

**A STUDY TO UNDERSTAND THE FACTORS  
RESPONSIBLE FOR THE INCIDENCE OF HIV /AIDS  
AND THEIR IMPACT ON WOMEN**



**EKTA - Resource Centre for Women  
Bethel Nagar, Bible Bhavan Street,  
Ponmeni, Bye Pass Road, Madurai - 10  
Phone: 0452-2381309 Fax: 0452-2382454  
Email: [mdu\\_ekta@sancharnet.in](mailto:mdu_ekta@sancharnet.in)**

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Bimla Chandrasekar

Director, EKTA

## **Preface**

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The HIV/AIDS epidemic is one of the greatest challenges facing human kind. It is an unprecedented threat to human development requiring political will and commitment on the part of the state on a sustained basis.

This study emphasizes the fact that women in the institution of marriage are more vulnerable to HIV/AIDS than men. Proactive strategies to prevent them from getting infected are not part of the state agenda. The contraceptive policy and the reproductive health care aims at stabilization of the population, and several health services related to this area are available through primary health care centers. However, less priority is given to provision of ART services, which are available only in selected district hospitals in the state.

The study clearly highlights the gendered impact of HIV/AIDS. Though women have the knowledge on strategies to protect themselves against HIV/AIDS, they cannot prevent themselves from getting infected by their husbands, as they do not have control over their body and sexuality. Mitigation of poverty, increase in local employment opportunities, free and good quality preventive and curative services (in the area of HIV/AIDS) and affirmative action to protect the rights of the people living with HIV/AIDS (especially women) are the long term solutions to combat this killer disease, and deal with its consequences.

Our greatest challenge is to mainstream gender perspectives into the policies and programmes of the state with regard to the curative and preventive measures. We are of the hope that this study will give insights on the impact of HIV/AIDS on the lives and livelihood options of women, and point to gender aware directions for prevention, treatment and dealing with adverse complications.

Bimla chandrasekar  
Director, EKTA

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# **A STUDY TO UNDERSTAND THE FACTORS RESPONSIBLE FOR THE INCIDENCE OF HIV /AIDS AND THEIR IMPACT ON WOMEN**

## **1.0 INTRODUCTION**

### **1.1 Background:**

In all affected countries with either high or low HIV prevalence, AIDS hinders development, causing a devastating toll on individuals and families. In the hardest-hit countries, it is erasing decades of health, economic and social progress – reducing life expectancy by years, deepening poverty, and exacerbating food shortages.

As the HIV/AIDS epidemic continues to infect and affect millions who were also impoverished, it is not only a public health problem, but also a development problem. It requires dealing with the conditions, which made people vulnerable. The economic, political and socio-cultural structures, programs and policies of a nation have an impact on the people's health. In the case of HIV/AIDS, this meant confronting the economic, social and political determinants of the disease.

Of the 39 million cases of HIV/AIDS worldwide, 23 million are in sub-Saharan Africa. Of these 57 per cent are women (Sharma, 2006). It is this "feminization" of the epidemic that is raising concerns everywhere. Many of them are wives of men who are HIV positive; men who did not bother to take any precautions. As a result, not only are their wives infected but also children produced by the men.

In India, the National AIDS Control Organization (NACO) says 25% of the 3.97 million Indian people living with HIV infections as on 2001 are women (TANSACS, 2003). UNAIDS notes that 0.8% of the total Indian adult population (15-49 years) are living with HIV/AIDS as of 2003, of which 1.5 million are women in the 15-24 years age group (Sridhar, 2006). The stigma surrounding HIV/AIDS is so extreme that the true figures may be much higher.

## 1.2 Gender and HIV

In majority of cases of married women, the women are contracting the diseases through sexual relations with their husbands. Even if they knew, and were aware of the precautions that ought to be taken, they would not have been in a position to insist that her husbands use male condoms. Thus, their subordinate position as women and as wives have ensured that they are infected with a virus that is equivalent to a slow and painful death. As observed by Dr. Prasanna Poornachandra, of the International Centre for Prevention of Crime and Victim Care, "*Women are extremely vulnerable even within marriages. Because they have nowhere else to go, they even put up with prolonged periods of abuse in return for promises of 'everything will be all right now.'* Where is the question of negotiating condom use when she cannot even protect herself from physical abuse?" (cited by Sridhar, 2006)

Even if she has the knowledge on protection through use of female condoms, she cannot afford to buy female condoms on her own as these are not available at the PHC level. Add to this the reality of women's health status where they are socialized to hide their ailments and not get treated on time. In the case of HIV/AIDS this can prove fatal as timely intervention can prolong life and stem the spread of the virus. Again, most women would not even know of this possibility. And finally the stigma attached to contracting HIV/AIDS is guaranteed to keep women out of the range of any treatment that could make a difference.

Here, in India, there is an added twist to the problem. If a woman, who has been infected by her husband, passes on the virus to her child, she is stigmatized and blamed. And if the infant happens to be a boy, then the woman is considered even more of a villain. The responsibility of the man in all this is completely overlooked which highlights the gender-differentiated impact of HIV/AIDS. Most importantly, the HIV/AIDS epidemic leads to changes in household structure and divisions of labour, because the victim is not able due to illness or stigmatization. Further, the women (if they are not infected) have to take care of the sick, thereby losing wages. Analyses of impact have focused mainly on the macro-demographic or macroeconomic impacts of HIV/AIDS, paying little attention to the consequences for reproductive labour burden or loss of social identities of people.

Another aspect that needs to be documented more thoroughly is the fallout of HIV/AIDS as seen in the increasing violence against women, and particularly girls. In India, there is a belief that if the infected male has sex with a female virgin, he will be cured. Every day, we read reports of girls as young as three years old being raped by men. There may be a connection and even if it is difficult to establish, it ought to be investigated. The Special Reporter mentions an alarming trend when she reports, "*Young women are fast becoming the new face of the HIV/AIDS epidemic. Worldwide, adolescents and young women are more than three times more likely to be living with HIV/AIDS than young men*" (Sharma, 2005).

Against the need to educate adolescents on HIV/AIDS, there is very little sex education in Indian schools. As a result, most Indian schoolchildren do not know what HIV is and children, particularly girls who dropout in larger numbers in rural and underprivileged communities, are very unlikely to be able to access prevention information passed on through schools. Non-health ministries do not prioritize HIV/AIDS because it is seen as a health issue, and coordination across ministries leaves much to be desired. There is no inter disciplinary approach and all the ministries leave HIV/AIDS related work to the NACO (National Aids control Organisation), a quasi-governmental organization, to take care of the entire burden

Equitable gender relations and ensuring that women's rights are respected within marriage and outside it are the essential ingredients of a just society. The spread of HIV/AIDS, and its "feminization", suggests that they are also imperative for a healthy society.

### **1.3 The need for the Study**

As part of its advocacy and lobbying interventions EKTA, a resource centre for women based in Madurai, Tamil Nadu, facilitated a State Level Consultation to review the then proposed Domestic Violence Bill and the National Health Policy. In this consultation, specific health issues pertaining to certain geographical regions of Tamil Nadu were discussed. HIV/AIDS was projected as an epidemic in alarming propositions in Theni district of Tamil Nadu. The statistics also proved this prevalence. Followed by this, NGOs working in Madurai, Sivagangai, and Virudhunagar and Trichy districts reflected



that the prevalence of AIDS is increasing in pockets where there is higher incidence of migration and drought.

The report of Tamilnadu Aids Control Society (2003) reveals that Salem, Nammakkal, Madurai, Theni, Trichy and Tirunelveli districts top the list on the incidence of HIV/AIDS in Tamilnadu EKTA. Because of its close proximity with Southern districts, EKTA proposed to coordinate a study on gender and HIV/AIDS in 5 districts in partnership with NGOs who have been working on various issues with EKTA in the above districts. Two partners in Madurai and one partner in each of the other districts were involved in this endeavor

#### **1.4 Aims and objectives of the study:**

The aim of the study is to understand the factors responsible for the incidence of HIV/AIDS and their impact on women, and suggest policies and strategies to combat the feminization of HIV/AIDS in Tamil Nadu

The specific objectives of the study are:

- To document the knowledge and attitude and prevalence of the disease amongst sangam members in Salem, Nammakkal, Madurai, Theni, Trichy and Tirunelveli districts
- To document the gendered impact of HIV/AIDS on women
- To document the link between the incidence of HIV/AIDS and the socio economic profile of women.
- To analyze the emerging needs and explore proactive strategies to reduce further victimization of women.
- To review the programmes and policies aimed at addressing the above issues from a gender perspective
- To suggest policies and strategies required on the part of government and NGOs to address the feminization of HIV/AIDS

## 1.5 Sample, methodology and methods

The six partner NGOs taken for this study are working in 300 villages and had facilitated the formation of 516 Sangams<sup>1</sup>

Table 1: **Area of operation and number of sangams formed by each NGO**

<b>Organization</b>	<b>No. Of villages</b>	<b>No. of sangams</b>	<b>No. Of women surveyed</b>
SWEED	70	89	150
PACHE TRUST	40	40	100
SWOT	40	74	150
NIWCRHT	40	74	100
WWSS	40	51	100
UDHAYAM	70	188	150
<b>Total</b>	<b>300</b>	<b>516</b>	<b>750</b>

Focus group discussions were held with 30 sangams out of a total of 516 sangams (6%). On an average 30 women participated in each FGD. The guideline which was used for the FGD with sangam is attached as Annexure 1. The discussions were recorded in audiocassette and in addition, photo documentation was also done. The FGD inferred the knowledge level of the respondents, the attitude /response of the different stakeholders towards care and support for the victims and their suggestions to mitigate the level of infection.

Interviews using individual survey format (attached as Annexure 2) was carried out with 750 women members of sangams for capturing and documenting their knowledge and attitude on HIV/AIDS. The age group of the women selected ranged from 18 to 45 years.

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<sup>1</sup> Sangam is different from micro credit SHG, and is the identity used by women to fight for their sectoral and gender issues

Apart from this, five women victims of HIV/AIDS from each district (in total 30 women) were interviewed to document the socio economic conditions before and after victimhood. The guideline used for this is attached as Annexure 3.

District level consultations with the members of panchayats, sangam representatives, influential male leaders, paramedical personnel and higher officials of PHCs / district hospitals and the district administration were also facilitated.

### **1.6 Structure of the report:**

The report is divided into five chapters (including this introductory chapter). The second chapter reviews available global and national literature on gender and HIV/AIDS. This sets the context for the analysis of the findings of the study in the third and fourth chapter. The analysis focuses on the links between the subordinate status of women and women's (in) ability to protect themselves against the HIV viruses, as well as the gendered impact of HIV/AIDS on women. The last chapter summarizes both the short term and long term measures required on the part of government and NGOs to address the gendered causes and consequences of HIV/AIDS

## CHAPTER II

# Review of Literature on Gender and HIV/AIDS

### 2.1 Global scenario on HIV/AIDS:

#### AIDS epidemic continues to expand: Vulnerable population at greatest risk

Global data indicates that the number of people living with HIV continues to rise in all parts of the world despite the fact that effective prevention strategies exist (UNAIDS, 2004).

- Sub-Saharan Africa remains the hardest-hit region in the world with extremely high HIV prevalence among pregnant women aged 15–24 years. Unprotected heterosexual sex is the main mechanism for spread of HIV in this region.
- In Asia, the HIV epidemic remains largely concentrated in injecting drug users, men who have sex with men, sex workers, clients of sex workers, and their immediate sexual partners. Effective prevention programming coverage in these populations is inadequate.
- In Eastern Europe and Central Asia injecting drug use is the main driving force behind epidemics
- IN Western Europe, sex between men or/and injecting drug use accounted for more than 10% of all reported HIV infections in Western Europe and 25% of HIV infections in North America.
- In Latin America and the Caribbean, 11 countries have an estimated national HIV prevalence of 1% or more as of 2004 .

In some of the worst affected countries, the living standards of many poor people were already poor before they experienced the full impact of the epidemic. On an average, AIDS care-related expenses could absorb one-third of a household's monthly income. Families have had to use their savings, sell assets such as land and livestock, borrow money or seek support from their extended family. They have also had to reduce spending on housing and clothing. AIDS is intensifying chronic food shortages in many countries where larger numbers of people are already undernourished. The epidemic is significantly reducing countries' agricultural workforce and families' income with which to buy food. This is especially damaging for people living with AIDS who need more calories than uninfected individuals. In general, AIDS-affected households are

more likely to suffer severe poverty than non-affected households; this is true for countries with low prevalence as well as those with high rates

### Women increasingly infected by HIV

In recent years, the overall proportion of HIV-positive women has steadily increased. In 1997, women were 41% of people living with HIV; by 2002, this figure rose to almost 50% (Human Rights Watch 2003). This trend is most marked in places where heterosexual sex is the dominant mode of transmission, particularly the Caribbean and sub-Saharan Africa (is this also not the case in Asia). Women also significantly figure in many countries with epidemics that are concentrated in key populations such as injecting users, mobile populations, and prisoners.

Nowhere is the epidemic's 'feminization' more apparent than in sub-Saharan Africa, where 57% of adults infected are women, and 75% of young people infected are young women and girls (Human Rights Watch 2003). Several social factors are driving this trend. Young African women tend to have male partners much older than themselves—partners who are more likely than young men to be HIV-infected. Gender inequalities in the region make it difficult for African women to negotiate condom use. Furthermore, sexual violence, which damages tissues and increases the risk of HIV transmission, is widespread, particularly in the context of violent conflict. A survey of 1366 women attending antenatal clinics in Soweto, South Africa, found significantly higher rates of HIV infection in women who were physically abused, sexually assaulted or dominated by their male partners. The study also produced evidence that abusive men are more likely than non-abusers to be HIV-positive (Dunkle et al., 2004). In some countries, one in five women report sexual violence by an intimate partner, and up to 33% of girls report forced sexual initiation (WHO, 2001).

Women may hesitate to seek HIV testing or fail to return for their results because they are afraid that disclosing their HIV-positive status may result in physical violence, expulsion from their home or social ostracism. Studies from many countries, especially in sub-Saharan Africa, have found these are well-founded fears (Human Rights Watch, 2003). In Tanzania, a study of voluntary counseling and testing services in the capital found, after disclosure, only 57% of women who tested HIV-positive reported receiving

support and understanding from partners (Maman et al., 2002). Young girls may drop out of school to tend to ailing parents, look after household duties or care for younger siblings. After a spouse's death, a mother is more likely than a father to continue caring for his/her children, and a woman is more willing to take in orphans. AIDS-related stigma and discrimination often lead to the social isolation of older women caring for orphans and ill children, and deny them psychosocial and economic support.

When their partners or fathers die of AIDS, women may be left without land, housing or other assets. For example, in a Ugandan survey, one in four widows reported their property was seized after their partner died (UNICEF, 2003). A woman may also be prevented from using her property or inheritance for her family's benefit, which in turn reduces her ability to qualify for loans or agricultural grants. The denial of these basic human rights increases women and girls' vulnerability to sexual exploitation, abuse and HIV.

Globally, AIDS is a significant obstacle to children achieving universal access to primary education by 2015 (a key target of UNESCO's Education for All Initiative and the UN's Millennium Development Goals). An estimated US\$1 billion per year is the net additional cost to offset the results of AIDS – the loss and absenteeism of teachers and cost of incentives to keep orphans and other vulnerable children in school. Children, especially girls, from AIDS-affected families are often withdrawn from schools to compensate for loss of income through a parent's sickness and related expenses, to care for sick relatives and look after the home. These families may also take their children out of school because they cannot afford school fees.

The epidemic has created a need for robust, flexible health systems at a time when many affected countries have been reducing public service spending to repay debt and conform to international finance institutions' requirements. So already weakened systems are being forced to cope with the extra burden of sickness and the loss of essential staff through sickness and death related to AIDS.

## **2.2 Asian scenario on HIV/AIDS**

### HIV/AIDS situation

An estimated 7.4 million people (range: 5.0–10.5 million) in Asia are living with HIV as of 2003. Around half a million (range: 330 000–740 000) are believed to have died of AIDS in 2003, and about twice as many—1.1 million (range: 610 000–2.2 million) are thought to have become newly infected with HIV. Among young people 15–24 years of age, 0.3% of women (range: 0.2–0.3%) and 0.4% of men (range: 0.3–0.5%) were living with HIV at the end of 2003 (cited in UNDP, 2005) .

Asia includes the world's two most populous countries—China and India with 2.25 billion people. Reported national HIV prevalence in both countries is very low as of 2004: 0.1% (range: 0.1–0.2%) in China and between 0.4% and 1.3% in India (UNAIDS, 2004). A closer focus reveals that both have extremely serious epidemics in a number of provinces, territories and states.

In China, 10 million people may be infected with HIV by 2010 unless effective action is taken. Each geographical area has its own distinctive epidemic pattern. In some, injecting drug use is fuelling HIV spread. A section of the rural people was selling blood plasma to supplement their meager farm incomes. Infection levels of 10–20% have been found, rising to 60% in certain communities. As a result, many people have already died of AIDS .

### Women, gender and HIV/AIDS

Similar factors are threatening women in South and South-East Asia, but the overall impact of HIV/AIDS in the region is much lower than Sub Saharan Africa because the epidemic in most countries is concentrated among injecting drug users and other key populations. At the end of 2003, women accounted for 28% of HIV infections in South and South East Asia (UNDP, 2003), a slight increase compared to end-2001 estimates. In South Asia, women's low economic and social position has profound implications. Congruence between indicators of women's poor status and their HIV vulnerability suggests a close link between patriarchy and vulnerability to HIV in South Asia (UNDP, 2003). Women typically have limited access to reproductive health services and

preventive options Social and cultural norms often prevent them from insisting on preventive methods such as use of condoms in their relations with their husbands.

Marriage and other long-term monogamous relationships (on the part of women) do not protect women from HIV. In Cambodia, studies conducted in the late 1990s found 13% of urban and 10% of rural men reported having sex with both a sex worker and their wife or steady girlfriend (Cambodian National Institute of Statistics/Orc International, 2000). The risk of this behavior to wives and girlfriends is clear. In Thailand, a 1999 study found 75% of HIV-infected women were likely to be infected by their husbands. Nearly half of these women reported heterosexual sex with their husbands as their only HIV-risk factor (Xu et al., 2000).

### **2.3 Indian scenario on HIV/AIDS**

#### HIV/AIDS prevalence

In terms of absolute number, India is second to South Africa with 5.3 million infected with HIV (HIV prevalence of 21.5% in South Africa). With an estimated 5.134 million people living with HIV in the adult population (15-49 years) in 2004, India accounts for almost 13% of the global HIV prevalence. Despite this large number of HIV-infected individuals, because of its large population size, India continues to be in the category of low prevalence countries with an overall prevalence of less than 1%. The number of AIDS cases in India as of 2005 is 111608, with 29% being women. Age wise break up of victims of AIDS suggest that a majority of them are in the 15 to 49 years (see Table 2). Greater proportion of male victims of AIDS are in the age group 30-49 years, while female victims are equally found in 15-29 years and 30-49 years, suggesting that they become vulnerable at a younger age (NACO, 2005).

**Table 2: AIDS cases in India across Age groups (as of July, 2005)**

<b>Age group</b>	<b>Male</b>	<b>Female</b>	<b>Total</b>
0 – 14 yrs.	2,860	1,994	4,854
15 – 29 yrs.	21,782	14,405	36,187



30 – 49 yrs.	48,342	14,508	62,850
> 50 yrs.	6,057	1,660	7,717
<b>Total</b>	<b>79,041</b>	<b>32,567</b>	<b>111,608</b>

**Source: NACO, 2005**

Though the overall national prevalence of HIV infection is low, six states have reached a prevalence of greater than 1 % rate, namely: Manipur, Nagaland, Andhra Pradesh, Tamilnadu, Karnataka and Maharashtra. Injecting drug use dominates in Manipur and Nagaland in the northeast of the country, bordering Myanmar and close to the Golden Triangle (Myanmar, Thailand and Nepal). In this region, HIV infection levels of 60–75% have been found among injecting drug users using non-sterile injecting equipment. In the southern/western states of Andhra Pradesh, Karnataka, Tamilnadu and Maharashtra, HIV is transmitted mainly through heterosexual sex, and is largely linked to unprotected sex work and unsafe sex on the part of infected men within the institution of marriage. Indeed, according to selected surveys, more than half of sex workers have become infected with HIV. In all four states, infection levels among pregnant women in antenatal clinics have remained at over 1%, suggesting that a significant number of men who have unsafe sex with multiple partners may have passed on HIV to their wives

In many of these highly vulnerable Indian states out-migration (e.g. Andhra Pradesh) or/and in migration (e.g. Maharashtra) are issues. In some states both occur (e.g. Tamil Nadu and Karnataka). Migration is a result of livelihood crisis, crisis in terms of assets, capabilities, and activities that allow people to meet their basic needs. Denial of livelihood rights within the local area has pushed men to migrate to other areas. The social sanction of promiscuous and unsafe behavior has resulted in the victimization and transmitting HIV to their wives.

HIV transmission through sex between men is also a major cause for concern in many areas of India. Recent research shows that many men who have sex with men also have sex with women. In 2002, behavioral surveillance in five cities among men who have sex with men found that 27% reported being married, or living with a female sexual

partner. In a study conducted in a poor area of Chennai in 2001, 7% of men who have sex with men were HIV-positive. Attention is currently focuses on areas with high-recorded prevalence, but there is concern about what might be happening in the vast areas of India for which there are little data (*UNAIDS, 2004*).

In India, knowledge about HIV varies across states. In a 2001 national behavioral study of nearly 85,000 people, 75% of respondents had heard of AIDS. However, awareness was particularly low among rural women in Bihar, Gujarat and West Bengal. Less than 33% of all respondents had heard of sexually transmitted infections and only 21% were aware of the links between sexually transmitted infections and HIV (*UNAIDS, 2004*).

The International Labor Organization's findings indicate that HIV/AIDS has a potential negative impact on economic growth and sustainable development, even in countries which have a huge population and low HIV prevalence such as India (ILO, 2004). The report also states that slow economic growth has serious implications with regards to both job creation as well as employment.

#### Gender dimensions of HIV/AIDS in India

In the six high prevalent states of India (Maharashtra, Tamilnadu, Andhra Pradesh, Karnataka, Manipur and Nagaland) the ratio of HIV infected male: female is almost equal. Like in much of South Asia, many women experience sexual and economic subordination in their marriages or relationships and are therefore unable to negotiate safe sex or refuse unsafe sex. The power imbalance in the workplace exposes women to the threat of sexual harassment.

Women's access to prevention messages is lower than men, and hampered by illiteracy, a state affecting more women than men worldwide. Even when aware of causes and consequences of HIV/AIDS, women are unable to protect themselves against infection through their husbands. Personal Law and policies that prevent women from owning land, property and other productive resources often support gender-related discrimination. Women in the institution of marriage are forced to have unprotected sex, even if they know that their husbands are infected Indian women with HIV infection also often experience more social blame and stigma than men in the same position. In

addition to their own increased risk of HIV, women also carry the social burden of the epidemic, in terms of providing care of relatives with AIDS. Indian women do not have a say in the decision making process and most of the marriages are arranged marriages

## **2.4 Global, National and Tamil Nadu response to HIV/AIDS and its gender dimensions**

### **2.4.1 Global Response t HIV/AIDS**

The connection between HIV/AIDS, development and human rights has led to an expansion of the global response beyond the biomedical paradigm. The United Nations General Assembly Special Session on HIV/AIDS Declaration of Commitment (UNGASS DoC) is a historic document signifying the recognition of state leaders that HIV/AIDS is a serious development problem, which can only be decisively addressed by scaling up both the national and international responses to the pandemic. The UNGASS DoC indicates the awareness of member states that the respect, protection and fulfillment of human rights is at the core of the fight against HIV/AIDS; that combating the epidemic is a major responsibility and obligation of the state. Thus, states should ensure that the necessary legal, procedural, budgetary, institutional and other mechanisms are in place so that the human rights, particularly of persons living with HIV/AIDS (PLWHAs) and vulnerable groups, are not violated United Nations General Assembly Twenty-sixth Special Session Doc: A/s-26/L.2 [adopted Wednesday 27th June 2001, New York]

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The UNGASS DoC calls for respect and protection of the rights of PLWHAs namely, the right to live and participate with dignity, self-respect and without discrimination in the community; to have access to health care, employment, education, travel, housing and social welfare as are available to others; to have access to timely, accurate, adequate, appropriate and relevant information about HIV infection/AIDS and its prevention; to privacy, including the right to decide about disclosure of his/her HIV status; to a full and satisfying sex life, without putting his/her partner at risk; to bear and raise children, if they choose; to legal representation; and to participate in the planning, formulation and implementation of programs.

Empowerment of people is seen by UNGASS DoC as a means of preventing HIV transmission through their having access to timely, accurate, adequate, appropriate and relevant information and resources is seen as essential. All HIV antibody testing should be voluntary with guaranteed confidentiality and adequate pre and post-test counseling. Informed decision making with counseling is essential in the protection of the rights of individuals. This also entails making available and accessible testing facilities/services with competent and responsible health personnel.

The formulation of socio-economic development policies and programs should include consideration of the impact of HIV infection and AIDS. Economic and social development improves people's ability to avoid HIV/AIDS by eliminating the conditions, which make them vulnerable to the disease. Making jobs, schools, hospitals, housing, food, roads and bridges available and accessible, increases people's choices and enhances their capability to combat HIV/AIDS.

#### **2.4.2 National and Tamil Nadu Response to HIV/AIDS**

The Indian government has established the National Aids Control organization (NACO) to coordinate implementation of programmes related to HIV/AIDS, which works through state level chapters. In Tamil Nadu, the Tamil Nadu Aids Control Society (TANSACS) is the state level chapter. Both NACO and TANSACS are quasi government organizations, and have greater autonomy than the line departments of the government. The efforts of TANSACS can be classified into four categories:

- i) Prevention,
  - ii) Treatment,
  - iii) Care and support services,
  - iv) Capacity building activities
- (Health and Family Welfare department, 2006).

On paper, the prevention activities of the TANSACS include:

- Integrated Counseling and testing services (including for prevention of parent to child transmission), to be made available through 655 centers including government medical colleges,

private medical college hospitals, district government hospitals, Taluk Hospitals, Corporation health posts, and community hospitals (including the Block PHCs).

- Intervention programmes (totally 53) amongst high risk population in 22 districts with commercial sex workers, men who have sex with men, injecting drug users, truckers, migrant workers, industrial workers, prisoners, and tribal population
- Condom promotion through government health service points, private shops, fair price shops and NGOs
- Awareness generation programme amongst public, health care providers, teachers, media and others
- Provision of safe blood programme.
- Programme on reaching out to young people in particular amongst youth and adolescents (in school and colleges, and out of school and colleges) and the white ribbon programme (raising awareness on sex and sexuality).
- Programme for rural women in SHGs through Tamil Nadu Women's Development Corporation to make informed choices

(Health and Family Welfare department, 2006).

The programmes on the treatment side of TANSACS are on paper four fold:

- Treatment of STIs to be available through government medical college hospitals, district headquarters hospitals, Taluk hospitals, and selected Block PHCs. These service points are to provide free investigation, treatment and counseling for STI patients
- Treatment for opportunistic infections, which are high amongst HIV positive people, to be available in government medical college hospitals, district headquarters hospitals and all ICTCs in Block PHCs
- Anti Retrivoral Therapy for prolonging the life span of those with HIV/AIDS to be available through 15 ART centers, 11 in government medical colleges, 1 in Government hospital for Thoracic medicine in Tambaram, 1 in district hospital in Namakkal and 2 for mothers in Institute of Obstetrics and Gynecology in Chennai and Raja Mirasudhar Hospital in Tanjavur. First line ARV drugs are supposed to be available free of cost for needy people

- HIV-TB treatment, Tuberculosis is the most common opportunistic infection of people living with HIV, with 60-70% of people living with HIV/AIDS suffering from TB.

As part of curative and support services the TANSACS through NGOs (on paper) runs 27 drop inpatient, outpatient and short stay care centers for people living with HIV and AIDS. In addition, six drop-in centers are supposed to have been established to provide a space for people living with HIV/AIDS to meet informally and support each other. People living with HIV/AIDS are also involved in sensitization programmes organized by TANSACSS. TANSACSS is also involved in capacity building of health service providers through the Directorate of Medical Services, Directorate of Public Health, Directorate of Medical and Rural Health Services. Recently, TANSACSS is also seeking to build capacity of private providers

While the policies of TANSACSS appear good on paper, are they really reaching the poor affected by HIV/AIDS? Are the rural women's programmes really enabling poor women to make safe and informed choices on their sexuality and sexual relations? Are women able to access prevention, and treatment, care and support services as men? These are questions that we turn to in the study

## **CHAPTER III**

### **FINDINGS**

#### **SOCIO ECONOMIC PROFILE OF THE RESPONDENTS**

##### **3.1 Age wise distribution of the respondents and victims:**

###### Profile of respondents:

The age wise profile of respondents 19.9 per cent of the 750 respondents covered as part of the study were below 25yrs. Twenty six per cent of the respondents were between 26 and 30 years. 22.5 per cent of the respondents are between 31- 35 years. 19.5 per cent of the respondents belong to the age group of 36 to 40 yrs and 10 per cent are above 41 years.

**Table 3: Percentage of respondents across age groups and districts**

	Madurai	Theni	Sivagangai	Trichy	Virudhunagar	Total
Below 25	22	35	15.3	20	11	19.9
26 to 30	28.7	25	27.3	31	30	27.7
31 to 35	21.3	25	20.7	22	27	22.5
36 to 40	15.3	15	21.3	22	19	19.5
41 & above	12.7		15.4	5	13	10.4
Total	100	100	100	100	100	100

Profile of Victims of HIV:

The case study analysis revealed that out of the 30 women victims of HIV interviewed 50% of the victims were within the age of 25 years and the remaining 50% were within 26 to 35 years. As majority of the sangam members are above 25 years (see Table 3), it is likely that significant proportion of the women victims of HIV may not have access to support from other women, or likely to receive preventive health messages of government imparted through SHGs.

**3.2 Caste Wise Distribution of Respondents and Victims**Respondents' profile

Nearly 39 percent of the 750 respondents are dalits, 13.3 percent are from most backward communities, 46 per cent are from backward caste and 2.5 per cent belongs to other caste groups. The higher proportion of dalits in the sangams than the state as a whole, points to the pro-dalit focus of NGOs forming the groups. See Table 4 for greater details.

**Table 4: Percentage of respondents across caste and districts**

	Madurai	Theni	Sivagangai	Trichy	Virudhunagar	Total
SC	41.3	13	28	54	39	35.5
ST	5.3	3	0.7			2.8

MBC	10	55	10		5	13.3
BC	38.7	29	60	44	56	45.9
OC	4.7		1.3	2		2.5
Total	100	100	100	100	100	100

### Victim's profile

The thirty women victims interviewed for the purpose of the study were from MBCs, BCS, Dalits and Muslims.

### **3.3 Educational Status of The Respondents And Victims**

#### Respondents' profile

Table 5 on educational profile of the 750 respondents, suggests that nearly 25 per cent of the respondents were illiterates, 27.5 per cent had studied below primary school education, 40 per cent had studied between 6th and 10<sup>th</sup> standard, and 8 percent have studied above 10<sup>th</sup> std.

**Table 5: Percentage of respondents across educational qualification and districts**

Educational status	Madurai %	Theni %	Sivagangai %	Trichy %	Virudhunagar %	Total %
Illiterate	38	27	20.7	21	46	25.3
Below5	26.7	42	28	29	23	27.5
6-10thstd	26.7	28	42	42	24	39.6
11 and above	8.6	3	9.3	8	7	7.6
Total	100	100	100	100	100	100



#### Victim profile:

Out of the thirty women victims, 29 had studied up to primary school and one person was an illiterate. That is, contrary to popular perception, access to primary education may not protect a woman from HIV/AIDS.

### **3.4 Occupational Status Of The Respondents and Victims**

#### Respondents' profile

Table 6 which profiles the occupation status of 750 respondents, suggests that nearly 4 per cent of the respondents were from small farmers' families 36 per cent were from agricultural labourers' families, 51 per cent were from daily wage earners' families (from non agriculture occupations) and rest belongs to government Sectors.

**Table 6: Percentage of respondents across occupational qualification and districts**

Occupational categories	Madurai %	Theni %	Sivagangai %	Trichy %	Virudhunagar %	Total %
Cultivators	12	12				4.4
Agri Labour	34	19	26	53	60	35.7
Coolie- non agriculture	41.3	55	67.3	43	33	50.7
Others	12.7	14	6.7	4	7	9.2
Total	100	100	100	100	100	100

#### Victim's profile

Out of the 30 women victims 13 were widows. All of their husbands were wage earners / agricultural laborers / lorry drivers. Most of the victims are earning as coolly workers. All the victims are indebted and they have borrowed money for medical expenses. All of

them contracted AIDS through their husbands. That is majority of victims come from already poor families.

### **3.5 Concluding observations**

On the whole 50% of the women victims are below 25 years, and a majority have education qualification of a maximum of primary class, come from backward castes, come from labouring families. While the sangam members also come from similar education, caste and economic background, 80% of the sangam members are above 25 years. There is hence a need for NGOs to bring women in the age group 18-25 years more into the sangam fold.

## **CHAPTER IV**

### **AWARENESS AND ATTITUDE OF SANGAM WOMEN RESPONDENTS**

#### **4.0 Introduction**

The knowledge, awareness and attitude of the 750 sangam women respondents on the following aspects of HIV/AIDS are analysed in this section:

- Causes
- Symptoms
- Prevention
- Treatment
- Outcome
- Investigations
- Total knowledge

The attitude of the respondents towards HIV/AIDS is classified into:

- Sympathetic to the victims of HIV/AIDS
- Empathetic towards the victims of HIV/AIDS
- Critical about the morality of victims of HIV/AIDS
- Untrusting of the victims of HIV/AIDS
- Punishing towards the victims of HIV/AIDS
- Expulsion attitude, that is feel that victims of HIV/AIDS should be kept separately
- Withdrawal from the victims of HIV/AIDS

#### **4.1 Overall awareness and attitudes on HIV/AIDS**

##### Awareness

The study reveals that 65.8 of the 750 respondents are aware of the causes of HIV/AIDS, 45.8 per cent on symptoms, 79 per cent on methods of prevention, 78.2 per cent on treatment, 55.9 per cent on outcome, 67.4 per cent on investigations (see Table 7). The (MPS) Mean percentage score for respondents' knowledge on preventive measures is the highest followed by treatment. The lowest score pertained to awareness about symptoms. More than two-third of the respondents are knowledgeable about the investigations and causes of the disease.

The focused group discussion with the sangam members confirmed the above findings. According to them, AIDS is found in persons having more than one partner and having unsafe sexual relationships, its consequences affected women and children more than men. Due to poverty men migrate to other areas to earn their livelihood. According to sangam women sex workers, granite quarry workers, lorry drivers, auto drivers, drug addicts and laborers are more vulnerable because of their sexual behavior outside the marriage, as well as sharing of needles. In Valayurpettai, Trichy district, women in absolute poverty are pushed into prostitution and they become victimized. Those men who go to foreign countries for construction and labour intensive occupations also contract AIDS.

The other important factor, that the sangam women pointed to, is that married women are more vulnerable as they contract the disease from their partners. They cannot compel their husband to use condoms nor resist the demand of their partners to have sex even if they have knowledge that their husbands are infected with the virus. The fear that they will be sent out from the matrimonial homes or even from the very relationship makes them keep quiet.

The sangam women were aware that HIV/AIDS spreads through blood, sexual relationship, and injection and through HIV virus. If the male member gets it, the entire family is affected. It's a killer disease. They gathered this information through visual medias like TV. The disease, they opined, comes from men to women. Few believe that it is a God's curse and cannot be cured. But they lack information about the symptoms and out come of HIV/AIDS. The findings reveal that two third of the respondents are relatively knowledgeable about HIV/AIDS in its totality

**Table 7: Respondents' Age profile and awareness of HIV/AIDS**

About HIV/AIDS	<25 yrs %	26-30 yrs %	31-35 yrs %	36-40 yrs %	> 40 yrs %	Total %
Causes	66	65	66	65	69	66
Symptoms	45	46	45	46	48	46
Prevention	79	79	81	78	80	79
Treatment	80	74	80	78	81	78
Outcome	54	56	55	56	60	56
Investigations	69	66	67	67	69	67

**Attitudes:**

Thus 750 women respondents hold both positive and negative attitudes, which reveals the contradictory feelings the issue evokes (see Table 8). On the positive side, a high 87% of the women respondents expressed they would pray for the recovery of victims of HIV/AIDS, and wish for their peaceful and dignified death (sympathetic attitude). Seventy five percent perceived HIV/AIDS to be a structural issue, and also issue arising out of marital in-compatibility (sensitive attitude). At the same time, nearly 50 per cent of the respondents are critical of AIDS victims- that is- they consider themselves to be of loose morale, engaging in extra marital relations, narcotic drug use, reading pornographic magazines, and engaging in drunken behaviour (critical). Fifty three percent of respondents went to the extent of saying that the victims of HIV/AIDS can be even given death penalty (punishment attitude). Fifty nine percent expressed that they did not trust victims of HIV/AIDSs, and felt that many of them wanted to take revenge on society and inflict the infection/disease to others. 72% expressed that the victims of HIV/AIDS should be kept separately and not be allowed to mingle with others (expulsion attitude). Fifty seven percent expressed that they will keep a distance from the victims of HIV/AIDS, and not have working relations with them (withdrawal attitude).

**Table 8: Age Vs attitude of the respondents**

Attitudes	<25 yrs %	26-30 yrs %	31-35 yrs %	36-40 yrs %	> 40 yrs %	Total %
Accepting	76	75	76	75	76	75
Sympathy	87	86	86	86	86	86
Untrusting	60	58	58	58	58	59
Critical	53	52	51	51	49	51
Punishing	54	54	50	55	51	53
Withdrawal	57	58	57	58	57	57
Expulsion	75	72	71	72	71	72

#### **4.2 Age vs awareness and attitudes:**

##### Respondents age profile and awareness about HIV/AIDS

Age seems to influence knowledge and awareness of the respondents on some aspects of HIV/AIDS (see Table 7), but not others. However, this influence is not statistically significant. The older the respondent, slightly greater is the knowledge on outcome, causes, symptoms, and treatment of the disease. However, age does not seem to influence knowledge on investigation procedures. Statistical significance of the impact of age on awareness merits greater investigation.

##### Respondents age profile and attitudes on HIV/AIDS

In general, the older the women, slightly less critical, hostile, untrusting, punishing and expelling they were. Again, the influence of age is not statistically significant. However, older women were equally likely to not interact with those with HIV/AIDS. Not much difference was seen with regard to sympathy and empathy. This matches earlier observation made about education profile of women victims of HIV/AIDS.

#### **4.3 Education vs awareness and attitudes**

### Education vs. awareness

More educated the women, the slightly greater (but not statistically significant) the awareness of the women on all aspects of HIV/AIDS: causes, symptoms, prevention, treatment and outcome. However, this education benefit was significant mainly if the women were educated upto 10<sup>th</sup> class level. That is difference in knowledge between people educated to primary level and those with up-to third class. Further, education upto 10<sup>th</sup> class may play a more significant role than age with regard to awareness on HIV/AIDS.

**Table 9: Education Vs awareness**

Dimensions constituting the knowledge	Up to III %	Primary education%	Upto 10 <sup>th</sup> %	> 10 <sup>th</sup> %	Total %
Causes	62	65	68	70	66
Symptoms	45	44	47	48	46
Prevention	76	79	81	83	79
Treatment	74	76	82	81	78
Outcome	55	55	57	57	56
Investigations	65	68	69	70	67

### Education vs. attitudes

Against the slightly greater awareness on HIV/AIDS with education, the attitude of those with 10<sup>th</sup> class education appears more untrusting, critical, punishing, and expulsion oriented than those with upto III class education.

**Table 10 Education vs attitudes**

Attitudes	Upto III %	Primary education %	Upto 10 <sup>th</sup> %	>10 <sup>th</sup> %	Total %
Empathy	75	75	76	75	75
Sympathy	84	84	88	89	86
Untrusting	57	58	59	62	59
Critical	52	51	51	53	51
Punishing	53	52	53	56	53
Withdrawal	58	58	57	57	57
Expulsion	71	69	75	77	72

#### 4.4 Caste vs. awareness and attitudes

##### Caste vs. awareness on HIV/AIDS

Though there is no statistically significant difference between awareness/attitudes on HIV/AIDS and caste, it is a concern that slightly less proportion of dalits, MBCs and BCs are aware of symptoms of HIV/AIDS than the forward caste; and also surprisingly scheduled causes. ON most aspects of HIV/AIDS, awareness of women from forward castes or scheduled tribes was higher than other caste groups. Correlating with education it is likely that women from forward castes had greater access to education. Scheduled tribe women on the other hand had greater freedom.

**Table 11 Caste vs awareness**

Dimensions constituting the knowledge	SC %	ST %	MBC %	BC %	OC %	Total %
Causes	67	68	59	67	65	66
Symptoms	45	50	44	46	50	46
Prevention	81	80	74	80	71	79



Treatment	79	79	70	80	75	78
Outcome	56	54	54	56	59	56
Investigations	67	71	62	66	65	65

#### Caste vs. attitudes

While forward caste women may be more aware on certain aspects of HIV/AIDS, they hold a more negative attitude towards victims of HIV/AIDS. This is reflected in the higher proportion of forward caste women expressing the need for punishing victims of HIV/AIDS, expelling them into a separate space, being critical or blaming them for the disease, and not willing to mix with victims. On the other hand tribal or adivasi women were more sympathetic and empathetic towards victims of HIV/AIDS than women of all other caste groups.

**Table 12 Caste vs attitudes**

<b>Attitudes</b>	<b>SC</b>	<b>ST</b>	<b>MBC</b>	<b>BC</b>	<b>OC</b>	<b>Total</b>
	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>	<b>%</b>
Sympathy	87	92	80	87	83	86
Empathetic	76	79	73	76	74	75
Withdrawal	58	58	58	56	61	57
Untrusting	57	56	59	60	56	59
Critical	52	47	51	51	54	51
Punishing	54	54	48	53	58	53
Expulsion	74	70	66	72	76	72

#### **4.5 Occupation Vs awareness and attitude**

While statistically, there awareness and attitudes on HIV/AIDS did not vary across occupation of women respondents, awareness on HIV/AIDS (other than on prevention) is higher amongst the landed class than the landless agriculture labourers, other coolies, and people of other categories. The MPS for agricultural labourers is slightly higher than other labourers and people of other occupations.

**Table 13: Occupation vs. Awareness**

Dimensions constituting the knowledge	SF (Small farmers) %	AL (Agricultural farmers) %	DW (Daily non agriculture coolies) %	OC (Other categories) %	Total %
Causes	67	67	65	65	66
Symptoms	48	46	45	46	46
Prevention	78	81	78	77	80
Treatment	84	80	77	75	78
Outcome	58	56	56	55	56
Investigations	67	68	67	66	67

With regard to the attitude of the respondents, slightly more women from agriculture wage labourers and non agriculture coolies were sympathetic than women from other occupations. The women from small farming households show more negative attitude like recommending expulsion of those with HIV/AIDS from community, not mixing with victims, considering those with HIV/AIDS as revengeful, or considering victims to be of loose character.

Occupation vs. attitude on HIV/AIDS

**Table 14: Attitude on HIV/AIDS**

Attitudes	SF (Small farmers) %	AL (Agricultural farmers) %	DW (Daily non agriculture coolies) %	OC (Other categories) %	Total %
Empathy	77	76	75	73	75
Sympathy	84	87	85	84	86
Withdrawal	61	57	57	59	57
Expulsion	77	74	71	73	72
Untrusting	60	59	58	60	59

Critical	54	50	51	53	51
Punishing	52	54	53	52	53

#### 4.6 Concluding remarks

The above analysis suggests that awareness on HIV/AIDS and positive attitudes towards victims of HIV/AIDS may not always go hand in hand. While the better educated women, upper caste women and women from small farming households were more knowledgeable about HIV/AIDS, they were often more critical, punishing, untrusting, expelling and withdrawing towards the victims of HIV/AIDS. The exception to this rule were the Adivasi women who were both more aware and less critical.

## Chapter V

### **5.0 Awareness of women victims on HIV/AIDS and their access to treatment & care**

Table 15 summarises the access of the 30 women victims of HIV/AIDS studied to information on prevention of HIV/AIDS, to treatment, and to care and support from family members.

**Table 15: Access of women victims of HIV/AIDS to preventive information, treatment, care and support**

S.No	District	Access to information on prevention	Treatment	Care and support from the family
1.	Theni	No	NGO	Non Acceptance
2.	Theni	None	None	Non Acceptance
3.	Theni	None	None	Non Acceptance
4.	Theni	None	GH	Non Acceptance
5.	Theni	None	None	Acceptance
6.	Virudhunagar	None	None	Non Acceptance
7.	Virudhunagar	None	None	Non Acceptance
8.	Virudhunagar	None	None	Non Acceptance
9.	Virudhunagar	None	None	Non Acceptance
10.	Virudhunagar	Minimum	None	Non Acceptance
11.	Trichy	Minimum	None	Non Acceptance
12.	Trichy	Good	None	Non Acceptance
13.	Trichy	Minimum	None	Non Acceptance
14.	Trichy	Minimum	Private	Non Acceptance
15.	Trichy	None	Kerala Ayurvedhic	Non Acceptance
16.	Madurai	None	Yes	Partial
17.	Madurai	None	Yes	-do
18.	Madurai	None	Ayurvedhic	-do
19.	Madurai	None	Private	-do
20.	Madurai	None	None	Non Acceptance
21.	Madurai	None	GH	- Non Acceptance
22.	Madurai	None	GH	Non Acceptance

23.	Madurai	Good	GH	Non Acceptance
24.	Madurai	None	GH	Non Acceptance
25.	Madurai	None	None	Non Acceptance
26.	Sivagangai	None	None	Acceptance
27.	Sivagangai	None	Kerala Ayurvedhic	Acceptance
28.	Sivagangai	None	Kerala Ayurvedhic	Non Acceptance
29.	Sivagangai	None	None	Acceptance
30.	Sivagangai	None	None	Non Acceptance

Access to preventive information:

25 of the 30 women victims (between 25 to 35 years) had no prior knowledge on prevention. Two of had access to sound information (please define) on preventive strategies, and seem to have had only minimum knowledge (Gandhi please define). In general awareness on prevention was lower than the women sangam members, who came from older age groups.

Access to treatment:

Out of the 30 respondents, 19 have AIDS and the remaining 11 are diagnosed as HIV positive. All the eleven who are HIV positive are not taking treatment on a regular basis. Out of the 19 AIDS, four are availing Ayurvedic treatment, five of them are availing treatment from government hospital, two from private hospital and one from a NGO. Two preferred to not reveal their treatment sources. Five of the 19 AIDS victim are not receiving any form of treatment. IN total less than 50% of the women victims of HIV/AIDS were receiving treatment.

Access to family care and support

16 out of the 30 respondents were not receiving any form of support from the family members. The family members of four respondents are neither positive nor negative in their attitude towards the victims Six of the respondents are

receiving partial acceptance. Only four of the 30 women respondents (13%) have full acceptance of their family

## Chapter VI

### **6.0 ANALYSIS OF THE FIELD FINDINGS ON VULNERABILITY OF WOMEN TO HIV/AIDS**

The field findings reiterate the findings from desk review that gender, poverty, globalization and weak health systems have an important bearing on the vulnerability of women to HIV/AIDS. Women are affected by gender issues more than men, and this is an additional factor contributing to their vulnerability to HIV/AIDS.

#### Poverty, globalization and vulnerability to HIV/AIDS

**The field study points that *poverty* and *globalisation* contributes to vulnerability of poor men and women to HIV/AIDS in many ways.** Being poor, they have lesser access to secondary education and lesser access to information on HIV/AIDS. Life skill and sex education in school begins at secondary level, by which time poor girls and boys have dropped out of school. As livelihoods of poor households are insecure, the youth in particular men (and at times women) are forced to migrate for long periods of time. Many spouses of the women victims had migrated to Thiruppur mill, Kerala, as bonded labours, With globalization opportunities for employment for unskilled workers in Gulf and South East Asia are increasing. In majority of the cases of women victims, the husbands were engaged in long distance migrant work within the country, and a few overseas. As society sanctions promiscuity amongst men, several had unprotected sex with women in the places they migrated to. Condoms were not readily available ten year back, and even now are not available in adequate volume and in appropriate places to meet the demand. Being poor, men and women from labouring and small farming households with HIV/AIDS cannot afford private sector diagnosis

and treatment, while government services are available in selected district hospitals with long waiting time.

### Gender and vulnerability to HIV/AIDS

**The field study suggests the addition to the above factors which affect both poor men and women, gender has a role to play in the added vulnerability of women and young girls.** In the field area, like much of South Asia, girls get married early (often by the age of 18 years), and to men older than them; which gives them little negotiation power. Arranged marriage is the norm; while in some instances the marriage is to relatives, in others it is not. In the latter case, the girl does not know much about the background of the person. Even if the girl knows that the potential groom has had relations outside, she often does not have the power to say no to her parents. Married women met reported that they have difficulty in negotiating safe sex with their husbands. In the rare instance they ask, men refuse to use condoms. Further, female sterilization is the major kind of contraception adopted by couples (median age of sterilized women is 26), making it all the more difficult for married women to negotiate condom use. In a few instances, the women victims of HIV/AIDS met knew that their husbands were positive, and could neither negotiate condom use nor leave them, as they did not have independent assets or livelihood of their own; and their natal families would not take them back. Some of the women victims were subject to domestic and sexual violence by their infected spouse or male relatives; and this is another reason for vulnerability. In Ulaganathapuram, Marimuthu, a 48-year-old widow is an AIDS victim. Her husband (who was not positive) had died some years ago and her sister's infected husband forced her to have sex and she got infected.

The case studies suggest that if women survive their infected husbands, they are divested of property of their husband, if any, and left to struggle by themselves to support themselves and their young children while they themselves are weak. If

they have children who are adults, they cannot always rely on their support. In one village, a infected woman was thrown out by her own sons, once her infected husband died. Without assets and family support, some women victims were pushed into sex work to earn a living.

The interviews with the 30 women victims suggests that they have lesser access to diagnosis, treatment and family care than their often diseased spouses; though they have spent considerable time and emotion in nursing the infected men. Family assets, if any, have been sold off for husbands' treatment. In Melur, one woman died because of lack of access to treatment. Further, women in rural settings cannot afford to go to state or district headquarters regularly, given their reproductive work. On a consistent basis, if they stop using the drugs, the killer disease again attacks the victims. The women reported that their social networks had shrunk more than that of their husbands when people in the community came to know that the husband or they were infected.

**This is not to say that gender construction does not have a bearing on men's vulnerability to HIV/AIDS. It does have, but the element of power by opposite sex is missing in how gender affects men's vulnerability to HIV/AIDS. Men are socialized into promiscuity, into substance use, into not taking protection; women do not force them into these. However, in the case of women's vulnerability the element of power and force by men and by society has a role to play**

#### Weak and gender blind health systems and vulnerability to HIV/AIDS

The biases in the health system in Tamil Nadu (though Tamil Nadu is comparatively better than other states) adds to the vulnerability of poor men and women to HIV/AIDS. Discussions with different stake holders like VHNs, PRI members, extension educators suggest that public health facilities still use unsafe needles and blood transfusions. One of the victims at Varushanadu has lost her husband because of the negligence in blood transfusion when her husband was treated during a major accident. Untrained private health practitioners still extending health care services and there is no monitoring on such services. Diagnosis and treatment facilities for HIV/AIDS, as well as other forms of STIs, are available only in selected district and medical college (public) hospitals. The victims reported that negative and judgmental attitudes from doctors, nurses and ward-



boys were common, and their felt anxious and afraid to go there. Service users reported that the most common manifestations of stigma took the form of neglect, denial of access to treatment or refusal to treat, shunting persons from one service to another, labeling, breaches of confidentiality and even violence. Such experiences cut across private and public sector health services. Breaching of confidentiality was common by providers, though the Supreme court has ruled that it can be breached to protect any prospective partner that a person with HIV is likely to marry or the spouse of an infected person.

The health system is also gender blind. Female sterilization is still the popular contraception, and condoms are promoted by public facilities only for protection of *men* against HIV/AIDS (especially when they visit sex workers or have sex with men). This makes it very difficult for married sterilised married women to negotiate condom use by their spouses. Female condoms are not available through public health facilities, which would put control into women's hands. Recent calculations on DALYs have led to situation with prevention of MTCT services, and treatment of infected infants being more available than for infected mothers

## CHAPTER VII

### 7.0 RECOMMENDATIONS

Flowing from the study are several recommendations to the state to address gender specific vulnerability of women and girls to HIV/AIDS. Some recommendations are for the short term, and others are some for the long term.

#### 7.1 Short term recommendations

On a short term in the basis the state should:

- Strengthen availability of confidential STI diagnosis and treatment at PHC and sub center level and through health camps; rather than only through district hospital level.
- Monitor the availability of treatment and utilization of treatment for women victims of HIV/AIDS. The DOTS model for combating TB could be used
- Stop sterilisation as a contraceptive method, and promote temporary and in particular barrier methods.

- Ensure availability of female condoms and sterilised needs through the PHCs, health sub centers and women's SHGs.
- Expand availability of life skills and SRH education to drop out children in addition to middle and high school children and college youth
- Provide life-skills, SRH and gender and HIV/AIDS education to women SHG members and women outside SHGs (with a focus on all caste groups and occupations)
- Strengthen housing security and livelihoods of women victims of HIV/AIDS through federations of SHGs. Have special schemes towards this.
- Gender and HIV/AIDS sensitization should be provided to health workers, PDS shop runners, teachers, ICDS workers, members of the PRI, health committees, and religious leaders
- The state 's RCH should stop focusing only on health of women during pregnancy, but of all women
- The state should monitor that blood banks and blood transfusions adhere to safe and legal standards. Licensing legislation of 1999 may be strictly monitored.
- The state should provide gender sensitive counseling to families, relatives and peers of victims of HIV/AIDS
- The state should encourage and support relatives to take care of orphans due to HIV/AIDS
- Through media interactive programme (radio and television) on HIV/AIDS may be launched to change negative attitudes such as 'punishing', 'withdrawal', 'expulsion', 'untrust-fulness' towards victims of HiV/AIDS
- Promote legislation for compulsory blood testing and disclosure of results in marriages to prospective partners.
- Strengthen powers and monitoring capacities of Patient Welfare committees at district and PHC levels, as well as Panchayat level development committees on whether HIV/AIDs prevention, treatment and care facilities adhere to policies.

Long term recommendations:

- Formulate comprehensive Law on Reproductive and Sexual Health which guarantees free choice in matters of marriage; access to reproductive and sexual

health-care services; non-discrimination in health-care access and personal security for all (including people with HIV)

- Promote legislation on compulsory secondary education, as education and awareness on HIV/AIDS seem related. Have special schemes for girls secondary education.
- Protect women from violence; and monitor implementation of Domestic violence act 2005;
- Strengthening poverty reduction strategies through promoting sustainable growth of the agriculture sector and promoting sustainable industrial development of towns
- Monitor mushrooming of the tourism sector, and commercial sex trade through tourism should be stopped.
- Monitor implementation of legislation on inheritance rights of women;
- Promote legislation towards compulsory re-registration of all property of men as joint property upon marriage.

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#### ANNEXURE 4:

#### FIGURES ON HIV/AIDS

##### People globally newly infected with HIV in 2004

Adults	4.3 million (3.7-5.7 million)
Children under 15 years	2.2 million (2.0-2.6 million)
<b>Total</b>	<b>4.9 million (4.3-6.4 million)</b>

Source: Aids

##### AIDS deaths in India 2004

Adults	2.6 million (2.3-2.9 million)
Children under 15 years	510 000 (460 000-600 000)
<b>Total</b>	<b>3.1 million (2.8-3.5 million)</b>

Source: AIDS Epidemic Update 2004, UNAIDS/WHO

### Number of people in which country living with HIV in 2004

Adults	37.2 million (33.8-41.7 million)
Children under 15 years	2.2 million (2.0-2.6 million)
Women	17.6 million (16.3-19.5 million)
<b>Total</b>	<b>39.4 million (35.9-44.3 million)</b>

Source: AIDS Epidemic Update 2004, UNAIDS/WHO

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### Number of people living with HIV in India in 2004

Male (in millions)	3.132
Female (in millions)	2.002
<b>Total (in millions)</b>	<b>5.134</b>

Source: NACO, 2005?

### Number of cases by risk/transmission category in India? Risk/transmission categories Number of cases Percentage

Sexual	95,941	85	96
Perinatal transmission	4,059		3.64
Blood and blood products	2,231		2.00
Injecting drug users	2,672		2.39
Others (not specified)	6,705		6.01
<b>Total</b>	<b>111,608</b>		<b>100.00</b>

Source: NACO of 31st July 2005

## **Annexure 5**

### **Basic facts on HIV/AIDS**

Please define hiv and aids- what is the difference between both

#### **Transmission of HIV**

HIV is transmitted through certain (proved) body fluids – blood, semen, vaginal fluid, breast milk, and body fluids containing blood, given the condition that the fluid has sufficient viral load and there is a port of entry.

#### **HIV is transmitted through:**

- Unprotected sexual intercourse
- Sharing infected syringes / needles
- Infected blood transfusion
- Infected parent to child transmission

The virus is not transmitted through air or water or by casual contact. An HIV infected person may develop AIDS symptoms after 8-10 years after infection.

#### **Signs of HIV infection**

### Major signs

- Weight loss of over 10% of body weight,
- Fever for longer than one month
- Diarrhea for longer than one month,

### Minor signs

- Persistent cough for more than one month,
- General itchy skin diseases
- Recurring shingles,
- Thrush in the mouth and throat,
- Long lasting, spreading and severe cold sores,
- Long lasting swelling of lymph glands,
- Loss of memory
- Loss of intellectual capacity,
- Peripheral nerve damage

As these symptoms are generic, HIV infection can only be confirmed through HIV test.

### **What are the later symptoms of HIV/AIDS?**

- Lack of energy. Weight loss. Frequent fevers and sweats. A thick, whitish coating of the tongue or mouth (thrush) that is caused by a yeast infection and
- Sometimes accompanied by a sore throat. Severe or recurring vaginal yeast infections. Chronic pelvic inflammatory disease or severe and frequent infections like herpes zoster. Periods of extreme and unexplained fatigue that may be combined with headaches, lightheadedness, and/or dizziness. Rapid loss of more than 10 pounds of weight that is not due to increased physical exercise or dieting. Bruising more easily than normal. Long-lasting bouts of diarrhea.
- Swelling or hardening of glands located in the throat, armpit, or groin.
- Periods of continued, deep, dry coughing. Increasing shortness of breath.
- The appearance of discolored or purplish growths on the skin or inside the mouth.
- Unexplained bleeding from growths on the skin, from mucous membranes, or from any opening in the body.
- An altered state of consciousness, personality change, or mental deterioration.

### **Testing and Diagnosis**

In the early stages of infection, HIV often causes no symptoms and the infection can be diagnosed only by testing a person's blood. Two tests are available to diagnose HIV infection – one that looks for the presence of antibodies produced by the body in response to HIV and the other that looks for the virus itself.

Antibodies are proteins produced by the body whenever a disease threatens it. When the body is infected with HIV, it produces antibodies specific to HIV. The first test, called ELISA (Enzyme Linked Immunosorbent Assay), looks for such antibodies in blood. If antibodies are present, the test gives a positive result. A positive test has to be confirmed by another test called Western Blot or Immunofluorescent Assay (IFA). All positive tests by ELISA need not be accurate and hence Western Blot and repeated tests are necessary to confirm a person's HIV status. A person infected with HIV is termed HIV-positive or seropositive. As ELISA requires specialised equipment, blood samples need to be sent to a laboratory and the result will be available only after several days or

weeks. To cut short this waiting period, rapid tests, which give results in 5 to 30 minutes, are increasingly being used the world over. Though rapid tests are more expensive, researchers have found them to be more cost effective in terms of the number of people covered and the time the tests take. If a person is highly likely to be infected with HIV and yet both the tests are negative, a doctor may suggest a repetition of the tests after three months or six months when the antibodies are more likely to have developed.

The second test is called PCR (Polymerase Chain Reaction), which looks for HIV itself in the blood. This test, which recognises the presence of the virus' genetic material in the blood, can detect the virus within a few days of infection. The process of getting tested for HIV can generate a variety of intense emotional reactions such as fear, anger and denial. Therefore, psychological counseling is essential to prepare individuals undergoing testing for the possible consequences. This is called pre-test counseling and is unavoidable for anybody preparing to take a test. If the test result is positive, it should not be disclosed without another round of counseling. This post-test counseling is more crucial because of the enormous stress and the multitude of emotions that the infected person could undergo on learning his/her HIV status. A positive test has been linked to increased suicide ideas and attempts and emotional trauma, both at the time of knowing the positive result and also at the emergence of AIDS-defining symptoms.

### **Is there treatment against HIV and AIDS?**

Till today, there is no conclusive treatment to eliminate HIV from the body; however, timely treatment of opportunistic infections can keep one healthy for many years. The commonly available treatment for AIDS is the treatment against opportunistic infections. Normally standard treatment regimens, used against such infections in non-HIV patients, also work well with the HIV-positive persons. If properly treated, almost all the opportunistic infections can be contained.

However, during the last decade, researchers have developed powerful drugs that check the replication of the virus at various levels. Called antiretroviral drugs, they are available in three classes and under various brands. Taken in combinations (called cocktail or combination therapy) under specialized medical advice, these drugs drastically reduce the viral load in blood. However, they do not permanently cure one of HIV. This line of treatment, called HAART (Highly Active Antiretroviral Therapy) has resulted in a huge reduction or AIDS-related deaths. Though many positive persons and caregivers have welcomed these drugs, others have experienced serious side effects. They are also very expensive and are out of reach for a majority of the infected people. But of late, the prices have been steeply falling.

### **Prevention**

Since there is no effective cure, best way to protect oneself from infection is by prevention. Avoiding certain risk behavior can prevent HIV transmission.

Sexual mode of transmission can be prevented by

- Abstinence
- Non-penetrative sexual practices
- Use of barrier method (e.g. male and female condoms)

Non-sexual transmission can be prevented by



- Avoiding sharing of syringe/needle
- Sterilization of medical equipment
- By screening blood/blood products before transfusion
- Prevention of infection from HIV infected mother to child by
  - Taking medication available which prevents transmission to child
  - Avoiding breast-feeding