. For an appropriate behaviour in fact the response should have been otherwise. Only about 16.4 percent of the respondents in all the age groups are having better or appropriate attitude towards the HIV/AIDS victims. This situation should be improved.

Table: 2.23, Attitudes towards HIV/AIDS People by Age

S.No	Age of the respondents	Good attitude	Better attitude	Total
1	16-25	67(82.7 %)	14(17.3%)	81(100%)
2	26-35	86(82.7%)	18(17.3%)	104(100%)
3	36-45	40(83.3%)	8(16.7%)	48(100%)
4	Above 45	16(94.1%)	1(5.9%)	17(100%)
5	Total	209(83.6%)	41(16.4%)	250(100%)

Attitudes towards HIV/AIDs victims by Sex

The survey reveals that men are better in having the right attitude towards the victims compared to women[7] (Table: 2.24). More women are showing negative attitudes towards the victims. This may be due to the fact that most of the women are housewives who will be in contact with victim in the house, while men spend time outside. Women have to handle clothes, utensils, etc., touched by the victims. Thus, they are very concerned about their children and family members. They would like to avoid the people who are suffering from the disease due to the fear that they may get the disease if they mingle with the HIV/AIDS people. Thus, there is need to educate the women to develop positive attitudes towards the HIV/AIDS people.

[7]The good attitude is not adequate enough to overcome the problems of stigmatisation of the victims and ill treatment meted to the victims.

Table: 2.24, Attitudes towards HIV/AIDS victims by Sex

S.No	Sex	Good attitude	Better attitude	Total
1	Male	100(80.0%)	25(20.0%)	125(50%)
2	Female	109(87.2%	16(12.8 %)	125(50%)
3	Total	209(83.6%)	41(16.4%)	250(100%)

Attitudes towards HIV/AIDS by Marital Status

In case of attitudes according to marital status, the survey shows that only 15.5 percent of the married respondents have better or appropriate attitude, while the majority have good attitude (85.0 percent). On the other hand among unmarried respondents, it is slightly better as 18.9 percent shows proper attitude and 81.1 percent have good attitude towards the people with HIV/AIDS. If we consider overall positive attitude, less than 20 percent of the respondents have better attitude which is required to give proper treatment to the victim (Table: 2.25). Here also the majority of them, i.e., 81.1 percent of people are having good attitude and only 18.9 percent are showing positive attitudes towards the people with HIV/AIDS. If we see overall positive attitudes by marital status, here also like the earlier discussion it is among the unmarried people than the married respondents, the knowledge is better.

Table: 2.25, Attitudes towards HIV/AIDS by Marital Status

S.No	Marital status	Good attitude	Better attitude	Total
1	Married	136(85.0%)	24(15.5 %)	160(100%)
2	Unmarried	73(81.1 %)	17(18.9 %)	90(100%)
4	Total	209(83.6%)	41(16.4%)	250(100%)

Attitudes towards HIV/AIDS by Education

Attitudes with reference to education of the respondents show that, as indicated in Table: 2.26, of all people with primary education (23.5 percent), have better attitude and it is followed by the people who are graduates (18.1 percent). This

shows that education does not correspond with the appropriate attitude towards the HIV/AIDS victims.

Table: 2.26, Attitudes towards HIV/AIDS by Education

S.No	Education status	Good attitude	Better attitude	Total
1	Illiterate	34(85.0%)	6(15.0%)	40(100%)
2	Primary education	26(76.5%)	8 23.5%)	34(100%)
3	Secondary education	48(84.2%)	9(15.8%)	57(100%)
4	Intermediate	42(89.4%)	5(10.6%)	47(100%)
5	Graduation above	59(81.9%)	13(18.1%)	72 100%)
6	Total	209(83.6%)	41(16.4%)	250(100%)

Attitudes towards HIV/AIDS victims and Occupation

Of all the occupational groups, students have better attitudes (24.1 percent) towards the HIV/AIDS patients. Private employees follow the students as 22.6 percent of these have better attitude. It is interesting to note that the government employees are the least to have better attitudes.

Table: 2.27, Attitudes towards HIV/AIDS by Occupation

S.No	Occupation of the respondents	Good attitude	Better attitude	Total
1	Students	22(75.9%)	7(24.1%)	29(100%)
2	Housewives	56(86.2%)	9(13.8%)	62(100%)
3	Private employees	48(77.4%)	14(22.6%)	62(100%)
4	Govt employees	21(91.3%)	2(8.7%)	23(100%)
5	Self employed	56(86.2%)	9(13.8%)	65(100%)
6	Unemployed	6(100.0%)	0(0.0%)	6(100%)
7	Total	209(83.6%)	41(16.4%)	250(100%)

To sum up the findings of the survey, 83.2 percent of the respondents have adequate knowledge of the HIV/AIDS. In this regard, the respondents in the age group of 16- 25 male unmarried, graduates and government employees constitute

the general public who has adequate knowledge about HIV/AIDS. With regard to the knowledge about transmission of the disease, only 28 percent of the respondents have adequate knowledge. These are mostly in the age group of 26 - 35, women, unmarried of both the sexes having education background up to graduates. These are mostly students and private employees. It has been found that only half of the respondents 51.2 percent have adequate knowledge about the prevention of HIV/AIDS. These are in the age group of 16-35, unmarried males and who are mostly graduates. The knowledge about prevention is almost equal among all occupational groups. As regards the attitudes towards HIV/AIDS patients, it has been found that less than 20 percent of the respondents, (16.4 percent) have proper or adequate attitude. They are unmarried males in the age groups of 16-35 who are educated from primary education to graduation and are employed in private establishments and those who are students.

CHAPTER-3

HIV/AIDS WOMEN VICTIMS AND THEIR BACKGROUND

The percentage of literacy in Hyderabad as per 2001 census as mentioned in the introduction among Scheduled Castes is 45.9 against 66.2 of the overall percentage of literacy. Since the most among 40 cases under consideration for the intensive study come from the Scheduled Castes and backward class category, we can expect low literacy rates. Further, it has been noted about the socio-economic characteristics of slum dwellers in Hyderabad are habituated to common habits of chewing pan and tobacco, smoking, drinking alcoholic and gambling. As most of the respondents of the intensive study live in slums, we can expect such behavior among the men. It has been further noted that migration of people has been contributing for high prevalence of HIV/AIDS in the cities and it is true even in case of Hyderabad according to APSACS. In this chapter, a brief analysis about the background of these victims followed by presentation of six cases of HIV/AIDS with a view that the reader is able to grasp the issue at hand. Apart from these, attempt has been made to understand their childhood experiences, views about marriage and sex, married life prior to infection, decision making powers, in what circumstances that they went to diagnosis, reactions towards husbands after the diagnosis of HIV/AIDS and opinion of the women about their husbands' previous lives.

Background of the HIV/AIDS Women Victims

Majority of the respondents are presently living in the slums and villages which are adjacent to the twin cities of Hyderabad and Secunderabad. The reason for living in these areas is that they get rented house quite cheap compared to other areas in the city. In general as population keeps increasing in slums while the space remains the same, these are over-crowded. This over-crowding deteriorates the conditions of slums, and it deprives the dwellers off all kinds of amenities and this extra population makes the standard of living poor.

The women are mostly in the age group of 25- 30 (21), 31 to 35 (13), 35 to 40 (5) above 41 (1) respectively. Thus majority (31) of them are young within the age group of 25-35.

Marriage Practices and HIV

The marriage patterns show that the respondents have followed typical norms observed in south India, in which marriage is arranged by the parents. After the puberty the parents sought the help of their brothers and sisters for a suitable groom for the daughter. First among their own close relatives is either father's sister's son (FZS) or mother's brother's son (MBS) (cross-cousin of the girl). The other category could be father's father's brother's daughter's son (FFBDS) or mother's father's brothers' sons son (MFBSS) of the girl. If no suitable person is found among the closer relatives, the help of friends is sought to identify someone among the non- relatives. Some do marry mother's younger brother also. But there is clear avoidance of parallel cousins, i.e., father's brother's son and mother's sister's son. However, the Muslims marry both parallel and cross cousins.

Living patterns

The present study represents five categories of women with reference to the living patterns. In the first category, there are married women (16) living with their husbands. The second category is of widows (16) living independently. The women who are unmarried but liveas sex workers (3) constitute the third category. The women who are separated from her husbands either before or after infection are three who from the fourth category. Among married, there are two women who have remarried after their husbands died. This is the fifth category of living pattern of the victims. Majority of them had arranged marriages. The proposal was brought by their relatives to their parents. Majority of them have been married to the close relatives.

Education Background

The educational background of the women and their family members including husband as observed from the literacy rate of slum dwellings can only be low. It is found that the most of the respondents are illiterate (18). Out of 40 respondents, only eight respondents have primary education whereas eleven respondents have completed their secondary school. Two women have said that they completed senior secondary school, whereas only one is a graduate. The reasons behind the low education among women are that, the women were not allowed to study or pursue studies, parents felt that it would be waste spending money on education because the main role of woman is to get married and look after her husband and children. Second, there are also some parents who want to send their daughter to schools but because of their poor economic conditions they could not afford to send them to school. In some cases, they are not interested in education.

Occupation of the Respondents

Out of 40 respondents, 14 respondents are housewives and they are dependent on the incomes of their husbands and family members. Eight respondents are working as outreach workers for non - government organisations which are working for the HIV/ AIDS patients. Five women are working as domestic servants, whereas three women are working in the enterprises run by the Prajwala[8]. Other three women are working as *aayas* in hospitals, schools and supermarkets. The rest (8) are engaged in organising petty business for their livelihoods. They got monetary help from NGOs for this purpose and the business includes selling dresses, tailoring work, etc. Thus majority are dependents. Thus, they are directly or indirectly supported by the NGOs, otherwise they would have been housewives only.

[8]Prajwala is an organisation which is working for the rehabilitation of sex workers. These two women earlier were sex workers but later they were rehabilated by the same organisation.

So far as occupations of their husbands are concerned, majority of them are engaged in unskilled, semi-skilled manual labourof different kinds - painting, petty business of selling cloth, running road side tea shops, truck driving, car driver, auto driving, rickshaw pulling and so on. Only in three cases, husbands are working in government offices: One had worked in railways, one is working as a cook now on contract basis in military and finally one is working as a watchman.

Size of the Family

The size of the family of the respondents is minimum two and maximum of eleven, whether the women are living with their natal families with married brother or other, or with conjugal families with in-laws and other siblings of husbands who are married or unmarried or finally staying alone with small children. Majority (23) of the women are in a family of seven members. Five of the respondents are living in a family where the members are above seven but less than nine; three of them are in a family of five members. In a eight cases the family size is four. Only one respondent is staying with her nine year old daughter. Thus, the victims are generally living in a fairly big family.

Economic Life

The economic life of the respondents and their families has been badly affected due to the presence of a member with HIV/AIDS. Majority of the women are poor as their husbands are engaged in low paid jobs and their monthly average incomes are less than Rs 1,500 per month. For 19 respondents, the income is less than Rs 1,500 only and in case of seventeen women, it is above Rs 3,000. In case of two families, the income is less than Rs5,000 and two only have reported an income more than Rs 5,000. In majority cases, the income is dwindling as their husbands are currently not able to work regularly as they frequently fall sick. A few women have stated that their husbands have stopped working altogether due to illness. The husbands of the married women do not allow their wives to work outside home, as they have to look after home and their little children. Some of them are borrowing money from their parents or relatives for time being and they do not

know how they will repay. Some widows are living in their parent's home and have been totally dependent on them since the death of their husbands. As mentioned earlier, these women are working outside and contributing income something or other to the family, as they do not want to be burden on the parental families.

Religion and Caste

The majority of the women are Hindus (32) followed by Muslims (6), and only two are Christians. Among the Hindus four of them have changed their faith to Christianity due to their association with Christians. In terms of caste of the respondents majority of them (22) are from the Madiga and Mala castes which are Scheduled Castes. They are followed by Backward Class castes: MunnuruKapu (7), Padmashali (3) and Vadla (3). There is one woman belonging to Komati and one Naidu which are upper castes in Andhra Pradesh. There are three women from other states: one woman from VedulakaluAlavar caste of Tamilnaidu, of two from Rajasthan one belongs to Meghawal and the other Barber caste.

The caste structure of the respondents reveals that, it is generally women from lower caste who become victims of the HIV/AIDS. Besides this, the low economic status makes them vulnerable to HIV/AIDS due to migration for livelihood.

Number of years since living with HIV/AIDS and the Stages

Two victims are with HIV for seven years. However,more than half of the victims (22) have been living with the HIV/AIDS for the last three to five years. About 12 of them are with the infection for the last two years. Whereas only four victims are found with HIV within last one year. Out of 40 women, 13 women are taking the medicine of ARV which is meant for the HIV. Eight women are taking treatment for T.B infection also and one is taking treatment for cancer too. The others are with the HIV/AIDS infection but are not under any treatment. The WHO classifies the HIV infection into four clinical stages based on the diseases

and the performance scale. The 1st stage is asymptomatic and the individual would be able to carry on the normal activities. This is followed by the clinical stage II. It is symptomatic with symptoms like weight loss of less than 10 percent, recurring upper respiratory tract infection and other illness, but the persons are able to carry on normal activities. They get tired often these days. In the IIIrd stage, along with symptoms like weight loss, the individual may suffer from problems like unexplained chronic diarrhoea for more than a month, unexplained prolonged fever, oral candidacies (fungal infection) pulmonary tuberculosis or several bacterial infections and the individual would be bedridden for less than 50 percent of the days during last one month. Thus, they experience physical challenge because of the HIV infection.

In the IV stage , along with wasting syndrome, the person may suffer from any of the disease like toxoplasmosis, pneumonia, herpes, Kaposi's sarcoma (skin cancer), cryptosporidiosis (brain infection) and others and or/bedridden for more than 50 percent of the days during last one month.

In this category, there are three women who are currently in the final stage of the infection. The forty case studies include women in all the four stages and most of them are in the first three stages.

In the following pages, six typical cases are presented for an understanding of the situation of the victims[9].

Case Study -1

Name- Saroja; Age -29; Education - 10th; Occupation - Housewife; Marital Status- Married; Husband's Occupation - Car driver; Husband's education- 10th; Number of children - 2; number of years of experience with HIV- 6; Total size of family - 5; Monthly income - Rs 4000; Religion –-Hindu; Caste - Naidu.

[9]The actual names are changed in order to protect the confidentiality of the women.

In my family, it's only me who is infected with HIV/AIDS. My husband and my daughters are safe and are not infected with the HIV virus. I belong to Bikala village, which is located in Warangal district of Andhra Pradesh. Our family consists of three sisters and two brothers. In childhood, I was staying with my grandparents, along with uncle's family (mother brother). My father and my uncle worked on the agriculture lands. I was very small at that time and I still remember that my father was not interested to work on the field, so he left to Mumbai in search of job. After a while, he got a job as building contractor in Mumbai. He was earning around five thousand rupees monthly. My father took my mother with him to the Mumbai and allowed us to stay back in the village as we all were studying there. At that time, I was studying fifth class. He said it was very difficult to get admission in schools in Mumbai, so he left us with the uncle and my grandparents. During first few years, my parents used to come frequently to see us, but later on, the frequency of their visits decreased.

When I got my first menses, we had a big function in the village. My uncle's son also started liking me. Since my parents used to like him, they decided on my marriage with him only. I also started loving him. When I was in my tenth class and when I failed in one subject, my parents thought of my marriage. At that time my uncle's son was studying degree. He was interested in doing teacher training but my uncle was not having enough money. When my parents asked them about our marriage, then my uncle said that his son's wish is to become a teacher. So he asked my father three lakh rupees for his education. But, my father was not ready for this as he has already given his house and land to them which we had in the village. They were not listening to anything and were adamant that the demand be met.

My father was shocked to see all this; actually my father was not able to spend so much on me considering my other two younger sisters who are also to be married. My father and mother requested my uncle to consider the proposal without or less

than three lakh rupees as dowry but they didn't listen to them. So, finally my marriage with uncle's son was cancelled, which was shocking for me. As I failed in my exam and my marriage got cancelled, my father took me along with him to the Mumbai. In Mumbai, my mother and me used to sell woolen items knitted by us. From this we used to earn three to four thousand rupees per month. Our products were in good demand during the festival of Ganesh Chaturthi.

During my stay in Mumbai, I observed that my father was not keen on my mother and was not coming home frequently. He used to visit our home once in a month or sometimes once in three months and so on. He used to say that he had to work in faraway places and therefore could not visit home regularly. But later on, I came to know from my mother that, he come home rarely to meet us because he was seeing some other women. This news was shocking to me and I was very angry. One day my father visited us. After seeing him I was so angry and shouted at him, I told him, why he has given us birth if he cannot take care. I told him that from childhood onwards we didn't see any love from you. All children got love from uncle and grandparents only and he is only responsible for cancellation of the marriage and all sorts of other things. But I found no impact on him and no change in his behaviour.

One day I got typhoid and fainted. At that time, my father was at home and he took me to a hospital. Doctor told my father that in my body there is no blood and so I required blood. My father's blood matched with my group and so his blood was transfused.

One day, when my father came to visit us he was suffering from fever, cough and vomiting. My mother took a great care of him. I was angry and told her why she is caring so much for him when he did not care for her. But my mother scolded me and told me that because of his blood only I am living and I am saying all the bad words against him. She also told me that it's written in women's destiny to look after their husbands. They are gods for them. I was getting irritated by

hearing all such words. Even after taking good care and there was no improvement in his health. We took him to another hospital where doctors told me that my father had T.B. and he was admitted in the hospital. Almost after fifteen days, he got cured from the illness.

One day my father brought one proposal for me. I didn't want to get married but because of my mother's wish and for my family I agreed to marry. I also said yes, because the man to whom I was going to be married shown interest on me and convinced me that he will love me and will never trouble me. So finally I was married to him. So my father sent me and my mother back to the village for the marriage. But my father himself didn't turn up for my marriage. Then finally it was my uncle who had taken care of my marriage. After my marriage, my brother and sisters went back to Mumbai along with my mother. Still we don't understand why my father did not come to my marriage. From that day onwards we don't know the whereabouts of our father. He destroyed my mother's life totally. Currently, my mother is suffering from cancer.

After marriage, I came to Hyderabad as my husband was working here. My first seven months of married life passed very happily. I always thought that I was so lucky to get a nice person in my life. My in- laws were also very nice to me. When I was pregnant with my first child, I was taken to hospital where doctor asked me for some routine checkups. That was the day when HIV test was done. Doctor told about this only to my husband. My husband was also not very clear about the HIV like we all. But he didn't tell me and asked my brother to take me along with him to Mumbai as in our place first delivery should take place in parents home only. So my brother took me to Mumbai. After two months I was blessed with a daughter.

My husband came to Mumbai but didn't take me along with him and told me that he is busy so he cannot take care of me and baby and asked me to spend some more days there only. Three months passed but he did not turn up to take me, so

my brother and mother took me to Hyderabad. From that day onwards I started observing changes in his behavior. He started shouting at me for very-very small things. He even started beating me. I was unable to understand why he was behaving like this. Being frustrated of his behaviour I informed my mother and I asked her to take me home again. When both my mother and brother came to Hyderabad and asked my husband why he was behaving like that with me. After a lot of pressing, he disclosed that I have HIV and told in front of everybody and said I got this because I had relationships with many men. I was shocked to hear this and cried a lot thinking about why he was telling in such things in such a manner. Without knowing anything about the disease, my mother-in-law also started shouting and cursing me and asked my mothers to take me back. But my husband did not want to leave me because he loved still me and told my mother-in-law that he cannot leave me and can't do anything if it is written in his fate. I confided to him that I never ever involved in any kind of relationship. My husband trusted me and started looking after me nicely. But my mother-in-law's behaviour has totally changed from that day onwards. She has been always shouting at me for small things and said many times that I slept with many men and that is the reason I got this disease. She kept my plates, cups and glasses separate from their utensils. I some time feel why I had been to the Mumbai. Mumbai has spoiled my life.

One day, I met the doctor with my reports when I went to Mumbai who was very close to my father with my reports. I asked him about the HIV/AIDS without showing the reports. Then he had counseled me and told about the disease in detail. Then he suddenly asked me why I am interested in such a topic. Then he said, whether I had knowledge about my father who had this infection. When I heard this I got a big shock and I cried a lot in front of the doctor, and then I told him that I am also having this infection and because of this my in - laws and my husband's behaviour got changed. I just shown my reports and told him that I was diagnosed with HIV/AIDS. Then doctor uncle asked me whether I had any relationship with any men other then my husband or else I had blood transfusion

in the past. Then I said I didn't have any relationship with men, but I told that before two years of my marriage father had given his blood to me. Then the doctor told me that I got this infection because of my father or may be because of my husband. He also asked me whether my husband and daughter also have this or not. I didn't know about their status whether they had or not because they have not gone for such testing. I cried a lot and then uncle told me not to worry and asked me to eat healthy food. I left home and asked my husband about this and asked him to go for test. He said what is the use of going for HIV test as if I don't have this disease. But after insisting a lot he came with me to the hospital and did checkups. I was very happy to know that my husband and daughter are safe and are non-reactive. After one year of all this I again became pregnant and delivered a second child. My second child is safe and free from the disease.

One day, I was sitting outside my house and chatting with my neighbours, at that time.Some people from some organisation came to our colony. They were providing awareness to the people in our area about the HIV/AIDS. They told us, if anyone wants to know more about the disease and related information, they could contact the organisation. After hearing all the information I felt good inside and thought or visiting the organisation once. As decided, one day, I went to that office, which is called Nrityanjali. I told them about my status of having virus for the last three years. The people of the organisation asked me to visit daily to the organisation and also asked me to work for their organisation as a volunteer of their awareness program if I am interested. I discussed the job at home with my husband and mother-in-law and what organisation people told me initially did not like me visiting the organisation and doing a job there, but after insisting a lot my husband was ready to send me. Afterwards I got the required training from the Nrityanjali, from the training I came to know more about the disease and developed the guts to understand how woman can fight for their rights.

I worked for the organisation for almost three years. In the beginning, they paid fifteen hundred rupees but later they increased my salary to three thousand rupees.

Now I do not work for them as that project is over and so there is no other work for me now. Here my husband is also not showing any interest in me. He wants to go for second marriage. I know that he has seen one girl in my village who is a widow with no children and is of young age, I also know her. My husband is insisting that I should agree for his second marriage and bring her to this home as a second wife. He asked me to convince that girl to marry him. He says that since I would be dying soon, she can take care of the children and of him. I was feeling so bad and shocked with whatever he was saying to me. He was telling me that after marrying to that girl also, he will love me but I don't trust him anymore. I do not believe after my death my daughters will be able to receive love from them. Currently both are studying 1st and LKG. I told him I don't have any problem if he remarries, but I want security for my daughters. I asked him to write his property on my daughter's name, then only I will help him to get that girl married to him. But he is taking a lot of time to decide about this but his ill treatment is continued.

Now I am getting frustrated with their behaviour. And I stopped taking my medicine. See now how my health is deteoriating because of their ill treatment. Now a days I am also not getting any support from my family. My family members also started asking to me to look after on myself. They are not asking about my health. Even I am not getting any help from my uncle's family, who has given me lots of love and support since my childhood. Actually I don't want to give them more trouble.

If I stay more with my in-laws house, with all their torture I would be dying soon. But I don't want to die soon. I want to do something for my daughters. I am not going to listen to them anymore and will not bother about whatever they do me. Even if they say something also it is better for me to hear from one ear and leave it out from the other. Now I will not stop taking medicine. I know that they want me to die only. But I won't let it happen. I won't stop taking medicine; I want to fight for my daughter's rights. Now a day, my mother-in-law started creating new

drama. She doesn't allow me to cook food for the guests who are coming from her family. She says that if I cook food for them, they will also get the disease. She told me this when my sister-in-law who is pregnant came to stay with us for some days. At that time she told me that if I cook food then there might be chances that she and her unborn baby will also get infected if they eat food cooked by me. She is not even allowing me to share comb or use toilets and tells me that she heard from somebody that using common comb and toilets can also transmit the diseases. Not only is this she even beating me because I am not agreeing for his son's second marriage. My husband says good word to me that he will take care but I know that he wants me to become a maid for his new wife if he marries again. But I won't let it happen.

I also want to share one thing that when I was working for Nrityanjali, I also met a one man who has lost both hands and is also suffering from HIV virus. In his family no one is there to look after him. I see him as a nice man; he also loves and cares for me. So, I have decided that I will continue to be firm in my decision of not allowing him to marry until he transfers the property on my daughters' name. After he does so I will give him divorce and will marry the other man whom I love. I have discussed this with some of the Nrityanjali staff but so far they are not supporting me. But I hope when the right time comes and when I will leave my husband forever at that time only they will surely help me.

Case Study- 2

Name -Vashanavi; Age - 37; Education - 12th; Occupation - Nurse; Marital Status - Widow; Late husband's Occupation - Clerk; Late husband's education - 12th; Number of children - Nil, number of years of experience with HIV - 2; Total size of family - 5; Monthly income - Rs 4000; Religion - Hindu; Caste - MunnuruKapu.

I was working as a nurse in Sapna hospital in Dilshuknagar, Hyderabad. I stopped working when I was diagnosed with HIV infection.

In my natal family, besides my parents we are two sisters and three brothers. I am the eldest most in my family. Now my sisters and one of the brothers got married, and the other two brothers are working in a real estate business. My late father was a mechanic who worked at NagarjunaSagar. My mother is a housewife. From the beginning, we are living in Dilshuk Nagar. We all studied in Hyderabad itself. When I was two year old, I met with an accident and got hurt on my right foot which made me handicapped. When I was studying tenth class, I was married to Srinivas who was working as a clerk in a chit fund organisation near Ameerpet. He left me after my marriage as their parents didn't inform him that I was light limping. My husband was a rowdy too. He had no good friends and had lots of enemies. I got this information through his sisters who quite liked me. I was my in -laws house almost for six months in the hope that one day he will come and accept me. But unfortunately he never turned up and had no relation with me. Their family was quite nice to me. But after six months of marriage, he was murdered by one of his enemies. After marriage I asked my parents to take me back. My parents were not agreeing as they felt that after marriage the parents have no role in the life of married daughters. After the death of my husband, I requested my father who is very close to me to take me back home and asked him to help me in my further studies. I joined intermediate and passed 12^{th} class. As I was kind hearted woman so I thought to become a nurse. So I did nursing from a private college. After finishing the course, I got a job in Sapna hospital. I was working in that hospital almost for the last 14 years. But when I was found to be HIV positive, I left the job.

For the last one and half years, I was suffering from fever frequently. I was not able to understand what was happening to me as I never ever got fever for a long time. I always took treatment from my hospital only. One day, I discussed this with my doctor. He asked me for some checkups. But I didn't like to go checkups in my hospital where I was working as I had fear that if I found with some disease then everybody in the hospital will come to know about it. One day I was very

sick, so with my brother and sister- in –laws help I went to Osmania hospital. There they conducted HIV test. And next day doctor asked us to collect the report. As my brother was busy in his work, I myself went after one week to collect my report from there. But the doctor refused to give me the report and asked for someone from my home. I asked the doctor why he was telling so and also told him that I was a nurse and if there is something bad about my health he should tell me. He said that he won't give information to me. I told my brother and told him that that doctor refused to give the report to me and he had asked me to send someone to collect the report. Next day my sister- in -law and brother went to the hospital to collect the report. The doctor informed them about the HIV infection. My brother and sister –in- law didn't know much about this. When we reached home, my sister -in -law told in front of other siblings and also in front of my mother that I had relationships with many people and told I was not doing job but for having relationship with men I was leaving home everyday. I was totally shocked and did not understand why she was saying like this. In a fit of anger, I slapped her. When my mother was shouting at her and asked why she was saying such things. My brother then told that I got HIV. I was shocked when I listened this. I was not able to understand how to react.

After crying a lot, I convinced them that I didn't have any such relation with any men in my life. I told them that who would like to have relationship with the disabled woman. I told them as a nurse I conducted several deliveries and that might be one of the reasons from where I got infection. But they didn't agree and asked my mother to keep my room and everything separate, because they feared they might also get the disease if they shared common things. After this incident, I worked almost for more six months and then stopped working, because I was not able to take care of the patients. I got tired after doing little things. And also I have a fear that if I conduct further deliveries for any pregnant woman, they may get the infection. So I stopped working after that. My family members started shouting at me like anything why I am not going to job and all. And they used to keep asking who will take care of my food and other things. I told them I have

enough money to look after myself. I have my provident fund savings. I used to give monthly thousand rupees to my own family for providing me food and shelter.

As I am staying at home, I observed that my family members were not talking to me much as they used to talk earlier. When I go out and sit with neighbours, they asked me not to talk with others because, if they come to know about me their image will go down and no one will visit home or speak to them. So I am spending my time in my room only. Whenever my married sister comes to visit us she never comes to me and asks about my health. I do not want to live as no one is there in my life to look after me. They are not even providing me food on time and when I asked them they give as if am a beggar. Because of me, my sister - in - law and my brother have shifted to some other house. Now a days they are not living with us. My other two young brothers are also not taking care of me and never speak to me. Some time when my mother sits in front of me my brothers shout at her and say why she is looking after the dead body and say always I will die soon. They were shouting at my mother when she says about my health and all. Whenever I want take medicine or during the time of visiting the hospital no one accompanies me. I go myself and spend my own money. I just spend my time praying to the god, Sai Baba, I am a great believer in him. He is one who has given life for us. I don't blame him for this condition, but I pray to him to give me strength and courage to live life alone.

When I got severe fever and was admitted in Osmania hospital, the staff members and aayas were not taking care of any patients there. They were keeping cloth or put hands on their mouth when they talk to us or come cleaning our beds. There I met a social worker who has informed me about the Shivnanda hospital. She said that I will get good food and medical treatment in this organisation and so by taking treatment I will recover soon. Then with the help of mother and a brother I was shifted Shivnanda Care and Support center.

But I am very much frustrated with the ill treatments by my own family. My brother wants to take care of me but because of my sister- in -law he is not able to do anything. My mother is also helpless. I am looking for a shelter where I get care. I am ready to give thousand rupees also per month but I do not know any such shelter.

Case study -3

Name -Ramya; Age - 30; Marital status - Widow; Education - 5th; Occupation - Nil; Late husband's Occupation - labourer, Late husband's education- illiterate, Number of years Experience with HIV/AIDS - 4; No of children - 2; Religion - Hindu/ Christianity; Caste - Mala.

Elder daughter is studying 1st class in a private school. In my family, I have one sister and one brother. We had a wine a shop at Sri Nagar colony near Secunderabad Railway station. I studied up to 4th class. One day when I was cooking food suddenly the cooking stove got exploded and I suffered burn injuries on my neck. It took almost six months to recover from this. After this incident, I told my parents that I do not want to go to school. They told me the importance of education, and asked me to go to school and become an independent person in future. But I did not listen to them. Finally, my parents agreed with my decision.

After I stopped going to school, I was spending most of my time by sitting in the wine shop with my father. Whenever my father had some work outside, it was me only looking after the wine shop. During this time only I met my husband. He used to come regularly to our shop and shown interest on me. I also started liking him. Finally we fell in love and thought to marry. But my parents didn't agree to this because he was working as a labourer and secondly he drinks a lot. But I did not listen to them. I thought that I don't have a good face, and I am also suffering with some burns, if I reject him, then no other person will come in my life. I also thought he loves me even though I have a burnt face. With the help of his friends

we got married in a temple. Then he took me to his parent's house in Guntur but they did not accept me. Then we came back to Hyderabad and started living in a rented house in Sri Nagar colony near Secunderabad station. Our life was going happily and I got pregnant and gave birth to a girl child.

My husband was happy but after drinking sometimes, he used to beat me. He earned two thousand to three thousand rupees in a month and spent most of his money on drinking only. I told him many times not to spend all the money on drinks only but he never listened to me. Since his income was low, I thought of working with him. However, he did not allow me to work by saying that I should look after the daughter as she is very small. He promised me that he will not spend money on his drinking. But all those were just false promises. I again became pregnant with my second child. When I was six months pregnant, my husband was not feeling well. He was frequently getting fever. I was not able to understand what was happening to him. I took him to many doctors but all in vain. He was alright for sometime but again he was getting fever. After seeing his condition, first I thought that, since I married against my family's wish, they must have done some magic on him. So I had shown him to some experts but was no use. By that time, I gave birth to my second daughter. When my daughter was six months old, my husband's health got worse. So I finally took him to Gandhi hospital. The doctor advised him to undergo a test. In that test only it was found that he was a HIV positive. I was not aware of what he was suffering from. Doctors explained to me everything but, I did not understand. Because of his ill health he could not go for work. So I did not have money to spend on his health. Nothing was there to feed him and to us. Then I went to my parents' house for help but they didn't help me and told me that whatever condition you have today, it's only because of you. During that time workers of Nrityangaliorganisation used to come to our colony for sensitizing people for HIV/AIDS for help. They gave three hundred rupees which was a great relief for me at that time. But there was no improvement in my husband's health. After fifteen days, my husband died. No one came from my family on his death. I don't know how my

neighbours came to know that he had HIV. All were scared to take his dead body for final rites. When no one came, the people of the Nrityanjaliorganisation came forward and conducted his funeral. I am very thankful to that organisation that they helped me on such a time, when no was there to help me.

After my husband's death, my house owner asked me to vacate the room in which we were living. I told them that I do not have any home or any support from my family, where I can go. After listening to this, the owner told me that if my family itself is not helping me then how you can expect others to help you. I felt upset and lonely with no ray of hope and help; I thought of committing suicide with my children. But I didnt want to kill my little daughters. They have not seen this world completely so far, but many times I also thought of what they will do even after seeing this world. Nothing is there to see but still I did not get guts to kill them on my own.

Since, my owner threw me out from home for few days, I spent on road only with my two little kids. Even my family did not feel anything towards me and showed no sympathy on me. One day when Usha madam from Nrityanjali came to our locality and saw me with luggage on road she asked me why I am there and I told her my entire story. After hearing my story and knowing that no one is there to support me, she took me to the Annamma old age home, which provided me shelter. She also told me to go for HIV test as my husband died because of the disease. I had undergone the test, and it was found that I am too HIV positive but luckily my daughters were safe and the disease was not transmitted to them.

The owner or manager of Annamma old age home gave me shelter and asked me to assist her in cooking and washing clothes of the old people. I accepted the job because I want a shelter for me and for my children. Her own widowed daughter-in-law is also infected with HIV/AIDS and is also staying in that old age home only. They are Christians. Aunty asked me to pray every morning and before sleeping. If we do prayer then god will save us from all problems. Actually I am

Hindu. But I didn't mind to pray to Jesus also. In fact after regular prayers I found many new changes in my life. Because of His blessing my daughter got admission in a good private school. I am not paying her fees but her school fee is taken care by the organisation named Nirikshana which is located in Narayanguda area of Hyderabad. I also get some ration items from the NrityanjaliOrganisation, which gives some help. I am also associated with another NGO's like NHP+ and also besides Nirikshanaorganisation. I get monthly ration from both the organisations. Now it is almost three years that I am associated with these organisations. Earlier they were providing good service for the HIV infected people, but now a day they are not helping us much. Every month, I attend the NHP+ meeting where I received the news that we will get loans and home for living but so far it is not done. I want to open a telephone booth so that I can take good care of my children. I don't have any money as I am not working, so whenever my daughter asked me for chocolate or something else, I could not give even a chocolate, I really feel bad and sorry for them.

Whenever I remember my husband, I get angry because of him only I am having this kind of life. Sometimes I feel no it's not because of him but because of my fate. My parents insisted that I study, but now I repent for not listening to them. If I had listened to my parents and continued my education, I am sure that today my life would have been on a different track, and if I was educated and if married to the same man, then at least I would be able to give a good life to my children and fulfilled their every wish like any other mother.

Case study- 4

Name - Fatima; Age - 25; Education- 6th (Urdu medium); Marital Status - Widow; Occupation - Housewife; Occupation of Late husband - contractor in welding; Religion - Islam; Size of family - 7; No of years Experience with HIV- 6 years.

I am living in Ferozguda, with my parents. I have three sisters and two brothers. I am the eldest in the family. When I was 13 years old, I got married to my mother's sister's son. He was also the eldest in the family, among from sisters and four brothers. He used to do welding jobs and earned around four to six thousand rupees monthly. I got married in very young age. I didn't know the meaning of marriage. For me, marriage meant a great function in the family. I was so scared of him after marriage that, I did not speak to him almost for three months. My in-laws and all my family members used to tell me that he was my husband and I have to all my life with him. But still I did not understand and I used to cry a lot. Then my in-laws used to say whenever I like I can stay with him. All the family members were very cooperative and my father-in-law used to say that as I was very small so it will take time me to understand my husband. I used to go home once in every week. My mother scolded me a lot and told that he was my husband I have to give everything whatever he wanted, and I had the responsibility to take care of him. As one day my husband got a contract in Balanagar, we planned to shift from Nizamabad to Balanagar. I was very scared to go along with him, but my parents and my family members told me that as I was his wife, I have to go and take care of him, and have to cook food for him. I cried a lot on that day. One of my aunts who stayed near my home, told me clearly about the marriage and about the relationship, about the children and all. From her only I got little idea about what is marriage. I was very proud that I got such loving husband; he loved me a lot and never said anything against me. I got pregnant after eight months of my marriage. I did not have any problem with him. He took care of me and never scolded me. After 2 years of my marriage, I got pregnant for second time and from that time onwards my husband started getting health problems. He often

complained about pains in his legs and waist. He coughed a lot, at that time we used to visit nearby clinics for treatment. And whatever he earned, he spent on his treatment only, my father and his family worried about him. So one day my father asked us to go to Gandhi hospital or to Osmania Medical College Hospital.

I and my husband went to Gandhi hospital. There the doctors had done tests and asked us to come after three days for the report. My husband went himself to collect the report, when I asked him what was the result of the test, he said, nothing happened and I was normal. But after that day onwards he was frequently falling sick. So then we decided to move to my in-laws house, as I was pregnant and no one was there to look after him. As I was pregnant, my husband asked me to stay with my parent's house only because I needed full rest. My parents were also very scared because of his health. One day, my parents went to see him. At that time, my parents came to know from his family that he is having a disease by name AIDS, which has no cure and death is inevitable as explained by their son.

In my family and his family, no one knew about the name of this disease. My mother was shocked and she told me that my husband is very sick and I am supposed to go and stay with my husband to look after him. At that time, my second daughter was one month old. But after I had gone there on the 10th day he died. My life totally went astray after my husband's death. I also thought of killing myself. But my mother supported me a lot and told me to live for my children. My mother only told me that my husband had such a disease which had no cure, so no one could help to save his life. After his death, my mother took me along with her to Ferozguda in Hyderabad. From that day onwards, I am staying in my parent's house only. My in-laws and his family are also very good, they used to keep coming and asking about me and my daughter. I also go but at the time of any festivals only.

There is one organisation by name Sidor, which works on health issues, like STDs leprosy and T.B. One day, my mother came across with that organisation and

simply told that my son – in - law died from the disease of AIDS. From that day onwards, the Sidor people came and asked me to join the organisation, so that they could give information about the disease in detail. But I didn't like them to visit all the time here. I told them many times that I was not interested to know about the disease as my husband had already gone, now what will I do by knowing more about the disease. But still they used to advice me and my family members to take care of my health and ask me to have food regularly. They asked me and my children to go for HIV/AIDS test. Their frequent visits irritated me a lot and I get frustrated and fought with my mother. But my mother understands me a lot. From the beginning, my parents supported me a lot. As my second daughter was falling sick all the time, finally I decided to go for the test.

For this, first we went to Narayanguda, with my both daughters and mother. They asked me to come for after three days. They reported that my both daughters were having the disease but I was not having. I was shocked and totally confused. My mother spoke to the Sidor people and they asked me to go for another test. After that I went to Osmania Medical College, there they reported that I and my eldest daughter are having the disease but my second child is safe. Again I got disturbed with their report. I don't know what to believe and what not to believe. One day my second daughter got very sick, so, we went to the chest hospital in Erragada. This time doctor conducted test for me and for second daughter. They said that my daughter and me were having HIV/AIDS and there was no cure for this disease. I was again confused and shocked, and told doctors that I have already undergone the test two times before and they said that we both are not having this. Then doctor told me that this is the accurate information and asked me to believe on this test, and asked me not to worry about it and told me to eat good food, so one can live long. I was sure about this report and again I went with my mother and daughter to Osmania Hospital. There again, the test was done and doctor asked me to come after one month for the report. All the time I was disturbed and used to cry. My mother supported me a lot. She used to say don't worry, if we are there then why you are worrying so much. All the family members are very

cooperative. They always come to help me. Here my daughter's health was not getting well. Her condition got worse.

After one month, I went to Osmania Hospital to get the results, there I met Sapna madam, who was counselor there at that time; I did not get any counseling before that. That was the first time. She told me not to worry about the disease. She also told me that she herself is living with the disease. By knowing this, I got great relief, as I am not the only one who is having the disease. She gave me counseling me and asked me keep coming to the hospital for regular checkups and asked me to intake food regularly. When my daughter was nine month old, she died. I got very upset. I thought to kill myself but my mother and my sisters told me that when they are there to look after them, why should I worry. I am very thankful to god, who has provided me such a family.

One day, the workers of Freedom Foundation came to my lane and asked all the people to contact them if they have any disease or any problem and they will work for them. One day, I was sitting with my mother in the shop. They came and asked me if you have any disease or any infection, come contact them. I was scared and I told them 'no' and "in my family nobody has any such problem, so don't come here. We are all o.k". Then they told me not to worry. They were coming here to bring awareness about this disease as most of the people do not know about such disease. So we were helping them in this regard. In that group there was one woman called Shabnam, who was also from Muslim community. As all the time I was in the shop so became good friends. One day I confided to her that my husband and my second daughter died because of this disease and now I am also taking medicine for this from the last six months. Then she said me why I had hidden this from them, and asked me to come and visit theirorganisation.

From that organisation only, I have came to know the details about the HIV. Now I have good knowledge about the disease I give counseling to the other infected

people. I liked providing such information to the people, but I get upset, when they say that they are not having any support from the family members, they blame the family members for discriminating against them. But in my family I have not faced such kind of problems so far. I share everything with my family members and siblings. I associated myself with the organisationfor almost one year. After that, I worked with a network of people living with HIV/AIDS for almost one year. There I used to get Rs1,500 per month. But now I stopped working because going and coming makes me weak. Earlier I was fat but after joining the organisation and working for the people made me thin. I liked working for them, but to take the patients to the hospital and drop them again at their houses, and travelling in the bus made me weak. So my parents also asked me many times to quit the job and asked to take rest at home only. But my heart doesnot listen, I want to help those innocent people who are not aware of the disease and not getting help from any source.

All my relatives all the time insisted on my family members to get me remarried. But I do not want to marry for, I have fear, that if I marry and if I don't get a good one then my life will be ruined. I know that I should marry a man who is also HIV positive, but in that also I don't know whether that man will understand me or not, like my first husband. So I don't want to marry again.

So far my family members and my in-laws only know about my disease. My neighbours know that I am working for an organisation that works for the HIV/AIDS victims but no one knows that I also a victim of the disease. I am not afraid of the society, because I know that the neighbours and my friends love me a lot and they will not stigmatise me if they come to know about the disease. I have no regrets. If that is written in my destiny, I have to face this. One cannot change destinies. So I don't blame anybody for this disease.

So far,I received counseling and sometimes material support from the organisation like food supplies- ten kilogram rice, one kilogram dal and I litre oil.

I don't have any problem in my family but as I am associated with some organisations I receive the same. So I wish that the government should do something for the poor. If others are getting support, then my wish is that I should also get some provisions because I am not different from them.

Many times someorganisations come with such information that government is giving loans to the infected people, a house and all. But they have not reached people. There are many helpless women who are not getting any support from anybody and they are uneducated also. Many times, the organisations come with plans of income generating activities but they are all not on regular basis. They stopped in midway, when we asked them, they said what we can do, when the higher association is not serious about this. The staffs of the organisation always give hope for our betterment but don't know when it will get fulfilled.

Case study – 5

Name -Keerti ; Age - 30; Education - 3rd ; Marital Status - Married; Occupation - House wife; Occupation of husband -Ballon Vendor; Husband's Education - 5th ; monthly income -Rs2000-3000; Number of Children - 2; Size of family - 6; No of years of Experience with HIV - 4 years; Caste- Kapu; Religion - Hindu.

My husband sells balloons at the stop lights or sometimes at marriages or any party. My family is staying in Laxmi Nagar near West Marredpally. I have four sisters and 2 brothers. My father was working as a peon in Air Lines at Begumpet and used to work for four thousand rupees a month. As I did not like to study, I stopped going to school after 3rd class. My mother and father always scolded me for this. When I was ten year old, I started working as a domestic servant in three houses and used to get Rs 600 per month. When I was 17 years old, my uncle brought a proposal for marriage. At that time, my husband was a mechanic and earning two thousand rupees per month. So finally my father liked the proposal and got me married to him. I have two mothers –in- laws and they both are nice to me. After one year of my marriage, I got pregnant and was blessed with a

daughter. Five years back, since my father- in -law died, there was no income for them. My husband was having two sisters at that time who were to be married. We thought that two thousand rupees is not enough for the whole family. So he thought of starting some business. He asked his mother to give Rs 10,000 to start the balloon business. From that money, he brought balloons and sold at the traffic signals near Secunderabd and also kept a stall at the time of marriage and other functions.

Three years back one day he got fever and my mother- law took him to a hospital near Marredpally. The doctor gave some medicine but still his fever did not subside. Then finally doctor asked him to undergo some test in Gandhi Hospital. My mother took him to the hospital because she loves very much. There we came to know that he was HIV positive and also informed her that there was no medicine for this and have a very short life, if we don't take care of him. Doctor also told my mother that your daughter should also undergo a test. I didn't know why I had to get tested. But there I was found negative and my daughter got positive. But still we were not sure of the infection. We didn't tell anybody about this. My daughter's health was also good but my husband's health was not at all good. Still he gets fever. Now a days he is not able to earn more than fifteen hundred rupees per month, sometimes he brings home 50 rupees only. My mother-in-law is having a small kirana shop and now she is helping us. One day the staff of Nrityanjaliorganisation came into our slum to organise an awareness programme about the disease. In beginning, we didn't tell them anything. But from somebody my mother –in- law came to know that this organisation helps HIV people and provides financial and material help. Without my knowledge, my mother went to the organisation and obtained the details. This people used to tell my mother - in - law and my husband that since my daughter is having HIV, your daughter - in - law may be having the HIV and asked us to go for the test once again. But I didn't listen to them. I heard that if people get fever, cough, vomiting, they will be having the disease. But I was not having any such symptoms so far. Last year, I got pregnant so I went to the Narayana Hospital. There these people

accompanied me and asked the doctors to conduct all the tests. In that hospital, they told me that I have HIV infection. But I did not believe them. In one hospital, they were saying I didn't have this and another was saying that I have infection. I did not know which report I should believe. But staff of this organisation was saying that I am a HIV person. Why do I accept this I have good health. I am a healthy so I will not accept it. Let them say whatever they want. They have registered my name, my daughter's, and my husbands's in their organisation and help us with some materials *rice, flour, oil* and *dal* every month. We are also associated with the Nirikshanaorganisation and from there also we get material help, because they came to know about my husband when we went to their hospital. Recently, I also came to know that the medicine has come for this disease and hope that now my husband and all will get cured from HIV and live life like a normal persons.

Case study -6

Name -Kondamma; Age - 26; Education - illiterate; Marital Status - Separated; Occupation - carpenter; Monthly income -Rs2500; No of years Experience with HIV - 2 years; Caste- Madiga; Religion - Hindu.

I came to Shivananda Rehabilitation Home two days back for my treatment. Earlier, I was admitted in the Chest hospital, located in the Erragadda, where I stayed for the last four months. As I was staying for a long time in the hospital, they discharged me, though I was not keeping well. Soon after, I joined here, with the help of Sunita madam, who is also helping me in getting further treatment.

Regarding my HIV/AIDS status, I am suffering from it for the last four year. I came to knew about it from one of my colleagues. She disclosed it to me in a fit of anger, when I had a quarrel with her. During the time of yelling at me, she said 'you will die soon as you are suffering from the disease'.

I was shocked when she told me about this. I was totally broken and cried a lot. Then I went and complained about this to my boss. She consoled me and said that I am not having anything like that and that girl was telling lies. Later, from one of my friends I came to know that, my colleague with whom I fought had a big scolding from my boss for revealing my HIV status.

I am living in Hyderabad from the last six years. Before that, I was living in the Bapatla town in Guntur District. I wanted to study but because of family problems I could not go to school. My mother died when I was 14 year old and left behind one younger brother. My father was a sweeper. Daily he used to earn Rs 100 and most of the money he used to spend on his drinks only, and never used to give money to run the house. When my mother was alive, she used to work in a purse making company, where she used to get Rs 60 per day.

My father's behaviour was not good towards us. He used to beat me, my brother and my mother daily and used filthy words. Because of his ill-treatment towards us, one day my mother, who was a sugar patient, became seriously ill and died. Even after her death, my father didn't change and continued with his drinks and abusive behaviour towards me and my brother. He always used to beat me and my brother for every small thing. Sometimes our neighbours give us food. Since my father was spending all money on his drinking, I thought to work outside so that at least we will able to have our three time meal. With the help of one aunty in the village, I got job in a rice mill, with the payment of forty rupees per day. My father used to snatch away my payment also for his drinks.

One day, my father beat me and my younger brother very badly I did not know why he beat us. That day beating was so horrible and intolerable, that I thought to run away from home. I did not know any relative or anybody and where to go but I had decided not to stay anymore in this home. At that time, I had five hundred rupees with me. I took my brother and some luggage and went to the Guntur bus

stop. I boarded one bus, which was going to Hyderabad and bought tickets for both of us. That was six years back.

After coming to Hyderabad, for I did not know what to do and where to go. I spent my days in Secunderabad railway station. Whatever money I had at that time I spent it for my brother's milk and food for us. The money was over within five days. So to have our food, I started begging in the day time and spending night in Secunderabad railway station. Many times I got scolding from the police men and was afraid of them. Men used to stare at me. Sometime people used to abuse me, and some of them even touched my body here and there and went away.

One day, I met a man by name Raju who was working as a waiter in a hotel near the railway station. He used to give me five to ten rupees daily for our food…Sometimes he used to bring food for us from the hotel. In this way, he became my friend and one day proposed me to marry. As I had no other alternative, I married him in the temple which is located near Secunderabad Railway Station. After marriage, he took me and my brother to his house but her family members were not accepting me. On that day, he took me to one of his aunt's house and we stayed there for a while.

Initial one month of my marriage went smoothly. After that, my husband told me that as he is not earning much to take care of both us,me and my brother. So he told me to get into sexual relationship with other men so that we can earn some extra money from that. I was shocked to hear this from him. As I did not agree to this, he and his aunt beat me and did not give food for us. In the meanwhile, I came to know that Raju also has physical relationship with the aunt with whom we were staying.

One day they gave me alcohol and beer and locked me in a room with a customer who used me. It continued almost for four to five days. Later, I myself decided to

get into this trade because I want to earn money and want to send my brother to school. It was almost three to four months that I was into this trade, and then I got to know that I have become pregnant. When I gave this news to Raju, he straight away denied that he was the father. He told me that it must be someone else's and not his child. I was heart-broken on hearing this. I was unable to understand what to do next. He was not accepting the child and daily used to beat me and my brother. My life became miserable. I remembered my natal family, as the situation was same, there also I didn't get any love and care and here also I am not getting that, I was just getting beatings and abuse. I thought to take my life, but I could not do that because of my brother. But I decided not to stay anymore in that house.

One day,Raju and aunt went outside and locked me and my brother in the room. In that room there was a one window through which we jumped and ran to a police station. I complained to them about my husband and aunt. I told them the whole the story about me and how Raju had cheated me. The police went to the said place and arrested them. He was beaten by the police, and ordered to take care of me, and then only he agreed to give name to my child. But I was not interested to be with him anymore with him because I was afraid about that once again he will beat me or even kill me and my brother. So I told police man that I will not go with him and was not interested in staying with him.

Then policeman told me about the Prajwalaorganisation whichis working for the deprived and down-trodden section of the society. I agreed to stay in this organisation with my brother. On that day itself, people from Prajwala came to take me and took me to the Prajwala women hostel. Then I interacted with the chief of Prajwala, Sunita madam. I told her about my past. After listening to my story, she told me that I can stay in the Prajwala hostel but for that I have to work in Prajwala enterprise. She said that by working for the organisation I will be busy in some work and she will pay me fifteen hundred rupees. I agreed and registered in this institution.

In the beginning, there were very few women in this organisation. No one used to talk to me. I got bored. I was not getting any interest there. So one day without telling anybody in the organisation I ran away from the institution along with my brother and again went to Secunderabad railway station. Unfortunately again I met Raju, who was insisting that I go along with him to his home. But I didn't listen to him. At that time he gave me two thousand rupees and told me to go along with him. I was not interested to go with him because he used to beat me and my brother. I stayed one more night at the station and later thought to go back to Prajwalaorganisation. Because I hoped that if I went there, then I may be able to send my brother to school. So I myself went to the Prajwala hostel back. On my return to the hostel, Sunita madam scolded me for what I did and said not to repeat it again in the future. She also gave me hope that she would take care of my brother's education if I stay there. In the enterprise I was working in the book binding section. When I joined I used to get Rs1, 500, but later it was increased to Rs 4,000.

As I was pregnant, I went along with my colleague for a medical checkup. After examining me, doctor, spoke to Sunita Madam, but didn't say anything to me. Doctor told her about my disease and told her to tell me to abort the child as I was HIV positive. I did not know what that was all about. Then madam told me if I don't do this, my child will die once he/she is born. I was not able to understand what they are telling because I never heard about this earlier. Anyhow, I agreed to abort my child.

After two months, I requested madam that I want to admit my brother in a school. Madam told me to admit in Prajwala School but I was not interested my brother to study here. I want him to go and study in Guntur. After requesting a lot, madam allowed me to send him to a school in Guntur. I went to Guntur along with my brother and admitted him in the 1st standard and came back to the Prajwala enterprise.

Days were passing by in the enterprise and every month many women joined the enterprise. Actually Prajwalaorganisation mainly deals with sex workers, so we used to get counseling from the counselors about condoms, etc. I never heard about condoms in my whole life and even my customers, who used to come in my husband's home, did not bring condoms along with them. Anyway many things I came to know from the organisation.

One day our organisation took us to an old age home in Vizag to give service to the old people. There we used to attend prayers every morning in the Church. I used to pray. One day, I met the Father of the church and told him about my past. Father told me to pray to god and He will help me out from the problems. From that day onwards, whenever I remember god, I pray and confess whatever the wrong things I did so far.

My brother was studying well in the school. I used to talk with him on phone every month. In beginning I used to send him Rs 500 rupees but later it increased to Rs1,500.Days were passing happily in Prajwala enterprise. But one day I had a quarrel with one of my friends.While fighting my friend told me that because I was in this trade I got HIV/AIDS and I will die soon. She abused me like anything and I was inconsolable. That day was very horrible for me. Whole day and night I was thinking about the disease. And also thinking what will happen to my brother if I die, who will look after him?

But unfortunately, it was not me who died but it was my brother who has left this world. He got cancer. It's all my bad deeds that had taken away his life. When I got this news, I fainted. I was totally broken. Now for whom I will live? With this tension I stopped taking food and proper care of myself. And because of this, my health got worse and suffered from T.B. Day by day, I was became lean and every three and four days I was getting fever. Then I got admitted in Shivananda hospital for treatment. Whatever medicine doctors used to give me, I never took

them because I didn't want to live. I was there for fifteen days and was given good care. Later I got shifted from there to Chest hospital Erragadda. I remained there for almost past six months. The doctors and the staff were not good there. They never came to me for regular checkup. Even the *aayas* were also not taking proper care of the patients. They did not come to me. If patient's family members or patient themselves gave some money to them, then only they would do the desired service. I did not like that place but I was quite lucky as Sunita madam used to send one lady from the organisation to look after me but those aunties also did not look after me very well. Whenever I asked for something to do they used to do it in a very irritated way. Many times, I did not get any lady from my organisation to give assistance. I did not have stamina to do my work for myself. But somehow I managed. Sunita madam used to give Rs 500 per week for fruits and other requirements. As far as the behaviour of those aunties was concerned, it was bad. Whenever I asked or spoke to them, they covered their mouths and noses with a cloth and then only they used to come closer to me. In the beginning, I felt very bad on the way they were treating with me. But slowly, I coped up with this kind of behaviour. One day, the doctor who used to come for checkup discharged me without informing me. I was not properly cured at that time and was not well enough to look after myself. After that,Sunita madam referred me again to the ShivnandaHospital for further treatment. Sunita madam is very good. She used to call me in the hospital and asked about my health.

As compared to Chest Hospital, the doctors and staff are very good in this hospital. Even the food they provided were also very good. All of them are very cooperative. My friends are also very nice towards me who come from the office to look after me. Hope I will get cured soon and again I do start going to my work.

I also have one friend named Manisha 24 year old woman who works as a carpenter in Prajwala enterprises for the last 2 years. She was a sex worker but not now. She is my good friend; usually she comes to give assistance to me in the

hospital. She informed me that, when Sunita madam told about her disease to the people staying in the organisation, many people got scared of me. When I was admitted in hospital and when Sunita madam gave them the responsibility of assisting me in the hospital, they were not ready to help me. She said that they all thought that if they come closer to me and touch anything used by me, they will also become victim of HIV/AIDS. She also said that, later they all were given proper training and counseling from Sunita madam. Now she says that she doesn't know about others but she doesn't feel any fear from me or the things which I use. Now we are very good friends. She also informed me that in the enterprise there are many of other women who are infected with HIV/AIDS but their conditions is not as bad as mine.

The remaining 34 case studies are similar. From these narratives and the discussions the researcher had with these women, besides the workers of the NGOs, the experiences of discrimination and stigmatisation are understood. The analysis has focused broadly on various strategies developed by these women to cope up with the stigma, the diseases and stress. These are presented in the following two chapters. What has been described in the following pages is about the experience of the women's childhood, marriage, and their views on sexual behaviour of the husband before marriage, extramarital relations of husband, decision making power, the reasons for undergoing the HIV test, the reaction towards the husband when the HIV test shown positive and so on.

It will be in order to state at this point about the method of analysis and presentation. Here, an attempt has been made to draw a general picture of the scenario or situation, rather than the statistical analysis. Hence, numbers and percentages are avoided as far as possible. This is so because the statistical analysis of 40 cases is meaningless for the reasons that these do not represent the universe. Given the nature of the problem it would be impossible to have any idea about the complete universe and what is the appropriate sample for this. Therefore, qualitative analysis has been given which transcends the statistical

analysis. The generalization made here ignore the deviations in order to give a general idea of the situation or the phenomenon.

Women's Experience of Their Childhood

It is well understood from the narrations of the HIV women that since childhood they are discriminated from their brothers. They are socialized to take care of their brothers very carefully, neglecting their own self. At the age of seven to eight years, they started doing household work. They assisted their mothers in cleaning the house and washing vessels, etc. Those women who were born and brought in the villages said that during the childhood they spent most of the time at home under the care of the grandparents. But at the age of seven to nine, they started helping their mothers in household chores.

A very few of them have gone to school. The women who have not been able to go to school have given the reason that they were not encouraged in the family to go to school. Rather than sending them to school, the parents asked them to accompany them to agriculture fields and play with children of others and take care of the young siblings. They started working at the early age of twelve years with dual responsibility of domestic and agricultural field work. They said that their brothers also were not sent to school because it was not there in their village. Thus, the bias towards the girl child in the family and lack of infrastructure in the village resulted in illiteracy. There are some women who said that they are educated have studied till their primary or secondary school from the village. But after attaining puberty, their education was stopped as they were to be married off.

Women who had spent their childhood in cities also stated similar life experiences of the women who grew in villages with few exceptions. Those women who were born and bought up in slums of the cities said that they didn't face any problems in getting education as they were enrolled in the government schools situated near their slums. However, they discontinued their education after a few years of

schooling. Some of them were not interested in studies hence stopped going to school and assisted their mothers in domestic chores. A few women engaged themselves as domestic maids even when they were 11-12 years old.

In the villages, women joined their parents in agricultural labour work or on construction sites. They used to earn thirty to sixty rupees. Like the village women, a few women, of the city who were going to school had stopped their education when they attained puberty. As some discontinued their education due to financial constraints of the family, their childhood was not different from that of the village women. Most of the times they stayed at home only and did their schooling and other household works. They also spent their time in chit chatting with their neighbours and friends. These women did not face much discrimination from their parents with their brothers except that brothers got freedom to go and play as per their wish which was not allowed to them. Thus, it has been observed that the onset of puberty marked restrictions in a girl's life; her movements were curtained and behaviour was controlled in both urban and rural societies.

Views about Marriage

Marriage is inevitable as the way the women conceive about it; they cannot avoid it as the parents do not allow them to remain unmarried. It is central part of women' existence[10]. In almost all cases, they were no voice or say in selection of husbands while their parents searched alliance for them. Most of the women did not like the selection but got married to the man whom their parents had chosen. They were told that their personnel likings were not required whether the man was suitable for them or not.One of the respondents shared her feelings like this,

> *"…..I did not like the man who came to see me, I told my mother about this. In turn, mother and other elders said, 'it is none of your*

[10]Krishnan, Suneeta et al (2004) Marriage and Motherhood: Influences on Urban Indian Women's Power in Sexual Relationships. San Francisco: University of California.

business' to know whether the boy is suitable or not. Their job was to get me married hence I got married."

Some women did not have any idea or thought about what is marriage at all. They simply got married after their parent's had selected a man for them. For them it is the occasion, when women get gifts and many more new dresses. These arethose who got married before they attained puberty.

Fatima (25), a widow, says,

"…..for me, marriage is arrival of lots of new dresses and lots of gifts from relatives and other family members."

Some of the women spoke negatively about the institution of marriage. They are not happy being married.

Pallavi (35), a widow, says,

"……after getting married, my life got worse, I had been controlled by parents before marriage and after marriage, by the husbands' family. Marriage gives only worries in a woman's life. I feel it would have been nice if I remained with my parents only without marriage."

Views on Sex

About half of them, had no knowledge about menstruation before menarche. The immediate reaction to their first period was usually described negatively in words such as "fear" and "shocking". They approached mothers, sisters, or friends for advice. Similarly, Women, except a few, had no idea about sex before marriage[11]. Women had little information on the nature of the sexual act and sexual relations

[11]Illiteracy, dropping out of school early (especially after the onset of menstruation), restricted exposure to mass media, the burden of domestic chores, and limited ability to communicate on issues related to sex and sexuality are some of the well-documented reasons for ignorance about sex among adolescents in India (Jejeebhoy 1998).

in marriage. Others had only the vaguest idea. This is because of their ignorance due to restricted mobility, early marriage and lack of proper education, lack of exposure to media or other potential sources of information.

Fatima (25), a widow, says,

> "……*I married at very early age of 12. What would l know about it at that age? I had no brains at that time. I used to think that after marriage a boy and a girl stay together and the girl has to cook for the family and I never thought that anything will happen beyond that."*

Married Life Prior to the Infection

By and large, for all of them the initial days of married life went off smoothly for some time, and husband was affectionate and his family members took care of them from the time of marriage. But gradually the situation changed with treatment from husbands and sulking of in-laws for bringing less dowry. They gradually increased harassment and in some cases reached the stage of torture.In some cases, they became the victims of violence at regular intervals by their husbands particularly in a drunken condition. They used very foul and abusive language. They were battered because of arguments made with in –laws, especially the mother-in-law and husband. The ill treatment was experienced particularly when they did not cook food properly, did not take care of children, visiting natal home and talking to neighbours and so on. Some were beaten up even for talking to the husband's elder or younger brothers also.

It is documented that women who are beaten or dominated by their partners are more likely to become infected by HIV than women who lived in non-violent households[12]. Only in six cases, they were happy after marriage, and their

[12]Dunkle, et al (2004) examined the connections between women's HIV risk and gender-based violence. The study explored associations between newly diagnosed

husbands were affectionate and had taken good care of them from the day they started living together. But even in these cases, after the diagnosis of HIV, the affectionate relationships got disturbed and they fought often for small issues. Sudha(31), a widow, says,

> *"……I was young at that time [when I got married]. I was happy in my mother-in-law's house. My mother-in-law was very affectionate. I got pregnant two months after marriage. We were happy for that. But after the diagnosis HIV, my husband and his family members changed and started blaming me only but not my husband for the disease and often charged me with very foul language."*

Decision Making Powers

The women who are living with their husbands and children enjoy greater decision making powers in a number of areas of domestic life like right over the distribution of husband's income, distribution of the household income and rearing of children and so on. However, there are some cases where the spouses are deprived of any decision making right, especially in the cases where they are in extended family situations. Here, the decision is mostly taken by their parents-in-law and their husbands[13].

HIV infection and experience of intimate partners violence, male control in relationships, child sexual assault, forced first intercourse, and adult sexual assault by a non-partner in women seeking antenatal care in Soweto, South Africa. The findings indicated a link between intimate partner's violence and high levels of male control in a woman's current relationship and being HIV positive. However, child sexual assault, forced first intercourse, and adult sexual assault by non-partners were not found to be associated with HIV status. Authors conclude that women with violent or controlling male partners are at increased risk of HIV infection. They suggest that abusive men are more likely to have HIV, or other STIs (sexually transmitted infections) that render women more vulnerable to HIV infection from another source. Abusive men are also more likely to impose risky sexual practices on partners.

[13]The women in South Asia generally have a very low status in society, and as a result, they are more vulnerable to contacting HIV/AIDS infection (UNDP 2002).

Reason behind Knowing the Diagnosis

The women narrated varied circumstances in which they have found out that they are HIV-positive. Such of them are: testing required following the husband's general illness, at the time of reproductive health check-up and testing when they fell sick. In a few cases, when children are treated for prolonged illness and prior to donating blood, they were asked to undergo HIV test.

After husband tested HIV-positive

Generally about half of the victims came to know about their own HIV-positive status when they had an HIV test after their husbands were diagnosed with HIV. When the couple underwent an HIV test in the course of seeking medical assistance for health problems experienced by their husbands, or when they took the HIV test following the death of their husbands. Usually men themselves went for HIV-positive in the course of seeking medical assistance for health problems, including fever, blisters and sores, diarrhoea and vomiting. In nine cases, women had an HIV test after their husbands tested HIV-positive. Not all women went for test immediately after their husbands were diagnosed with HIV. In four cases, women were asked to have an HIV test along with their husbands in the course of seeking treatment for health problems experienced by their husbands.

Karuna(29), a widow, says,

> *".....my husband developed blisters on his mouth and lips after shaving. There were boils in his ears too. I took him to a private hospital. There they asked us [my husband, daughter and me] to have an HIV test. My husband and I were tested positive."*

This is a usual processes, the women had undergone test by which they came to know their HIV test. Usually, it was at the time of undergoing the routine antenatal check-up or in the course of seeking treatment for complications experienced during pregnancy, including symptoms of reproductive tract infection, or prior to delivery. In some other cases, when they fell sick and sought

treatment for problems such as heavy bleeding, they came to know their status of HIV. Some women said that they found out about their HIV status when they sought treatment for conditions like delay in conceiving. In case of some victims, when their children fell sick, the woman was asked to undergo test for HIV along with her child, and they were found with HIV.

Opinion on their husbands and their previous lives

These women, in general, had never heard about the HIV earlier. So initially they have taken the results of the HIV test very casually. The counselors or doctors or the social workers who are working in this field are the ones from whom they heard about the infection. When once they came to know about the transmission of the infection, they developed suspicion on their husband's sexual behaviours, but earlier they never thought negatively about their husbands' behaviour, and never suspected their relationships with other women. The women came to know about the truth only when husband or they themselves were diagnosed with HIV infection. For instance, RajyaLaxmi(26), a married woman, says,

> *"……I have trusted my husband like anything but when he was diagnosed with HIV positive and told me that once he had a relationship with a woman before marriage, I was totally broken. I was not able to understand, I cried a lot. Then my husband said that he had relationship before marriage but not after marriage."* Further, she says, *"How can I believe that he had relationship before marriage only?" He might have continued relationships after marriage also, who knows about his whereabouts."*

There are some women who are very much aware of the risk behaviour of their husbands but they are not bold enough to ask them stop going to other women. It is because if they say anything against their behaviour, they will be beaten up and thrown out of the house and they can go nowhere. It is the cultural norm also, not to fight against the husband. Therefore, women accept all ill-treatment meted to

them by their husbands. If they say a little aloud, they are beaten up, they add insult to themselves only, the neighbours think badly about woman only. Yaddamma(34), an illiterate widow, and currently working as a domestic servant in Marredpally near Secunderabad railway station, says,

> *"…..My husband was a labourer and he used to drink a lot and every time he used to beat me up for small things. From my neighbour I came to know that he had relationship with other women. When I asked him about that he had beaten me a lot and abused me with filthy words and thrown me out from the house. Even my mother- in-law did not come forward to protect me. He never used to give money to me. From that day onwards, I stopped asking him anything with the fear that, if he throws me out then what can we do, and where do we go?"*

Similarly, another woman Kamala(30), a wage labourer, says,

> *"…..I know very well that my husband has relationship with another women but I never tried to stop him as I was busy to look after my children and even I thought if I say anything, he will throw me out of the house, then where I will go?"*

But there are some women who have doubts about the behaviour of their husbands who don't want to accept. They do not want to make it an issue or attempt to suppress it out to fear and shame and also their dependency on men. A woman is kept under man's subjugation because she is physically weak and economically dependent upon him. She should be devoted to her husband. Women in Indian society are considered subservient to men. This consideration owes its roots to the patriarchal, patrilocal and patrilineal structure of the society, which wants that the daughter to depend upon her father, wife upon her husband and mother upon her sons in social and economic spheres, responsibilities and

wellbeing. The protagonists of this view draw their logic from the Hindu sacred texts, notably the Manusmriti. Such a view, which has become the common practice, has shaped not only the behaviour pattern of men and women in the Indian society; it has also percolated down so deep in the culture, which has shaped the mental outlook of the people. To dominate is the prerogative of an average man and to yield to the will of man is considered to be the duty of an average Indian woman.

CHAPTER-4

STIGMATISATION, PROBLEMS AND CHALLENGES

This chapter discusses the life of the women after they are diagnosed with HIV/AIDS. It includes the reaction of the spouse towards the illness and there after reaction of the other family members. As the family members or neighbours come to know about how the HIV/AIDS spreads, if they did not know it earlier, suddenly the reputation of the woman and her family dips or fall abysmally level. The stigma of sexual immorality of the woman or even her husband's becomes intolerable. Discrimination in every aspect becomes an excruciating pain that one has bear in the absence of any defense mechanisms. The experience of HIV/AIDS creates many problems for the woman. She has to face the challenges of imminent danger of death, discrimination and stigmatisation and the hostile family members and the community. This chapter deals with these issues.

Across the world, the global epidemic of HIV/AIDS has shown itself capability of triggering responses of compassion, empathy and support, bringing out the best in people in the community and their families (Dube 2003). On the other hand, many studies have shown negative and rejecting responses from families and communities (Hackl, et al 1997, Hough, et al 2003). These findings reveal that the HIV/AIDS is also associated with stigma, repression and discrimination, as individuals living with HIV/AIDS have been rejected by their families, loved ones, communities and those responsible for caring and treating P LHAs.

The survey results reveal that only 16.4 percent of the respondents have better attitude towards the HIV/AIDS victims. The overall adequate knowledge has not been converted to appropriate attitude towards the victims. Therefore, in the detailed case studies, discrimination, stigmatisation and isolation of the victims can be expected. This chapter basically tries to explore how these victims are treated in the conjugal and natal families, work place and hospital situations.

The family is an important social institution in India. Though the joint family system is gradually disintegrating in urban India, the emotional ties with the extended family and its members continue to be as strong as ever. In many instances, approval/disapproval of the extended family- even if they are not in the vicinity- is an ever-present issue for individuals. This strong emotional connection with the family is even more palpable in the case of persons who have been infected with HIV.

Family responses to infected relatives are heavily influenced by community perceptions of the infection. Families that include an individual with HIV may fear isolation and ostracism within the community (McGrath, et al 1993, Warwick, et al 1998, Bharat and Aggleton 1999). Consequently, they may try to conceal an HIV diagnosis, which, in turn, may cause considerable stress and depression within the family (Bharat and Aggleton 1999). Because most people living with HIV/AIDS in India maintain such secrecy, the epidemic is not socially visible. Given this secrecy and invisibility, it would appear that there have been relatively few actual instances of community-based discriminatory responses. However, stigmatisation and discrimination may arise when an individual identified as HIV-positive is seen as a source of infection to others, or when the physical appearance of someone with AIDS produces revulsion or fear. By contrast, a person who is known to have HIV, but whose behaviour or appearance is "non-threatening," is sometimes tolerated and may even be offered support in the community (Bharat 1996). Nevertheless, misconceptions about how HIV is transmitted continue to fuel discrimination.

From the cases presented in the earlier chapter and the information collected from the rest, the general social background, the situation of the victims can be discerned. Their background reveals the oppressive situation in which the victim is likely to encounter extreme mental strain and emotional stress. From the childhood, a woman generally is molded to be a home maker, and she has to take care of young children in the beginning and later the adults, besides giving

economic support to the parents and her own family. She is not to be in company of men and be friendly with the boys. Girls are generally not encouraged to go for higher education and this limits their exposure to wider society. Several of them have no idea about the sexual responsibilities that follow the marriage and so on. The social norms are to be strictly followed. Otherwise, the neighbours consider the girl to be of a bad character. If she talks to a boy regularly, rumours spread that she is having an affair with the boy. No boy likes to marry such girl nor do parents of boy come forward to get such girl married to their son.

In the situation where an unmarried girl or woman is dominated by the norms or values, she remains subservient to parents and males-surrendering her freedom. She is supposed to be innocent in all matters particularly about sex and matters outside the family but should be knowledgeable about domestic affairs of keeping the house and taking care of its members. She is not expected to talk back or go against the desires of the elders and parents. She has no role to play in the decisions of the family matters. Given the cultural ethos, the husband who is older in age and consideredsocially superior to her has to be listened, meekly obeyed and respected. He is an esteemed divine person, and she is expected to love and serve him. She is not expected to argue with him or do anything against his knowledge or wishes. When a boy is presented to her parents by relatives or friends of the parents for marriage, they give a very good report about him that he is a bachelor and gives respect to elders and obedient, he is hard worker and not quarrelsome and does not have bad habits such as drinking alcohol and so on. A Telegu adage which is translated into English says," in order to conclude a marriage, one may lie one hundred times". Thus, there is social sanction for telling lies for arranging a marriage for a boy or a girl. So the true nature of a boy or girl is hidden. When the marriage is over, she would have very high expectations about him. Being a good person, she expects him not in the habit of drinking, using abusive language and even in battering. As she is virgin, she also expects him to be a bachelor having no sexual relationship with any other woman. She expects reciprocal love from her husband.

Her parents and relatives also expect the same behaviour as expected by their daughter. Of course, all of them know that these are ideal norms and individuals often do not live up to the ideals. But then these violations are not expected to reach a point where the family should suffer. There can be tolerable situation at the most. Son-in-law can also bringa bad reputation to the parents, if he does not take care of his family properly. Then the parents of the girl come to the rescue of their daughter by taking care of her and her children. However, the girl once married does not like to go back to her parents' house and become a burden for them. Moreover, if she has a brother with the parents, his wife does not like her to be a burden on her family and she looks down upon her. Her children have no rightful place in the house of her brother or parents. In the social and cultural milieu, one has to understand the stigmatisation, problems and challenges that women victims of HIV/AIDS encounter. The patriarchal social system and the male dominated society as such generates stress and emotional problems for a woman. But when she is attributed loose character, immorality and has to depend on parents after marriage, her already precarious conditions further aggravates, there will be great stress on her and the situation creates serious anemotional imbalance.

Family constitutes the basis of society and therefore it warrants special attention with reference to acceptance of the women with the dreaded infectious disease. The family extends the widest and most comprehensive protection and assistance to its members for mental, physical and psychological growth. It caters to the individual's needs and preferences through its resources and helps overall development. HIV/ AIDS is an infection which brings misery, both to the victim and the family. The kind of relationship that the person shares with the rest of the members of the family needs to be understood. Along with the person (him/her), the impact is also upon their immediate family and their reaction is significant when they come to know that one of the family members is a HIV infected person. They may either protect the person or react against him/her.

Stigma[14] and discrimination

The HIV/AIDS for a common person who knows about the contagious roots means promiscuity of the person; it is mindless or uncontrolled involvement with prostitutes. Though this behaviour is considered bad for a man, it is worse for a woman. The bad behaviour of a man may be exonerated as it speaks of virility or masculinity, but in case of woman it is an unpardonable terrible behaviour. So, when the husband comes to know about wife's HIV status, knowing very well about his own wayward life or even is not of that type, he immediately blames or suspects his wife that she must have or had sexual relations with other men. This becomes a great scandal for the wife who is innocent. Her reputation is under fire. There is no way that she can prove her innocence. The parents or brothers or sisters of the husband normally believe that their ward is innocent, and say that only his wife has proved to be of a bad character. The stigma goes till the husband confesses. But then if the husband does not confessing his wayward behaviour, she will carry the stigma till her death. Besides carrying the stigma, she faces discrimination in the family and outside with or without sympathy due to fear of she being a threat to the health of the rest of the family members or colleagues. Since her presence itself is felt as contagious besides the things that she uses, she is asked to confine herself to a place or restricted from talking to

[14]Stigma exists in a larger historical, social and cultural context, this context requires participation of the individual members of a society.It is related to the notion of social cognition that encompasses "attitudinal" and "schematic" approaches. Crocker and Lutsky (1986: 98) explain that an attitudinal approach has "much in common with sociological definitions. According to this approach, individuals hold strong pre-existing beliefs (in a form of stereotypes) about the stigmatised, which influences the social interaction. Stigma is sustained through individually held attitudes that reflect larger social and cultural contexts." Thus, stigma is static and doesn't allow for attitude change. On the other hand, Crocker and Lutsky continue, the schematic approach and emphasizes "cognitive approaches that may be responsible for the construction, application, and revision of social perceptions and evaluations. Individuals may hold pre-existing beliefs that they don't endorse personally. The process of categorisation, attitude construction and information application operates on various past and present sources of information" (Ibid: 99).

neighbours,children are not allowed to play with others and so on. She and her children are withdrawn voluntarily at times.

She has to meet the challenges of not her own survival, but also her husband and children also if they also affected. She has to live with the stigma and discrimination- experiencing all the indignity and ignominy. Finding employment and meeting the daily needs of living is one problem and getting medicine is another problem. She needs help and assistance to go to hospital when she is sick. When the husband is sick, she has to take the responsibility of maintaining the family and looking after him. Similar is the suffering with the sick children. In the following pages, the issues of stigma and challenges of life of the victims are examined.

Immediate reaction of the husband

In four cases, the husbands deserted the wives immediately when the women were diagnosed with HIV. They took the wife and children to their parents and left them in their home blaming that the woman alone was responsible of the infection, but not he. This happened when the pregnant woman was found to be HIV positive and the test was not done for the husband. The husband started blaming the wife without himself undergoing the test. Some women received very violent reaction when they questioned the whereabouts their husbands. Instead of telling the truth, the husbands beat them up in front of other family members and then blamed the women only for the infection. The husbands vehemently refused to undergo the test. But in some other cases the husbands were supportive and tried to control their wives' anger[15].

It has been observed that response of the spouse in most of the cases was negative and women were seen as main culprits, the husband attacked the character of the wife. The men accused their wives, having known very well that their wives are

[15]Similar findings were noted by Pradhan and Sunder (2006). It was observed that more women are supportive of their HIV positive husbands (12.4 percent) than men are of their HIV positive wives (8.5 percent).

no way responsible for the infection. The men abused the women and started shouting at them in very foul language in front of the family members and also in public. As reflected in the literature, HIV/AIDS related stigma and discrimination reinforced the existing social stereotypes and inequalities in which women are inferior to men. Also, the cultural attribute of respect rests with the man more than the woman because man is generally considered to be the head of the house.

It seems the women positively accepted the negative remarks by their husbands. It is evident that the women have meekly internalised the blame when they are deserted without any protest as this will be vain. Generally, the women did not react as the men did when the latter was diagnosed with the HIV. It is because they are not supposed to question the behaviour of the husband. On the other hand, men have the privilege to talk whatever they like against the wife[16]. As a result women, find themselves ostracised, rejected and abandoned. The victims in this study confirm the argument that there is no shared responsibility created or encouraged in public messages about HIV/AIDS but that women are by nature made accountable for the disease (Richardson 1989, Burry, et al 1992).

Whether infection has come from husband or believed to have come through women, the fact remains that, in both the cases, it is the woman who has to face the suffering of more stress and pressure, compared to man. As it is she, who is not prepared to question her husband even if it is related to her well-being and she has to accept everything as her fate, she being totally dependent on him in social terms and also with no alternative help in most of the cases.

This form of gender discrimination, i.e., male arrogance is very widespread in the society. Man can exhibit his manhood in terms of violence, and the same continued in the context of HIV. The women say their place is in the home and to prepare food, produce children, nurture them, and to meet the sexual needs of the

[16]As has been reported by Nashandi (2002),women are blamed for their own infection and that of their partners.

husbands. They shall be confined to the house, and not to go outside, and accept whatever is dictated to them by men.

Immediate reaction of wife

It was shocking news for the woman who came to know for the first time that her husband is suffering from HIV/AIDS for which there was no cure for the disease. While some reacted in disbelief, some other accepted it as reality. They thought it occurred because of their innocence, otherwise they would have taken some precaution and prevention. This only speaks of their ignorance. Some of the victims still don't believe that infection is with the husband and they are not taking any medication, and still live in the same life style which they were living prior to the diagnosis. Some women know about unfaithfulness of their husbands and that they are engaged with prostitutes and that is how they got the infection.

Gradually, the women started worrying about their future. The more they learnt about the infection, more they are worried about the death besides the prejudice and stigma attached to this disease. The big question before them is how to survive and face the death. They are concerned with how to bear with the indignity and, how to manage with the stigma?

Experience with HIV status

Women are generally not aware of the consequences of infection.When they came to know about death sooner or later, it was shocking news and immediate concern was about their little children. Women were very upset and got angry with their husbands for the infection. When they came to know how the infection spreads or gets transmitted from person to person, they understood, it must have been due to life style of the husband either before the marriage or after that. They were angry that their husbands visited prostitutes. From the sex worker, the husbands got the infection and from him later it was spread to them. The anger was not so much about the fact that husband had visited sex workers or had pre-marital or extramarital relationships but it was because the infection has a serious impact on the entire family. These victims seem to have tolerated the husband's life style but

bitterness towards their husbands is due to the disruption caused in the family relationship and economy. The wives are convinced that these problems are invited problems which could have been avoided. As economic hardships have grown day by day and resources dry up, there is more frustration and bitterness. Wives perceive that their husbands are directly responsible for their suffering. The following is an example of this reaction,

Gayatri(35), a married woman, says,

> "…..*I knew that my husband has extramarital relationship but I am not angry that he went to another woman. I don't mind what he does. Let him do anything. But I am concerned about myself and my children. I don't want that my children are deprived of anything. I told him this when I heard that he had this illness and how he got it. I got angry and fought with him. I was very angry at that time. Now there is no use in being angry. It does not change anything. But whenever I become irritable and angry, I tell him that he has ruined our lives forever*."

For women, the HIV means death and they think that they are going to die shortly because of this dreadful disease. These responses come from the women who are diagnosed with HIV and TB.

A few victims were totally broken when they heard about the disease because they were quite aware of the consequences of being infected with HIV/AIDS as they had seen and learned about this in newspapers and on TV. In fact, some have first-hand experience as they had experienced and witnessed the painful death of their husbands and children. This is an agonizing experience. One woman said with a big question in mind, "being a wife and mother, we can take care of the sick husband and sick children but who will take care of us when we become sick'. They are concerned and worried about who will take care of their children after their death, in case they pre-decease the children.

There are a few who still do not believe the fact that they are HIV positive. While some of the victims are embarrassed to face their families because of the infection. A few other have decided to keep the HIV+ status as a secret with others, as they fear discrimination and rejection.

Helplessness of women in sexual matters

Majority of women are the victim of sexual violence before the infection too but the diagnosis of HIV/AIDs infection did not change the behaviour of the husbands. They are not having any sympathy with their wives and still continue abusing them. Women said that their sexual activity is low following the birth of their childrenand lower after diagnosis of the husband's illness.Though all the married women are aware of the importance of using condoms during sexual intercourse, they are helpless to protect themselves from the risk of not using condoms. Almost all of them said that they have been advised by the counselors and the social workers for resisting unprotected sex but they are helpless. They said that in the beginning of the diagnosis they used condoms but later on it was stopped. For this, some have given the reasons that, they have stopped using because it was not available at home which they received free of cost from the NGOs. Their economic background is now so poor that they cannot buy these from the market. Some of them said as their husbands do not like it, they have stopped using it. These women also said that they feel shy and awkward to ask their husbands all the time for using it. If they insist, the husbands try to convince their wives that the HIV all results are wrong and stupid and they do not believe in the results. Thus, they are putting their health at greater risk. There are a few women who said that as the HIV/AIDS already exist in the body and even if they use condom, the situation cannot be changed. So they have to accept whatever the husbands want. Therefore, it can be said that the women have very little control over their body and this has very serious implications in the case of HIV/AIDS.

Stigma and discrimination faced by the infected family members

The consequences of HIV/AIDS not only affect the infected member, but also the victim's family members too. The family members face discriminatory action from their relatives or by the community members[17]. It has been found that families are facing discrimination from their relatives because one member in the family is infected with HIV/AIDS. HIV-related stigma impacts the family member's interaction with one another. Some families try to avoid discussion of HIV/AIDS-related topics. Sometimes the family members find it very uneasy when HIV-related words are mentioned.

For instance, a sister-in-law of Chinamma(30), a widow, says,

> "*…..because of my brother and sister- in- law's status….neighbours are not talking with us. Not only this, now a days they are not inviting us for their functions."*

This is very unfortunate, and it clearly demonstrates how a victim of HIV/AIDS puts the entire family on the discriminatory map.

One more, a mother (62) of an infected woman, SubhaLaxmi (27), says,

> "……*because of my daughter's status I could not visit my relative's house in order to avoid HIV/AIDS discussion from them. They all knew that my daughter has HIV. I feel bad when they discuss this topic."*

[17]There are a number of studies that have shown family members facing discrimination from their own relatives and people around them (Bharat 2001, Verma, et al 2002, Indian Express 2003,Erica Lawson, et al 2006, Sandra Roman 2006).

Therefore, the impact of stigma and discrimination is not limited to the victim but the entire family of the victim. So the behaviour of all members gets altered. All become sensitive to the matters of HIV/AIDS.

The mother-in-law (52), ofIndramma(28), says.

> "……*when people came to know that my son- in- law died because of this and my infected daughter is staying with us, we experienced a big difference in the attitude of our neighbours … Before that, they always liked to visit us and chat with us, but now-a- days they are not visiting our house at all."*

So it is true that because of HIV/AIDS infected person in the family, the social relations in the community gets changed to the disadvantage of the victim's family. Even for any good reason the neighbours attitude is different, there is scope for the victim's family to misunderstand and misinterpret, because they begin to suspect everyone. Thus, there is a clear psychological change in the family of the victim.

The mother-in law (55), of infected Savita (28), says,

> *"…… all my relatives stopped visiting our house because I am staying and supporting my infected son and daughter in law."*

Yet another woman, sister of 26 year old widow Mamta, says,

> *"…...my infected sister is very close to my brother but because of this infection, his wife told my brother to vacate the house. She doesn't allow my brother to speak with her."*

Thus, the stigma impacts interaction within the family. It affects social relations in the community, among friends, coworkers, and neighbours. Because of

stigmatisation, many family members have changed their behaviour. Some family members of PLWHA are ashamed of being a relation of a victim and tried to avoid interaction with others.

There are also families who expressed efforts to hide the HIV status of the PLWHA because of fear of social discrimination and ostracism. When the HIV status is disclosed, voluntarily or involuntarily, the entire family experienced major changes in their interactions within their community and their social networks. The mother (55) of 27 year old Sushma, says,

> " *.....I don't know about the disease much but when I started attending the meetings held by the organisation and from others I came to know the infected people, how they are being discriminated by their neighbours because of the disease…so I decided not to disclose this to anybody. I asked even my daughter also not to say anything about this to anyone."*

Discrimination in Community or social life

In general, the victims are not only losing the status in the family, but they also have to lose face in the community. It is seen that community relations and social interactions also get adversely affected due to HIV/AIDS. They are ignored and avoided by their friends, relatives and neighbours. They are not invited for functions and other social gatherings. If they happened to attend such events, they have to face insult**s**.

The majority of the victims have not disclosed their HIV status to other than their family members. But the neighbours generally come to know about the status at the time of death. Initially, they enquire about the cause of death with innumerable questions. From these replies, they conclude themselves, the death is due to HIV/AIDS as they knew about the AIDS through television and other media channels. Before the death they usually maintained cordial relationship with the family members. But after knowing about the disease, they stop

visitingthe families of the deceased. Some widows said their neighbours stopped even talking to them and their family members. Because of this they have shifted their home to some other place. One victim says that the home owner, after knowing the cause of husband's death, asked her to vacate the house.

Chinamma(30), a widow victim,explains her situation like this,

> "……*My neighbours stopped talking to me besides my family members. My children and their children were very good friends and we often spent time together before the HIV/AIDS status. But when they came to know about this they stopped talking to us".* "*Whenever I come across them, my neighbours stare at me. They do not talk to me. It is very painful. I have only two children but they are negative. Even then they are not getting friends of their age. The neighbours have refused to play with my children."*

Discrimination in Health Institutions

The health care providers are required to give treatment to the people suffering from any illness with care and sympathy. But it has been observed that the doctors have denied providing service to the HIV/AIDS infected person or women under the pretext that they cannot provide the special treatment required by them and thus they are violating the rights of the infected people. In case of HIV/AIDS, the health care system is required to do diagnosis and provide counseling and support. After the diagnosis, they have to follow ethical guidelines, with reference to disclosure of HIV/AIDS status informing the patient. This follows against a backdrop of post test counseling. The patient has to make the choice and decision regarding further disclosure, in order to maintain confidentiality. But it has been observed that the victims were accompanied by other members of the family. Thus their status is revealed to their family members when HIV/AIDS is diagnosed. The doctors inform the patients and the person accompanied, if he/she is knowledgeable or not. Sometimes, the patients are asked to bring a responsible

member of the family such as husband or mother-in-law or father or brother, etc., so as to reveal the diagnosis. For example, there is a woman who is working as a nurse in a private hospital. She said that she went to hospital alone to get HIV test done but the medical staff didn't inform the results to the patient but informed her brother who disclosed her condition in front of everyone in the family stating that it was very bad. From that day onwards, the family members did not come close to her. They did not allow her to go outside and talk to the neighbours. They felt that they would be in trouble in future because of her[18]. Some women were denied delivery facilities in private nursing homes and were referred to the general public hospital. Even in general hospitals, they faced problems and were not treated. One of the respondent, Pallavi(35), a widow, says,

> *"….. Doctors refused to conduct delivery for me in the hospital as I was infected with HIV. Further, the doctor asked my aunty to conduct the delivery as guided by the doctors."*

Discrimination always hurts but it hurts most when it comes in healthcare settings because people who go to hospitals are already in physical distress or pain. One respondent Anita (30), a widow, shared her feelings towards health care system :

> *"…..We, HIV infected people, expect that at least doctors should help the patients. They are doctors for us, but if they do like that, how do we believe that other people will take care of us?"*

[18]In an ILO study (2002), on the extent of stigma and discriminationinIndia, it has been found that nearly 34 percent of the HIV+ people interviewed had mentioned that they had faced stigma and discriminationinhealthcare settings. It has been observed in the other studies carried out by Indian scholars and others that the common forms of discrimination faced in the health care setting are the following: refusal to attend to HIV+ pregnant women and to conduct deliveries; refusal to give injections, food and to change bed sheets; and refusal to do surgery. There are some common forms of discrimination faced by HIV+ people at the hands of healthcare providers in Hyderabad also.

In some cases, the victims are separated from other patients. The staff have refused to provide personalized care. The food and medicines are given to them from a distance. Ayesha (28), a widow, says,

> "……*when I went to ENT hospital in Koti, the doctors treated me very badly. The doctors spoke to me from a distance and they didn't even touch my file."*

> Further, she says, "…..*whenever I went there they attended me at last". "…..… One day, when I was talking to the aaya of that hospital anotheraaya came and told in front of me that she should not to talk to me as I was infected with HIV/AIDS as she would also get it if she continued talking to me. In this way, she had hurt me. Thus, not only doctors, but other supporting staff also stigmatise the infected person. No wonder, the behaviour of the aaya or others would not be different, if the doctor herself or himself behaves indifferently."*

Another woman,Kondamma(26), says,

> "…..*when I got admitted to the Chest Hospital at Erragadda, the doctors were not regular in the hospitals and they never visited my ward and never looked at me or other infected patients*".

> Further, she said, "…..*even the nurses did not give medicine to my hand. They just dropped from top into my hand. Whenever this happened, I felt very bad and thought many times why god doesn't grant me death."*

Thus, from the above statements, one can understand the pathetic situations of the HIV/AIDS women. It is cruel behaviour of the hospital staff. The discrimination

in healthcare settings is beyond description. When the victims require a sympathetic attitude, they are treated badly by the hospital staff. Thus, one can conclude that such responses perhaps exist out of ignorance of the staff; they are not sure about the mode of transmission of HIV.

Experience of stigma and discrimination in Work Place

The majorities of the infected women are not working and hence have no experience of discrimination at the work place. But there are six infected women who have experienced discrimination where they had worked as domestic servants. One of themMeera(36), a widow, who has worked as an *aaya* in a private school has the following experience:

> "……*I was infected with T.B and HIV. One day, I had fever, so I took leave from the school where I worked as aaya. As I was liked by the principle of that school, I showed my medical document to him. So he asked me to take leave for some days and asked me to come to the school after I recovered. But after a week when I went to school sir told me not to come to the school as they have appointed some other lady in my place. On my instance, the principal told me that as I was infected with HIV, it would be dangerous to the other people in the school. That's why he removed me from the job."*
>
> Later, she states "…..*now I am looking for a job to take care of my parents and my children as no one is there to look after them. So I am looking for a new job and now I have decided not to disclose my status to anybody."*

Rajamma (28), a widow, says,

> "…..*one day, I fainted while cooking food in the landlord's house. So I was taken to hospital where the HIV test was done. When the test came positive for the HIV, I was asked to search for another job. I was working in that house foralmost three years but because of this, I had to leave the work."*

Another married woman Gayatri(35), says,

> "……*I lost my job because I was reducing my weight day by day, so my owner suspected that I was infected with HIV so they asked me to leave the job."*

Thus, from the above statements, it is clear that women with HIV positive will not be able to continue in employment. No one likes to employ a woman with HIV status. The landlords do not allow them to stay in their houses as it is believed that they are not of good character and it will have an impact on them and other people living in that locality.

Stress due to economic loss

The stress is related, not only to the stigma and discrimination, but also the challenges that are posed to the victim. The victim finds herself over-burdened to take care of her sick husband and or a child. The economic loss due to this requires some kind of substitution for which she has to earn or she needs support of parents or brother. If she has to work or earn to compensate husband's earning, gradually she finds very stressful as she gradually enters the second stage or next stage of infection. When she fails to acquire the economic security, it too adds to the stress she is already undergoing. She has to receive some support from parents or brother for survival. She acquires a new status of being dependent on

herparents. This also adds to her stress. In the following pages, the stress arising from economic reasons is examined.

Burdened family

AIDS has created a severe economic impact on the household. The effect of HIV infection is obvious. The death of one partner affects the family's access to resources. The economic effect of AIDS is felt first by the individuals and later their families[19]. This has led to rapid transition from relative wealth to relative poverty in some families. The impact of the disease within household varies according to their productive activities, and the economic and socio-cultural context in which they live.

In many cases, economic situation even prior to the HIV/AIDS diagnosis was not sound enough to meet to both ends satisfactorily. The HIV/AIDS worsens the situation thereafter. For most of the victims, their economic life gets adversely affected due to the HIV/AIDS. In the beginning, before knowing the illness and at the time of the sickness, they used to spend most of their earnings on treatment. The immediate impact of the disease is depletion of savings and drastic decrease in the income. In several cases, the husbands held unskilled jobs and they were daily wage earners, so when they did not go for work, they lost the wage for that day. Whatever little they earned was spent on alcohol and because of this, they were unable to buy medicines and were not taking medicine regularly. They frequently fell ill and henceforth put women in great distress. As the majority of the women are housewives, their job is to look after the husband and their unmarried children. Since the woman has to take care of the sick husband or children or sometimes herself, the situation creates emotional stress as to how to

[19]These effects then ripple outwards affecting firms and businesses and the macro- economy of the country.UNAIDS (2004) finds that household responses differ between urban and rural settings. In urban settings, households often resort to informal borrowing and using their savings. Rural households tend to sell their assets, migrate or rely on child labour.

meet the expenditure. This is another kind of suffering, besides economic deprivation.

The widows are very poor because of the depletion of financial resources. Given the medical costs and meager income, they are unable to meet the minimum needs. In this situation, taking care of their children is now a big problem. The death of husband puts the burden on them to meet the expenditure on clothing, paying house rent and children's school fees. One victim said that she was evicted out of the house by the landlord, because she was unable to pay the rent.

A similar observation was made in Mumbai by Ranjan Singh and T.N Sathyanaryana (2006). Their study reveals that the first and the most basic impact of HIV/AIDS is on the economy. These households are already poor and the episode of HIV adds to the problems through increased medical costs, transportation costs and expenditure on obtaining adequate nutritious food. Further it was found that the households often reallocate their resources to cope up with the disease, example, withdrawing children from school to help at home, working for longer hours, selling household assets or turning to friends and relatives for cash and other kinds of assistance**.** The **s**ame has been observed in the present study.

Women and Children

Children who are dependent on their parents are particularly vulnerable to stigma and discrimination. They also experience the economic burnt. Because of the effects of HIV disease and the social conditions that are often associated with it, parents living with HIV may have limited financial, social, and emotional resources to draw upon in raising their children. Furthermore, if parents become incapacitated or die, others need to take over the role of care takersfor the children.

The victim, as a mother, loves to see her child, but if she has to abort the fetus voluntarily it is a painful experience. Also, no woman would like to see

herinfant's death. In few a cases, women had to abort the fetus as they came to know that their inborn child is also infected with HIV and child will have no life after birth. Some have reported that their first child died within 10 days after the birth due to infection which was very painful. In several cases, the 2nd or third child died because of the HIV/AIDS infection in the age group of one to eight years. About one third of the victims of the present study said that one of their children is infected with HIV/AIDS. Not even one sixth of the victims are with children free from the HIV infection.

Women have children of 21 years or less than this age and most of them are in the age group of 1- 12 years. In almost all cases, the children are not informed of the mother's HIV positive status. They believe that the child is too young and tender to know about the disease. Even if they revealed that, the children cannot understand. They felt, it is also due to the fear that the children may disclose to their relatives or neighbours and, in turn, they may face discrimination from them. So it is thought wise and safest not to disclose the HIV positive status even to the children. They do not like to even to tell the children that the father died of HIV/AIDS. They believe that if the children know about it, it will have bad impression on them about the father. They said that they will wait till the children get to know about it by themselves only.

Some women who have children in the age of above 13 years have revealed their illness to them. The reason behind in informing about the disease to their children is to let them know as they are educated and understand well the consequences of the impact of the disease in the family. In most cases, they are compelled to tell the children in order to explain the economic crises in the family. The children are dependent on their parents- both economically and emotionally. For these women their children are very supportive in every manner. They are the ones who can look after their widowed and sick mother. It has been observed that the HIV infection of the parents have affected immensely in the life of the children as they are no longer able to enjoy childhood like other children and thus they are deprived of from many things.

The experience of widows living alone with children is worse than that of married women who are staying with husband and children along with parents- in- law or in the conjugal family. Some of the women after the death of the husband had returned to their natal homes because the parents could extend them support. Their children are getting comparatively good education and other support from the family members. The women are not earning sometimes because of sickness for which they feel bad. They are not able to fulfill the wishes of the children. One widow victim, Sushma(26), says,

> "…..*one day, my six year old son asked me to buy a toy for fifty rupees but I could not give him as I was not earning".* Further, she said, "*I am happy that my parents are taking good care of him.*

But this is not the case with other infected women who stay alone after the diagnosis. A few women commented that their children are lostthe education and all other facilities due to the severe impact of the HIV/AIDS in their life. After the death of the husband, the children were forced to stop going to school because there was no money. As most of the women are working with very meager income, to meet daily needs of the family. One widow,Shanta,(34), says,

> *"……My HIV infection affected the needs of my children. I am unableto give them the necessary care since am I suffering from both HIV and T.B and I am a widow and unable to go for work regularly. Because of this my two children havedropped out from school since I could not meet the expenditure on education.*

Another woman Rajamma(28), a widow says,

> *"……My daughter started working as a domestic worker for three hundred fifty rupees to pay her school fee, as I told her I am unable to pay her school fee I feel bad but I am helpless because my small*

income doesn't enable me to pay the school fees of the both the children."

The life of the women with infected children is even more pathetic. They are unable to send the children to the school because they often get sick and they need more care. When both fall sick, it would be miserable.

Conjugal family

Generally, victims are not the first ones to get to know their HIV/AIDS status. They were accompanied by at least one family member at the time of getting the test done. These members include husband, mother-in-law or sister-in-law, father-in-law or brother- in-law, brother, sister, mother, father or any other close relatives. Thus, we can say that women did not get the chance to hide the information about the disease from their family members like what has been experienced in the other countries. In countries like USA, women or HIV patients have a fair chance to discuss their status with the members to whom they want to or want to hide about their disease, where there is protection of privacy.

The relatives accompanied the woman not only when she was pregnant or sick but also a child's or husband's illness or at the time of blood donation. The status HIV was shared by other close family members. It has been noticed that gender is a significant factor against daughter, wife, and daughter-in-law. There is high level of discrimination as compared to son, husband and son-in-law, in both natal and conjugal families. The majority of women are discriminated against especially in conjugal family. As it is widely believed that only immoral people can get the infection, the WLHA bear the brunt of the blame. It has been revealed that, in the beginning, they had very cordial relationship with their in-laws and other family members and other members in the society. But as days went by, the relationships were no longer the same and they had tiffs over for very small things. Usually in some cases, woman's relations with her in-laws are less than cordial, because of the dowry demands and other small issues. In these

families,the women victims are quickly slapped with the blame of bringing the disease for their son and their grandchildren. These women are thrown out after the death of the husband by the conjugal family members. A woman is treated with dignity and respected till the husband is able to earn sufficiently for the whole family. Even if the husband indulged in drinks and gambling, the family member did not feel bad for this wayward life. The dutiful daughter-in-law is expected to take of care of him. But the moment the husband lost health and income, the wife has been found at fault. The stigma faced by widows in traditional societies is immense. In some cases, stars of the women are blamed for death of the husband; in some other, the stars of the husband are blamed. Widows also face harassment from the parents of the husband who deny them everything even though they very well know that the woman is not responsible of the disease. Most of the times, they are forced to leave the home of the in-laws in case they were living in a joint family. There has been increasing awareness that the prevailing relationships within and between the sexes, or gender relations as they are usually called, affect not only the development of the epidemic, but the manner in which individuals, groups and communities respond (Formative Research Report 2006).

It is evident from the following response that there are family members who practice the discrimination. Rajamma(28), widow, says,

> "……*In my in-law's family, they respect and care their son more than anybody else because he is their son…when their son gets sick, they look after him well and fulfill all his wishes….but when I get sick, they do not even bother to take me to the hospital for the treatment."*

Power is not distributed equally between men and women. While men are constructed as thinkers, public speakers, decision-makers and property owners, women are constructed primarily as domestic beings, whobelong to the home or

to the kitchen (Dube2003). In this construction, women do not deserve any importance.

A 29 year old widow said that when she and her husband got sick, they were treated differently. When her husband was sick, everyone helped him, but when she got sick, she was not helped. When her husband demanded something, he was attended to immediately, but when she asked for anything, they did not listen to her. The woman is expected to discharge her duties even in her sickness, but a man is always excused in such circumstances. RajyaLaxmi(26),a married woman, says,

> "……*A woman has to take all responsibilities on her shoulders even though she suffers from any illness. Many times, I had to take care of myself. When my child and husband got sick, then also I had to take care of both of them. They still depend on me because I am a woman."*

Gender and Stigma

Gender is found to be a critical factor when analysing the responses in most families. Married HIV positive women were found to be at disadvantageous positions. Not only did they have to care for their ill husbands, while simultaneously being positive themselves and in need of care, but also the in-law family provided them with no support at all, neither for their care giving role, nor for their own health status, even when they were living in joint households with their in-laws.

Rajamma(28), a widow, says,

> "…….*When my husband was ill, I used to look after him by myself. Even when I was in my in-laws' place, I used to look after him, they never helped me, even though he was their own son. They knew very*

well that even my health is not well, and I required somebody's help. But they did not bother about it."

The in- laws of the victims are normally unsupportive especially while the husband is alive, considering the fact that it is duty of wife to take care of her husband. Poor relations between the daughter-in-law and parents-in-law only aggravate the situation. They have a negative perception of the infection that the daughter-in-law is somehow responsible for the son's sickness. In some cases, the daughters-in-law are abandoned, despite the fact that they could support the family. In such cases, property distribution is the central issue after the death of the in-laws. When a person falls sick, it is the responsibility of the man's brother to take care of him. Instead of taking care of the sick brother's family, the brother creates a negative image about the sick brother's wife. In this way, they try to drive away the daughter-in-law so that the entire property can be distributed among the surviving brothers. So, in such cases, the degree of discrimination has increased because of greedy of the brothers.

Fear grips all family members because of little knowledge that they have about the disease. It has been observed that an HIV person's family members restrict the movements of the HIV women and her children. The non-infected mothers do not allow their children to play with or to spend time with the infected person, or infected children for the fear that the healthy person or children may get infected of the disease.

From the point of view of the family, having a HIV-positive member isconsidered a matter of shame. The family keeps this fact as a closely guarded secret for the fear of losing social status and inviting social ostracism. The main concern about the women or infected person with the family member is that the family will be shunned and their sons and daughters will not get good marriage alliances.

Families are the primary caregivers to sick members. There is clear evidence of the important role that the family plays in providing support and care for people

living with HIV/AIDS. It is not that all family members are having a negative attitude. It has been noticed that the women shared the HIV status with their natal family members who accepted the situation. The victims received very good response from mother and other family members. For example, RajyaLaxmi (26),a widow, says,

> *"…..…When I came to know that I was HIV positive, my mother was very supportive by coming with me to find out more about HIV and AIDS and now she can assist me with whatever things I need."*

This finding reflects on the position of women in relation to HIV/AIDS in India and has brought to light evidence that gender is a specific factor shaping experiences of HIV/AIDS stigma and support. The experiences of these women reveal that HIV/AIDS affect women and men both but it affects women differently than men. The men are being respected more than women.

The experience of woman victim of HIV/AIDS with stigma and discrimination is unusually multiple and complex. The victims have described how they are doubly stigmatized both as 'women' and as 'people living with HIV/AIDS' once their status is known. Even if the woman is not showing any symptoms still the family says you have HIV and you are not useful for the family as you are going to die soon. Some women said that even as they are bed ridden, the family members cursed them for HIV status and not allowed themto live with dignity, especially in the in-laws family.

The behaviour of man is always tolerated, but a woman's neglect of a norm is intolerable. One married woman victim,Saroja(29), says,

> *"…..My family members knew that my husband used to go with some women.……but still they do not have any problem and say that he is a man so he can go around and do whatever he likes…..but a woman is not allowed to go even from the four walls of the house.……if*

sometimes I go without telling the family they used to ask me where did I go and with whom did I spend time and often they use abusive words."

Men are excused for their behaviour even though it resulted in the infection, but women are not. The cultural norms encourage man to engage in relationships with multiple partners, but not in case of woman. Women victims felt that if a woman is diagnosed with positive status and subsequently her status is disclosed to other family members, she is subjected to unfair and unjust treatment. In this way, women are more vulnerable to be affronted by being HIV/AIDS victims.

The above finding agrees with the studies of Bharat (1996, 2001). Men received more care and support, whereas women are more discriminated in the same HIV status. They are refused shelter; denied a share in household property; denied access to medical treatment and care; and blamed for a husband's HIV status, especially when the diagnosis was made soon after the marriage.

Response of Natal Family

It is seen that the infected woman receives more support in her natal family than her husband's family. After the death of the husband, the woman may haveshifted to her natal family's residence because either she is thrown out or moved on her own. There she received support even though she is HIV positive, and usually it is the mother than father and other members of the natal family who is more supportive. For a few it was seen that their father has come forward when they received ill-treatment from their own mother and other family members. It is the father who encouraged and helped in boosting the confidence to live life with HIV with respect and dignity. Mother is always supportive but sometimes she too gets frustrated when things do not happen the way she desired because of HIV status. Then mother also shouts and blames her for the disease as the woman or victim is partly responsible to get it. Otherwise, most of the time, the mother helps the victim in cooking, washing and caring her and the children.

Other than mother and father, the woman also receives support from her brother and sisters. Unmarried brothers and sisters are more supportive than the married siblings. A few victims are staying with families of their married brothers. In such situation, the victim receives ill-treatment from her sister-in-law. It may be because she takes an additional burden though the victim has cordial relationship with her brother. Still she faces ill treatment because of his wife. It is the brother who has to spend his income on the whole family and to her treatment, so sister-in-law is annoyed because income gets drained away due to the victims' ill health. She does not allow her children to mingle with the children of the victim. The sister-in-law fears that her children may get infected by the disease, so she maintains distance with the infected sibling of the husband. In some cases, the victim receives very filthy words from her sister-in-law.

Self Stigmatisation

Self stigma, or felt stigma, is also called internal stigma which refers to ways that socially stigmatize themselves, some people living with HIV/AIDS, particularly those who are newly diagnosed, may view themselves as somehow guilty or responsible for their situations. They may even worry that they pose a threat to the health of those around them. People living with HIV/AIDS are in constant fear of losing their families, communities, homes, and jobs,etc, if disclose their HIV status. In order to protect themselves from such a loss, some practice withdrawing from the family or community. There are women who wish to leave their family members for ever and are looking new place for themselves because of their behaviour. Sometimes, some deliberately isolate themselves in spite of the fact that they are not stigmatised in the family.

Kamala(30), a widow, says,

> "……*I don't share my items like plates, glass, bed and other things which I used with my children and other family members as I am suffering from the T.B and HIV infection."*

It is so because Kamala knows that HIV does not spread through sharing of her items, but TB can spread in this way. Therefore, there is self imposed isolation.

Another awidow, Ayesha(28), says,

> *"…..in my family, I am not stigmatised but I insist my family members not to share the plate and tumbler that I use as I am suspicious that if I share, others may get infected, and I do not want my family members to become miserable like me."*

Rajamma (28),a widow, says,

> *"…..Doctors informed me that I cannot transmit the infection by sharing utensils and other things but still I don't share my things with my children as I am suffering with T.B, as well as with HIV positive."*

Gayatri (35), a married woman, says,

> *"…..we both husband and wife are infected with HIV and T.B. So we sent our children to my mother's house so that they do not get infected."*

From these statements, one can conclude that people living with HIV/AIDS are often influenced by not only thebehaviour of those around them, but also their own attitude. Even counseling has no effects on them. People with HIV can have

very negative feelings about themselves, especially when they are first diagnosed. However, we can say that stigma is far more than cultural phenomena of social blame and insult. When stigma generates self stigma, people living with HIV and AIDS suffer at multiple levels. And thus self stigma and stigma impact the health and well being of people living with HIV by eroding their self esteem, self respect and dignity.

Lee, Kalichman and Sikkema (2002), who conducted a study looking at the internalized stigma among PLWHA in Milwaukee and Madison, Wisconsin and New York City, found out that the majority of the victims have internalised stigma related to HIV status. They mentioned that individuals who experienced high internalised HIV stigma had been diagnosed with HIV more recently; their families were less accepting of their illness. They were less likely to ever have attended an HIV support group, and they knew fewer people with HIV. Furthermore, individuals with high internalised HIV stigma also are worried more about spreading their infection to others. Lee, Kochman and Sikkema have found out that internalised HIV stigma has contributed significantly to levels of depression, anxiety, and hopelessness.

Emotional Reaction towards Illness

Fear of Death

Almost all victims regard that HIV tag is the death sentence, and thus being diagnosed with the disease means death is imminent. The fear of death is looming large in the minds as there is no permanent cure. The people, who have been diagnosed with HIV/AIDS before five years, are totally depressed. This is more in cases who have seen the death of husband and children. One victim, Meera (36), a widow, says,

> *"……I am so scared and began to think a lot, I have seen my daughters and my husband's death. Now it is my turn". "I am more worried about the last stage of the illness. Who is going to take care of me?"*

Ramya (30), a widow says,

> "….. *I am not worrying a lot about it but sometimes I worry about myself what will happen to my children. I don't want to die now. There is no one to look after my two daughters; I want to see them to grow."*

The fear has a devastating effect on the health of the victims and actual impact of the death on the children if they die before the children are grown up. This is not true. One can live a little longer if there is proper medication and change in the life style. Even those women who are on ARV medication and positive lifestyle habits are also fearful because of family conditions and the discrimination. Thus, death is a serious threat when an individual experiences multiple losses, being faced with an HIV positive, women brought up the issue around the future implication for their children and the family at large. Even if the victims continue to live, they are not in a position to give proper support to the children because they are unable to earn due to ill health. Whatever they earn is hardly sufficient to meet their needs. Therefore, economic burden is so great that they are worried how to take care of the children and further worry is that who will provide economic support to children after their death.

To conclude, it may be said that there is sufficient evidence to suggest that women with HIV/AIDS and their family members suffer from stigma and discrimination. Woman face stigma at the hands of their own family members and the community. They are facing discrimination in health care settings and employment. They are also victims of self stigma. The nature of stigma is deeply rooted in the socio-cultural set up of the Indian society. There are so many reasons behind the stigmatisation and discrimination at different levels. The most important factor is that people have many misconceptions about the disease. After so many years of HIV/AIDS campaign, people still have less knowledge about the

transmission of HIV infection and they fear that the HIV/AIDS is a contagious infection and if any healthy person shares anything with the infected people, there is a chance of infection spreading to healthy people. They believe that HIV/AIDS means only death. Thus, the non - infected people want to maintain distance with the infected person. Women are stigmatized and discriminated more because of their low status in the society. In Indian society, the woman's condition is worse even from her childhood both in her natal and marital homes. Gender role plays a crucial role in determining one's status within the family**.** Because of the subordinate role, middle and lower class women and especially village and illiterate women are sexually vulnerable. Women are provided with rights under law but the illiterate women are not aware of their rights. If the women are aware of their rights then also they do not like to visit the police station or court because they do not want to disclose their family matters in public places as it brings shame for the entire family.

Thus, an abused Indian woman is, in most cases, not protected by anyone. Although they are given comfort and sympathy by their friends and neighbours, the mother-in-law is often the greater enemy. Women always receive ill treatment from their in-laws even for small things also. But when a woman is diagnosed with HIV, her condition gets worse. She is blamed for the disease and considering unlucky for their son and for the whole family. Instead of getting care, she will only receive blame for the disease. If anything goes wrong anywhere in her family or natal family the blame falls on her only. Despite knowing the fact that the woman must have contracted the virus from her husband she is blamed by all. Even though women are innocent so far as HIV/AIDS is concerned, still they are not taking any action against those who unnecessarily blame them. They are being thrown out of the house for no fault of theirs.

After the death of son, some parents refuse to take the responsibility of the well being of the daughter-in law. Instead, she is asked to leave the house. So, women have no alternative except to go back to their natal family or else she is forced to support herself. In several cases, women are not getting any support from their

maternal homes. Woman has not been taking care by her own siblings in difficult times. They are also denied a share in the family property because HIV means early death. The issues which hurt women with HIV the most is the denial of the right to live and denial of any rights in parental property and in her in-law's or husband's property. She is hurt badly when the family members or community members point fingers at her character, even though they know she is innocent.

Fear of discrimination often prevents people from seeking test or treatment for AIDS or from admitting their HIV status publicly. Not only in India,people are still having the perception that the HIV/AIDS is a contagious infection, but also in other countries (Nyblade, et al., 2003).People suspected with or suspected of having HIV are turned away from healthcare services, removed from employment, evicted from home by their families and rejected by their friends and colleagues. The stigma attached to HIV/AIDS can extend into the next generation, placing an emotional burden on those left behind. So in order to tackle this situation women empowerment needs to be taken up by social interest groups because, by and large, women have no voice. A woman, in general, is unable to take decisions about her own well being.

The government has provided many provisions for women to fight for their freedom or fight for their rights. But in Indian society, many of the women are illiterate and so they are not aware of their rights. Women can be empowered only when they get proper education and know their rights. The government should facilitate women to exercise their rights also. Indian Constitution guarantees right to education through Article 10 of the Constitution. But still, literacy among women continues to be abysmally low. The disparity between women and men shows that the female literacy has remained constant 25 percent between 1961 and 1991 Census. According to the Census 2001, though 54.16 percent women can read and write, an overwhelming 245 million women are still illiterate, making this the largest section of unlettered women in the world. More than 50 percent of girl's dropout of school by the time they reach middle school (DFID Report 2006).

Stigma and discrimination act in the life of HIV/AIDS infected people means a violation of the basic Fundamental Right to live. A person who has been infected has to face the brunt of the disease, the perception and attitudes of the family members. The community shapes the individual's own perception and attitude. When community members and family members believe that the person was affected of the disease because of bad character, it impacts the self-worth and self-esteem of the individual which severely degrade the individual. This results in a fatalistic view of life and moreover woman who feels herself hapless and thinks that this has happened because of her *karma* (deeds). Accepting discrimination meekly without any resistance at the natal and marital homes, the HIV stigma only adds to the burden. So there is need to empower women and create awareness about their Fundamental Rights in general. Only with this, the women will be able to combat with the situation.

There are a number of NGOs and government agencies which are working towards overcoming the HIV related stigmas. The NGOs are trying to empower and enable the HIV infected women to exercise their Rights. Not only this, they are also helping and supporting the HIV infected persons to cope with the consequent diseases. These organisations are providing services of counseling, shelter and other monetary help and so on, to the HIV/AIDS infected people who are not receiving any support from the family members. The next two chapters will discuss the different coping mechanisms used by the HIV infected women and the kind of support they are receiving from the organisations from both victims' point of view and from the organisation's point of view.

CHAPTER-5
COPING STRATEGIES

The earlier chapter makes it clear that HIV/AIDS victims have experienced extreme form of discrimination and stigmatisation in the family, neighbourhood, workplace, in hospital and so on. It is a challenge for them to withstand the stress and tension generated by the discrimination and stigmatisation, on one hand, and living with the opportunistic diseases in their bodies, on theother. They have to cope up with these two. This chapter will examine the coping strategies of these victims. First, an attempt has been made to conceptualize the theoretical position in this regard and then examine the ground reality.

The theorization of coping strategies largely focuses on psychology of the affected individuals. According to Caplan (1964, 1974), first the individual feels the stress and then reacts to the situation. The reaction depends upon on the strength of the ego to face the situation. The strategies to cope up with the stress depend again on the sources of information and availability of information. At the same time, the individual experiences and expresses the positive and negative feelings of stress. The problem is broken down into bits and pieces so as to take appropriate action to manage the stress. Help is sought from others as well. In this kind of managing the feelings, one has to trust oneself and maintain optimism about the outcome. This approach is quite comprehensive to deal with the coping behaviour of the individual. Lauzars and Folkman and others (1984) have placed the onus mainly on the cognition of stress and cognition of availability of resources to meet the challenge of the stress. Thus, psychological state of the individual plays a significant role in developing coping strategies focusing mainly on emotion and problems that the individual faces. That is, some strategies are to deal with the psychological problems, i.e., emotional, whereas other deal with the sociological problems. Parker and Endler, on the other hand, concentrate on the practical way the individual handles the situation to deal with the coping

strategies. It involves in choosing between approaches like avoidance, engagement, disengagement, and so on.

It is said that HIV/AIDS infection is a silent killer and so the victims of the HIV/AIDS also show little concern in the early stages of the virus infection. These stages are described already in the previous chapter. More so, the infection never shows up any severe symptoms like pain, fever, cough, etc., in the infected person in the early stages. But as far as the socio-psychological and economic conditions are concerned, there are far more serious implications which demand different behavioral patterns from the victim and so the family members and others will have to come to aid the victim.

In the light of the above discussion, the situation of women victims of the HIV/AIDS is analysed, taking emotional or psychological, as well as the sociological, problems that they had to face. Further, as Shinn, et al (1984) have pointed out, coping strategies occur at different levels: individual, societal (family) and service agency. Therefore, strategies of the individual also would be in response to society as well as service agency. Following these theoretical approaches, the present chapter presents the analysis of coping strategies of the HIV/AIDS victims.

I. Coping with fear of death and anger

a) Coping with the infection/disease-controlling medicines
b) Hope as a strategy to survive
c) Fate and spirituality
d) Helping and educating other infected persons

II. Coping with social problem arising out of discrimination and stigmatisation

a) Suppression/control of emotions
b) Care free- indifference

c) Avoidance and concealing the infection/disease

III. Coping with economic loss- problem of survival-gender and economy

a) Taking support of family members
b) Taking care of children
c) Self-support by taking up petty business

Psychologists have defined the term 'coping' as "the process of managing taxing circumstances, expending efforts to solve personal and interpersonal problems, and seeking to master, minimize, reduce or tolerate stress or conflict (Zeidner, et el 1996 and Snyder 1999).

Considering the fact that HIV/AIDS in not a curable disease, the victims use various ways to cope up with the stress and strange feelings attached to the infection. It is seen that 'acceptance of the infection' is the common way by which the individual accepts their living status. The common belief among them is that they cannot change their situation and health even if they would like to. Thus, in case of HIV/AIDS, some infected persons learns to understand the situation and their condition along the way with the time and others may still look on the good side of the condition and give more attention and emphasis on the better things that would bring more positive and good things in their life.

Women face discrimination both from their family members and from the society at large, as described earlier. For them, the discrimination and prejudice against HIV is a heavier burden than the disease itself, especially due to the stigma attached to their condition and the negative attitudes they receive from their own communities, especially from their loved ones. Other than this, lack of support groups that could help them especially in most difficult times also influence their condition. This kind of situation often leads them to a stress full life and sometimes they feel like committing suicide because of the stereotype response and attitude behaviours they receive from the others thereby instigating a feeling

of them being not useful to the society or to their families, hence feel guilty and shame for the family.

The coping strategies are directed at meeting the challenges from physical, social, and economic consequences of the disease. By and large, coping has been understood and defined as methods, which an individual employs to resolve his or her problems. Coping is not a single act but a group of acts and thoughts released by a set of demands that change with time. At the time of diagnosis of the infection, initially the victims express disbelief and sense of denial. But with the passage of time, they accept the reality and go through a process of adaptation.

Some coping mechanisms are unconscious and most people may be unaware of the particular coping strategies they are using. To understand this, this researcher tried to find out what they thought or did when they were informed about the disease and how they engaged themselves even though they cannot change the situation. Related things like, whether they are taking any information or seeking the company of others or trying to see the things in a positive light, seeing the situation as hopeless, avoid thinking about the problem and so on are the areas into which investigation has been made.

Coping with fear of death and anger

In simple terms, emotion focused coping refers to the feelings which has emerged during the time they came to know that they are infected with the illness. Within that, victims narrated different aspects of this emotional process, which were called upon being HIV patients. In most of the cases, the victims never heard about the disease earlier. Some of them at the time of diagnoses heard about the HIV/AIDS. They revealed what they are suffering from but they didn't inform the details about the disease. Their knowledge about what HIV is and how it will affect their life has gradually increased. Those who did not know anything about the disease were provided with counseling after they are diagnosed with HIV. They received both pre- test and post -test counseling. So from the counseling the infected people are able to cope up with the consequence of HIV/AIDS. But after

receiving the results of the diagnosis, the victims expressed a wide range of feelings. Most of them expressed deep sadness and acute hurt. A lot of emotional feelings came out which were uncontrollable and unstable.

They were fear gripped when heard about the infection, as they were told that there is no medicine for the illness, and death for the individual is at close quarters. This was shocking news and immediately turned into confusion not knowing what to do next. They were so saddened and felt helpless as no one seems to help them. That is, everyone started saying there is no place to go or doctor to see who can provide any treatment, whatever be the cost. There is no hospital and there is no doctor either in Hyderabad or anywhere else that can cure the illness. They never expected such thing can to happen to them. They immediately felt that their life has gone and they will be no more like other normal people. One of the VictimsRenuka(30), a married, says,

> "……*I was very shocked when I heard that I am HIV positive and my life is going to be changed permanently because of this."*

She explained that she was told that she cannot be cured, and would suffer, and only thing she has to do was to take medicines regularly and eat nutritious food. She wondered how she will be able to eat good food and who will provide that.

Shock is the immediate reaction to something unexpected[20]. They were not ready to accept the infection. It is because at the time of diagnosis most of them were in the second stage of the infection. Also, they led normal life's, except some sporadic sickness which is common to all. So they answered that they are normal like anybody else. When the doctor said you are infected, they simply could not believe the words of the doctor[21].

[20]Dunbar and Meuller (1998).
[21]The same was also observed by Mokhokha in her study in Tshwane, that after being diagnosed with HIV, the woman went through different emotions and the initial reaction was shock and disbelief (2000).

They were angry with their husbands for transferring the illness to them. Some women were aware of the high risk behaviour of their husbands and, in some cases, they were very sure and confident that their husbands were loyal to them. On demand some men admitted their indulgence in high risk behaviour before the marriage. This made them to get angry with the husbands for cheating them. But on the other hand, the women are blamed as they were responsible for the disease. Thus, the cheating and blame caused many victims to fume against their husbands. The anger continued not only against their husbands who are alive or dead, but against themselves also because of the hapless situation, inability to cope up with the situation, and frustration for the changeless situation. The anger comes up often whenever they think of the misbehaviour or attitude of their in-laws or neighbours who unnecessary irritated them.

According to Westbrooke and Viney (1992), anger, as a psychological reaction to the onset of chronic illness, and is often generated by feelings of frustration associated with the illness. As stated by Mokhoka (2000) anger seems to be mainly directed at the people who were thought to be responsible or infecting them. The difference in verbalizing and admitting to these feelings and anger seemed to be related to the type of relationship between the women and the person who possibly infected them. Simons (1979), views anger as integral part of the grieving process.

Doctors and counselors provide necessary information to the infected individual after the test results. The counselors tell the victims about the consequences of the HIV/AIDS clearly and provideemotional support and explain how one should cope with the disease, even informing about the life span of the individual. While discussing their condition, the counselors ensure that the person should receive immediate emotional support from the partner, family members, relatives or friends.

Even after getting all the initial information from the experts, the infected person generally will have bitter experience from the family members once they disclose the status. But gradually, the infected person and the family members start accepting the situation and try to cope with the status. Frequently, they visited the hospital for check up where they got more information.

However, some women did not get any counseling when they were diagnosed seven years back. But after coming in contact with non-government agencies, they came to know more about the disease. Some women had peer-counseling.[22]

Self Blame

In the study, there are two sex workers who admitted that they engaged in high risk behaviour, despite the warning given by the social worker about the consequences of unprotected sex with their customers. At that time, they did not know the importance of the condoms and other measures as their main objective was to make the customers happy. They ignored the danger of contracting HIV/AIDS through unprotected sex and are now blaming themselves for not taking necessary precautions. There are some other married women also who blame themselves for they were aware of the high risk behaviours of the husband, but still they engaged in unprotected sex with them without any resistance, ignoring the warning.

Coping through Adherence to medication

Victims gradually realise that they have to somehow mange with the infection and there was no point in fearing death or being angry with the husband or the helplessness situation. They understand that death can be postponed by taking

[22]Peer counseling is the way of counseling is provided to the people with HIV/AIDS and affected with HIV/AIDS by people with HIV/AIDS and affected with HIV/AIDS. In peer counseling, the peer supporters provide information and support to the persons and help them to come out from the illness through this processes. The counselors received training from the APSACS and from non - government organisation about counseling.

medicines regularly. Women believed that by taking medicines regularly they can reduce the strain or impact of the infection, maintain health, and avoid falling sick frequently and having tension which is due to HIV/AIDS. For instance,
Sakira Begum (28), a Muslimmarried woman, says,

> "……I *take my medicines daily and on regular basis from the day one …but my husband doesn't take them on time and so he often gets sick. Many times, I remind him but he ignores….but I have to take care of myself…..if I don't take medicines and get sick, who will look after me?…I have three children…I am supposed to look after them…so I take medicines."*

From the above case, it is observed that how the women expressed the importance of HIV medicines. She feels and hopes that taking medicines will help her in improving health condition which, in turn, will help her to look after their children and family. She is not having any fear of death. Similar view has been expressed by another woman Meera, who says,

> "…..I *want to stay alive for my children….. So I believe that if I take my medicines it will help me in living for more number of years…..so I can take care of my children."*

Some of them stop taking medicine after sometime, because of frustration and ill-treatment that they are receiving from their families, which impacts a lot on their health status.In this regard the NGO workers counsel and encourage them to take the medicine. For instance: RajyaLaxmi (26), a widow,says,

> "…..*organisation sir told me that if I take medicine regularl,y I won't fall sick and get any disease. By doing so, I can live for a longer period."*

In another case, Saroja(29), a married, says,

> *"…..for the last four years, I have been taking my medicines regularly but some days back I had a fight with my mother- in -law. Because of her attitude towards me, I stopped taking medicines. But from then onwards, my health is deteriorating…see my health now…but now I have decided I will not stop taking medicine whatever be the case I have to live…I have to live for my children's sake. I also guide other patients about the importance of the ARV medicines."*

Therefore, commitment of taking medicine regularly by HIV/AIDS people can be seen as one of the coping mechanisms.

Hoping to Survive

The women who are tested positive, but not yet experienced any symptoms of any disease believe that they are perfect and free from viruses. They express a hope of recovery especially after knowing that the anti-retroviral medicine that they are taking is meant for the infected people. They have come to know that by taking medicine regularly and certain precautions they are able to reduce the stress. Apart from medicines, a few are practicing yoga which also helped reduce the effect of HIV virus. They think that the difficult time will get over when they become normal. Further, they are having a hope that more effective medicine will also come into market soon which will help them.

Keerti(30), a married woman, says,

> "……I *came to know that medicine will come soon for this also and so I hope after taking that medicine, myself and my husband will be able to live longer."*

Similarly, another married woman,DhanLaxmi(27), says,

> "……*I lost my child because of this disease but I hope that one day I will become a mother again of a non- infected one."*

From this statement, it may be noted one hopes and wishes to be a non - infected mother in near future with a healthy baby and that hope helps to cope up with the infection.

Thus, People living with HIV/AIDS experienced the fear of death when they first heard about their HIV/AIDS status. But when these women openly talked about the infection with the medical practitioners and others and when they started taking anti-retroviral treatment, they got a hope of better future for themselves. Such hope makes them feel better and increase their zeal for living reducing the stress and fear which is generally experienced for the first time.

Other set of people are also there, who are more concerned about their acceptance again by their family members, who have rejected them due to the infection. A few victims said that they are living with the hope that one day their family members will accept them and they will again behave with them in the normal way like they were before the disclosure of the infection.

Priyanka(30),a widow, says,

> "…*My husband left me when he came to know about my HIV positive status. But I know that he loves me and my son. I hope one day he will come back and accept both of us. I am waiting for that day."*

In above case, the victim expressed her hope in future that one day her husband who deserted her and her child because of HIV diagnosis will soon accept them in near future.

Similarly, Vashnavi(37), a widow, says,

> "….*I only want that my brother should speak to me and should inquire about my health. He should take care of me and also allow their children to talk to me…as we used to when my infection was not disclosed."*

Therefore, hope of accepting by their family members in the near future in helping the victims to cope with disease effectively. Thus, hope can help people living with HIV/AIDS to deal with the HIV situation and help them to improve their life styles.

Rose and Clark (1999) find that maintaining hope and optimism are emotive-focused coping mechanisms to avoid the problem and to deny the facts and implications. In this sense, some of the victims are found to have been employing this mechanism to cope up with the disease. According to Consultation Report on Health (1999), people live longer when they can hope for and plan future activities, achievements and relationships. Hope sustains them through the inevitable "bad days" and increases the capacity to appreciate periods of good health. Feelings of hope fluctuate daily, and sources of hope differ from person to person. Thus, hope is sustained by maintaining employment and relationship with co-workers, becoming involved in activist groups, cultivating social and family ties, and finding meaning in new roles and experiences. (Cited from Ravichandran 2004:45)

Fate and Coping

Many women believe that it is their fate[23] to get infection, which has been employed as one of the coping strategies.[24] They believe that it is God's desire for them to live with lot of sorrow or it is the plan of God that they should suffer this

[23]It is God's plan of restitution, which has to be accepted without questioning.
[24] God causes problem as punishment for misdeeds committed.

way for which there is no escape, hence they got it and one cannot change the God's plan. So they resolved to live with it. Such reasoning 'justifies' ones careless behaviour as a preordained act. It is justified that getting the virus is written in their destiny. But sometimes they twist the argument and say that it is the form of punishment of God for their bad deeds. With this belief they think they will live the rest of life, as they cannot change the infected status even if they like to change. For instance,
Pallavi(35),a widow, says,

> "……*I think I happened to be the victim of this disease because of my bad deeds in past birth. It is only because of my earlier deeds that God has given me this disease and made me to suffer from it. "*

This notion of fate among the people is so strong that they accept the disease with a strong resolution, implying their adjustment with the changed health condition. This perhaps helps a person to look for some positive changes in the health as one gets to know about the disease in course of time and that person is able to handle life of infected status normally. This is a psychological adjustment with the disease and a step towards taking it as a challenge.

Enhanced religiosity

The respondents expressed religious beliefs and practices to handle the diseases either negatively or positively. In a negative sense, the responsibility lies with God: they are now suffering because of their bad deeds in last birth. In another sense, it is their fate. To come out from this kind of metaphysical dilemma, the victims try to involve themselves in praying to God in whom they believe. It is believed God alone will help them now. A Muslim woman says that she prays to Allah that she can survive and help her children for getting proper care. There are others who turned to Jesus under the influence of friends and Father of a church who told to them to have faith in God who will provide relief from the stress and the problems. These women say that after believing in Jesus they found a change in their lives. They visit the church for spiritual support and giving thanks to God

who heard their prayers. The other women also said that they often offer prayers to their respective Gods to get rid of the problems which they are facing.

Rajamma(28),a widow, says,

> *"…..…When I worry a lot I go to church…I tell the Father about my problems and he prays for me and sometimes I go and pray by myself."*

Another woman, earlier a sex worker, Kondamma(26), says,

> *"…..I pray to God that I might get better".*

Almost all the victims believe that it was God's will for them to get this kind of punishment. So pray regularly and request god to give life until their children stand on their own feet. Spiritual coping strategies, involving relationship with self, others, Ultimate other/God or nature are found to be helping individuals to cope with their ailments. This may be because of finding meaning, purpose and hope, which may nurture individuals in their suffering[25].

[25]The use of spiritual or religious coping strategies is restricted to individuals who hold religious belief (Baldacchino D Draper P 2001).Folkman (1997) in the study of gay caregivers' coping processes identified spiritual beliefs and practices, which intensified after the partner has passed on. In the present study, religiosity was observed either positively, in the sense that the victims were praying for the well being of children and family. Or negatively, by having thoughts of their faith being tested or it being a punishment from God - hence the question from God that why he or she got this disease. Melnick (2002), found among voluntary caregivers, faith as one of the coping mechanisms employed in the arena of HIV/AIDS care giving. Cotton S, et al (2006) observed most patients with HIV/AIDS belong to an organised religion and use their religion to cope with their illness. Thus, faith is one of the coping mechanisms employed in the arena of HIV/AIDS patients.

Helping and Educating other Infected Persons

Some victims are engaging themselves in helping and educating others with HIV-related problems as outreach workers for an organisation. It is one kind of coping strategy. Doing this, they get the strength to look at life in positive ways.One Victim, Aruna (30), a married, says,

> *"……I am working for the DAREorganisation where I provide counseling to the people living with HIV/AIDS. Not only this I have also provide knowledge and awareness to the infected family about the disease. Sometime I go for home-based care for those people who cannot come to the clinic, but are not bedridden. I encourage them to stand up and go to the clinic. This gives me great pleasure and by doing so, I feel good and forget my own problem…."*

From the above case, it is learnt that women are counseling the infected people. They encourage them for taking treatment for HIV/AIDS and live with dignity. By providing knowledge, she is getting great relief. Discussion on topics with other victims helps them to cope up with the disease. Similarly, Priyanka(30), a widow, says,

> "…..*almost all the women patients with whom I interact I always try to educate their husbands who are also suffering and tell them to stop drinking and advise them to take treatment regularly so that they can be fine. By doing this …I feel that I am doing a good job for the people."*

Therefore, by educating others they are becoming role model for them, by giving true information about the infection and sharing the experiences with the other victims, they made a great impact in lives of the victims. By doing this, they feel courageous, confident and strong. Otherwise, they will feel lonely, worried and frustrated. Lavanya(26), a widow, says,

"……I *am working for one of theorganisations. I feel happy to educate the people in my work area and convince the people to undergo the test. There are some who found to be positive, while others are normal. As I am working for the people who are also suffering with the disease like me…..I feel I am doing right thing in my life. Therefore, by helping others in providing the knowledge about the disease, I get great satisfaction".*

Madhu(28), a widow, says,

"…. *within my area, I educate people, and I convince and help them to go to the clinic. I have disclosed my status to the people. Now I don't bother much about my infection. I feel that, if God has given me this diseas,e then one good thing has given me in this life is that I should help other people like me. By helping others, I feel good.*"

DhanLaxmi (27),a married woman, says,

"*…I am HIV positive….and also felt bad when I first heard about it. But by helping similar people like me I reduce my stress and tension. I am working for some organisation and educate the infected people about how the disease is transmitted, how to deal with the situation after they contracted the disease and so on. I also tell them that they should not think that infected means people are having bad character, it is not true. Rather infected means they also have life and can live for a longer period like any other normal people, if they take care of themselves."*

Intervention programmes such as an outreach programme is one model that can be used by HIV infected people for involving themselves with the community and impart knowledge about the infection. Through this, the victims share their history and knowledge about HIV/AIDS both with members of the community and people living with the infection. Through this, the non- infected people or

healthy persons learn and try to change their attitude after seeing the impact of infection. They foster the idea that people who are suffering from the disease can live openly and with dignity. Thus, the outreach programmes use dual approach in which there is a behaviour-modification and coping with effectiveness. Because HIV infection typically occurs as a result of certain behaviour, these types of intervention programmes may be useful in teaching problem-solving skills and life options, managing symptoms, and promoting adaptive coping strategies.

Coping with social problems

Avoiding Confrontation

Majority of the women try to avoid the circumstances that place them in discrimination and stigmatisation as far as possible. They do it by not involving themselves or not interacting much with such members. They keep themselves secluded and confined to a single room. By doing so, they try to remain in their own world and keep themselves away from ill-treatment.

Vashanavi(37), a widow, says,

> "…..*in the beginning, whenever I received negative comments from my brother and family members, I felt bad as it hurt me a lot. Because of it, I often had fights with them. I even cried many a times. But later on, I adjusted with the situation and became normal with them. I avoid any kind of confrontation with them now. I feel that this is the only option I have in order to remain normal in the family. I can't do anything else other than this for my sake."*

Therefore, the victims try to avoid confrontation with their family members, as the situation makes it worse. The more they mingle with them, more worries and tensions. So they feel it is better not to engage much with family members and others associating with them who are likely to discriminate against them. [26]

[26]Similar observation are made by Ranjana Singh (2007) where most of the respondents of her study tried to avoid the situation as far as possible, especially

Concealing the HIV/AIDS Status

Some victims have not yet revealed their infected status even to their family members. However, the husbands of the married women know about their status and both of them together have decided not to reveal it to others. They have not disclosed it because of the fear that if they disclose their HIV infection, their family members will start discriminating them and may become worried about themselves and the victims. As they do not want to make them unhappy, they are concealing their status. For instance,

Mamtha, (32), a married woman, says,

> "…..*in my family only me and my husband know about the disease. We have decided not tell anyone in our family about the disease, as my husband's parents are very old and if we tell them that we are suffering from the disease which has no medicine then they will be more worried."*

From the above statement, it is clear that the woman and her husband felt that disclosure of HIV/AIDS causes unnecessary or unhelpful emotional distress on the family members. The disclosure of HIV/AIDS status may create multiple problems for the victims themselves also. So, they feel that by concealing the disease, they can protect themselves and some other significant members from pain and depression.

Similarly another woman Rajamma(28), a widow, says,

> "…… *I did not inform anybody about my infection even in my family because if I tell them, it is possible that I will face discriminatory*

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the respondents who were being verbally abused by their family members and neighbours. To avoid hearing such abuses and unnecessary fights, most of the HIV/AIDS patients preferred to stay at home only.

action from the family members and my husband is also not there. Who can look after me? For a woman how it is possible to survive with children with discrimination. So I thought not to tell anyone about this. But my elder daughter who is fourteen year old knew about this. I only told her and asked her not to tell anyone otherwise no one will allow us to enter into their houses. So I am not disclosing my infection to them."

Thus, by concealing the HIV status from victims are equipping themselves somehow to deal with the infection better, otherwise the disclosure may put devastating effects on them. Similar response was given by Rashmi (33), a widow, says,

"…..My *husband's family is blaming me for his death. They used to tell that my family members performed sorcery against my husband to kill him or which resulted to his death. They always shout at me for small things. If they come to know about my status then definitely they will throw me out from the house. That's the reason I have not disclosed my status."*

Thus,above cases highlight clearly the fact that people do not like to face problems with their near and dear ones by disclosing their health status. Since most of them face ill treatment, the best choice for them is to avoid any form of interaction or confrontation otherwise it may further add to the stress. So for them concealment is one of the means by which they cope with the infection.

Controlling Emotions

The victims most of the time control themselves, i.e., putting on a brave face, especially when they receive ill treatment from their family members. They control their emotions when they see the face of their innocent children. They say that by seeing faces of the children, they want to live for the sake of children and that is how they are getting strength to deal with the HIV situation and

discrimination meted to them. They say that showing real feelings of distress could affect the children and other family members and their worry will worsen their condition. This shows that most of the time the women try to control their anger towards the family members or others because of their children's well being. They say that if they fight with anyone in the family then the impact will fall on their children too. Thus, by controlling their feelings they were protecting from extra stress generated in the family. Vandana(26), a widow, says,

> *"…..…whenever my parents get frustrated and they show anger on me,I feel so bad that I weep, but hide myself so that they cannot see me. Otherwise it could be worse if I react and reply to them."*

Therefore, controlling emotions means, not exhibiting the feelings publicly but keeping them inside without outburst. The feelings are put up and ventilated within and expressed in isolation, without the knowledge of others. According to Lazarus and Folkman (1989), one factor that influences an individual's coping strategy is self-control. Putting on a brave face and concealing the hurt, anger, disappointment or anxiety help them to function best. Being in control of emotions help the victims to be courageous to persevere difficult circumstances and to have hope about the future.Thus, victims are trying to employ self controlling mechanisms when they are irritated by the family members. It is one of the coping mechanisms.

Living for Children

Children are the most important reason which is helping them in coping with the diseases. For instance,

Ramya(30), a widow, says,

> "*….my husband is no more…..I have three children to take care, there is no one else to look after my children if I die….though I have disease I want to live for more years so that I can do something for*

my children till I am alive. This will help them later when I am not there….I want my children to be happy."

From the above case it is clear that the HIV mother is more concerned about her children. She believes that after her death no one is there to look after her children, as she already lost her husband. She has seen the suffering of many children, whose parents died due to HIV/AIDS, and the miserable conditions in which these children live. She does not want to have such life for her children. So mother's responsibility towards her children is to give good future once. This attitude in fact help the victim cope up with the infection.

Similarly, Chinamma(30), a widow says,

"……*I don't want to die,….but I also know that I have a short life…. I have one small daughter… I will live rest of my life only for her. I don't want to show her my pain and sufferings now….I want to live my life happily."*

In this case also, it is observed the woman is concerned about her daughter, as no one will be there to look after the daughter after her death. She wants to live for the sake of her child. Kamala,(30), a widow says,

"……I *know that I am going to die soon because of this disease…..but whenever I see my child …I feel happy and forget all my sorrows."*

From the above case it is observed that woman attempt to create a happy environment for her children in spite of the devastating effects of HIV/AIDS. Her most important concerned is her children[27], who would have long life to live.

[27]Stigma makes woman's status as spoiled identity and "mentally disabled". Stigma experienced by the women in presents study confirms Goffman's idea that the women were unaccepted and avoided because they were thought as "polluted" ones because of their promiscuity. Both stigma visible (discredited) and stigma

Thus, like above cases, many of the victims have small children and the strong desire to raise them up, made them to live with the infection and disease effectively, by spending most of the time playing, talking and caring the children and try to forget about the situation. Hence, children are source of sustenance to the victims. In a way the children are helping their mothers to cope up with the diseases without their knowledge. Mothers get the strength to deal the situation effectively and look further for the future of their children.

Coping with economic loss

Seeking Support from the Family Members

'Seeking support' describes the process by which the victims sought information regarding HIV/AIDS and care, as well as economic, physical, and psychosocial support from family members. Lazarus and Folkman (1980) termed it 'problem-focused coping strategy'. When individuals are faced with a stressful situation and are inclined to use problem-focused coping rather than emotive-focused coping (Rose and Clark-Alexander 1999, Lazarus and Folkman 1980).

In the present study, it is observed that mother is the first one who received the information of HIV/AIDS status of the daughter whether married or not. In some cases, the victims informed their status to a very close family member with the hope of getting assistance and support in need. Mother helps them most of the times in washing, bathing and cooking and looking after the children of her

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hidden (potential discredited) were put on the women. These types of stigma are also kind of shadow that inherited and encompassed by the whole family, and gave discrepancy, virtual social identity and actual identity of the women with HIV/AIDS. The mother's HIV positive status brought spoiled identity to the child and whole family. Spoiled identity simply means that a person cannot be fully himself/herself to change to fit in situation(s). Aloofness/distance, social prejudice and social exclusion nourish stigma. Consequently, when the normal meet the stigmatised, the interaction grows to be tense and uncertain. However, sometimes and in some cases, stigma could be diminished or disappeared. It depends upon the individual how and what individual think about groups and persons that are the victim of stigmatisation (Crocker and Lutsky1986: 95).

daughter even when they are sick. After mother, siblings come forward to help. Among them, brothers help financially and sometimes sisters help the victim. In a few cases, both sister and brother helped for taking the victim to hospital and also looking after her health. The father sometimes encouraged and supported them. But in a very few cases, support is extended by mothers-in-law. Thus, family members are playing an important role in helping the respondents economically, socially, and emotionally to come out of the situation which they are facing.

Being careless

There are some infected women who nevertheless believe that they are physically fine and feel that they are not having virus in their bodies. The reason for such thinking is that they have not experienced any HIV symptoms as yet. These are of the view that getting HIV means people start losing weight. Since they are not losing any weight they assume that they are not infected with the HIV. They believe that HIV occurs in those women and men who have multiple sexual partners, and as their husbands are faithful to them, they do not like to think of getting or having HIV virus in their bodies. So they do not take AVR or use condoms.

There is another reason for such indifferentbehaviour. In this case, the reason is that when they visited hospitals for diagnosis, some hospitals reported the result of the test as negative and some other as positive. In the absence of accurate information about the infected status, they do not accept their positive status.

For instance, Keerti(30), married woman, says,

> "….*after my husband told me that he was suffering from the disease, I went to the government hospital for my own check up. The test showed negative result, but, at the same time, when I again went for tests as suggested by the organisation, their report showed positive. I am in a confused state…I don't know which report I should*

believe….I am in dilemma whether I have infection or not…..But I think that since two reports are showing different things my status is not yet proved, for me to lead a normal life'. She further states,'*….my health is not deteriorating like that of my husband. So how can I believe that I have the disease. I know that those who get this infection start losing weight but, in my case, nothing has happened and also I am not falling sick regularly….so I am fine and normal."*

Initially, when the symptoms of the infection are not manifested, the women do not accept the fact that they are infected. They are not willing to accept the infection till they encounter any feeling or experience any kind of symptoms related to the infection. Till those symptoms become pronounced, they have a feeling that they are living like a normal non-infected person assuming their health as being normal and fine. Nevertheless, such feelings have a positive impact in the sense that they help them psychologically to accept their situation, if not immediately, but slowly when they actually come to face the symptoms later on.

Coping Through Associating with Some Organisations

When a woman discloses her health status to the family, she is faced problems from her in-law as described and discussed earlier. In some cases, a woman has been thrown out of her husband's house and, in some cases, though she is allowed to stay with them but has to live in isolation in one corner of the house with lots of restrictions. In such circumstances, the social networking comes as a saviour and the women are provided with much needed support that reduces some of their worries and sufferings. These networks function mainly in the form of organisations that are involved in enhancing the lives of HIV positive people. It is only after coming into contact with these social network organisations the women have developed the needed confidence that they can also live with dignity. This support has helped them in coping with their situation that they find themselves in.

Joining a NGOS working for the HIV positive people play a veryimportant in this respect. After joining the organisation, one realises that she is not the only person who is living with the HIV but there are many other like her.This gives her some kind of moral strength to adjust to the new life style. About thirty two of them are associated with at least one organisation. These women visit their organisations once or twice a month for counseling and other help and these are the venues where they can share their experiences with other. It also provides them a platform to build social networks through formal or informal relations where all can narrate their experiences, share their pain, chat and develop friendship. This is evident in the response of a twenty-eight year old married woman,Saroja, who is associated with an organisation. She says,

> "…..*after joining the organisation and working for the people living with HIV, I feel it a great challenge to live. By coming here and speaking to other people, I get courage. I feel bold from inside. Now I don't bother and care about my family members who always ill-treat and discard me because of the infection."*

Other than providing them a platform to share their sorrows and pains, the organisations also provide infected people with material benefits such as medicine, grocery, financial aid, education to children and so on, though not in all cases. Sixteen women are getting material support from more than two NGOs every month in the form of provisions such as rice, ragi, flour, dal and oil. Others who are not receiving such a kind of help other than medical treatment said that they are not aware of any such NGOs that provides material support. But interestingly, one married woman,Gayatri(35), says,

> "…… *if I go and take the material from the organisation, my neighbours will come to know about my status……so I don't like to be associated with any suchorganisation.*"

On the other hand,Mangamma(28), a married, says,

> "……*I will be grateful to god if someone provides economic support to us. We are very poor people and because of this disease we have sold out many of our assets and are living in very miserable condition.*"

Thus, it is paradoxical to say whether the material support really helps coping with the infection. It helps but, at the same time, it makes indirect public announcement of one's health status which the victim likes to keep secret.

Association with certain organisations working for HIV/AIDS has helped six women in getting jobs also. They are working as outreach workers for the organisation and help other infected people by providing them knowledge about the infection and give them the courage to live with a positive outlook. Eight women are receiving educational support for their children from organisations. These women are grateful to their organisations because of which they are able to send their children to school and the children are able to continue their studies.

Thus, one can say that institutional interventions are very useful for infected people to cope up with the situation. As these organisations support them by providing medicine free of cost, arrange vocational rehabilitation, nutritional support, shelter, employment, job, placement, grant of loans and educational facilities to their children. It reduces their burden as they are not capable of getting these by themselves. Other than material support, an important role NGOs play is by providing information about the infection and how to handle their lives meaningfully. The next chapter will discuss the material benefits and support extended by the NGOs.

Some Petty Business/Job as a Coping Strategy

Some women have engaged themselves in the pursuit of some kind of livelihood in order to keep themselves busy and to get rid of the tension and stress that the situation has brought on them. For some, though total support is available from the family members, they feel that they are a burden to their parents as they are staying with them after the death of the husbands. Moreover, other than this, they themselves don't want to sit idle at home in order to avoid brooding over the issues. Hence, they have engaged themselves in some kind of small business. By doing some work/job, they keep themselves busy and remain occupied. This helps them in moving away from the mental tension and stress and also instills hope that they are also productive like any other non-infected person and can work and earn as well. For instance, Fatima(25), a widow, says,

> *"…..I don't have any problem at my parent's house but I feel bored. Every time I think about my child and about the disease. Now I have enrolled myself to the stitching classes. This way, I spend most of my time over there and so my mind is constructively occupied and get less time to bother about other things*."

Engagement with some kind of income generating activities will help them to forget about the infections and diseases and temporarily divert their mind from the thoughts as most of the time they spend in learning and doing the job. This is satisfying as their children are not a burden to the family members. Some other women like Vijay Laxmi, Lata, Varalaxmi and so on also took up petty businesses, such as petty grocery shops, cloth business, tailoring and so on near their homes.[28]

[28]Similar observations are made by Ranjana Singh (2007) that HIV victims are engaged in different kind of activities in order to keep themselves busy.

Coping strategies of families

Similar to the individuals with HIV/AIDS, their family members had the same emotional experiences when they heard about the infected status of their dear and near ones. The family, along with the person, also experienced a wide range of emotional reactions of shock, fear of losing the loved ones, and helplessness. While some in-laws abandoned the woman after the death of their sons, some parents had to receive their daughters who returned home in search of shelter and for the survival of self and their small children.

In the beginning, when the infection was disclosed to the family members, their reactions towards the victims were obnoxious. They were angry and feared that the death has knocked their door as described before. But later, they overcame such fears and the natal family members began to play an important role in providing emotional support and care to the infected women. They are, in fact, overburdened with the demands of taking care of the infected member. In addition, they had to face stigmatisation. The more distressing factor relates to financial matters taking care of the sick member, added to financially burden. These experiences and coping up strategies of the families are presented in the following pages.

Coping with Economic Burden

Generally, parents or in-laws of the victims are not working, and they mostly depended on the women's husband's income or their other children's income for the survival of whole family. When the infected son, daughter, daughter-in-law stopped working due to the illness, it caused financial crises in the family of meeting the daily needs of the family, and providing medical care and nutritious food. The financial need caused tremendous stress and frustration when money was not available. To cope up with this situation,the head of the family member would pool together resource of all the working members. So whatever meager income that they can make, is spent on victim's treatment and children's education. These families felt happy when some organisation came forward to help their daughters financially by providing loans or jobs, and grandchildren with

educational fees/scholarships. The majority of the families gratefully accepted the food provisions provided by the NGOs.

Showing anger and controlling emotions

Despite the fact that families are taking care of the women, the members at times lose patience and show their anger towards the victims. This kind of reaction becomes apparent when things are not happing in the way that the family wanted. For every misfortune or a bad thing that happens in the family, the infected woman is blamed. But later they cool down and try to reconcilate with their daughter about their misbehaviour. This means they are trying hard to control themselves when they fail psychologically to adapt to the situation.

After that, the family members restrain themselves from emotional outburst in the presence of the infected member. They believe that showing true feelings of distress would affect the victim badly which will worsen the condition. This shows that most of the times, family members live with mental tension and are controlling their own feelings about their dear ones' status. For instance, mother of one of the victim named Vashanavi(37),a widow, says,

> *"……I feel so bad for my daughter as her brother is not looking after her after knowing about her diagnosis. I am helpless I couldn't help her, I cry all the time for her fate, but hide it from her so that shecannot see me. Otherwise she will worry over my concern for her and that will aggravate her health condition. Whatever life she is having now I just want to make her happy till I am alive. As the mother, it is my responsibility to make her feel good and I should support her in whatever way I can."*

Accepting the fact

Acceptance of the person living with HIV virus is also viewed as a way where family members cope with the ill effects of the disease at the psychological level. Most of the family members of HIV infected women did not admit that they

feared the disease. This is perhaps because the family members accepted the fact that they have to live with the problem. In order to cope with the new status of their dear one, they are treating the disease like any other chronic disease, and helping the victim in their own way to lead a life like any other non-infected person in the family. Family members are assisting the victims to deal with the problem effectively in terms of accompanying her for regular check-ups, support emotionally, physically and socially. It has also made the family member themselves turning emotionally stronger for the victims and enabled her to learn from the situation. But there are some family members who find it difficult to accept the conditions which they are facing, and to learn to live with the challenges of the diagnosis, as well as the physical debilitation,when they first heard about the HIV infection. Nevertheless, they feel that they have to accept the victim's situation in a more positive spirit and accept her, and then only they can provide courage to the victim to live life happily. One of the victims (BhagayaLaxmi), a mother says,

> "……*I told my daughter to tell and share with me whatever apprehensions she is having. I suggested to her not to conceal any form of difficulty and feeling of hurt. I wanted her to say everything to me. By doing this at least she will get relief and, in this way, I may also help her to come out from some of the problems."*

This shows that this kind of encouragement of family members leads the victims to a free talk by which they try to cope up with the situation. This kind of sharing also results in feelings of relief and acceptance for both the family members and the victim.Thus, acceptance of the life with the infected status by the family members to some extent is an encouragement to the daughters and other infected members to live openly with the virus in order to reduce the burden. Outwardly, the members express being okay but actually they are not okay. This strategy is to initially nullify the negative impact on the health of the victim and they are afraid of losing the dear one if they show any negative feelings.

Feelings of hope

Although the families of infected women have accepted the fact of life and also expressed helplessness and feeling of confusion, they are really hoping for the best. They are in a hope that one day the things will be fine for the infected daughter, her children and a great relief to the members in the family. This sense of hope is present due to the results of the ARV's medicine which are supplied free of cost. They feel that, by taking the medicine, the infected member will get cured soon and will be able to look after herself and her family on her own. For instance, one of the infected womanmother says,

> "……*now I am relieved from tension of my daughter's life, with the supply of ARV's medicine to her. I feel that now everything will change, my daughter will get cured and her son will not be motherless."*

The families are also having a lot of hope on government andNGOs. They believe that in future the organisations will do something for the infected families. As most of the family members who are accompanying the victim's group meetings organised by the NGOs are receiving information and knowledge about the infection and other activities. Such hopes made families to look at the positive side of life for the infected person in near future.

Concealment and avoidance

The family member who gets to know about the HIV/infection women often conceals the health status from other family members and relatives in fear of getting discrimination and stigmatisation. They fear that if any relative comes to know about it, they may stop visiting the family. Not only this, they also fear that their other children will not get good marriage proposals if someone knows about the HIV/AIDS status of the infected member in the family .

The families, whose HIV/AIDS status has been known to other family members and to neighbours, tryto not mix much with them. They feel that if they

mingle,there is a chance of others coming to know about the infection. So in order to avoid any kind of negative reaction from others, they think it is better to restrict their interaction to only those who know about the health status of the victims.

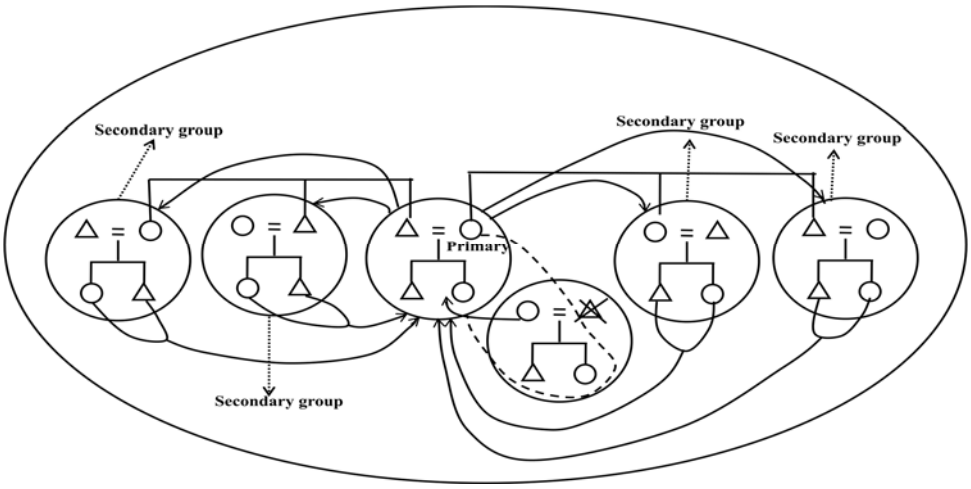
Fate and Religiosity

Like HIV/AIDS victims themselves, their family members also believe that it is the fate of their dear ones to get the infection/disease and to lead life with it and it is not in their hands to avoid it. The family members are also turning towards their respective gods for spiritual support and praying for a better life of their dear ones. They pray for the recovery of their children soon. Some families feel it is god's wish that such things are to happen in their families and they are helpless. They cannot change anything and are accepting the things that have happened to them according to god's wishes. It is a positive acceptance of the situation as something unavoidable.

Gathering support

The family members are also gathering support from different institutions with regard to the information on HIV/AIDS and care when there is a member with HIV status. They are also seeking economic, physical and psycho-social support from relatives, NGOs, health care workers, etc. A few of the family members have disclosed the infected status of the women to their relatives so that they could get assistance from them in times of dire need. There is greater consolidation of social resources using social kinship. The ripples are spreading to secondary groups also.

Figure: 5.1, HIV effects: Consolidation of Groups



Above figure shows the internal dynamic relationship between HIV woman and the institution of family. It is mentioned in earlier chapters that after the death of husband the HIV woman usually comes back to natal home either on her own or when thrown-out by her in-laws. In such case primary group of the HIV woman comes into forefront and tries to take care of her and children's survival. In this process one can observe internal family dynamics. Though woman generally first turns towards the immediate primary kin (parents or brothers or sisters) may be unable to provide her assistance, but, then if not immediately but later they approach the secondary groups support under the compelling conditions. Here the secondary group members that include HIV woman's mother's sister or brother and their children come to support the family which is in need. In other words, the primary cousins and their families of the HIV woman also join her primary group who otherwise keep themselves away. Thus, the dependency of HIV woman on her family reveals that there is a consolidation of kinship groups at the time when any kin member face suffering or difficulty.

From the above discussion, one can say that the stigma and discrimination traumatizes not only HIV/AIDS victims, but their families as well, because they also have to struggle to maintain confidentiality about the positive status. One can tackle this situation by creating awareness within the community about HIV/AIDS. This will be advantageous in two ways.Firstly, the spread of the virus

would be controlled.Secondly, the community would be sensitized to the experience that families of HIV/AIDS victims have to undergo. With this intervention, one can also eliminate myths and misconceptions about the disease, thus help in minimizing the stigma that is attached to the disease.

But presently, among women who are living with HIV status, it is seen that they and the family members are both adopting more or less similar kinds of coping strategies to deal with the infection/disease effectively. In the case of women victims it is found that they are applying individual efforts and efforts from family members and other social groups providing them help in coping with the infection. Denial of the infection, avoidance of confrontation that led to ill treatment, concealing the HIV status and staying economically productive are some of the ways by which they try to live their livesas normal beingsto the extent possible. One can also state that generally family members are playing very significant role in the lives of HIV infected people. They are providing all forms of strength and support to reduce the tension and stress with the knowledge of having the virus that they are getting from the NGOs. It is also noticed the families have achieved the success to some extent in coping HIV situation. Many women have emphasized upon the importance and the value of counseling about the HIV/AIDS that have helped them and their family members to bravely face the emotional upheavals.

Lastly, it can be said that the role of counseling, training and education are important mechanisms for the HIV infected women since these strengthen their coping mechanisms. But, other than psychologically improvement, one does not find much improvement in terms of their economic background. The women are still living in dire poverty, though some of them are fortunate to receive material support from NGOs, but the rest of them live in miserable conditions because of poverty. It has some implication in the sense that this, in turn, influences the poor coping mechanisms among those who are living in poor social conditions.

So far, the discussion has centred on the coping, mechanisms or strategies adopted by women in general. In the following pages, the analysis will focus on the different experiences and coping strategies among the woman who are having husbands,vis-a-vis widows, women living independently vis-a vis women living with in-laws, differential experiences among caste and religious groups, illiterate and educated women. Finally, the disposals of the dead and changing practices of it are discussed.

Residential patterns of women victims in married status and widowed victims

While more than half of the married women victims are living with their husbands independently away from the husband's family members, the rest are living with the husband's family in a joint family set up. In contrast to this, majority of the widows have gone back to live with their parents after the death of the husbands except a few less than a quarter who are living independently. Only one woman is living with her in-laws, but even in this case the woman has become a widow very recently.Therefore, she may be in the transit stage to join her parents. Thus, it is evident that in-laws are not supportive to the widow victims or widows are incapable of adjusting with the in-laws after the death of the husbands. But for the parents, it is a filial obligation or obligation of the sibling rooted in the cultural norm of taking care of a daughter or sister who is in a crisis situation. Even in the case of natural death, if a young woman becomes widow, she may like to return to her parents and they may not refuse to provide a shelter to her. A middle aged woman usually does not return to her parents with her children, she may continue to live where she is used to live with her husband. But in the case of HIV/AIDS, the many victims desire to return to their parents because they need the social and economic support for themselves and their children. In the former case, the widow can carry on her life by some means of living and take care of her young children, but in the latter case, she is unable to take care of herself and her children.

Economic problems and discrimination among the victims in married status and widow victims

The severity of economic problem is high among women who are living alone than those living with their husbands or with their families because the burden is shared either by the husbands or his family members. Her income is supplemented by her husband in case the woman is working, and in case she is not working, the parents or the brothers of the husband are extending help. In case of widows, when living independently, the economic burden is worse. The women with husbands and widows are, however, to some extent free from discrimination by near relatives or family members who come to know about the health condition. But in the case where a woman is living with her conjugal family, the discrimination is very high compared to the one living with her natal family.

The women who are staying alone with their children are facing difficulties in raising their children. They are physically constrained when they get sick, as they cannot take care of children when they fall sick. The women, who are in the third stage of infection, live with constant fear of what will happen to the children after their death. They also live with fear that if anybody comes to know about their infection, what will happen to the children. Will society accept them? The women whose children are above 15 years are helping them in every respect, but in case of others, their plight is pitiable.

Condition of children of victims in married status and widow victims

In both cases, if the children are young and attending primary school, somehow thevictims are able to send their children to school except in a few cases.But if the children are older and going to higher classes, in several cases, the children are pulled out of school, because of economic reasons. In a few cases where the children are above 12 years, they are not only pulled out of school but are sent to work as domestic maids or work in factories as wage labourers to earn money to support the family. In exceptional cases with the help of NGOs, these children are able to continue their education.

Stigma and discrimination faced in the family.

There are nine women who are presently living in their parents' houses after the death of their husbands. These women revealed that at the time of diagnosis they were living with their husbandsfamilies and had experienced discrimination from their in-laws when their husbands were alive. They said that these women were blamed for the infection. Their relationship with the in-laws and their family members were not good even from the day they were married and the HIV/AIDS had aggravated the relationships. They often became victims of domestic violence by their in-laws and husbands. For instance,

Yaddama(34), a widow, says,

> "…..*after my husband's death my in- laws blamed me for his death, beat me up and abused me. Out of frustration, I came to Hyderabad and am now working as a domestic servant here with the help of an uncle who had brought me from there."*

Sujatha(30), says,

> *"…..when my husband's family came to know about the health status of myself and my husbandthey separated us and confined us and our children to a single room to live and a bathroom to use. They did not allow to have a common kitchen".*

Another woman, RajyaLaxmi(26), a widow, says,

> *"…..when my in-laws came to know about mine and my husband's HIV status, they sent me to my parent's house and also denied the share in the property as they believe that we both will die soon"*

Another woman Shravanthi(36), a widow, says,

> "…..*my in-laws have taken away all my gold ornaments and do not want to return the same. They are saying that they have spent*

everything on my husband's treatment and exhausted all savings. So they didn't have to return the ornaments. Even my mother in-law said," whatwill you do with the ornaments as you are going to die soon?"

From the above episodes, one can understand the social and economic situations of the widows.After the death of their husbands, the women have shifted to their parents' houses, to be free from the torture and abuse from their in-laws.

Stigma and discrimination faced in natal families.

In a few cases, women who are living with their parents are also facing negative attitudes. These women are sometimes abused by their parents, when the things are not happening positively. They were blamed for that. For instance, onewoman RajyaLaxmi(26)a widow, says,

"…..my parents are looking for alliance for one of my brothers but since he is not getting good proposals my mother says it is because of me."

There is a case of a woman who says his son does not listen to her at all and even beats her up, yells at her and makes fun or castigates her by referring to her health status. She says it is very painful to get such treatment from her own son.

Emotional and physical challenge

The widow victims become physically weak and mentally distressed because of the opportunistic diseases. They suffer from shame and guilt for themselves. Some live in the constant fear that when their children come to know about the disease and would hate their parents. Thus, the widows face physio-psycho problems and lose interest in the daily life and neglect their health especially at the beginning of the diagnosis. Along with these, lack of social contact, sense of insecurity, isolation and other factors affect their health adversely. They become restless, irritated and frustrated due to the distress with fear when they think about

the future of the children and their health in the last stage of the illness. Most of the women withdraw themselves from talking with friends and relatives and isolate themselves from others and thus suffer from personal loneliness in life.

Status of women staying in rehabilitation centre

There are three women who are staying in the rehabilitation centre. Among these, two are sex workers and one is a widow who is staying in one of the old age homes. According to one woman, she experienced discrimination. No one talked to her and everyone staying in the rehabilitation centre avoided her. But after the counseling by the organisation, now everyone in the centre is good towards her. When she gets sick, the friends come to her help her in washing and bathing. One woman is supported by an NGO but staying in a rented house. But she has been harassed by the neighbours. She feels her situation is better than the one staying in the rehabilitation centre. The organisation is very cooperative, yet her problem is that she is entirely dependent on the organisation for the survival of her and that of her small children. She cannot provide a good life to the children. She wants to work outside and provide a good future to her children.

Education and knowledge about the HIV/AIDS women

As far as education and knowledge about HIV/AIDS is concerned, the illiterate justify that they got infected because they are uneducated and belong to the poor families. However, the educated women blame the educational system and government for not including such aspects in the curriculum that will bring awareness about the HIV infection. Thus, there is a significant difference in perception about the infection among the illiterate and literate people, especially from the women those who have completed their senior secondary school. As far as education and coping strategies of HIV/AIDS are concerned, there is no significant difference between the illiterate and educated ones. All the women live with fear, shame and guilt after knowing their health status. As far as coping strategies are concerned, similar strategies are noticed in all educational groups, like one who is illiterate did not disclose the infection to family members due to

fear of harassment and stigmatisation, even a graduate woman did not tell her status to the family members for the same reason.

Caste and religion of the women victims

It is generally women from the economically weak sections who become victims of the HIV/AIDS. For a lower caste person, with low economic status it is very difficult to lead life with HIV/AIDS. Irrespective of the caste identity, the situation of woman is very bad. These women are victims of domestic violence, manifested in verbal abuse accompanied by physical assault and also sexual assaults. The alcoholism of husbands also contributes to this domestic violence. Thus, there is no significant difference with regard to the caste background and discrimination among the victims.

It is interesting to note that out of six, five of the Muslim women who did not blame their husbands for contracting HIV infection. The reason could be that the women got married close relatives in young age. The family members clearly understand that the woman is not responsible for the infection, as she got married at young age and she has been under close observation of the family members. These women are married to a cross or a parallel cousin. This close kinship ties with the family prevented them engaging in the blame game as they liked to continue the same cordial relations. In one case the woman did not disclose the status to the family members as the husband of that women is suffering from T.B and the family members had been attending to him carefully.

Health seeking behavior among the women with husbands, widows and other women

The women who are diagnosed with the HIV/AIDS may or may not be vulnerable for the opportunistic infections in early days of the diagnosis. When they fail to take the treatment, there will be rapid decline in CD4 T-cells which will lead the victim to the opportunistic infections. They require treatment in order to reduce the sufferings of the PLWHA and to lead an active life. None of the women with

their husbands are seriousnow about treatment except two whose CD4 is down and are infected with T.B whereas the majority of the widows are suffering from the opportunistic infections. The women generally spend most of the money first to take care of the husband ignoring their own health until it got worse[29]. By the time the husband dies, their health deteriorates and then become seriously ill. By then they have already spent whatever they had in the private hospitals. When they lost all the money, they approached the government hospitals being referred by the private hospital and others for free treatment. There are a few women who are suffering from sexuality transmitted diseases but are not consulting any doctor because of shame.

Challenges and problems faced at the time of death

The HIV/AIDS person and his family not only experience discrimination and stigma while the person is alive but face different problems and challenges at the time of death. The relatives, neighbours and friends do not come near and touch the dead body for fear of getting infection when the cause of death is known. If the person dies in hospital, they do not even get transport to bring the dead body home for performing the customary last rites before the funeral. Even if someone is ready, the charges of tempo or taxis are exorbitantly high but there is no alternative except to pay the demanded amount. Not only this, the driver of auto or tempo also puts some rules or conditions to finally take the body for taking some precautions. In one case, it was observed that the tempo driver first asked the family members to put a plastic cover and then only the dead body was allowed to be placed in his tempo. Not only this, in two cases,it was found that the relatives also did not come forward to lift the body for placing it in the taxi.

[29]In the study conducted in Zambia it is learnt that women reported that when money was limited, households often chose to spend treatment for the men rather than on women. (UNAIDS/UNFPA, UNIFEM 2004).

Sujatha (30),a widow, says,

> "…..*my husband's family and relatives did not come forward even to lift the dead body of my husband.Hisown brother hesitated to lift the body in the beginning. But later when the NGO staff touched and lifted the dead body, with shame he also came forward and lifted the body*."

If the community/locality people know that the person is dead due to HIV/AIDS, they will not allow the body to remain for a long time in the area. If the person lived in the rented house, the condition will be worse. The owner would not allow the family to keep the body for a long time and force the family to take the body as soon as possible. In one case, the woman and her husband's friends took the body to the cremationground. According to Ramya(30), a widow says,

> *"…..At the time of my husband's death no one come forward to help me. Instead of helping, they were yelling at me to remove the body as soon as possible. My family also did not help me to take the body to the funeral site, as they do not want to touch the body……later I requested some of his friends with whom he often drank and roamed here and there. First, they also did not accept to do the favour but later they helped me to take his body to the funeral site. They held only the corners of the bed sheet on which his dead body was lying."*

So it is found that friends of the deceased victims extended help and sympathized with the family. The death brought certain changes in the religious behaviour. Usually, before the funeral, the dead body is washed with water and fresh clothes are put on by the close relatives. But in these cases, as advised by the doctors, the body was not touched.Instead water is simply poured on the body and there is no change of clothes. Among the Hindus, the body is either buried or cremated as per the customs. But now, as advised by the doctors, the dead body is invariably cremated, even by those who traditionally bury the dead.

CHAPTER-6
ROLE OF NON-GOVERNMENTAL ORGANISATIONS

As discussed in Chapter 3, the analysis of the knowledge of the general public about the consequences, transmission, prevention and attitude shows that about 83.2 percent have some kind of awareness about HIV/AIDS. However, only 28 percent of them actually know how HIV/AIDS is transmitted and equal percentage know how it can be combated. Only 20 percent of the population has the right kind of attitude. The socio-economic background of the 40 cases studied for detailed analysis, shows that they follow the general patterns of: low literacy or illiteracy, low income, unskilled labour or merely being housewives, as found in the slums of Hyderabad. These findings have implications to understand the role of the Government and NGOs in fighting the HIV/AIDS epidemic. The public still needs to be educated about HIV/AIDS, and there should be more effective ways and means to bring total awareness among the people. This massive effort cannot be carried out by Government alone. It has to be supported by other organisations and individuals as there is dire need of extension work. Since HIV/AIDS is not simply the problem of individuals alone and is a national calamity, the State has to primarily come forward to deal with the situation effectively as the victims are helpless - given their socio-economic conditions. The Government in this respect has taken the support of several NGOs. It is in this context that the role of the NGOs is examined in this chapter.

In fact, in the earlier chapter, the role of the NGOs has been briefly mentioned by making a mention of the support received by the victims and their families. But here, the discussion is on various activities of the NGOs, in general, and specific activities such as identification of the victims, supply of the relevant information, counseling, providing technical and material support, promotion of condom use and so on. The chapter includes the views of NGOs on controlling the spread of HIV/AIDS, views of the victims on the support of the NGOs.

There are various International non-governmental funding agencies of both faith ideologies and secular based, that have been working in partnership with numerous NGOs in India. These NGOs have different patterns of orientation: a) Charitable Orientation, b) Service Orientation, c) Participatory Orientation, and d) Empowering Orientation. With different orientations, these NGOs operate at various levels, i.e., city, rural and tribal areas (Christopher 2007).

According to an estimate of a website, www.indianngos there are anywhere between 1.5 million to 2.0 million NGOs working in India. Their report suggests that these NGOs are engaged in a large number of sectors, with their functions classified in terms of their involvement. Classification of their function suggest that most of the NGOs are working in the areas of care of the aged, children, agriculture labour, differently disabled people, housing and slums, on water sanitation and conservation, arts and crafts, on education, culture and heritage, women, microfinance, environment and wild life, health, rural , poverty, tribal, disaster etc. But the number of NGOs that are dealing especially with HIV/AIDS is not given clearly. But it has been observed that whether the NGO is small or big, several of them are dealing with issues related to HIV/AIDS, apart from its other main agenda. Hence, it can be said that a large number of NGOs in India are involved in tackling the HIV/AIDS issues in their own area, city, district, state or elsewhere.

The role of NGOs in dealing with the issues of HIV/AIDS can be explained through several factors. NGOs, gained prominence in the late 1980's with the realisation that HIV/AIDS was no longer just a medical problem, limited to medicos, but it is also a social problem. This thought came mainly as an outcome of the need of care and support required by those infected with HIV/AIDS. This aspect led to the realisation that HIV/AIDS has multiple dimensions with the sociological interface requiring immediate attention as was given to medical or biological front (Small 1997).

With increased rate of infections and little or inadequate response from the nation, NGOs came forward to fill the gap, in terms of getting more involved and devising solutions to the problems inflicted by HIV/AIDS. Stimulated by social exclusion, its increased spread, neglected public responsibility and threatened employment status, HIV/AIDS organisations were born in early 1990s, by a group of people who faced such challenges. The initial focus of these organisations was to meet the challenge of exclusion and member's livelihood. But today, the initiative has gone beyond looking at themselves (PLWHAS) to face this challenge but to teach the whole world about the instant need to come together to fight the dangerous infection (Jamil and Muriisa 2004).

In the USA, the gay men's health crisis (GMHC) was the first response to the needs of those infected with HIV. Small (1997) notes that specialised organisations have developed in order to respond to the needs of women with HIV/AIDS. Katz and Eugene (1976) see self-help groups as vehicles through which outcaste person can claim and grow towards new identities - redefining themselves and society. For them, self-help groups are means through which the socially excluded persons can overcome their solitariness. Through identification with a reference group, sometimes they can work towards social ends or social change. Putman (2000) argues that the increasing number of self-help groups, as in the case of HIV/AIDS, reflects the application of social capital remedies to a set of previously neglected problems that they bring were thought to be private problems into the public realm.

In India, NGOs working in the field of HIV/AIDS got multiplied because of the need to help the people living with HIV/AIDS virus who are generally poor. It has been observed that the NGOs, which are working on HIV/AIDS issues, formed self-help programmes within their organization to provide support to the HIV/AIDS affected persons. The *Indian Network of People* living with HIV/AIDS is one such national level NGO of a self-help organisation which has formed itself to support the socially excluded persons and to provide care,

counseling services and community outreach programmes to the infected people. This organisation, formed in 1997, has currently grown itself to be the biggest NGO providing HIV/AIDS related services to the infected people in India.

Context and Analysis

There are a number of organisations in the twin cities of Hyderabad and Secunderabad, which are working in the field of HIV/AIDS and helping the people who have been excluded because of the HIV/AIDS infection. For detailed study of this issue, eight NGOs are chosen.

Selection of NGOs

As stated earlier, the researcher contacted APSACS and Clinton Foundation for obtaining a list of NGOs. From the list of eighteen NGOs, the researcher approached fifteen NGOs with a request to provide information of their activities - particularly the support extended to HIV/AIDS victims. But only eight of them showed interest and cooperated for the study. So, the researcher limited the study to these eight NGOs about the nature and kind of support provided by them to the needy people. After collecting the required information and observing the functions of the eight NGOs, the following observations are made.

Table: 6.1, list of NGOs

S.No	Name of the Organisation	Location	Years of Establishment
1	Development Action for Rural Development (DARE)	Gandhinagar, Hyderabad	2000
2	Chatinaya Mahila Mandali (CMM)	Sethafalmandi, Hyderabad	2004
3	Freedom Foundation	Bolaram, Secunderabad	1992
4	Integrated Rural Development Service (IRDS)	Tarnaka, Hyderabad	1999
5	Lepra India	Marredpally, Secunderabad	1998
6	Network for HIV Positive People	Saroornagar, Hyderabad	2004
7	Prajwala- An Anti Trafficking Organisation	Charminar, Hyderabad	2003
8	Venktashwara Social Service Association (VSSA)	Malkajgiri, Hyderabad	2000

It can be said that all the NGOs are having a common mission, i.e., working for the people living with the HIV/AIDS. There is very little difference in addressing the issues of HIV/AIDS. It is also observed that, except one, these NGOs are also engaged in development issues other than HIV/AIDS. Among the above mentioned organisations, the HIV/AIDS infected persons themselves run one organization called Network of HIV + People. In other words, the persons infected with HIV virus are appointed for different jobs in this organization.

Focus of activities and Age

There are three NGOs that focus on trafficking and rehabilitation work for the HIV infected persons and not just infected sex workers (Prajwala, IRDS, and CMM)). The remaining organisations are engaged in other health and non-health related issues, along with HIV/AIDS. So, most of the organisations are working on different social and health issues, along with HIV. As can be seen from Table 6.1, out of eight NGOs, three are five years old, followed by two NGOs started six to ten years ago. Another three NGOs are 10-15 years old. Only one organisation is running for more than 15 years.

Activities of the NGOs

The NGOs cover a wide range of subjects, such as rural development, care of children, health services, women empowerment, and prevention of human trafficking. They also conduct awareness campaigns on various social issues, specifically the HIV/awareness programmes along with rehabilitation and restoration of infected and affected families.

Table: 6.2, Objectives and activities of the NGOs

S. No	NGOs	Objectives of the NGOs	Activities
1	IRDS	• To enable sustained livelihood for the street boys in the twin cities. • To prevent HIV among sex workers. • To promote organic farming among the tribals. • To increase their capacities to carry out Research and development.	• Street children rehabilitation, Rural development and micro finance, Natural resource management • Employment opportunities and & Income generating activities • Awareness programme, Referrals for care, support and treatment
2	CMM	• To organise socio-economical development programmes - with focus on welfare rehabilitation • To establish health care and drop in center • To partner with government and other non government organisations	• Works for sex workers right. • Work for women empowerment, Awareness programmes • Employment opportunities, Income generating activities • Referrals for care, support and treatment
3	NHP+/TNP+	• To function as a coalition of community based organisations and serve as the district level network of PLHA in Andhra Pradesh • To improve the quality of Life of PLHA in society through knowledge, health care, advocacy job and skill training. • To create a stigma and discrimination free society for PLHAs. • Provide employment opportunities.	• Capacity enhancement, Advocacy meets, Positive speaker bureau, Awareness programmes • Positive meets, Family counseling • Employment opportunities, Income generating activities, Family get-together • PLWHAs support groups, PLWHAs as Resource persons, Legal support (through DLSA) • Referrals for care support treatment • Outreach to access people living with HIV/AIDS
4	Prajwala	• To combat sex trafficking in all forms • To provide alternative sustainable livelihood options to survivors of sex trafficking • To reintegrate survivors in the society at large • To lobby for policies to combat sex trafficking	• Prevention- second generation/sensitisation • Rescue and restoration • Providing psycho, economic and civic aid for the victims. • Advocacy in policy and legal, Awareness programme, • Employment opportunities Income generating activities • Referrals for care, support and

			treatment.
5	VSSA	• Prevention and control of STIs, HIV/AIDS in high risk groups' behaviour • Provide care love and development for children living on the streets and living with HIV/AIDS • To promotion primary, secondary, colligate technical and professional education for physically handicapped children.	• Old age homes • Day care centres • Crèches • Girls' hostels • Girls hostel • Referral system
6	Freedom foundation	• To enhance access to quality health care and treatment for people living with alcohol/drug abuse and/or HIV/AIDS through a commitment to increasing awareness, treatment, care, support, advocacy, expanded linkages and networking and create a platform for promoting best practices and cross learning.	• Providing care and treatment to the HIV/AIDS infected persons • Providing shelters for orphane children • Referral care and support, Awareness programme
7	Dare	• Providing psycho-social pre-counseling to HIV test, To help the person for early detection of HIV • To provide the counseling and testing to HIV facility and definite spot • Provision of basic information on modes of transmission and prevention of HIV/AIDs, for behavioural change and reducing vulnerability. • Linking people with HIV/AIDs to other HIV prevention treatment care and support centres	• Livelihood promotion • Vocational training programmes • Widow pensions, old age pension, physically handicapped and orphanage • Sponsorship programmes for children infected and affected with HIV/AIDS.

8	Lepra India	• To prevent the spread and limit the effects of HIV/AIDS • IEC campaign dealing with HIV/AIDS awareness, its modes of transmission and means of prevention using all possible forms • Care, support to HIV+. Minimize the stigma associated with HIV/AIDS. • Facilitate referrals for Anti Retroviral Therapy • Partnering with NGOs who deal with drug abuse programmes, reproductive child health, young people to address HIV/AIDS issues • Partnership with the corporate sector organisations like De Beers Group and Automotive Manufacturers in setting up vocational centres for PLHA and mobile VCTC van. Advocacy & mainstreaming partnerships with stakeholders	• Provide educational fee to infected and affected children • Provide vocational training and facilitate socio-economic rehabilitation • Provide baby care kit to HIV positive mothers

All the NGOs reported that they register the patients on the basis of their HIV reports only. The programmes related to HIV/AIDS among all the NGOs are to mainly reduce further spread of HIV and mitigate the impact of AIDS. They are also to facilitate access to treatment, care and support to the infected and affected families (see Table 6.2).

According to the objectives of the NGOs, all of them provide counseling to people at pre-test and post-test of HIV. In pre-test, the counselors provide the information to the individuals and their families before taking an HIV test. In the process, the counselor prepares the individual for the test by explaining what an HIV test is and also providing the knowledge by correcting myths and misinformation that are associated with HIV/AIDS. In post-test counseling, the counselors help the individual to understand their test results and initiate adoption to their sero-positive or sero-negative status. Due care is taken on the sensitivity

of the matter and provide emotional support and help while discussing how she or he will cope with the HIV positive results. The counseling is provided to not only the patients, but also the family members. They also provide links with the other HIV prevention, treatment, care, support centres for the HIV/AIDS infected persons. The NGOs are also engaged and involved in the activities to prevent the spread of HIV/AIDS and limit the effects of the HIV infection, through Information, Education and Communication (IEC) campaign dealing with HIV/AIDS awareness, its modes of transmission, care and support to people living with HIV.

In order to perform their activities to reach the objectives, they use mass media, all possible electronic media like, pamphlets, posters, street plays, documentaries, etc., as channels of communication for infected and non-infected persons. The staff of the NGOs, especially outreach workers and counselors are responsible for distributing IEC materials and dissemination of information related to condoms, STD diagnosis and treatment. These persons visit the HIV/AIDS prone areas like slums and where there is a large gathering of people such as bus stops, railway stations for dissemination of information about HIV/AIDS. For illiterate low income and high risk population, these NGOs provide information through skits and streets plays also. Other than these, they facilitate referrals for Anti Retroviral Therapy (ART) at the government institutions. They also have partnering with other NGOs which deal with drug abuse programmes, reproductive child health, and young people to address HIV/AIDS issues. In the present study, there are three NGOs which are focusing on the issues related to sex workers and anti-trafficking programmes. They have rehabilitation and advocacy programmes for the HIV/AIDS patients. These NGOs provide care and support to the sex workers and also to the children of sex workers. When they come across HIV/AIDS patients but not sex workers, they refer them to Development Action for Rural Development (DARE), Integrated Rural Development Service (IRDS) and Shivananda organisation. In sum, it can be said that all the NGOs have the same

mission of prevention of HIV infection and also to provide socio-economic rehabilitation to the people who are already infected with the HIV virus.

Funding Agencies

The nature of agencies funding for the NGO is an important dimension in the entire gamut of activities undertaken by the organisations. The NGOs are getting funds from both national and international organisations (See Table 6.3). In the national category, there are agencies such as APSACS, NACO, Sarva Siksha Abiyan, Satyam Foundation and Saathi. On the other hand, the International funding organisations category includes Elizabeth Glaser Pediatric AIDS Foundation, Global Fund for AIDS, TB and Malaria Round II and IV KNH and Christian Churches Council for Youth and Children (CCCYC), Elizabeth Taylor AIDS Foundation. Overseas Women's Club, United Nations International Children's Emergency Fund(UNICEF), United States Agency for International Development (USAID), Disease control prevention (CDC), Clinton Foundation, Christianity Children's Fund (CRS), Global Fund to Fight AIDS, T.B and Malaria (GFATM), United Nations Children's Fund (UNIFEM), MISEROR Catholic Church Organisation, LERGER Foundation, EDUKANS Foundation, Asian Youth Centre, Japan (AYCJ), CLO Canada and Andheri Helfe Germany. Though the organisations are getting financial help from different sources, APSACS is the common funding agency for all the eight NGOs. It is the state's nodal organisation spearheading a synergic relationship with the government. There are three NGOs which also receive funds from the central government as well. From all the organisation, Freedom Foundation receives funds from most of the agencies - both national and international.

Table: 6.3, Funding Agencies to the Organisations

Name of the NGOS	Funding Agencies	Total
Freedom Foundation	National AIDS Control Organisation (NACO) Overseas Women's Club State AIDS Control Societies of Karnataka, Tamil Nadu, Andhra Pradesh and Goa Elizabeth Taylor AIDS Foundation Chennai Corporation AIDS Prevention and Control Society Foundation Elizabeth Glaser Pediatric AIDS Global Fund for AIDS, TB & Malaria Round II & IV KNH & Christian Churches Council for Youth & Children (CCCYC)	8
Lepra India	UNICEF, APSACS, USAID, NACO, ALLIANCE, CDC	6
DARE	APSACS, Satyam Foundation, Clinton Foundation, Serva Siksha Abhiyan, CRS	5
NHP+/TNP+	INP+, GFATM, CDC, APSACS, SAATHI	5
Prajwala	APSACS,UNIFEM, MISEROR, CRS, LERGER Foundation and EDUKANS	6
IRDS	APSACS, Asian Youth Center Japan, CLO Canada and Andheri Helfe Germany	4
VSS	APSACS and Clinton Foundation	2
CMM	□□ APSACS and NACO	2

In the following pages, more details of a particular organisation, namely, NHP+/TNP+ are provided. This is followed by four brief case studies to understand the impact of NGOs. Then, the detailed analysis of the role of NGOs in the lives of the victims is given.

Case study: Network of People Living with HIV positive

Telugu Network of People Living with HIV/AIDS (TNP+) is a state level self-help group with its administrative network in Hyderabad. The TNP+ runs its network in each district of Andhra Pradesh. Network of People Living with

HIV/AIDS (NHP+) is one among the networks which works for the Ranga Reddy district of Andhra Pradesh which has been studied.

Indian Network of People Living with HIV/AIDS (INP+) is a national self-help group registered as a Society, in May 1997, under the Tamil Nadu Societies Registration Act. In short, INP+ serves as a strong voice for PLHAs in India (INPLUS 2009). The INP+ aims to improve the quality of life of people living with HIV/AIDS and gives them a sense of belongingness, political empowerment and strength of spirit. It provides a voice for PLHA at the national, regional and local levels in order to facilitate systemic change in vital areas such as care and support, access to treatment and reducing stigma and discrimination in society. The INP+ has now grown into a singular national movement for people living with HIV/AIDS in India. Its secretariat is based in Chennai. It has its network in different states of India: Andhra Pradesh, Assam, Goa, Gujarat, Karnataka, Kerala, Maharashtra, Manipur, Nagaland, Pondicherry, Rajasthan, Tamil Nadu and West Bengal. The INP+ organises meetings twice every month in Chennai with their state networks where the board members have discussions on the activities and programmes of the network positive. The underlying principle of INP+ is GIPA, i.e., Greater Involvement of People Living with HIV/AIDS.

On the similar lines of INP+, the TNP+ functions at different levels of having clear-cut hierarchal levels of positions and roles. The President, Vice President, General Secretary and Joint Secretary at secretary in the state and district levels are chosen by the members of the TNP+ and each category has a different role to play for the network. Election takes place every two years. Telugu Network of People living with HIV / AIDS (TNP+) was registered on January 24, 2003 at Vijayawada. It aims to improve the quality of life of People living with HIV/AIDS and provide support for the families. During the initial establishment, the TNP+ had only 30 members but now the network has 18,640 members and, more than 36,000 beneficiaries in 18 districts. The TNP+ has its officials in various institutions and centres like VCCT, government hospitals and NGOs. These members play a key role in bringing together HIV/AIDS infected persons

to become a part of the network through counseling when they visit these places. TNP+ conducts monthly group meeting in their respective districts where they have group discussions with members, officials and non-officials. TNP+ is a self-support group and its tasks are categorised into: taking up of projects, training programmes and creating awareness in the HIV infected and non-infected people.

Funding Agencies

The TNP+ works in the collaboration with (APSACS). However, the TNP+ is mainly associated with INP+ and its sources of fund are: National AIDS Control Society (NACO), United States Agency for International Development (USAID), Family Health International (FHI), Bill and Melinda Gates Foundation, Center for Disease Control and Prevention (CDC) and United Nations Development Programme (UNDP).

Objectives of the TNP+

The aim of TNP+ is to target certain issues of the HIV positive persons. The following strategic objectives have been identified to help achieving the aim. These are to facilitate and improve access to treatment for PLHAs, to provide access to information, to promote and protect the human rights of PLHAs, to promote involvement of PLHA at all levels of decision-making, to promote social acceptance and end stigma and discrimination and to provide PLHAs with better opportunities.

For providing full support to HIV infected persons, the NHP+ has its set of activities or function mechanisms which can be categorised into various programmes like capacity building for promotion of GIPA, Family Counseling Centres, positive living projects and positive speakers. Three levels of training programmes with the members of the HIV+ have been conducted to achieve the above said programmes into three levels. First Level of training provides information on life after understanding issues affecting PLHA, basic facts on HIV/AIDS and sexuality, positive Living – nutrition, opportunistic Infections and treatment, ARV, prevention of transmission of HIV, values and attitudes, HIV and Family disclosure and drug use and HIV; second level of training include

information on understanding issues affecting PLHA stigma and discrimination, gender and HIV, human rights and HIV, access to treatment, access to information, sexual minorities in HIV, drug use and HIV, GIPA positive speaking. Third level of training relates to: skills and capacity building of positive which include, policy development and advocacy, leadership, fundraising, networking, working with media, organizational management, project management and proposal writing and reporting.

Other than the above said training, the TNP+ is also playing an important role in the life of HIV infected persons by providing of nutritional support and financial help. Nutritional help may not be much in financial terms but all the members of this network are provided with Rs 100 monthly for their diet/food. Financial help includes help for income generation activities provided according to the qualifications of the infected person. In terms of financial help, the infected persons are provided professional training according to their educational qualifications. Some of these members are, in turn, placed in different positions in their own or different organisations.

Importance of TNP+

It can be said that the TNP+ is playing a major role in the life of HIV/AIDS women, mainly in the emotional and psychological sphere of their lives. There are more than a hundred women who are part of this group and participate in the local level meetings conducted by the NHP+/TNP+ in every month. Further, such meetings give them a platform to overcome the stress related to their HIV status. In these meetings, by coming together, they share, support and discuss on how to cope and live more productive and fulfilling lives. Meetings are usually free of charge, ongoing and open to new ideas.

Though the TNP+ is a seven year-old network, it is still working towards strengthening its targets/aims through various initiatives meant for the people who are associated with TNP+. The importance of TNP+ is evident with its ongoing strengthening of activities and new plans to be taken, along with its effort to reach more HIV infected people, thus benefiting them, in various ways.

Importance of TNP+ can be assumed from the point of view of beneficiaries getting help or support from the network. The cases described below reveal the emotional importance that the NGOs provide. The women are happy equally in psychological sense and cope with their HIV status due to various awareness and counseling programmes organised by the network.

Case study-1

Dhan Laxmi, a 27 year old woman, married to K.K Reddy, who is working as a driver in the Andhra Pradesh State Road Transport Corporation (APSRTC). She studied up to intermediate and is now working as a counselor in Network of People living with HIV/AIDS for the last six months. Before joining the TNP+, she was quite upset and in great stress as she found her status of HIV infection when she went for the pregnancy checks up for the first time. The doctor advised her to abort the fetus as the chances are there that her inborn child may carry the infection. Not only this, she has undergone family planning operation as suggested by the doctor due to fear of passing the infection to her future babies. Knowing about the infection, she felt psychologically depressed and felt alone, as there was no one to understand her problems. She thought that she was the only one who got infected with this disease and also had fear of dying soon.

However, her husband came to know about TNP+ network help for the HIV people. So, they went to the organisation and disclosed their problems and feelings. After coming to the organisation, she felt very much free to talk to persons who were also infected with HIV and it showed her a path to think positive. About the organisation she said:

> *"…..In this organisation, I met many people and came out with the perception that in life there are many more like me who are also infected by HIV."*

She received a lot of psychological support as members of the TNP+ encouraged her to accept the disease and gave guidance and trained her to live with dignity. It also made her aware of the fact how she can take care of herself and her husband

after getting HIV infection. Not only this, they have given her hope that if she took proper treatment and proper care then she may become a mother through artificial insemination.

No one knows about their status in their neighbourhood. She thinks that if she reveals it, there will be a possibility of she and her husband facing discrimination and stigma attached to the disease. Working as counselor has helped her financially, on one hand, and, on other, made her busy in work with the people those who are also infected and somewhat making her to overcome the attitudes attached to the disease. Now she is very confident about herself and has learnt many things from the organisation, which she was not aware of before joining the TNP+.

Case study 2

Karuna is a 39-year-old widow, working as a counselor in Freedom Foundation- an organisation that is providing care and support to the HIV/infected persons. She studied till 8th standard. She has been working in this organisation for the last two years and gives counseling to the HIV infected persons and their families. She first came to know about her HIV infected status six years ago. She is not directly related to the TNP+ but she regularly attends the monthly meetings organised by the TNP+. She felt comfortable attending the meetings as she met peer groups with similar infection. By attending such meetings, she learnt several things from the members which she was not able to learn from the institute where she is working. She also reveals that no one knows about her status except her family and the peer groups, who are very supportive. She considers TNP+ members as her own family members, where she can discuss and share her experiences. Not only this, she also interacts with the new infected persons and gives advice/suggestions and makes them aware of the different programmes and activities meant for them and suggests to them to participate in these activities which will help one and all in the future.

Case study -3

Sandhya is a 25 years old widow who is working as a counselor for the TNP+. But now, she is taking rest at home as suggested by her parents. But she likes to attend the meetings organized by the TNP+ as it gives her an opportunity to meet friends during these meetings. These meetings also serve as a get-together where they can have fun with each other and also discuss matters relating to their families family and children with the peer groups. She also invites other members of the organisation to her home during festivals or other occasions. Her family is very cooperative and whenever required gives suggestions and helps other infected people who come to meet her, and whose status is not disclosed to their own family members.

Case study- 4

Shahnaz is a 27-year-old housewife. Her husband runs a cloth business. They both came to know about their HIV status last year. She came to know about the TNP+ from the resource person of TNP+ from the Osmania General Hospital. Before joining this TNP+, she was depressed and used to fight every time with her husband as he passed this infection to her and her second child. She has not revealed her status to anyone due to fear of discrimination. She did not disclose this to her own family members as they are already discriminated her husband is suffering from T.B too. She has attended the meetings of TNP+ only twice. She does not feel very comfortable while interacting with other people who come for these meetings, as there are less number of people of her own community. More than that, she feels isolated in these meeting as the peer group discusses the matters in the local language, which she does not know. She is new to the TNP+. But regarding of the programmes and activities started by the TNP+, she is quite satisfied. According to her, she spent lots of money for herself, husband on her child's health as they all are infected. She has hoped from the organization that one-day she may get an opportunity for a job or some other new opportunities, where she can contribute financially to the family. She also said that in these two meetings she learned several things on HIV and received a positive outlook to the

life even with the infection, which she thinks will also definitely mould her life and attitudes in the near future.

Thus, from these brief case studies, it can be said that, all the people felt a sense of denial and discrimination from others, when they first got to know about their infection status. With this, they suffered from depression and a sense of loneliness. They had a fear that if someone gets to know about their disease, they will be ill-treated by the neighbours and others. This shows that people with HIV infection live with the fear of stigma attached to the disease. But the self-help support groups like TNP+ has brought about some changes in their life to some extent. These people have at least got benefited more in emotional sphere, thus reducing their feeling of loneliness and depression. Such groups have helped them live happily and allowed them to have a positive outlook to life despite being infected with HIV but through proper treatment and care. Moreover, for the people infected with the disease, such groups as TNP+ become more like a domain, where they can discuss and solve the problems related to issues of HIV/AIDS, affecting them in one or more, which otherwise would be impossible to discuss because of the stigma associated with the disease of HIV/AIDS. Thus, TNP+ in AP could be viewed as an effective community support to people with HIV+. Thus, the network-playing is a coping mechanism for the HIV/AIDS infected persons.

Further analysis is as follows:

Source of Information to the PLHA

All the NGOs have their own staff members deployed in all the government and other Voluntary Confidential Counseling and Testing Centres (VCCTC) located in Hyderabad. When the staff members of any of the organisation find anyone with positive reactions to HIV, the staff counsels the individual and their family members. They also give information to the individual regarding the services provided by their respective organisation and the different supports provided by the other organizations and also inform the services of APSACS. Information on

nutritional needs of the infected person and medical support available with the NGOs is also informed to them.

Most of the victims come into contact with the NGOs staff at the hospitals where they come to know about HIV/AIDS for the first time. However, some met the councelor when the latter visited at their localities for campaigns. Usually, the initial reaction is the rejection of the report of having HIV, and their disbelief in the report. But when they meet other HIV infected persons and get to know that they are receiving some benefits from the NGOs, then only they build trust in the organisation and their engagement with organisation increases and starts visiting the organisation on a regular basis.

Role in Identifying HIV Patients

The NGO workers visit slums and other localities not only to provide information about the HIV/AIDS, but also for follow-up action for ups the infected and affected families. They inquire about their health status. During such visits, they disseminate the information to other members in the locality suffering from HIV or initiate personal interactions on one-to-one contact basis.

Counselors are the main mediums through whom the organisation identifies the HIV infected persons. These counselors, who are recruited by the NGOs, are educated and can be HIV infected or non-infected members who are adequately trained on pre-test and post-test and follow up counseling through the APSACS and from other experts. These counselors establish rapport with the patients and encourage them to associate with their organisation for further help. They also refer the patients to other NGOs according to the requirement of the patients.

Providing Support to the PLHA

Psycho-social Support

As mentioned earlier, one of the major tasks of NGO is to provide psychosocial support to the persons living with HIV/AIDS through the counselors. They inform PLHA about various stages of the disease and encourage them for getting out of

depression, confusion and dismay. They try to instill in them a hope to develop a positive attitude towards life and have great determination to cope with the infection to the extent possible. They explain that the victims mental strength and their will to live will help sustain them the emotionally and enable them to live longer. They tell their clients/patients that the one thing that gives PLHA power over HIV/AIDS is moral preparedness to live with a positive attitude towards their ailment. The counselors advise them that one of the ways to overcome both the anxiety and the stress is by sharing their burdens with the workers of the organizations and the counselors. The counselors of the organisations also provide counseling to the families of the infected persons and ask them to take proper care of the infected person, and about information on the facilities and support provided by the government and non-governmental organisations. At least two outreach workers or counselors are dedicated to the concerns of the infected persons in each of the eight NGOs. Most of these counselors are themselves infected with HIV/AIDS. The main reason behind keeping them as counselors is that if they work as counselors and support them, the PLHA will identify them as one among them and will listen and follow their instructions in a positive way. As one of the counselor from DARE organization stated,

> "…...*if we provide counseling to the infected persons, it will leave a positive impact on them. They could know that we are also infected with the disease but are living a healthy life. It will help them in understanding the disease better and in a way get strength." She further pointed out,*
>
> *"……If people suspect that they are developing a disease or they are into a next stage, a counselor will try to motivate them for check up often and live as healthy as possible by having a proper diet and exercise. We also advice the male victims to avoid the habit of drinking and chewing tobacco, etc., which influence the growth of the infection.*"

Thus, counseling is extended to the infected individuals, their families, children and the community to enable them to overcome the psychological and emotional problems. Counseling is also provided to families that have lost one of their members and to the community to strengthen attitudes that generate changes in behaviour and foster greater willingness to discuss issues relating to sex and AIDS. Advice is also given on voluntary screening. This often enables infected couples to take a decision about having children, avoid multiple sex partners, leaving the habits of drinking, etc., on a whole range of matters that vary from one person to another.

Technical Support

All the government hospitals in the twin cities of Hyderabad and Secunderabad are entrusted with the job of treating the HIV/AIDS patients. Other than these, there are some organisations which are providing various services to the vulnerable group of persons infected with HIV/AIDS, as stated above. It is observed that there are limited beds in the government hospitals, so when a patient stays there for too long period because of the illness, there is no room for new comers. So the doctors discharge old patients regardless of the health status whether they are stable or not and admit new ones. In such cases, these patients turn to other care and support centres. Three of the NGOs have doctors and nurses who look after the patients, both in their organisation and in hospitals. The Lepra India has the large number of doctors and nurses especially available for helping the infected persons. There are fifteen medical doctors and two hundred and sixty-six nurse practitioners. These doctors and nurses are appointed in government and non-government organisations. The other NGOs have at least two doctors who are providing fulltime services to the infected persons. They have consultant doctors who visit and check up the patients occasionally. In other four NGOs, they do not have the facility of resident doctors or nurses, but whenever any infected person comes there for help, they refer them to the organisation which provides the related services. Each of them have minimum ten beds meant for the HIV/AIDS patients but they admit them only for four to seven days.

All the NGOs also mentioned that other than helping the HIV infected people who come to their organisation on their own, they also refer patients to the government hospital for the treatment when they come in contact with any one of them. Their outreach workers help the patients to visit the hospitals, this helps patients avoiding long queues in the government hospitals to consult the doctors as outreach workers know the doctors and thus, can get early checkup for the patients. This also saves time of the patients when they visit the hospital with the staff of the organisations. All the organisations also reported that they take care of expenses of infected person for visit to the hospitals, if they go there, but it totally depends upon the requirements of the patients.

Financial Support

Among all types of support, financial support is the most important one to the patients for sustaining themselves. As far as financial support of organisations is concerned, it is found that all of them are providing some sort of financial help to the infected and affected families. The Telugu Network People Living with HIV/AIDS provides financial help to a few of their beneficiaries for starting small business that the person wants. But the amount is very small, i.e., only eight hundred to one thousand rupees. It is too meager to start any business. So it can be assumed that, infected person may use this amount for the daily treatment and expenses, rather that opening any business as such. All other NGOs provide financial help mainly towards the traveling of the infected person and accompanying family member to the hospital. Further, they provide help for education of children with tuition fees. NGOs provide six hundred rupees monthly through CFC project to the beneficiary patients whose children are studying. But it cannot be stated that, all the infected persons who go to the organisation get these kinds of help. Rather, these organisations give first preference to those infected who are below the poverty line and to the children of those patients who are infected and affected from the HIV/AIDS.

The Freedom Foundation Organisation supports orphaned children whose parents have died due to AIDS. Their programmes encourage the maintenance of orphans

in their families and community. Various other types of support provided include: food, clothing, and payment of school fees, medical and legal expenses. The organisation encourages families and the community to share support and provide care for children. So far, the organisation has provided they provide such facilities to seventy children.

DARE organization provides loans to the infected and affected families through collaboration with other micro-credit organisations. They associate the PLHA patients with financial institutions of SC and ST, minorities for loans. The PLHAs also receive loans through the nationalised banks. All NGOs have taken the role of mediators for getting widow pensions to the needy PLHA, old age pension, and pension for the physically handicapped persons from the government.

Thus, it is seen that NGOs provide financial assistance to the people living with HIV/AIDS. Whatever help, whether small or big, that the infected persons receive from the organisation is very important because most of the infected people have lost their jobs due to the AIDS, and in case of widowed women, it is more problematic as they are not able to support their children for better education. Therefore, all the financial support of the organisations is helping them in this regard. Organisations also provide loans to the capable person to become independent and stand on their feet.

Nutritional Support

Other than financial and technical support, nutritional support is very important as it is an essential need. When an infected person's defense system is impaired, other germs take advantage of this opportunity and, further weaken the body and cause various illnesses, such as fever, cough, itching, tuberculosis, diarrhoea, etc. The time it takes for HIV infection to become a full blown AIDS depends on the general health and nutritional status before and during the time of infections. Many people can live longer with the virus if they take a nutritious diet. As the viral load increases, the infection puts extra demand on the immune system and increase the body needs for energy and nutrients. Given the frequent illness and

malnutrition, the body gradually becomes weaker; weight loss or wasting becomes a serious problem, and diarrhoea occurred more often and lasts longer.

In India, most of the PLHA are from the poor families. They are not able to consume nutritious food, because of poverty. So in this regard, the NGOs become a boon for the poor and infected people. The NGOs provide nutritional support, so that the infected people can cope up with the disease and economic crises. In this regard, monthly ration is provided to the infected and affected families.

Four NGOs said that organisational support, they provide every month in the form of food items, whereas others gave them reference of other organisations that can provide them security of food. An important point to be noted here is that from NGOs' side, if a patient is associated and taking help from one NGO, he/she can also receive help from as many others organisations as possible which are ready to help them. There are no rules and restrictions from the organisations side that the registered infected patients can avail benefits only from one NGO. One can become a member of any organisations working in the area of HIV/AIDS to receive support that they provide.

DARE organisation states that they, provides every month the following items to almost sixty patients in their organisation at their premises: five kilograms *wheat flour*, three kilograms *ragi* malt, two kilograms pulses, ten eggs and sometime also seasonal fruits to the infected people. Chaitanya Mahila Mandali- provides the following items to thirty beneficiaries enrolled with it: twenty kilograms of *rice*, ten kilograms of *wheat flour* , five kilograms of *Dal* , two boost packets , two kilograms of meal maker , three kilograms of raagi malt and five kilograms of sugar. This organisation works for the rehabilitation of sex workers. Network of HIV positive people provides two kilograms of wheat flour and one kilograms of Raggi to nearly hundred infected people registered in their organisation. Prajwala Organisation provides soya bean, *upma rawa, ragi, moong dal* groundnut and fruits to the registered HIV sex workers enrolled with this organisation. Freedom foundation and Lepra India also provide low cost nutrition food to the PLHA, but have not given the details.

Out of forty women, thirteen are receiving ration items from at least two of the NGOs at the same time. Though there are a few who are not receiving any help and there are some who are taking help from two or more organisations. The reason for not providing rations to all is that preference is given only to those coming from poor families (below poverty line) and also to old patients of their organisation. So, it can be stated that organisations are playing an important role in providing the nutritional items to the people living with HIV/AIDS and helping them in reducing some kind of economic burden. From this kind of nutritional support and help, the PLHA can live longer and also provide a helping hand to the family members who are taking care of them.

Condom Promotion and Distribution

The condom usage is a key preventive measure in the sexual transmission of HIV. The surveys have found that condoms can lower the risk of contracting HIV, but many of those in lower socio-economic group are unwilling to purchase condoms. Thus, the organisations are providing condoms free of cost to the sex workers, young people, people living with HIV/AIDS (PLWAs) and to other interested persons. Most of the NGOs provide condoms to PLHA on a daily basis. One organisation, Prajwala, provides condoms only on a monthly basis. Nowadays, the PLHAs are coming forward for condoms but earlier they were shy of asking for these.

Vocational Training

All the NGOs provide vocational training to the PLHA, as their social and financial situation is very precarious. The training in developing skills is to make the PLHA financially independent. This also helps supporting their families for procuring food, medicines and pay for the children's education. The training is for a period of two to three months and it includes tailoring, knitting, embroidery and the making of jute bags, artificial flowers, dolls and soft toys, detergent and liquid soap, phenol, computer training to the educated PLHA and so on. They also pay for their bus fare to the training centres and back home, thereby reducing their

financial burden to learn such activities. In some cases, if NGOs don't have facility of their own, they refer the interested women to other NGOs or institutions which provide such training. Several women got trained for such pursuits, but that is not helping much. They are not getting jobs immediately. Even some of those who were provided with jobs said that they could not join such jobs because the place was far away from their homes. Therefore, it has less impact.

Apart from this, NGOS also provide Peer Education Training Programmes for the PLHAs. They encourage PLHAs to provide counseling to the other infected persons about nutrition, hygiene and other issues related to HIV/AIDS. As already mentioned, every NGO has employed at least two persons infected with HIV/AIDS and their job is to visit the homes of PLHAs and provide counseling to the infected and affected families. For this, the NGOs conduct special courses with the infected people and equip them with skills to take care of the increasing challenges of AIDS.

Shelter and Clothes

Freedom Foundation has provided shelter to seventy HIV/AIDS infected and affected children so far. Prajwala has provided shelter to the sex workers' children and the children infected with or affected with HIV/AIDS. It has also provided shelter to the women who are victims of sex trafficking but they have their own limits. The NGOs also collect used or new clothes donated by philanthropists and distribute the same to the Victims

Meetings with PLHA

The NGOs usually arrange monthly meeting of PLHA separately, wherein the HIV patients discuss their day-to-day problems. During these meetings, these organisations also provide material support. So, people come, receive their ration and interact with the peer groups. In these meetings, PLHAs establish contact with each to another and identify themselves as belonging to "one family". They

say that they have created a kind of family over here and would like to interact and discuss their problems with each other. The counselors encourage them to feel free and make it a participatory meeting where speaker asks them questions related to HIV/AIDS and expect answers from the women. They also advice them for taking medicine regularly and eat the nutritious food. The president of the organisation also informs them about the various government programmes and details of other NGOs important for them. In such meetings, it is also observed that people from other NGOs also visit and inform them about different services provided by their organisations and ask them to join the organizsation and enjoy the facilities.

To attend these monthly meetings, women get one hundred rupees each but thirty rupees is withheld as savings of the patient. In their view, the savings will help them in future for starting a business or some other useful vocation. While they are happy that at least in this way they are able to save thirty rupees every month, they have a worry that accounts for their savings are not shown. There is no passbook or some such arrangement. In the absence of pass book or any proof of their savings, they are not sure whether they will be able to get the money saved any time.

Number of Patients Receiving Support from the Organization

Telugu Network of People is on the top of the list of those providing services to the maximum number of PLHA. The organisation has registered twenty eight hundred patients till date. Freedom Foundation provides its services almost to fifteen hundred infected people, followed by the DARE organisation which has registered three hundred and ten patients. VSSA has registered one hundred seventy patients from its formation, whereas Integrated Rural Development registered sixty HIV/AIDS patients, followed by Chaitanya Mahila Mandali that has registered only thirty HIV/AIDS patients.

Synergy of NGOs

From the above description, it is clear that all the organisations work hand in hand with one other and government especially through APSACS. These organisations take part when government takes important decisions for the HIV people. They involve themselves in different meetings with the APSACS and other meetings organised by other NGOs to decide on certain issues. For example, they all participated in a meeting that decided on the venue for international AIDS day celebrations and in these meetings they inform the people about the services and role played by them. They also give reports on how they have utilised funds of the donors. Thus, it can be stated that, through linkages and connections among the NGOs, synergic relations are built and this has led to better coordination of activities and programmes among various NGOS.

NGOs' Opinions about the Prevalence of the HIV/AIDS

NGOs are of the view that there is no decrease in the number of people infected with HIV/AIDS. The main reasons for increase are: lack of knowledge about the HIV/AIDS, illiteracy, trafficking of women, female sex workers, etc. They also consider migration as an important factor particularly among the young people. According to them, people are not following the preventive methods. But two NGOs, believe that there is a decrease in the number of people living with the HIV/AIDS, as compared to the previous year. For them, the main reason behind is that now people are aware of the importance of their health. Distribution of free condoms is enabling them to practice safe sex method.

Opinion of HIV/AIDS victims about the role of NGOs

Women have acknowledged the fact that after diagnosis with the HIV/AIDS infection, their life got shattered, but the NGOs have provided emotional and social support to them and to their families which they badly needed. They are encouraged to lead life with dignity. There are a few who have said that because of the NGO only they are still alive. Otherwise, they would have perished long back. For them the NGO workers have become the family members with whom

they shared the deepest secret of their life. For instance, Rajamma (30), a widow, states,

> "*….whenever I get sick, my family members never take me to the hospital….so I call the NGO and from there someone will come and take me to the hospital."*

Another woman, Saroja (27), said,

> "*…we are very much satisfied with the work of NGOs. Because of their help, we are alive. They have counseled and taught us about the disease. They also provide material and economic help to our family and I think that much help is sufficient for us."*

Apart from the counseling, there are a few fortunate women who are receiving social support from the organisations in different ways. For them, the organisations have provided, loans, education to their children, and nutritional food. Particularly, these women are most satisfied with the assistance that they are receiving from the organisations .

Sakira Begum (26), a married woman, says,

> *"…..I am grateful for the funders and donors who are helping us and because of their help we are able to send our children to school. Otherwise, otherwise it would have been very difficult us, to send our children to schools."*

Ramya (30), a widow, says,

> *"…because of the ration which NGOs are providing every month and helping us to get shelter within our homes, we are alive. Their help is important as I think no one want to feed us, unless we are contributing something to the family."*

Unlike the above opinions, there are a few people who are not so much satisfied with the provisions provided by the NGOs. They have complained that they are not regular in providing the services. A woman reports,

> *"…Earlier, we used to get rice, dal, flour, oil and dalia…but now a days they are providing only flour and one kilogram dal which is not sufficient for the whole family. We wish to get rice too from the organisation. So if they would provide that, it would be nice."*

There is a discordant note by some with the monthly meetings which they attend in the respective organisations. According to them, in every meeting, the NGOs come with new schemes and programmes like providing houses for the infected widows but these schemes are not implemented. There are a few women who did not like deduction of thirty rupees as a saving for future assistance as there is no any proof of these savings. However, many are happy with the meetings and enjoyed meeting with people, sitting and chatting comfortably with their communities. Thus, organisations have helped them in reducing the sense of isolation which most of the women were facing in their own families.

From the above discussion, one can say that NGOs are playing an important role in the lives of the PLHA in providing care and support. It is important to note that the people who are associated with these NGOs are able to access information, and develop appropriate behaviour towards one another as well. NGOs are playing the role of facilitators in bringing people together. The information that they receive from the NGOs and the experience they share in the meetings organised by the NGOs is the starting point for reducing stress related problems. It helps them in sustaining their livelihood and protection especially from food security.

In spite of the above said services, the NGOs have their own limitations and, most importantly, these NGOs limit themselves to the slums and there is no such

service to those living in rural areas. No doubt, NGOs are playing an important role but these organisations are providing benefits to very few individuals. The vocational training that organisations are providing to the infected people is not helping much. Even after receiving good training and acquiring some skills in specific activities, they are still sitting idle at home or working in other areas in which they are not trained.

It can be said that people infected with HIV/AIDS are living with the burden of stress and pain and find it difficult to cope with the infection and problems related to the disease, stigma and discrimination. However, when they find some helping hand in the form of NGOs, to some extent, their stress and anxiety gets reduced. It is the help of these NGOs only that provide them awareness and give them information which is useful for them to live a normal life. Moreover, those coming from poor strata cannot afford to access required medication and care on their own. In such a scenario, NGOs are playing an important role in providing them material and social support in whatever way they can, thereby showing their responsibility towards the welfare of society and its people. On the part of infected people, such help and support from various organisations is a step towards their coping with the illness and a hope to lead a normal life like any other non-infected persons.

CHAPTER-7
SUMMARY AND CONCLUSION

In the conclusion, it is necessary to examine if the coping mechanisms of those infected with HIV/AIDS are in any way different from the strategies of victims of other stigmatized diseases in order to understand the predicament of the HIV/AIDS women victims. Diabetes, tuberculosis, cancer, leprosy are some of the stigmatized diseases which may be considered in this respect. In each case the patient/individuals develop certain mechanisms to cope up with the stigma and discrimination.

Diabetes is considered to be a genetically inherited disorder. The other causative factors are: obesity, sedentary life style and stress on individual. It is not an infectious disease, and as such and also due to the factors mentioned it is not so much stigmatized. But there is professional blame on the victim or individual in health care management. Great emphasis is laid upon the individual's responsibility to maintain dietary control, exercise and control over life style. The victims are often blamed for their irresponsible behavior. The stigma is associated with the powerlessness of the individual and lack control on the self. Because of this, the individuals have self inflicted stigma by avoidance. Their strategy of coping includes not only bypass but also resignation to the disorder, and often 'not accepting the disease as it is' or 'not recognizing the disease calmly'. The community members in the church seek divine intervention, and oftentimes the individuals ask the church members for the spiritual support (Iwasaki, et al 2004, Sunday, et al 2001).

Cancer is considered as a serious bodily infliction and dreadful disease, and healthy individuals are afraid of touching the cancer patient fearing contract of the disease though mere touch does not cause cancer in a healthy person. The individuals in chemotherapy experience hair loss, and it is seen as manifestation of confrontation with a serious and fatal illness. Their primary strategy to

camouflage the stigma is to wear a wig. The victims do not like to interact with friends and families for fear of disclosure of cancer which may affect people. The disclosure may prevent seeking financial or social support. Self-image may be seriously affected particularly the employer may ask the individual to stop working. Smokers do not like to disclose, as they may be asked or advised to stop smoking as it causes or aggravates lung cancer and so on. Some do not disclose their health status to others, as they have already experienced stigma when talking to others (Chappel, et al 2004).

Pulmonary tuberculosis is a highly contaminating and infectious disease. It is stigmatized due to the nature of the disease, healthy individuals avoid the things used by the patient as advised by the doctors. The health care professionals also use masks when interacting with the patients. Children are not particularly brought closer to the patients. The employers retrench the worker if found having contracted pulmonary tuberculosis. Usually individuals do not like to disclose the disease, and conceal the fact for fear of retrenchment or losing job and social stigma. The coping strategies include seeking support from the family members, treatment and faith in God and so on (Arora, et al 1992).

Leprosy is another important disease which is highly stigmatized, as it causes serious physical deformity. The families with leprosy patients face socio-economic problems. The family is castigated, and they have to incur expenditure on medicines and taking care of the individual who is incapacitated due to the illness. The entire family undergoes the stigma, as they are physically avoided. It seems the families with a deformed patient undergo stigma ten times more than the families with a non-deformed leprosy patient. Usually the non-deformed patient is accepted whereas the deformed victim is not accepted. While the deformed victims cannot conceal the deformity, the non-deformed victims can conceal themselves.

What makes HIV/AIDS different from other stigmatised disease discussed above is that the stigma is associated with the innocence of the victim to some extent in case of diabetes, cancer, tuberculosis and leprosy. Though individual's life style is blamed in these cases, the life style is not considered illegal or immoral. More often, the stigma is self-imposed by the victim, but in case of HIV/AIDS, it largely comes from outside. In case of HIV/AIDS, it is associated with sexuality, disease and death and the behavior that may be illegal and immoral. Forbidden taboos and sexual relations are associated with pre or extra-marital sex, sex worker, sex between men, and injecting drug and so on. Thus, stigma builds upon and reinforces on existing prejudices which are taboos and make life difficult for the people living with HIV/AIDS.

It is clearly observed from the above that some similarities exist between HIV/AIDS victims and the patients with the above mentioned illnesses which are also stigmatised. The patients with T.B, mental illness, diabetes, cancer and leprosy mostly adopt the emotion coping mechanisms like acceptance, concealing and avoidance. Belief in God also helps them to deal with the disease effectively. As regards to HIV/AIDS victims, the strategies include problem solving or coping rather than emotion coping mechanisms to deal with the opportunistic diseases. As The HIV/AIDS people are getting opportunistic disease, they require support group, both self help groups and NGOs. These are helping them financially, socially and politically to cope with and fight the disease with stigma, which is not much observed in other stigmatized diseases.

To recapitulate what has been discussed in the forgone pages, in recent times HIV/AIDS has emerged as major challenges to sufferers as well as health providers across the globe. Globally India is the third only to the South Africa and Nigeria in the number of HIV infected people. Reportedly there are 2.5 million people living with HIV/AIDS (NACO 2007). Among them women (40 percent) constitute are the most vulnerable group. Though HIV/AIDS is a physical illness, it affects the psychological as well as social, wellbeing of the human being.

According to the WHO definition, health is physical, mental and social aspects are all closely related. Anthropologists prefer describing illness as a social rather than a biological event because the condition of suffering denoted by illness is a subjective experience that usually results in individuals modifying their behavior. Therefore, while a disease represents a medical entity that can be defined in terms of biological, physiological and psychological function, an illness can be regarded as a social entity definable in terms of social functioning. The HIV/AIDS is both medical and social problem. Moreover the epidemic of HIV/AIDS carries stigma both to the infected person and their families leading to the psychological trauma and social ostricisation.

Stigma derives from the infection as it is associated with sex, disease and death, and the behaviours that may be illegal or immoral. In such experiences of stigma, discrimination and denial, developing and maintaining social interaction and relationships become difficult. They have to develop strategies and cope up with the infection and opportunistic diseases. In the following pages, important findings of the present study are mentioned.

The research design included a survey, 40 case studies of HIV/AIDS women victims and detailed enquiry with 8 NGOs which are providing social support to these victims besides the support extended by the Government agency, i.e, APSACS. The survey covered 250 samples collected from both the sexes in three different locations for eliciting views of the general public about awareness, knowledge, beliefs and attitudes towards the people living with HIV/AIDS. Majority of the respondents (82.2 percent) have adequate knowledge about the HIV/AIDS disease. It is believed that this knowledge is probably good enough to take preventive steps for control of HIV/AIDS. In this regard, the respondents in the age group of 16-25 male, unmarried, graduates and government employees constitute the general public who has adequate knowledge about the HIV/AIDS. With regard to the knowledge about transmission of the disease, only 28 percent of the respondents have adequate knowledge. These are mostly in the age group

of 26 - 35, women, unmarried, people having education background up to graduation who have adequate knowledge about the transmission of the disease. These are mostly students and private employees. From the survey it is also found that only half of the respondents (51.2 percent) have adequate knowledge about the prevention of HIV/AIDS infection. As regards the attitudes towards HIV/AIDS patients, it has been found that only 16.4 percent have a proper attitude towards the infected people. These are unmarried males in the age groups of 16-35 who are educated with primary education to graduation and are employed in private establishment and students.

A number of studies have been carried throughout the country to find out the awareness, knowledge towards the HIV/AIDS victims, but it is very difficult to compare the present study with those because there is no similar study which can be compared with the present study (For example Bharat and Aggleton 2002). But from all the studies it can be noted that the general public have a good knowledge about the awareness about the HIV infection, modes of transmission and prevention method especially among the youth. But the respondent's attitudes towards the victim are not positive among the majority of the people irrespective of age, sex, marital status, education, occupational status. The increased awareness may be due to the efforts of government, non- government and media efforts. But the present study reveals that several of the 40 HIV/AIDS victims were not aware and even those aware of it, did not suspect their husbands. Those who suspected the extra marital relations of the husband did not dare to question them. Even those women whose husbands contacted HIV could not insist on the use of condoms even though they are advised.

The knowledge that HIV is not transmitted through touch, using the items used by the infected person, did not bring positive attitude towards the victims. The reason for this could be that the association of HIV/AIDS with the stigma. And stigma can be understood with the deviant behaviour. According to the classical sociological classifications, deviance occurs when the individual's behaviour

violates established norms of how an individual should behave (Stafford and Scott 1986). Secondly the knowledge or information has not convinced them totally; there is still some doubt that infected person can cause troubles, hence the healthy avoided the infected person.

When people come to know about a person is infected with HIV/AIDS, they conclude that individual got the infection because of promiscuity and believe that the person is a bad character. And one does not want to mingle with the person who has violated the morals or norms of the society and have looked down. This negative attitude and distancing oneself is due to fear of contracting the infection. The infection has several myths and misconceptions. The people have fear that if they mingle with the infected individual, their health will be at risk, if one share any items used by the patient will get infection, and also they have view that the infection has no permanent cure and death is compulsory. So to protect themselves from the infection they avoid the infected person and also stigmatize and discriminate the people with HIV/AIDS. Thus, the study supports Coleman's (1986) argument that "what gives stigma its intensity and reality is fear." [30]

From the survey it became very clear that a majority of the population has adequate general knowledge about HIV/AIDS, but only few (28 percent) have adequate knowledge about the transmission of HIV/AIDS. Only half of the population knows the prevention of HIV/AIDS. In the kind of scenario, it is reasonable to assume that stigma and discrimination can be rampant and there can be little check for the spread of the infection for there will be less use of condoms. Given the slum background where illiteracy, poverty, uses of intoxicants, unhealthy and social environment prevail, there can be high incidence of HIV/AIDS victims. They would have been suffering from the acute stigma, discrimination and finding difficult to cope with these as well as the opportunistic illnesses due to poverty. In this background, the experience of stigma and coping

[30] Certain diseases elicit fear because the etiology of the disease is unclear, unpredictable or unexpected (Sontag 1978, Doka 1997, Coleman 1986).

strategies of the 40 cases selected for in-depth study are examined. Also, these cases, through do not representative of the universe, they represent the slum dwellers of Hyderabad and Secunderabad. The slums of this twin city are inhabitated by poor belonging to lower caste mostly illiterate, less expose to media, and they live in unhygienic conditions. The survey results, the slum background match very well with those 40 cases in all socio-economic parameters.

It is natural to experience shock instantly when someone first hears that she or he is infected by the HIV/AIDS virus for which there is no cure and death is imminent. Since some have heard and seen HIV and AIDS patients and their status in the society and so they were terribly disturbed. For large many it did not mean anything initially as they could not make sense what it means to be with HIV+ as they were doing well. But gradually they realised what it is to be when their health started falling. In many cases the husbands rejected the HIV infection, denied then immoral behavior besides blaming their wives. Almost all women experienced stigma and discrimination in their conjugal families, even though most of them got the infection through their husbands. Not only this, there are few women whose husbands have deserted them after diagnosis of the infection. HIV status of women was disclosed by the doctors/counselors in front of other family members and did not give a chance to the victims to disclose it to others or not. Thus there is complete failure so far as maintaining individual confidentiality is concerned which is very important for psychological well being of the individual. More than one fourth of the women living with HIV/AIDS are widowers and have more burdens to raise children and generate incomes for their families. Women faced stigma and discrimination both in the conjugal and natal home. But in marital home it was intolerable, hence they either returned to the parental home or living independently; in fact some were thrown out by in-laws. Several women have experienced domestic violence by their husbands and family members, especially through their in-laws.

In several cases, women are blamed to have infected their husband. Men tried to cover up their misdeeds casting wild allegations against women, turning the table around. Since time immemorial, women's role in the family has been to take care of family members. When family members fall ill, it is the duty of woman to provide nursing care and look after them. But when she herself becomes sick and faces the risk of death, there is no one to take care of her. She is seldom considered a sick person. Instead, she is expected to continue providing service in spite of being sick. Especially in the marital home, the women are not helped by the other family members, in-laws showing more care to her son but not his sick wife. She is not encouraged to visit the hospitals for the treatment or they are not ready to accompany her to hospital. Men are more qualified for care by virtue of their gender. Even though wives are infected, they neglect their own needs and engage themselves in providing care to their husbands. A mother does the same to her children. Though some women are cared for by their parents in their natal home, they are also seen as burden in natal families. However, they make no demands for care, there is also no one to show special concern to the sick women. In fact everybody blames the women only for bringing home the diseases and troubles.

After the death of husband, most of the victims were sent back to natal home, the family members are not ready to take the responsibility of the women and her children. In fact, it was throwing the responsibility on the natal family members implying the women is responsible for the infection to husband. But natal family expressed full faith on their daughter and accepted her with children, as also it is their moral obligation. At the same time sometimes when they failed to bear the burden ill-treated her.

Being a HIV infected woman, she has to follow rules and restrictions imposed by the family. She cannot talk to the other non-infected members and children in the family. Not only this, the children of the woman are also not allowed to mingle with the other children both in family and the community. She cannot move freely

in all parts of the house. She cannot use things like glass, plate, bedding, etc., used by them and her items are kept separately, and others do not touch them. It is seen that community relations and social interactions also got adversely affected due to HIV/AIDS. She and her children are ignored and avoided by their relatives and neighbours. The victims are not invited for functions and other social gatherings. If they happen to attend such events, they have to face insults. Such treatment has made most of the HIV infected women to create self-imposed isolation and stop attending weddings and other social gatherings in order to avoid experiencing unpleasant incidents in such functions. Here the women victims are discriminated by the family members and the others.

A Few victims also face discrimination in the hospital also. The hospital staffs denied them conducting delivery in most of the private hospitals on the pretext that they do not have facilities to take care of HIV/AIDS victims. They treated them, and referred to general public hospitals. Even in general hospitals they faced problems and were not treated. In some cases, the victims are separated from other patients and are denied personalized care like anybody else. The food and medicines are given to them from a distance. In this way, the women have undergone humiliated experience. Few had experienced discrimination where they worked as domestic servants. Thus, women are greatly affected not only by HIV/AIDS, but are also subjected psychological strain. The victims had to take care of other person living in the family who is infected who may be husband or child or both. The most miserable and humiliating experience is the stigma and discrimination by their dear ones and community that once loved and whom they had loved also.

The women are in tension simultaneously living and in fear of death. They are worried because their children who are still young and the children will be orphaned if they die, and no one will take care of them; they will become victims of spoiled identity. Because of the spoiled identity related to the HIV/AIDS women are more worried about their children and their well being along with

other members that generally make them helpless if they are not well placed. Thus, these women are found to be worried with the feeling of helplessness. Hence, become the victims of depression. They are undergoing tremendous mental strain due to the infection along with the fear of other people's response and behavior towards them. They have limited social life and communication, and even lost their jobs as consequences of their HIV/AIDS status. To avoid such challenge of stigma and discrimination they do not want to reveal their HIV situation to family and relatives. To come out from such challenges and stigmatization process of the family and neighbors the women developed some coping strategies.

Among all family members it is especially mother who came forward to extend support to the victim. However, it is important to note that though the natal family received her and her children, she is subjected to stigma and discrimination and abusive language from the family or others. The woman has nowhere to go but try to control her emotions. But she seeks support from others especially for children in order to protect them from problems. The victims had to accept the infection and opportunistic diseases and take the medicines regularly meant for them with the hope that in future there will be permanent cure. Such beliefs and hopes are helping them to cope up with the strain from diseases as well as ill treatment meted to them. Dependence on god and spiritual support to deal with the disease and the circumstances are other means of coping strategies. Most of the times they are remembering god and praying for the well being of self and for other infected members in the family. The study confirms the findings of Majumdar (2004) and Nyblade, et al (2003) that becoming more religious and getting comfort through immersing oneself in religious matters are coping mechanisms. Some women believe that the suffering with HIV/AIDS is written in their destiny and it is god's plan and god's punishment for the bad deeds in the past. This is close to the observation of Roemer (1960: 14). He finds that victims think the diseases are the consequence of punishment, the sick man was marked with certain stigma.

Almost all women express that after acquiring better knowledge about the HIV/AIDS they have become more positive and are able to take care of themselves. This was possible by associating themselves with the NGOs who have helped them see the life in the positive way and live life with dignity. Thus, NGOs are playing a significant role in providing awareness and preparing them to cope with the stigma. Counseling centres of HIV/AIDS have been playing important role in improving the mental and physical condition, as well as social integration.

Some women are engaged in social network groups and some other are engaged in helping and educating others with HIV-related problems as outreach workers for some organizations. This has enabled them to have a sense of worth in their life. Participation in social network has reduced physical and social isolation. The study agrees with Nyblade, et el (2003) who argue that involvement in a support group or identifying oneself with individuals who suffer the same condition is an acknowledged way of coping with HIV stigma. Doing this, they get the strength to look at life in positive ways.

Women avoid the circumstances that place them in situations of discrimination and stigmatization as far as possible. They do it by not involving themselves or not interacting much with such members. They keep themselves secluded and confined to a single room. By doing so, they try to remain in their own world and keep themselves away from ill-treatment. Some victims who have not yet revealed their infected status even to their family members interacts very consciously. They have not disclosed it because of the fear that if they disclose their HIV infection the family members will start discriminating them and may become worried about themselves and the victims. As they do not want to make them unhappy, they are concealing their status about the disease. Not only this, if somebody comes to know their status, the reputation of the family will go down and no one will come forwards to help in needs.

Several victims have small children. This has worked positively as they made them live with the disease effectively, by spending most of the time playing and talking with them. Almost all women expressed emphatically that children are the most important reason to cope with the diseases by caring the needs of children and try to forget the situation. There are other set of women, who think they are not infected with HIV virus because they are physically fine. They think so because when they visited hospitals for diagnosis, some hospitals reported the result of the test as negative and some other as positive. So with no accurate information about the infected status they do not believe in their positive status. They are passing off their lives as normal persons. .

A few women are engaged in the pursuit of some kind of livelihood activities in order to keep themselves busy and to get rid of the tension and stress. In these cases women are applying their own efforts as much as possible taking help from family members and other social groups to cope with the disease effectively. Denial of the diseases, avoidance or confrontation that lead to ill treatment, concealing the HIV status and keeping economically productive are some of the ways by which they try to live their life as a normal being as much as they can. One can also state that family members generally are playing very significant role in the lives of HIV infected people with some exceptions. They are providing all forms of strength and support to reduce the tension and stress with the knowledge of having the virus that they are getting from the NGOs. Many women have emphasized the importance and the value of counseling about the HIV/AIDS that have helped them and their family members to overcome the emotional upheavals.

Lastly, it can be said that the role of counseling, training and education are important mechanisms for the HIV infected women that enhanced their coping abilities. But, other than psychological improvement, there is not much improvement in terms of their economic background. The women are still struggling in dire poverty, though some are fortunate to receive material support

from non-government organizations, but several of them live in miserable condition because of poor economic background. It has some implication in the sense that this in turn influences the poor coping behviour.

The experiences documented here show that women and girls are the ones bearing the burden of the disease of HIV/AIDS because of the stigma exist strongly in society. While familial support is not always available for most women, they do receive some positive support from non-government organizational level in a structured support group setting. The results further confirm the argument that support systems are key to women living with HIV/AIDS for coping with their infection at personal, social and community level especially due to the contribution made by the Government and NGOs. By such support the victims experience less emotion and more confidence than those who were not receiving support. The studies agrees with Van Dyck (2001) who said that in support group members become experts of their lives and are empowered to help care and satisfy the needs and concerns of other group members. Other studies have confirmed that counseling services and support structures especially the self help groups prove to be a major support for victims, who share similar experiences and are able to learn more about HIV/AIDS (Dorn, et al 1994, Were 2000, Richard Son 1989). The present study confirms the same.

The significant contribution made by the support groups has been realised in the expressions of many PLHA, who wished to die early are now wishing to have their useful lives for many years to come especially for children who are now at very young age. That reflects a really big difference for themselves and for others. The enlightenment through sympathetic approach is perhaps the most important factor that helped the PLHAs overcome stigma. No one likes to be isolated, but everyone likes to receive support and likes their families and communities to stand by so that they can help themselves to stand up.

The present study substantiates the arguments made in theoretical framework of coping strategies of stress. It is argued that when the individual are infected with life threatening infection of HIV/AIDS the same society where the infected victims received once abundant support will condemn them and withdraw support. The women have experienced rejection or abandonment from their partners, families, communities, and even health care providers due to stigma attached to the infection. The lack of knowledge about HIV/AIDS in the community and in the families and lack of agents of support are the contributing factors to the experience of stigma. In the health care setting also the victims experienced unsatisfying interpersonal relationships with the health care providers. The health care providers lacked the ability to provide support, tangible assistance and information. The myths and misconceptions around transmission of HIV/AIDS and social cultural constructions of disease and gender reinforces stigmatisation. The study has shown that stigma and discrimination is still present among HIV and AIDS patients despite the awareness and sensitization programme provided by the government and non-government agencies. Many PLHA still live and wish to live many years to come especially for children who are now at very young age. Enlightened sympathy and respect is perhaps the most important factor that the people with HIV/AIDS wish to have in order to help them overcome stigma.

Majority of HIV and AIDS patients are receiving some help especially from the natal families and from support agencies. Since the infection is an irreversible condition and they have to live with it for rest of their life and the best way is to cope up with the disease and its acceptance as soon as possible by both the persons themselves and their family members as well as community where the individual with HIV/AIDS is living. It can help them psychologically to lead as normal persons but with some difference. Along with this for the total success of their life equally important thing is the material aspect of their life. This is related to the psychological aspects also. Better financial status means less worry for accessing treatment, non-dependency and better scenario for self and family.

Hence, other than helping the victims emotionally one should not neglect the ways that allows them to become financially sound and one way would be that the victims should be provided with equal opportunities for material support and should not be discriminated due to their infected status to access such opportunities, as it means a lot for them to lead a life with accepted reality.

The present study throws light on three important facts of Indian family. These are: the nature of joint family in to social relations, development of new families, and cooperativeness of the joint family. In these aspects, the ideal and normative behaviour are embedded. The changes effected in these aspects in the context of HIV/AIDS are discussed in the following pages.

In Indian joint family the hierarchical relations between mother-in-law and daughter-in- law are very important for the reasons that they either foster continuation of the joint family or act a force for formation of new nuclear family. The good or cordial relations between the mother-in-law and daughter-in-law enable continuation the joint family in which mother-in-law (parents-in-law) is/are taken care of by the daughter-in-law when the former become old. If the relations become save and make it impossible to live together, then force out the daughter-in-law and son to set up a separate family. In several cases frequent squabbles and disengagement between them are underplayed, and the men somehow pull on to continue joint family. In this kind of scenario, the HIV/AIDS has made the life of daughter-in-law miserable when the relations were already bad with mother-in-law. The man/son who is already affected becomes helpless to side his wife and separate his family from the parents, nor is he able to advice parents to stop ill treatment as they are dependent. In normal situation young widows usually lived close to the in-laws if not together with parents-in-law and her children are taken care by husbands brothers. But now in the context of HIV/AIDS the daughter-in-law is thrown of the house. Or else she once for all leaves the conjugal family. Thus, the HIV/AIDS has disturbed the structure and function of the joint family.

Marriages are not individual affairs. Arranging marriage is the responsibility of parents. As children become adults, the parents look for suitable alliance. The prospective boy or girls family should be ideally respectable maintain by good character of its members. If any member is known having bad character with the habbits of drinking, gambling and so on, the family lost its prospect of being chosen for the marital alliance. Therefore, the alliance seekers enquire not only the character of the prospective boy or girl but also character of the other family members of the family. For example, if a member has married from a lower caste or entered a forbidden relation, alliance in that family is not preferred. In this context, HIV/AIDS has acquired a strong negative character grievously hampering the marriage prospect of the members who has a member affected by HIV/AIDS. This has a direct attract on the responsibility of the parents who should arrange for their son or daughter. In other words, one of the important functions of the family come under serious threat.

Finally, another function of the family is concerned with the distribution of its property among the sons who have the responsibility of taking care of the old parents. In the absence of sons, the male grand child who inhibits the property shall take up his, fathers' role. In this context, though majority of the informants considered for the study came from economically lower or lowest strata, it appears that this particular function has also come under threat. The parents-in-law as stated earlier did not allow the children of the deceased son in the house. One reason that appears to be is that the parents do not like to give a share of property to the grandchild. It is feared that the grandchild may die and as a child the property may be claimed by maternal grandparents for they are taking care of the child. Even if the grandchild survives, there is no guarantee that he will take care of the grandparents for he may develop disliking for the paternal grandparents for the antecedents that occurred.

The study has clearly demonstrated that a past Indian society, which may be tiny ones, has been visibly disturbed. If neglected, the disturbance can become a wild fire. The family and community have encountered a situation created by the HIV/AIDS that caused cracks in them. It has disturbed their structures and functions, and now the society is under adjustment to the situation. This adjustment is being facilitated by the government and the civil society. The government has been forced to bring change in its medical institutions to deal with HIV/AIDS. It has started partnership with NGOs. Together to intervene in the family by providing socio-economic and psychological support so that family continues performing its function meeting its needs, and community remains integrated. This is carried out making efforts my minimising stigma and discrimination and enhancing capabilities of HIV/AIDS victims and then family members to cope up with the situation for restructuring and continuation of functions of the family.

Bibliography

Ali, M. A and Kavita, Toran. (2004). "*Migration, Slums and Urban Squalor: A Case Study of Gandhinagar Slum*". (www.yorku.ca/bunchmj/ICEH/.../Ali_M_ICEH_papers_1to10.pdf . Accessed on 3/11/2009).

Alliance, AIDS. (2008). *"Supporting Community Action on AIDS in India"*. (http://www.aidsallianceindia.net. Accessed on 15/6/2008).

Ankrah, M. (1993). "*The Impact of HIV/AIDS on the Family and Other Significant Relationships: The African Clan Revisited*. AIDS Care, 5(1), 5-22.

APSACS. (2009). *"Andhra Pradesh state Annual Action plan 2009"*. Hyderabad. APSACS, Government of Andhra Pradesh.

APSACS. (2008). *"HIV Prevention"*. (http://www.apsacs.org/english/hivprevention.htm. Accessed on 9/6/2007).

APSACS. (2005). "*HIV/AIDS in Andhra Pradesh Situation and Response: A Report*. Hyderabad: APSACS, Government of Andhra Pradesh.

APSACS. (2004). "*Annual Report 2003–2004: HIV/ AIDS Situational Analysis in the State of Andhra Pradesh"*. Hyderabad: APSACS, Government of Andhra Pradesh.

Arora, V. K., Amit, Johri., Ramesh, Varma and Palani. (1992). *"Post-treatment Adjustment Problems and Coping Mechanisms in Pulmonary Tuberculosis Patients"*. Indian Journal of Tuberculosis, 39, 181-184. (http://lrsitbrd.nic.in/IJTB/Year%201992/July%201992/July1992%20H.pdf. Accessed on 2/9/2011)

AVERT. (2010). *"Overview of HIV and AIDS in India"*. (http://www.avert.org/aidsindia.htm. Accessed on 20/10/2010).

Bailey, A. (2008). *"Culture, Risk and HIV/AIDS among Migrant and Mobile Men in Goa, India"*. Amsterdam, Rozenberg Publishers.

Baldacchino, D. and Draper, P. (2001). *"Spiritual Coping Strategies: A Review of the Nursing Research Literature."* Journal of Advanced Nursing, 34(4), 833-841. Barnett, T and Whiteside, A. (1999). *"HIV/AIDS and Development and a Conceptual Framework"*.

(http://www.ukzn.ac.za/heard/reseach Research reports/1999/Ejde.pdf. Accessed on 16/6/2009).

Barnett, T and Whiteside, A. (1999). *"HIV/AIDS and Development and a Conceptual Framework"*.
(http://www.ukzn.ac.za/heard/reseach Research reports/1999/Ejde.pdf. Accessed on 16/6/2009).

Barnett, T and Whiteside, A. (2002). *"AIDS in the Twenty-first Century, Disease and Globalization"*. Palgrave Macmillan, New York.

Bennetts, A., Shaffer, N., Manopaiboon, C., Chaiyakul, P., Siriwasin, W., Mock, P., Klumthanom, K., Sorapipatana, S., Yuvasevee, C., Jalanchavanapate, S., Clark, L. (1999). *"Determinants of Depression and HIV Related Worry Among HIV Positive Women Who have Recently Given Birth, Bangkok, Thailand"*. Social Science and Medicine, 49, 737-749.

Bharat. S and Aggleton, P. (1999). *"Facing the Challenge: Household Responses to HIV/AID in Mumbai, India"*. AIDS Care. 11(1),31-44.

Billings, A and Moss, R. (1981). *"The Role of Coping Responses and Social Resources in Attenuating the Stress of Life Events"*. Journal of Behaviour Medicine, 4, 139-157

Bloom, D. E and Godwin, P (ed). (1997). *"The Economics of HIV and AIDS: The care of South and South East Asia"*. Delhi. Oxford University Press.

Burry, J., Morrison, V and McLachlan, S. (1992). *"Working With Women and AIDS"*. Medical, Social and Counseling Issues. London : Routledge.

Bunting, S. M. (1996). *"Sources of Stigma Associated with Women and HIV"*. Advances of Nursing Science, 19,63-72.

Bunting, Sheila, M., Donna J. Bevier and Susan, K. Baker. (1999). *"Poor Women Living with HIV: Self-Identified Needs."* Journal of Community Health Nursing, 16, 41-52

Caplan, G. (1974). *"Support and Community Mental Health"*. New York: Behavioral Stratton.

Carballo, Diéguez, A. (1989). *"Hispanic Culture, Gay male Culture, and AIDS: Counseling Implications"*. Journal of Counseling and Development, 68, 26-29.

Cauble and Patterson, J.M. (Eds) (1983). *"Family Stress, Coping and Social support"*. Springfield. I. L Charles, C. Thomas.

Census of India, 1981. (1989). *"Andhra Pradesh, Special Report on Hyderabad City"*. Part- X E. Series- 2. New Delhi.

Census of India, 2001. (2001). *"Data Highlights. Migration Tables (D1, D1 (Appendix), D2 and D3Tables"*. (http://www.censusindia.gov.in/Data_Products/Data_Highlights/Data_Highlights_link/data_highlights_D1D2D3.pdf. Accessed on 12/12/2007).

Census of India, 2001. (2007). *"India at a Glance, Religious Composition"*. (http://www.censusindia.gov.in/Census_Data_2001/India_at_glance/religion.aspx. Accessed on 12/12/2007).

Chandra, Shailaja. (2005). *"There's No Time to Lose Against HIV/AIDS : Needs to be Taken a War"*. Footing. Poineer, June, 7.

Chapple, A., Ziebland, S and McPherson, A. (2004). "*Stigma, Shame, and Blame Experienced by Patients with Lung Cancer: Qualitative Study"*. British Medical Journal, 19**,** 1470–73. (http://www.ncbi.nlm.nih.gov/pubmed/15194599. Accessed on 2/9/2011).

Chesney, M. A and Smith, A.W. (1999). *"Critical Delays in HIV Testing and Care"*. American. Behavioral Scientist, 42, 1162–1174.

Christopher, Daniel, J. (2007) "*NGO management and capacity building Initiatives for GLI(UK) networks and Social networks and social Entrepreneurs in Tamilnaidu, India" (*http://www.socialdesignsite.com/content/view/317/73. Accessed on 16/7/2009).

Cobb, S. (1982). *"Social Support and Health Through the Life Course"*. In H. I. McCubbin, A. E. Cauble, and J. M. Patterson (Eds.), *"Family Stress, Coping, and Social Support"*. Springfield, IL: Charles C. Thomas. 189-199.

Cohen, S and Wills, T. A. (1985). *"Stress Social Support and the Buffering Hypothesis"*. Psychological Bulletin, 98, 310-357.

Coleman, L. (1986). *"Stigma: an Enigma Demystified"*. In Ainly, C. S., Coleman, L. M., and Becker, G (Eds.). *"The Dilemma of Difference: A Multidisciplinary View of Stigma"*. New York: Plenum Press.

CORHE. (2008). "*Women, Slums and Urbanisation: Examining the Causes and Consequences"*. Centre on Housing Rights and Eviction; *Women and Housing Rights Programme*. (*sheltercentre.org/.../COHRE_* Accessed *on 10/12/2009).*

Crandall, C. S and Coleman, R. (1992). *"AIDS Related Stigmatisation and the Disruption of Social Relationships".* Journal of Social and Personality Relationships, 9, 163-167.

Crocker, J and Lutsky, N. (1986). *"Stigma and the Dynamics of Social Cognition".* In Ainly, C. S., Coleman, L. M., and Becker, G (Eds.), *"The Dilemma of Difference. A Multidisciplinary View of Stigma".* New York: Plenum Press.

Dilip, T. R and Duggal, Ravi. (2002). *"Incidence of Non-Fatal Health Outcomes and Debt in Urban India".* Draft Paper Presented for Urban research Symposium, December 9-11.The world Bank, Washington, D.C. (www.ucl.ac.uk//drivers_urb_change/urb_society/pdf_health_educ/CEHAT_Ravi_Non_ Health India.pdf. Accessed on 18/9/2009).

D. Cruz, P. (2003). "*In Sickness and in Health: The family Experience of HIV/AIDS in India".* Mandira Sen for Stree, Kolkota.

D. Cruz, P. (2004). "*The Family Context of Care in HIV/AIDS: A Study from Mumbai".* India. The Qualitative Report, 9(3), 413-434.

Doka, J. K. (1997). *"AIDS, Fear, and Society: Challenging the Dreaded Disease".* USA: Taylor and Francis.

Dorn, N., Henderson, S and South, N. (1994). *"AIDS: Women, Drugs and Social care".* London: Falmer Press.

Dube, M.W (ed). (2003). *"HIV/AIDS and the Curriculum. Methods of Integrating HIV/AIDS in Theological Programmes".* Geneva. WWWC, Publications.

Dunber, H. T and Meuller, C. (1998). *"Psychological and Spiritual Growth in Women Living with HIV".* Social Work, 43(2), 369-390.

Dunkle, K. L., Jewkes, R. K and Brown, H. C. (2004). *"Gender-Based Violence, Relationship Power and Risk of HIV Infection in Women Attending Antenatal Clinics in South Africa".* The Lancet, 363 (9419), 1415-21.

Exner, T. M., Ehrhardt, A. A and Seal, D.W. (1997). *"A Review of HIV Interventions for At-Risk Women".* AIDS and Behavior, 1(2), 93-124.

Folkman, S. (1997). *"Positive Psychological States and Coping with Severe Stress".* Social Science and Medicine, 45 (8), 1207-1221.

Formative Research Report. (2006). "*Stigma and Discrimination Faced by Women Living with HIV/AIDS. A Report for Breakthrough by Prastut Consulting supported by DFID and NOVIB".*

(www.breakthrough.tv/images/.../79/stigmaanddiscrimination.pdf, Accessed on 8/2/2009).

Friedland, J., Renwick, R and Mcou, M. (1996). *"Coping and Social Support as Determinants of Quality of live in HIV/AIDS".* AIDS Care, 8, 15-31.

Freund, P and McGuire, M. B. (1991). "Health, Illness, and the Social Body: A Critical Sociology". Englewood Cliffs. New Jersey: Prentice Hall.

Ganguli, S. K., Rekha, P. P., Gupte, N., Charan, U. A. (2002). *"AIDS Awareness among Undergraduate Students, Maharashtra".* Indian Journal of Public Health, 46, 8-12.

Gielen, A. C., Campo, P. O., Faden, R. R and Eke, A. (1997). *"Women's Disclosure of HIV Status: Experiences of Mistreatment and Violence in an Urban Setting".* Women Health, 25(3), 19-31.

Goffman, Eriving. (1963). *"Stigma Notes on the Management of the spoiled Identity".* Englewood Cliffs. N. J. Prentice Hall.

GHMC. (2007). *"City History, Greater Hyderabad Municipal Corporation".* (http://ghmc.gov.in/greaterhyd.asp. Accessed on 28/11/2007).

Gupta, G. R. (2000). *"Gender, Sexuality and HIV/AIDS: The What, The Why and The How".* U.S.A. International Research for Research on Women.

Hackl, K. L., Somlai, A. M., Kelly, J. A and Kalichman, S. C. (1997). *"Women Living With HIV/AIDS: The Dual Challenge of Being a Patient and Caregiver".* Health and Social Work, 22 (1), 53-61.

Hahn, R. A. (1995). *"Sickness and Healing: An Anthropological Perspectives".* Yale University, Press, New Haven.

Hays, R. B., Catania, J. A., McKusick, L and Coates, T. J. (1990). *"Help-seeking for AIDS-Related Concerns: A Comparison of Gay Men with Various HIV Diagnoses".* American Journal of Community Psychology, 18, 743-755.

Hays, R. B and Peterson, J. L. (1994). *"HIV Prevention for Gay and Bisexual Men in Metropolitan Cities".* In R. J. D. Clemente and J. L. Peterson (Eds.), *"Preventing AIDS: Theories and Methods of Behavioral Interventions".* New York: Plenum, 267-296.

Herdt, G and S. Lindenbaum (eds). (1992). "*In the Time of AIDS - Social Analysis, Theory, and Method".* Sage Publications. In California, London.

Herek, G. M and Glunt, E. K. (1988). *"An Epidemic of Stigma: Public Reactions to AIDS".* American Psychologist, 43, 886-891.

Hertzman, C. (2001). *"Health and Human Society".* American Scientist, 89, 538-545.

Hough, E. S., Brumitt, G., Templin, T., Saltz, E and Mood, D. (2003). *"A Model of Mother-Child Coping and Adjustment to HIV".* Social Science and Medicine, 56,643-6555.

Hudson, A. L and Morries, R. I. (1994). *"Perceptions of Social Support of African Americans with Acquired Immonodeficiency Syndrome".* Journal of the National Black Nurses Association, 8, 36-49.

ICRW Research Update. (2002). *"Understanding HIV-Related Stigma and Resulting Discrimination in Sub- Saharan Africa, Emerging themes from early data collection in Ethopia, Tanzania and Zambia"*. Research Update. Washington. International Center for Research on Women.

ILO. (2003). *"Socio- Economic Impact of HIV/AIDS on PLHA and Their Families".* New Delhi: International Labour Office.

Indian Express. (2003). *"Living in the Shadow of AIDS".* An article by Reshma Patil. December.

INP+. (1997). *"Indian Network of People Living with HIV/AIDS 1997"*. (http://www.hivpolicy.org/biogs/HPE0344b.htm Accessed on 17/6/2009).

Iwasaki, Y., Bartlett, J.G., and O'Neil, J.D. (2004). "*An Examination of Stress among Aboriginal women and men with diabetes in Manitoba"*. Canada. Ethnicity and Health. 9(2), 189-213.

Jaggarajamma, K., Rajeswari, R., Nirupa C., Chandrasekaran, V., Muniyandi M and Sudha G. (2008). *"Psycho-Social Dysfunction: Percieved and Enacted Stigma among Tuberculosis Patients Registered Under Revised National Tuberculosis Control Programme".* Indian Journal of Tuberculosis, 55, 179-187. (http://medind.nic.in/ibr/t08/i4/ibrt08i4p179.pdf Accessed on 2/9/2011).

Jamil, I. (1998). *"Transactional Friction Between NGOs and Public Agencies In Bangladesh: Cultural Dependence".* Contemporary South Asia **7**(11).

Jamil, I. (2004). "*Building Social Capital in Uganda: The Role of NGOs. Inmitigating HIV/AIDS Challenges"*. (www.istr.org/conferences/toronto/workingpapers/jamil.ishtiaq.pdf. Accessed on 2/5/2008).

Janeway, J., Charles, A and Paul, Travers. (1997). Chapter 10: *"Failures of Host Defence Mechanisms. IN Immunology*, 3, ed. Charles,A., Janeway, Jr and Paul Travers, eds. Singapore: Stamford Press.

Jejeebhoy, S. (1998). *"Wife Beating in Rural India: A Husband's Right? Evidence from Survey Data"*. Economic and Political Weekly, 33(15), 855-862.

Johnson, T. M and Sargent, C. F. (1990). "*Medical Anthropology: A Handbook of Therapy and Method"*. Praeger Press: Newyork.

Johnston, D., Stall, R and Smith, K. (1995). *"Reliance by Gay Men and Intravenous Drug Users on Friends and Family for Aid Related Care"*. AIDS Care, 7, 307-309.

Joseph, E. B. and R. S. Bhatti. (2004). *"Psychosocial Problems and Coping Patterns of HIV Seropositive Wives of Men with HIV/AIDS"*. Social Work in Health Care, 39(1-2), 29-47.

Kalichman, S. C and Nachimson, D. (1999). *"Self-efficacy and Disclosure of HIV Positive Serostatus to Sex Partners"*. Health Psychology, 18, 281-287.

Kalichman, S. C. (1998). *"Influencing HIV Transmission Risks"*. Focus, 113, 1-4.

Kaleeba, N., Kalibala. S., Kaseje, M., Sebbanja, P., Anderson, S., Van Praag, E., Tembo, G and Katabira, E. (1997). *"Participatory Evaluation of Counseling: Medical and Social Services of the AIDS Support Organization (TASO) in Uganda"*. AIDS Care, 9, 13–26.

Kausalya, P and Deepika Ganju. (2008). *"Positive Women Lives in Namakkal District India"*.
(http://www.popcouncil.org/pdfs/wp/India_HPIF/007.pdf. Accessed on 12/6/2009).

Keulder, C. (2007). *"HIV/AIDS and Stigma in Namibia: Results of a Qualitative Study among Support Group Members"*.
(www.ibis.dk/dokumenter/ibisdoc46_ibis_stigma_report.doc Accessed on 11/28/11).

Kidd and Clay, S. (2003). *"Understanding and Challenging HIV Stigma: Toolkit for Action"*. Trainers Guide. Washington D.C: Change/ICRW.
(www.changeproject/technical/hivaids/stigma.html Accessed on 5/2008).

Kimberely, J. A and Serovich, J. M. (1996). *"Perceived Social Support among People Living with HIV/AIDS"*. American Journal of Family Therapy, 24, 41-53.

Kongsin S. (1995). *"Economic Impact of HIV/AIDS Mortality on Households in Rural Thailand"*. Journal of Health Science, 4 (4), 333-344).

Krohne, H W, (1996). "*Individual Differences in Coping"*. In M. Zeidner and N. S. Endler (Eds), (1996). *"Handbook of Coping: Theory, Research, Applications"*. (381-409). New York.

Lazarus, R. S, Folkman, S. (1984). *"Stress and Coping"*. New York, Springer.

Lazarus, R. S. (1991). *"Emotion and Adaptation"*. London: Oxford University Press.

Folkman, S and Lazarus, S. (1980). *"An Analysis of Coping in a Middle-Aged Community Sample"*. Journal of Health and Social Behaviour, 21, 219-239

Lee, R. S, Kalichman, S. C and Sikkema, K. J. (2002). *Internalized Stigma among People Living with HIV/AIDS"*. AIDS and Behaviour, (64).

Lesko, I. (2005). *"Attitudes and Beliefs Around HIV and AIDS Stigma. The Impact of the Film: The Sky in Her Eyes"*. (etd.uwc.ac.za/usrfiles/modules/etd/.../etd_init_7220_1176472088.pdf Accessed on 8/30/11).

Lester, P., Partridge, J.C., Chesney, M.A., Cooke, M. (1995). *"The Consequences of a Positive Prenatal HIV Antibody Test for Women"*. Journal of Acquired Immune Deficiency Syndromes and Human Retrovirology, 10,341–349.

Link, B and Phelan, J. (2001). *"Conceptualizing Stigma"*. Annual Review of Sociology, 27, 363-385.

Levin, L. S and Ellen, L. Idler. (1981).*"The Hidden Health Care System": Mediating Structures and Medice"*. Cambridge, MA: Ballinger publishing Co.

Lucia N. Makoae., Minrie, Greeff., Rene, D. Phetlhu., leana, R. Uys., Joanne, R. Naidoo., Thecla, W. Kohi., Priscilla, S. Dlamini., Maureen L. Chirwa., and William L. Holzemer. (2008). *"Coping with HIV/AIDS Stigma in Five African Countries"*. Journal of the Association of Nurses in AIDS Care, 19(2), 137-146. (http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2346777/ Accessed on 5/6/2010

Mach, A., WHO. (1997). *Amartya Sen on Development and Health. In to our Health: The Internal Newsletter of the World Health organization.* (http://www.who.int/infwhat52/to_our_health/amartya.html Accessed on 6/5/2010).

Majumdar, B. (2004). *"An Exploration of Socioeconomic, Spiritual and Family Support among HIV Positive Women in India"*. Journal of the Association of Nurses in AIDS Care,15(3), 37–46. (http://www.ncbi.nlm.nih.gov/pubmed/15165374 Accessed on 5/6/2010).

Malla, A. Reddy. (1995). *"Slums Improvement: The Hyderabad Experience"*. Ms Publications, Delhi.

McGrath, J. W., Ankrah, R. M., Schuman., D.A, Nkumbi, Lubega, M . (1993) *"AIDS and the Urban Family: Its Impact in Kampala, Uganda"*. AIDS Care, 1993, 5, 55-70.

Mehta, A. K and Gupta, S. (2006). *"The Impact of HIV/AIDS on Women Care Givers in Situations of Poverty". Policy Issues.* (http://www.chronicpoverty.org/uploads/publication_files/CPRC-IIPA_31.pdf. Accessed on 8/10/2010).

Mann, J and Tarantola, D. (1996). *"AIDS in the World II".* Oxford University Press, Newyork.

Martin, J. L and Dean, L. (1992). *"Effects of AIDS Related Bereavement and HIV-Related Illness on Psychological Distress among Gay Men: A 7 Year Longitudinal Study, 1985- 1991".* Journal of Consulting and Clinical Psychology, 61, 94-103.

Melnick, M. (2002). *"An Investigation of the Coping Strategies of Caregivers Providing Home-Based Care for People with Advanced HIV Infection".* Unpublished Master's Thesis. Bellville: University of the Western Cape.

Meursing, K and Sibindi F. (1995). *"Condoms, Family Planning and Living with HIV in Zimbabwe".* Reproductive Health Matters, 5:56–62.

Mokhoka, M. D. (2000). *"Black Women Diagnosed as HIV Positive: Their Psychological Experiences and Coping Mechanisms".* Pretoria. University of Pretoria.

Molemoeng, S. (2006). *"The Experiences and Coping Strategies of HIV/AIDS Primary Caregivers Within. Two Disadvantaged Communities in the Western Cape Metropole".* (etd.uwc.ac.za/usrfiles/.../etd_gen8Srv25Nme4_65871210838683.pdf. Accessed on 16/6/2009).

Moneyham, L., Seals, B., Demi, A., Sowell, R., Cohen, L and Gullory, J. (1996). *"Experiences of Disclosure in Women Infected with HIV".* Health Care Women International, 17, 209–221.

Mukhapadhyay, S., Nandi, R., Nundy, M., Sivaramayya, J. (2001) *"Living Under a Shadow: Gender and HIV/AIDS in Delhi"*: ISST.

Muriisa, R. (2001). *"NGOs and Rural Developmet in Uganda".* Public Administration and Organization Theory. Bergen, University of Bergen.

NACO. (2003). *"Report on HIV/AIDS Surveillance in India".*

NACO. (2006). *"HIV/AIDS Epidemiological Surveillance and Estimation Report for the year 2005"*.

NACO. (2007). *"NACP III: Programme Priorities and Thrust Areas"*. (http://www.nacoonline.org/National_AIDS_Control_Program/Programme_Priorities_& Thrust Areas. Accessed on 3/8/2008).

Nag, Moni. (1996). *"Sexual Behaviour and AIDS in India"*. Vikas Publishing House Pvt. Ltd. Delhi.

Namir, S., Alumbaugh, M. J, Fawzy, F. I and Wolcott, D. L. (1989). *"The Relationship of Social Support to Physical and Psychological Aspects of AIDS"*. Psychology and Health 3, 77-86.

Nashandi, J. C. (2002). *"Experiences and Coping Strategies of Women Living with HIV/AIDS: Case Study of Khomas Region, Namibia"*. Unpublished Masters Thesis. University of the Western Cape.

Naveet, W., Lakshmi, R., Pal, H., Vivek, A., Chander, M. M and Sunil, K. A. (2006). *"The Impact of HIV/AIDS on the Quality of Life: A Cross Sectional Study in North India"*. Indian Journal of Medical Sciences, 60(1) 3-12.

Nelkin, D. (1991). *"AIDS and the News Media"*. The Milbank Quarterly, 69(2), 293-307.

Nyblade, L., Pande, R., Mathur, S., MacQuarrie, K., Kidd, R., Bantenyerga, H., Kidanu, A., Kilonzo, G., Mbwambo J., Bond, V. (2003). *"Disentangling HIV and AIDS Stigma in Ethiopia, Tanzania and Zambia"*. Washington, DC: ICRW.

Nyamathi, Adeline M., Ravi. R. William., Kalyan, K Ganguly., Sanjeev Sinha., Anisa Heravain, B.A., Cynthia, R. Albarran., Alexande, Thomas, B., Greengold, M Aria., E. P. Ramakrishna and Rama Rao. P. (2010). *"Perceptions of Women Living with AIDS in Rural India Related to the Engagement of HIV-Trained Accredited Social Health Activists for Care and Support"*. (http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3038639 Accessed on 3/7/2011).

Ogden, J and Nyblade, L. (2005). *"Common at Its Core: HIV-Related Stigma Across Contexts"*. Washington, DC: ICRW.

Pallikadavath, S., Gardal., Apte, H., Freedman, J., Stones, R. W. (2005). *"HIV/AIDS in Rural India: Context and Health Care Needs"*. Journal of Biosoc Sci, 37(5), 641-655.

Parker, R and Aggleton, P with Attawell, K., Pulerwitz, J. and Brown, L. (2002). *"HIV/AIDS-Related Stigma and Discrimination: A Conceptual Framework and Agenda for Action"*. Washington: Horizon Program.

Parker, J. D. A and Endler, N. S. (1992). *"Coping with Coping Assessment: A Critical Review".* European Journal of Personality, 6, 321–344.

Parker, J. D. A and Endler, N. S. (1996). "Coping and Defense: A Historical Overview. In M. Zeidner and N. S. Endler (Eds.), "*Handbook of Coping - Theory, Research, Applications* (pp. 3-23). New York: Wiley.

Parker, W., Oyosi, S., Kelly, K and Fox, S. (2002). *"On the Move: The Response of Public Transport Commuters to HIV/AIDS in South Africa".* Pretoria: Department of Health.

Parker, J. D. A and Endler, N. S. (1992). *"Coping with Coping Assessment: A Critical Review".* European Journal of Personality, 6, 321–344.

Pearlin. L and Schooler. G. (1978). *"The Structure of Coping".* Journal of Health and Social Behaviour, 19, 2-21.

Population Council. (2001). *"Power in Sexual Relations: An opening Dialogue among Reproductive Health Professions".* New York: The Population Council. Inc.

Pradhan, B. K and Sunder, R. (2006). *"Gender: Impact of HIV/AIDS in India".* (http://data.undp.org.in/hivreport/Gender.pdf Accessed on 20/5/2007).

Priya, Ritu. (2003). *"Health Services and HIV Treatment Complex Issues and Options".* Journal of Economic and Political Weekly, 3, (15), 13.

Putnam, R. D. (1995). "Bowling *Alone: America's Declining Social Capital"*. Journal of Democracy, 6(1):65 - 78.

Putnam, R. D. (2000). *"Bowling Alone: The Collapse and Revival of American Community".* New York, Simon and Schuster.

Putnam, R. D. (2001). *"Social Capital: Measurement and Consequences".* (http://www.isuma.net. Accessed on 5/7/2008).

Putnam, R. D., R. Leonardi, et al. (1993). *"Making Democracy Work : Civic Traditions in Modern Italy"*. Princeton, Princeton University Press.

Ramamurthy, V. (2004). *"Strategic Approaches to HIV and AIDS Prevention and Control".* Authors Press, Delhi.

Ramasubban, R. (1995). *"Patriarchy and the Risks of STD and HIV Transmission to Women".* In Desgupta, M., Chen, L. C and Krishnan, T. N. (eds), *"Women Health in India".* New Delhi: Oxford University Press.

Ranjana, Singh. (2007). *"Behavioural Changes in the Family and Community of HIV-Infected People: A case study of Mumbai".* Journal of Social Change, 37(2), 1-27.

Ravichanddran, N. (2004). *"Life with HIV/AIDS: Striving towards basic Rights".* Pantagon Press. New Delhi.

Ravi K. Verma., Niranjan, Saggurti., Madhumita Das., Saumya, Rama, Rao, and Anrudh, Jain. (2007). *"Patterns and Implications of Male Migration for HIV Prevention Strategies in Andhra Pradesh".* Technical Brief from Population Council India. (http://www.popcouncil.org/pdfs/India_TechBrief.pdf. Accessed on 6/5/2009).

Ravi, K. Verma., Salil, S., Veera Mendonca., Singh, S. K., Prasad, R and Upadhyaya, R. B. (2002). *"HIV/AIDS and Children in the Sangali District of Maharashtra. India".* (www.unicefirc.org/research/ESP/aids/chapter8.pdf Accessed on 3/5/2009).

Robinson, N. (1998). *"People with HIV/AIDS, Who Cares?"* Journal of Advanced Nurses, 28: 771-778.

Rose, M. A., Clarke, Alexander, B. (1996). *"Quality of Life and Coping Styles of HIV-positive Women and Children".* Journal of the Association of Women in AIDS Care, 7:28–43.

Rose, M. A and Clark-Alexander, B. (1999). *"Coping Styles of Caregivers of Children with HIV/AIDS: Implications for Health Professionals".* AIDS Patient Care and STDs, 13(6), 355-342.

Rahangdale, L., Pradeep, B., Amita, S., Janet, M., Turan, Craig, R, Cohen. (2010). "Stigma as Experienced by Women Accessing Prevention of Parent-to-Child Transmission of HIV Services in Karnataka, India". AIDS Care, 22(7), 836-842.

Rajput, K. S. (2007). *"Knowledge of HIV/AIDS: Hindu-Muslim Differentials. Man and Society".* A Journal of North East Studies, 4, 97-107.

Richardson, D. (1989). *"Women and the AIDS Crises".* New Zeakand: Allin and Unwin Publishers.

Roemer, Milton I., ed. (1960) *"Henry E. Sigerest on the Sociology of Medicine".* New York: MD Publications.

Roman, G. S. (2006). *"An Exploration of the Stigma Experienced by Women Who are Living with HIV/AIDS".* (etd.uwc.ac.za/usrfiles/.../etd_gen8Srv25Nme4_3586_1210750790.pdf Accessed on 5/102009).

Rothenberg, K. H., Paskey, S. J., Reuland, M. M., Zimmerman, S. I and North R. (1995). *"Domestic Violence and Partner Notification: Implications for Treatment and Counseling of Women with HIV"*. Journal of American Medicines, Women's Association, 50(3-4), 87-93.

Sack, W. H., Clarke, G. N and Seeley, J. (1996). *"Multiple Forms of Stress in Cambodian Adolescent Refugees".* Child Development, 67, 107-116.

Schaefer, C., Coyne, J. C and Lazarus, R. S. (1981). *"The Health Related Functions of Social Support"*. Journal of Behavioral Medicine, 4, 381-406.

Schwarzer, R., Dunkel-Schetter, C and Kemeny, M. (1994). *"The Multidimensional Nature of Received Social Support in Gay Men at Risk of HIV Infection and AIDS".* American Journal of Community Psychology, 22(3), 319-337.

Seidel, G. (1998). *"Making an Informed Choice: Discourses and Practices Surrounding Breastfeeding and AIDS.* Agenda, 39, 65-81.

Seigel. K and Krauss, B. (1991). *"Living with HIV Infection: Adaptive Tasks of Seropositive Gay Men".* Journal of Health and Social Behaviour, 1991, 32, 17-32.

Shinn, M., Rasrio, M., Morch, H and Chestnut, D. (1984). *"Coping with Job Stress and Burnout in the Human Services"*. Journal of Personality and Social Psychology, 46, 864-876.

SIDA. (1998). *"Gender HIV/AIDS Transmission and Impacts: A Review of Issues and Evidence"*. Stockhom: Swedish International Development Cooperation Agency.

Singer, M. (1992). *"AIDS and US Ethnic Minorities: The Crises and Alternative Anthropological Responses"*. Human Organisation, 51, 89-95.

Small, Neil. (1997). *"Suffering in Silence? Public Visibility, Private Secrets and the Social Construction of AIDS."* In Peter Aggleton, Peter Davies and Graham Hart (eds) *"AIDS Activism and Alliances",* Taylor and Francis, London.

Smita, Jain. (2005). *"Bringing the Virus".* Nov 27. The Hindu. 2005.

Smith, M. Y and Rapkin, B. D. (1996). *"Social Support and Barriers to Family Involvement in Caregiving for Persons with AIDS: Implications for Patients Education"*. Patient Educ Couns, 27(1), 85-94.

Snyder, C.R. (ed.) (1999) *Coping: The Psychology of What Works*. New York: Oxford University Press.

Sontag, S. (1989). *"Illness as Metaphor and AIDS and its Metaphors"*. London: Penguin.

Sowell, R. L., Lowenstein, A., Moneyham, L., Demi, A., Mizuno, Y., Seals, B. F. (1997). *"Resources, Stigma and Patterns of Disclosure in Rural Women with HIV Infection"*. Public Health Nursing. 14(5), 302–312.

Sowell R, Seals B, Moneyham L, Guillory J and Mizuno Y. (1999). *"Experiences of violence in HIV seropositive women in the south-eastern United States of America"*. Journal of Advanced Nursing. 30(3), 606-615.

Stafford, M. C and Scott, R. R. (1986). *"Stigma, Deviance and Social Control. Some Conceptual Issues"*. In Ainly C. S., Coleman, L. M., and Becker, G (Eds.), *"The Dilemma of Difference. A Multidisciplinary View of Stigma."* New York: Plenum Press.

Stein, M., Freedberg, K., Sullivan, L., Savetsky, J., Levenson, S., Hingson, R., Samet, J. (1998). *"Sexual Ethics: Disclosure of HIV-Positive Status to Partners"*. Archives of Internal Medicine, 158(9), 253-257.

Strebel, A. (1995). *"Whose Epidemic is it? Reviewing Literature on Women and AIDS. South African"*. Journal of Psychology, 25(1), 12-20.

Stowe, A., Rose, M.W, Wodak, A., Thomas, G.V, and Larson. (1993). *"Significant Relationships and Social Support of Injecting Drug Users and their Implications for HIV/AIDS services"*. AIDS Care, 51, 23-33.

Subramanan, T., Gupte, M. D., Dorairaj, V. S., Periannan, V and Mathal, A. K. (2009). *"Psycho-Social Impact and Quality of life of People Living with HIV/AIDS in South India"*. AIDS Care, 21(4), 473-481.

Sudha, R. T., Vijay, D. T and Lakshmi V. (2005). *"Awareness, Attitudes,and Beliefs of the General Public towards HIV/AIDS in Hyderabad: A capital city from South India"*. Indian Journal of Medical Sciences 59, 307-316. (http://www.indianjmedsci.org/text.asp?2005/59/7/307/16506 Accessed on 2/3/2009).

Sudhir Verma. (2005). *"Vulnerability of Women in Rajasthan to HIV/AIDS for Suggesting Measures to Reduce it and Ameliorating the Condition of Women Already Infected".* (http://ncw.nic.in/pdfreports/vulnerability%20of%20women%20in%20Rajasthan%20to%20HIVAIDS%20report.pdf Accessed on 2/2/2009).

Sunday, Eyles and Upshur. (2001). *"Applying Aristotle's Doctrine of Causation to Aboriginal and Biomedical Understandings of Diabetes".* Culture, Medicine and Psychiatry (80).

Suneeta Krishnan, Rohini Pande, Sanyukta Mathur, Kalyani Subbiah, Eva Roca, Diana Measham, Sanghamitra Iyengar and Anuradha R. (2005). *"Marriage and Motherhood: Influences on Urban Indian Women's Power in Sexual Relationships".* Paper prepared for presentation at the Annual Meetings of the Population Association of America, March 31-April 2, 2005, Philadelphia. (http://paa2005.princeton.edu/download.aspx?submissionId=50605 Accessed on 16/7/2009).

Swantz, L. (1990). *"The Medicine Man Among the Zaramo of Dares Salaam. Uppsala, Scandinavian".* Institute of African Studies.

Temmerman, M., Ndinya, Achola J., Ambani, J and Piot P. (1995). *"The right not to Know HIV-Test Results".* Lancet, 345,969-970.

Thoits, P. A. (1994). *"Stressors and problem-solving: The Individual as Psychological Activist".* Journal of Health and Social Behavior, 35, 143–159.

Turner, H.A., Hays, R. B, and Coates, T. S. (1993). *"Determinants of Social Support Among Gay Men: The Context of HIV/AIDS".* Journal of Health and Social Behaviour, 34, 37-53.

Westbrooke, M. T and Viney L. L. (1982). *"Psychological Reaction to the Onset of Chronic Illness".* Social Science and Medicine, 16(5), 899-905.

WHO. (2000). *"Violence against Women and HIV/AIDS: Setting the Research Agenda. Meeting Report. Gender and Women's Health".* Geneva: Wealth health Organization.

WHO. (1995) *"Women and AIDS: Women Face Avoidable Risk of AIDS".* Press Release, August 23.

Woudenberg, J. (1998). *"Women Coping With HIV/AIDS"*. Royal Tropical Institutes Bulletin, 344.

UNAIDS. (2000). "*Caring for Carers: Managing Stress in those Who Care for People with HIV and AIDS"*. Geneva.

UNAIDS. (2002). *"Report on the Global HIV/AIDS Epidemic"*. Geneva, Switzerland: UNAIDS.

UNAIDS. (2004). *"Report on the Global AIDS Epidemic"*. Geneva, Switzerland: UNAIDS.

UNAIDS. (2004). "*Women and HIV/AIDS: Confronting the Crisis"*. (http://www.unaids.org Accessed on 2/6/2007).

UNAIDS (2008). *"Report on the Global AIDS Epidemic"*. August.

UNDP. (2006). *"Gender and Impact of HIV/AIDS in India"*. (http://www.beta.undp.org/undp/en/home/librarypage/hiv-aids/gender-impact-of-hiv-and-aids-in-india.html Accessed on 3/7/2009).

UNDP (2002). "*Law, Ethics and HIV/AIDS in South Asia: A Study of the Legal and Social Environment of the Epidemic in Bangladesh, India, Nepal and Sri Lanka.* (http://www.undp.org/hiv/docs/alldocs/Asia%20-%20Law,%20Ethics%20and%20HIV-AIDS%20%20Study%20of%20the%20Legal,%20Social%20Environment%20of%20Epidemic%20in%20Bangladesh,%20India,%20Nepal%20and%20Sri%20Lanka.pdf Accessed on2/2/2010).

UNIFEM, SARO. (2000) *"Community Based studies and HIV/AIDS"*. New Delhi.

UNIFEM, REAPS. (2003), *"Equalizing Gender Relationships in the Context of the HIV/AIDS epidemic"*.

Van Der Straten, A., Gómez, C. A., Saul, J., Quan, J and Padian, N. (2000). *"Sexual Risk Behaviors among Heterosexual HIV Serodiscordant Couples in the Era of Post-Exposure Prevention and Viral Suppressive Therapy"*. AIDS, 14(4), 47-54.

Van Dyck, A. (2001). "HIV/AIDS Care and Counseling". South Africa Education.

Vasuddeva, Rao. (1992). *"Status of Women and Children in Slums: A Study of Hyderabad City"*. Navrang Publications, New Delhi.

Verma, R. K., Bhende, A. A and Mane, P. (1999). *"NGOs Response to HIV/AIDS: A Focus on Women. In Implementing a Reproductive Health Agenda in India: A beginning.* Edited by S. Pachauri. New Delhi: Population Council.

Vimla, Veeraraghavan and Shalini, Singh. (1999). *"HIV/AIDS : Women at Risk". In* Vimala Beeraraghavan and Shalini Singh (eds). *"HIV and AIDS: An Interdisciplinary Approach to Prevention and Management*". Mosaic Books, New Delhi.

Were, B. (2000). "Positive "*Living: The Situation of Women Living with HIV/AIDS in Uganda".* A paper presented at an Expert group meeting on the HIV/AIDS Pandemic and its Gender Implications. 13-17 November 2000. Windhoek: Namibia.

Wikipedia. (2008). *"Hyderabad District, India.* (http://en.wikipedia.org/wiki/Hyderabad, _India. Accessed on 15/4/2010).

World Bank. (2009). *"HIV/AIDS South Asia".* (http://go.worldbank.org/FKLVQCCF40. Accessed on 10/4/2009).

Zinc, J and Temoshok, L. (1987). *"Perception of Social Support in Men with AIDS and ARC: Relationships with Distress and Hardiness".* Journal of Applied Social Psychology, 17, 193-215.

Zeidner, M. & Endler, N.S. (ed) (1996) *Handbook of Coping: Theory, Research, Applications*. New York: John Wiley.

ANNEXURE-I

QUESTIONAIRE FOR THE GENERAL PUBLIC

KNOWLEDGE, ATTITUDES, BELIEFS AND PREVENTION OF HIV/AIDS: A STUDY IN HYDERABAD

Location:

1) Name,

2) Age

3) Marital status

4) Sex a) Male ☐ b) Female ☐

5) Occupation

6) Education

S.No	Questions on knowledge of HIV/AIDS	Strongly Disagree	Don't Agree	Can't Say	Agree	Strongly Agree
1.	AIDS is the contagious disease					
2.	AIDS cannot be cured and causes compulsory death					
3.	A Pregnant lady can transmit AIDS to her offspring					
4.	AIDS is a problem to men who have sexual					

	contact with other men					
5.	HIV can be transmitted by sharing infected needles					
6.	Blood transmission can cause AIDS					
7.	Unsterilized needles may cause AIDS					
8.	A person having a many sexual partners has more chances of contacting HIV/AIDS					
S.No	**Questions on myths and misconceptions about HIV/AIDS**					
9.	I may get HIV/AIDS, if the HIV/AIDS person coughs or sneezes at me					
10.	Mosquito and other insects bites may cause HIV/AIDS					
11.	Using HIV/AIDS patient's comb can cause HIV/AIDS					
12	Using HIV/AIDS patients clothes too can cause HIV/AIDS					
13.	Kissing an HIV/AIDS patients may cause HIVAIDS					
14.	HIV/AIDS can be transmitted through a person who even appears					

	healthy					
15.	Living with a HIV/AIDS patient in the same house may cause HIV/AIDS					
16.	HIV/AIDS is transmitted by drinking in common cups and glasses					
17.	HIV is transmitted by sharing soap of infected persons					
18.	HIV/AIDS may be transmitted by barber's and their saloons					
19.	Persons having STDs are at high risk of HIV/AIDS infection					
20.	Men get HIV/AIDS only when they visit the sex-worker					
21.	I feel comfortable using a common toilet with someone who I know or suspect has HIV/AIDS					

S.No	**Questions on society's attitudes towards HIV/AIDS**	**Strongly Disagree**	**Don't Agree**	**Can't Say**	**Agree**	**Strongly Agree**
22.	If someone has HIV/AIDS, his/her family should take care of him/her completely					
23.	If a member of my					

	family has HIV, I would keep it secret					
24.	It's important for the infected person not to infect others					
25.	Owner of the house should have right to expel an HIV/AIDS person from his house					
26.	I allow HIV/AIDS person to visit my house					
27.	I allow HIV/AIDS person to work in my house					
28.	I would have food cooked by the HIV/AIDS person					
29.	I will be willing to take care of any other infected member					
30.	I feel comfortable sharing a meal with someone who I know or suspect has HIV/AIDS					
31.	I feel comfortable using a common toilet with someone for who I know or suspect has HIV/AIDS					
32.	I will use utensils of infected person					
33.	I feel comfortable hugging, touching a person whom you know					

	or suspected to have HIV/AIDS infection					
34.	I think HIV/AIDS infected students be allowed to attend the same school, where my children are studying					
35.	I don't allow my children to play with an infected child					
36.	I don't allow my children to play with the children of infected parents					
37.	I think that HIV/AIDS infected person should be terminated from the job					
38.	I think HIV/AIDS infected person be allowed to continue to work but make him or her isolated from other staffs					
39.	I think that the HIV person should be given less work load					
40.	AIDS employees should be given job as long as they can work					
41.	A person having AIDS virus can work normally					

	like other normal person					

S.No	Questions on prevention of HIV/AIDS	Strongly Disagree	Don't Agree	Can't Say	Agree	Strongly Agree
42.	HIV can be prevented with only one faithful partner					
43.	HIV can prevented with the use of sterilized or disposable needles					
44.	Children at the age of 12 years should be given awareness about AIDS in school					
45.	HIV can be prevented by avoiding homosexuality					
46.	One should get blood transfusion before it is screened					
47.	AIDS conformation test can be done by the blood test.					
48.	Condom is only used for family planning					
59.	Condom also used for prevention from the STDs/HIV					
50.	Government should pass the legislation of getting compulsory HIV test before marriage					

ANNEXURE-II

INTERVIEW SCHEDULED FOR THE ORGANISATIONS:

1. Name of the organisation:
2. Address:
3. Founder of the organization:
4. Motivation behind starting the organisation:
5. The organisation works in the area of:
6. Mission of the organisation:
7. Objectives of the organisation:
8. What is the nature and role of the organisation?
9. Who are the supporters of the organisation?
10. What are the different activities of the organisation?
11. What is the management structure of the organisation?
12. What is the organisational structure of the organisation?
13. What are the rules and regulations of your organisation?
14. Does the organisation provide counseling for the people working in this organisation with regard to HIV/AIDS?

15. The Organisation provide support to which group of people

A) Sex workers
B) MSM
C) Married
D) Unmarried
E) Widows
F) Children
G) People from rural
H) People from slums
I) All the above equally

16. What kind of information, the organisation provides to the HIV person to become a part of the organisation?

17. What initial response does the organisation get from the patients?

18. On what basis does the organisation register the HIV/AIDS patients?

19. How does the organisation identify the HIV/AIDS persons?

20. Till date, how many HIV/AIDS patients have been registered in this organisation?

21. Does the organisation provide technical support to the HIV/AIDS patients? If yes, how many doctors and nurses are available for them?

22. Does the organisation refer HIV/AIDS patients to the Government and non Government organisation?

23. Does the organisation provide any financial support to the HIV/AIDS patient? If yes, how much per individual and how often?

24. Does the organisation provide any nutritional support to the HIV/AIDS patients? If yes, how often and list out the items?

25. Does the organisation provide shelter to the HIV/AIDS patients?

26. Does the organisation provide clothes to the infected and affected families? If yes, how often?

27. Does the organisation provide any training programmes to the HIV/AIDS patients for their empowerment?

28. Does the organisation provide free education to the children of HIV/AIDS patients?

29. Does the organisation have any special programmes for the women and children?

30. Does the organisation provide any loan to the HIV/AIDS patients to start new ventures?

31. Does the organisation provide any pensions to the HIV/AIDS patients?

32. What are the different programmes and activities the organisation has for the HIV/AIDS affected families?

33. Does the organisation keep meetings with HIV/AIDS patients? If yes, how often
A) Once in a week
B) Twice in a month
C) Once in a month
D) Once in a three months or more

34. In meetings what kinds of issues have usually been discussed?

35. Are HIV/AIDS patients encouraged to do volunteer service for the other HIV/AIDS patients? If yes, what type of work they usually perform?

36. Does this organisation supply condoms free of cost to the HIV infected patients?

37. How often you supply condoms to them?

38. Do patients themselves ask for condoms?

39. Has the organisation constituted any policy for the HIV/AIDS patients?

40. What are the activities and programmes the organisation has for the non HIV/AIDS persons?

41. What information and advice the organisation provides to the non HIV people?

42. Does this organization think that there is an increase or decrease in the percentage of the HIV/AIDS patients? If yes, give reasons?

43. What are the major achievements of this organization until now?

44. Are there are any other issues that this organization wants to discuss?

ANNEXURE-III

INTERVIEW GUIDE FOR HIV/AIDS INFECTED WOMEN

1. Name of the respondent
2. Age
3. Caste and religion
4. Occupation
5. Monthly income
6. Education
7. Marital Status
8. Number of years spent in Hyderabad
9. Name of the respondent's Husband/Father

a. Age
b. Education of the husband/Father
c. Occupation
d. Monthly income of the husband/Father

10. Family Background:

a. Place of residence
b. Number of family members : Natal (if staying with parents) and Conjugal (if staying with in-laws/husband)
c. If married, who has brought you the marriage proposal?
d. Tenure of marriage

a. ‘Number of children:

b. Age of the children

c. What they do?

d. Who takes cares of your children?

e. How is your relationship with your husband?

f. How is your relationship with your husband's family members?

g. Does your husband have any bad habits, like drinking alcohol, gambling .chewing tobacco etc?

11. HIV/AIDS status

a. How you got to know about your HIV/AIDS status?

b. What was your instant response?

c. What was your husband’s response?

d. Had you ever heard about HIV before it infected you, if yes from where you got this knowledge?

e. Were you accompanied by someone when doctor suggested that you undergo for the HIV test?

f. What was the person’s reaction toward this?

g. Have you received any pre-counseling for this test? Yes / No

h. What kind of information was provided in pre-counseling?

i. Who was with you at that time?

j. Were you nervous at that time?

k. If yes, what kind of thoughts came in your mind?

l. Did you receive any post-counseling, after the test?

m. What information has been provided in this session?
n. How did you feel after the counseling session?
o. Did you find it useful?
p. Did your family members get any counseling for this?
q. Do you believe that you are suffering from HIV?
r. Is any other member of your family also infected with HIV?

12. Response and Reaction towards their status:

a) Have you disclosed your HIV status to anyone in the family? Natal or Husbands family
b) What was the reaction of the family?
c) How do your family members behave with you after knowing your status?
d) Have you observed any change in their behaviour after telling your status? If yes what kind of changes you have been observed?
e) Do your family members abuse you and use filthy languages because of your status?
f) Do your family members avoid physical contact with you?
g) Do your family members avoid talking to you?
h) Are you allowed to do usual house work in your house?
i) Are you allowed to touch, look after and play with children?
j) Are clothes, towels, utensils, etc, kept along with others?
k) Do your family members avoid accompanying you to the institutions?
l) Does anybody in your locality/neighborhood know about your status? Do they behave differ knowing about your condition?
m) What you do to overcome the reactions you get from others?

n) Are you taking any medicines or treatment?

o) How often you fell sick because of the infection and who takes care of you?

p) Where you usually go for the treatment?

q) Do medical persons know about your HIV status?

r) Do hospital members cooperate you with friendly gesture?

s) Have you faced any misconduct by the medical personnel till now?

13. Respondents Perception about their Status

a) Do you feel you are personally responsible for the misfortune of getting HIV?

b) Do you feel guilty or a shamed because of your status?

c) What according to you is the main reason for getting infected with HIV?

d) Do you follow suggestions given to you by the Doctor related to your care? If No, what are the reasons?

e) What are the ways you adopt to cope with the stress/thoughts related to your HIV status?

14. Organisational Support

a) Which organisation are you associated with?

b) How you came to know about this organisation?

c) How often you visit this organisation?

d) What kind of support you receive from this organisation?

e) Are you satisfied with the support you are receiving from this organisation?

f) Did you receive benefits easily?

g) Did you receive help free of cost?

h) Do you visit or take help from any other organisation than this?