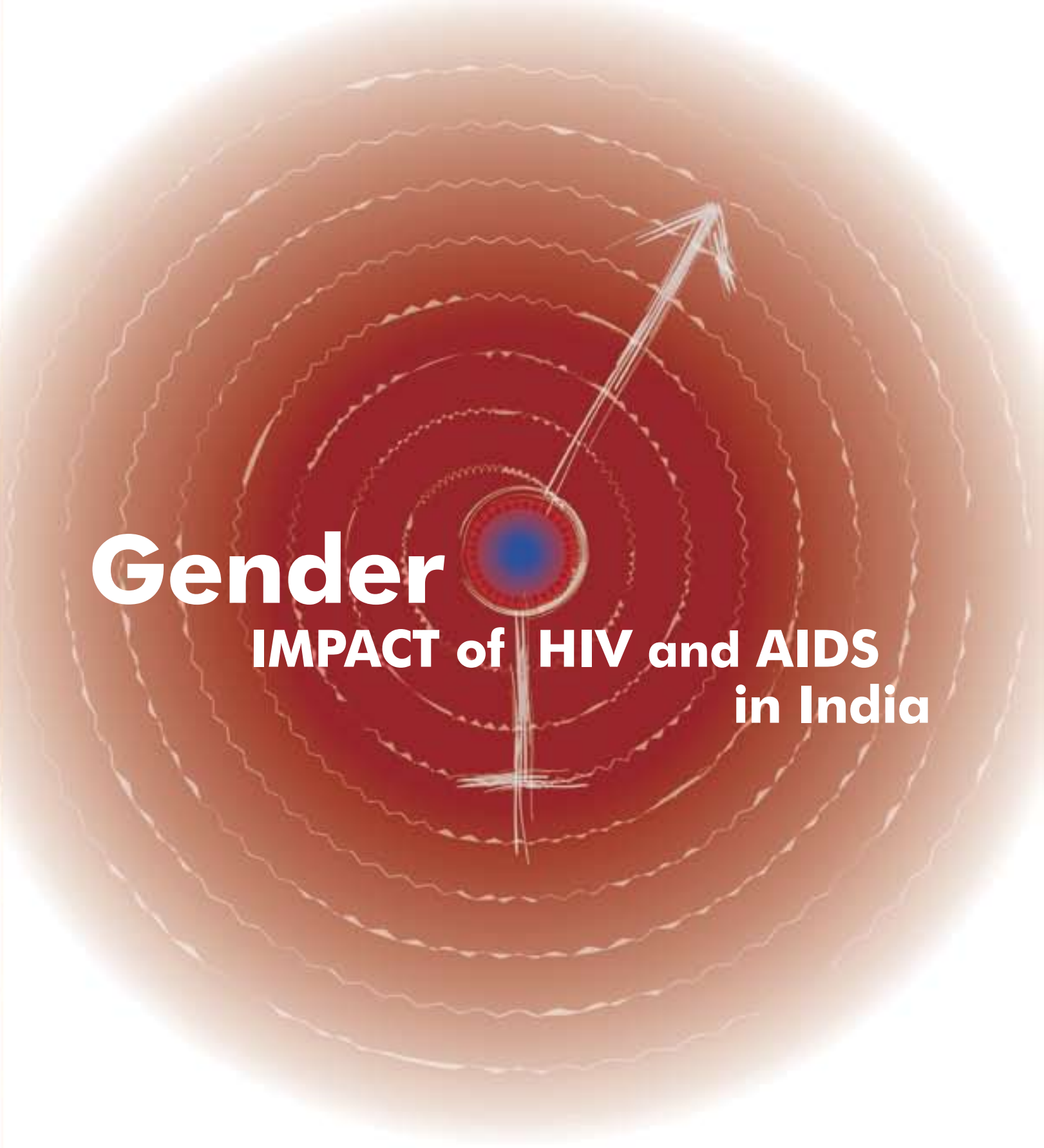

Gender

IMPACT of HIV and AIDS in India

NACO

NCAER

UNDP India

Gender

Impact of HIV and AIDS in India

Basanta K. Pradhan
Ramamani Sundar

NACO
NCAER
UNDP India

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सत्यमेव जयते
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Foreword

The study on the Socio-Economic Impact of HIV and AIDS which was conducted in the six high-prevalence states of India, is an important initiative to assess the impact of HIV and AIDS on households and make projections at the macro and sectoral level. The National AIDS Control Organisation (NACO) commissioned this study to address the need for concrete evidence on the social and economic consequences of HIV and AIDS in India.

A unique feature of this study is the scale of the research. It is noteworthy for its detailed analysis of the phenomenon of stigma and discrimination and of the impact of HIV and AIDS on households, on people living with HIV and AIDS (PLWHA) and their family members.

There are many issues of concern highlighted in this study. The additional financial burden imposed on households with people living with HIV and AIDS (PLWHA) is forcing them further into poverty. An important indicator is the reduction in the aggregate income of the PLWHA households surveyed by around nine percent. This has a devastating impact considering that most of the sample households were from the low income group.

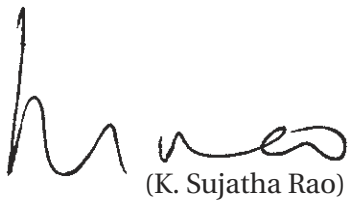
There are various factors that bring about a fall in income levels. One reason for lower income levels is the higher prevalence of HIV and AIDS among working people. Also, on an average, the per capita medical expenses of HIV households were four times higher than those of the non-HIV households. To meet this expense, almost 43 percent of the households had either borrowed or sold assets. As a result of lower savings and expenditure, dependants in the households such as children, spouses, caregivers and the elderly were also affected. For example, in Andhra Pradesh the number of children from HIV households who had to absent themselves from school due to their parents' illness was four times higher as compared to non-HIV households.

The study is timely for NACO and State AIDS Control Societies (SACS), particularly now as we are finalising the National AIDS Programme Phase III (NACP III) and the state level Programme Implementation Plans (PIPs). I have no doubt the study will be invaluable in guiding us on the road ahead. The States AIDS Control Societies (SACS), district and block level officers will also be able to tap state and district level findings to advocate for better decentralised cooperation.

The macro-model prepared in this study suggests that the long-term impact of HIV and AIDS is likely to be severe, on both aggregate and per capita GDP. NACO will use these findings to mobilise actors such as the private sector, media and non-health government ministries and to add momentum to ongoing efforts. Clearly HIV is not just a health issue and its impact has both social and economic ramifications. To overcome the challenges posed by HIV and AIDS we must ensure greater synergy between the efforts of several sectors as well as urgent action.

For instance, 39 percent of the women account for the total infections in India. A significant portion of the new infections occur in women who are in monogamous marriage and have been infected by their husbands who may have multiple sex partners. The study on "Gender Impact of HIV and AIDS in India" clearly indicates that women are even more affected by HIV having less access to information on HIV, few opportunities on access to treatment and they are also the main care givers. The study recommends the need to design programmes to empower women to negotiate safe sex with their husbands, access to information on HIV and tailor made programmes for HIV-positive widows.

I would like to congratulate the National Council of Applied Economic Research (NCAER), the United Nations Development Programme (UNDP), PLWHA networks, state level bodies, SACS and Voluntary Counselling and Testing Centre (VCTC) counsellors for their excellent contribution to the study.



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Message

Globally, by the end of 2005, an estimated 40.3 million people were living with HIV and of these, as many as 17.5 million i.e. more than 40 percent were women. Though the "feminisation" of the pandemic is more apparent in Saharan Africa, the HIV infection rate among women in India is also steadily rising. In India, women account for around 2 million of the approximately 5.2 million estimated cases of people living with HIV in 2005, constituting 39 percent of all HIV infections. Of the 1,11,608 cases of AIDS reported in the country till 31 July 2005, females accounted for nearly 30 percent. It has been found that the impact of HIV and AIDS reaches far beyond the health sector with severe economic and social consequences and the impact is much more severe on women than on men. Women and girls seem to bear the brunt of the pandemic in many ways and the disease disproportionately affects them psychologically, socially and economically.

This report clearly brings out the adverse impact of HIV and AIDS on women and female children and highlights the heavy burden of care, domestic work and economic responsibilities on women in the HIV households and the role of women as caregivers. The report focuses on the gender differences in the health-seeking behaviour and out-of-pocket expenditure incurred by the HIV households on the treatment of opportunistic infections (OIs) and the gender gaps in the education of children from the HIV affected households. In our society, where gender differences exist in all walks of life, it is surprising that HIV-positive women face stigma and discrimination in the family and community. The study finds lack of knowledge among women about the modes of transmission of the infection to be greatly responsible for their negative attitude towards PLWHA and their families. A comparison of HIV widow households with the other HIV households in terms of their living conditions, the assets and consumer durables they possess, household income, pattern of consumption, savings and borrowings brings out the pitiable economic condition of the widows.

We are grateful to the United Nations Development Programme (UNDP) for entrusting this important and sensitive study to National Council of Applied Economic Research (NCAER).

We hope that the findings of this study would be helpful to policy makers, researchers and NGOs working in this field for designing and implementing various programmes for the welfare of the women living with HIV and AIDS.

I would like to thank Dr. Basanta Pradhan and Mrs. Ramamani Sundar for the successful completion of this pioneering study.

Suman Bery
Director-General

Message

The multi-dimensional nature of vulnerabilities that result from HIV and AIDS are at first glance difficult to comprehend and measure. At the global level, research is increasingly focusing on the relationship between HIV and other socio-economic issues.

In India, the impact of HIV and AIDS is not very visible due to the low prevalence rate and large population size. In such a scenario, it is even more important to document both human and economic dimensions of HIV and AIDS. Research studies conducted till date in India have measured the impact of HIV and AIDS on stigma and discrimination and income but their limitations lie in their small sample size. It was therefore thought necessary to conduct this study on a more comprehensive scale.

The study brings out the negative impact HIV is likely to have over the next decade on economic growth and livelihoods of people, particularly the poor, if current trends are not heeded. A case in point is the study finding that highlights that Persons Living with HIV and AIDS that have minimum social security, such as unskilled wage labourers, are even more at risk. This was substantiated by the sectoral study which revealed that HIV and AIDS hit those sectors harder that use unskilled labour intensively. Work in several African countries has highlighted that high-prevalence rate of HIV infection can lead to a reduction of the Gross Domestic Product. Not surprisingly, when such a trend sets in, it is the poor that are most affected.

The pervasiveness of stigma and discrimination is another cause for concern, making a strong case for mainstreaming HIV in the work of non-health sectors. In Maharashtra, for example, 56 percent of those surveyed had not disclosed their status in the community and 79 percent had not disclosed their status to the employer.

In the case of women, the discrimination was much higher than against men. A distressing finding of the study is the burden on women. When it comes to care of the people living with HIV and AIDS, women account for more than 70 percent of the care givers. More alarmingly 20 percent of these care givers are HIV-positive themselves. In case of access to information on HIV and treatment, the scenario is much worse. The most daunting finding is that nearly 60 percent of the HIV-positive widows are less than 30 years of age and staying with their natal families. These findings clearly

underline the urgent need for women-centric components within the HIV and AIDS programmes. This reiterates UNDP's position that a stronger focus on women is necessary to empower them and make them less vulnerable to HIV and AIDS.

UNDP is happy to have supported NACO in this study and hopes that the findings will be useful to strengthen evidence based planning for a more comprehensive response to HIV and AIDS in India. We hope this study will contribute to enhancing our collective understanding of the impact of HIV and AIDS beyond the health sector. Finally, I would like to congratulate the research team at NCAER under the leadership of Dr. Suman Bery for making this study possible.

Maxine Olson
Resident Representative
United Nations Development Programme

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At the United Nations Development Programme, New Delhi we would like to thank Dr. Maxine Olson, UNDP Resident Representative and UN Resident Co-ordinator for her leadership and guidance. We would especially like to acknowledge the continuous advice and inputs from Ms. Alka Narang, Head, HIV and Development Unit, Dr. Hari Mohan, National Programme Officer and Ms. Sabrina Sidhu, Research Associate.

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Abbreviations

AIDS	Acquired Immuno-Deficiency Syndrome
ART	Anti-retroviral Therapy
CFAR	Centre for Advocacy and Research
FGD	Focus Group Discussion
F/M	Female - Male Ratio
HIV	Human Immuno-deficiency Virus
HH	Households
MDG	Millennium Development Goals
MSM	Men who have Sex with Men
N	Number
NACO	National AIDS Control Organisation
NCAER	National Council of Applied Economic Research
NGO	Non-Governmental Organisation
OIs	Opportunistic Infections
PLWHA	People Living with HIV and AIDS
PPTCT	Prevention of Parent to Child Transmission
PWN+	Positive Women's Network
SACS	State AIDS Control Society
SNA	System of National Accounts
STI	Sexually Transmitted Infection
UNAIDS	Joint United Nations Programme on HIV and AIDS
UNFPA	United Nations Population Fund
UNICEF	United Nations International Children's Education Fund
UNIFEM	United Nations Development Fund for Women
VCTC	Voluntary Counselling & Testing Centre
WHO	World Health Organisation

Executive Summary

Introduction

According to the estimates of NACO for the year 2005, in India, women account for around two million of the approximately 5.2 million estimated cases of people living with HIV and AIDS (PLWHA), constituting 39 percent of all HIV infections. The surveillance data indicates that, in high prevalence states, the epidemic is spreading gradually from urban to rural areas and from high-risk groups to the general population. A significant proportion of new infections is occurring in women who are in monogamous relationship and have been infected by husbands or partners who have multiple sex partners. According to NACO, of the 1,11,608 AIDS cases reported in the country till 31 July 2005, females accounted for nearly 30 percent.

Biological, socio-cultural and economic–factors make women and young girls more vulnerable to HIV and AIDS. The HIV virus is more easily transmitted from men to women than from women to men; male-to-female transmission during sex is about twice as likely as female-to-male transmission. In India, the low status of women, poverty, early marriage, trafficking, sex-work, migration, lack of education and gender discrimination are some of the factors responsible for increasing the vulnerability of women and girls to HIV infection.

The impact of HIV and AIDS reaches far beyond the health sector with severe economic and social consequences and it has been found that it is much more severe on women than men. Women and girls seem to bear disproportionate brunt of the epidemic psychologically, socially and economically. This study attempts to assess the impact of HIV and AIDS on women and female children in India in terms of:

(a) Burden of care, domestic work and economic responsibilities on women in the HIV households and the role of women as caregivers;
(b) Health-seeking behaviour and out-of-pocket expenditure incurred by the HIV households on the treatment of opportunistic infections (OIs) suffered by the PLWHA;
(c) Ever and current enrolment of girls in school, gender differences in the reasons for discontinuation of schooling and the type of school attended by the children from HIV and non-HIV households;
(d) Stigma and discrimination experienced by the PLWHA in various contexts such as family, community, workplace and healthcare facilities;
(e) Knowledge, awareness and misconception about HIV and AIDS,

and attitude towards PLWHA among the general population; and

(f) Status of HIV-positive widows.

Data and methodology

The present study supported by the United Nations Development Programme (UNDP), is based on the data collected by the National Council of Applied Economic Research (NCAER) through a household survey conducted to assess the socio-economic impact of HIV and AIDS in India. The survey was conducted during October 2004 to May 2005 with the support of UNDP and NACO. The survey covered selected rural and urban areas of the six high-prevalence states of Andhra Pradesh, Tamil Nadu, Karnataka, Maharashtra, Manipur and Nagaland and included both HIV and non-HIV households (controlled group) so that cross-sectional analysis could be carried out by comparing the two types of households. Besides, qualitative research techniques like case studies and focus group discussions were also applied.

The survey covered 2,068 HIV households and 6,224 non-HIV households spread over the rural and urban areas of six HIV high-prevalence states. The number of PLWHA interviewed was higher at 2,386, since wherever there were more than one adult PLWHA in a family, an attempt was made to interview the second person also. Of the 2,386 PLWHA who were interviewed, 1,043 i.e. nearly 44 percent were women.

Profile of the sample

Most of the sample HIV households belong to low economic and educational strata of society. The average household income is Rs. 47,260 for the HIV households and marginally higher at Rs. 48, 900 for the non-HIV households. The sample included mostly households whose heads had poor educational background.

Most of the sample PLWHA is in the age group of 20 to 40 years. While a majority of men, i.e. 48 percent are in the age group of 30-40 years, a majority of women (59%) are in the younger age group of 20-30 years. While more than one-third of the sample female PLWHA are widows, the percentage of widowers among sample male PLWHA is much lower at 4 percent. The level of education of the sample PLWHA is also quite low, as 24 percent of men and 30 percent of women are illiterate. The gender differences in the level of education are visible not only from the higher percentage of illiteracy among the female PLWHA, but also from the fact that only 8 percent of women have studied beyond senior secondary level, while 13 percent of men have gone beyond the school level. The sample is generally spread over all occupations. While 22.6 percent of men are transport workers, hardly any woman is employed in this sector. More than 40 percent of the women are housewives. Among women, the salaried (13.3%) form the highest percentage. Nearly one-fourth of the men and 28 percent of women are working as labourers either in agriculture or in the construction sector or in other non-agricultural activities.

The survey covered 2,068 HIV households and 6,224 non-HIV households spread over the rural and urban areas of six HIV high-prevalence states

Burden on women

An attempt has been made to assess the burden on women by comparing the time-use pattern of women of HIV households with men of these households as well as with women from non-HIV households. All the household members who were 15 years of age and above were asked to report various activities performed by them on a normal working day. In all, the survey covered 5,829

persons–2,769 men and 3,060 women from the sample HIV households and 19,710 persons–10,062 men and 9,648 women from the non-HIV households.

The data on time-use reveals interesting gender differences in the time spent in system of national accounts (SNA), extended SNA and non-SNA activities not only between HIV and non-HIV household members but also between the 15-60 and 60 and above age groups. In both HIV and non-HIV households, men spend much more time in SNA activities as compared to women, the difference is more pronounced in the non-HIV households, indicating that women from HIV households are devoting more time to productive activities in an effort to supplement the household income.

Women account for more than 70 percent of the caregivers and 21 percent of these women themselves are HIV-positive

As expected, when compared to men, women from both HIV and non-HIV households are spending more time in extended SNA activities which include household work, child care and care of the sick and elderly. Although there is not much difference in the average time spent in extended SNA activities between women of HIV and non-HIV households for the 15-59 age group, there is a considerable difference in the time spent by older women. This suggests that the 60 years and above women from the HIV affected households are shouldering the additional burden of taking care of the HIV and AIDS affected family member and/or household work.

As a consequence of women from HIV households spending more time in SNA and extended SNA activities, they are left with lesser time to spend in non-SNA activities not only as compared to their male counterparts, but also when they are compared with women from non-HIV households. This clearly indicates that women from the HIV households get lesser time for relaxation, leisure, and self-maintenance.

Details about the family caregivers were collected from the HIV households to understand the role of women as caregivers. Of the total 2,376 PLWHA interviewed, 683 reported that they need care and 882 household members are providing care to these persons who are at the advanced stage of HIV infection. Women account for more than 70 percent of the caregivers. It is a matter of concern that nearly 20 percent of caregivers themselves are HIV-positive. The percentage of PLWHA among the caregivers is marginally higher among women; it is 21 among women as against 17 among men. Nearly one-third of the female caregivers are also employed. Although the percentage employed is much higher among the men (58%), it is to be remembered that in the case of women, in addition to these two responsibilities (of caregiving and employment), there is a burden of household chores as well.

Health status and health-seeking behaviour

Though the prevalence rates of non-hospitalised as well as hospitalised illnesses go up with the increase in the stage of infection for both males and females, the rates are generally lower for the females. While the prevalence rates of non-hospitalised illnesses are only slightly lower for females compared to that of males at each stage, the reported number of hospitalisation cases shows greater variation. There could be a number of reasons for women reporting lower prevalence of illnesses, especially hospitalisation. First, women may not be taking minor ailments very seriously. Generally, as far as possible, women would try to avoid going to the doctor,

in particular, avoid getting hospitalised as the household routine is likely to be disrupted more by the sickness of women of the household. In households where both men and women are sick, more importance is given to get the man who is the breadwinner.

There are significant gender differences in the percentages of untreated opportunistic infections (OIs). Not only the percentage of women's illnesses which go untreated is higher than that of men, but in the case of women, financial constraints turn out to be an important reason for not seeking treatment. The source of treatment indicates that a lesser percentage of women take treatment from private providers, whether for non-hospitalised or hospitalised illnesses. For both hospitalised and non-hospitalised illnesses, the cost per treatment in case of women is less than that of men, be it in a government health facility or in a private one.

This is in spite of the fact, that nearly the same percentage of men and women suffer from the same diseases, and even the number of days of hospitalisation is nearly the same.

As compared to men, women have poorer access to healthcare. In a few of the sample states where HIV-positive women who were better educated, had better access to health facilities. The financial constraint is also a big impediment for getting proper healthcare and it is more so for women.

Impact on education of female children

Although there is hardly any gender gap in the ever enrolled percentages for the children of HIV as well as non-HIV households, with the exception of 6-14 years age group children of non-HIV households, the current enrolment percentages are lower for the girls. This gender gap in the current enrolment percentages is marginally more for the HIV households as compared to non-HIV households for both 6-14 and 15-18 years age groups, implying that the girls are more likely to be withdrawn from schools in the HIV households.

While in the HIV households, boys are mostly withdrawn from schools to take up an income earning activity, girls discontinue schooling in order to take care of their younger siblings and household chores. These gender differences in the reasons for dropout clearly bring out the differential gender roles expected from boys and girls in our society. Besides, in the case of HIV households, the percentage of girls attending government schools is significantly higher than the percentage of boys attending government schools. The HIV-positive parents feel unhappy about shifting their wards from private to government schools. However, given the limited resources, they would rather spend more on the education of boys than girls.

Not only the percentage of women's illnesses which go untreated is higher than that of men, but in the case of women, financial constraints turn out to be an important reason for not seeking treatment

Stigma and discrimination

Nearly 74 percent of male and 70 percent of female PLWHA have reported that their families are quite supportive, in spite of there being slight hesitation initially by a few (in the case of females, 'family support' implies mainly support from the natal family). However, there is a gender gap in the family support, irrespective of whether the sample is urban or rural area. While nearly 5.5 percent of female PLWHA have been asked to leave home after being tested positive, only 1.9 percent of the male PLWHA have been subjected to this. Also, in cases where the family is not supportive but the spouse is, it is noticed

that more women are supportive of their HIV-positive husbands (12.4%) than men are of their HIV-positive wives (8.5%). Again, the percentage reporting problems like "deprived of using basic amenities" is more in the case of women than men and this gender difference is irrespective of the place of residence. Discrimination in the form of neglect, isolation, verbal teasing was reported by a higher percentage of women in both urban and rural areas. On the whole, although the family support is only marginally higher for male PLWHA, the discriminatory attitude towards women is much worse.

In the Focus Group Discussions (FGDs), it was pointed out that while there were some fortunate ones who were being looked after by their families, there were also those who were being discriminated against in some way or the other in the family. But one thing that came out clearly was that the daughters-in-law were treated much worse than the sons. Some even said that there was no place in the family for a daughter-in-law after the death of the son.

As compared to men, a marginally lower percentage of women has heard about HIV and AIDS. However, when it comes to detail, women seem far less knowledgeable than men

Knowledge & awareness about HIV and AIDS

The gender differences in knowledge and awareness about HIV and AIDS among the general population are assessed based on the survey of non-HIV households, covering 3,299 men and 2,925 women residing in the rural and urban areas of the sample states. These men and women were asked a series of questions not only to judge their knowledge and awareness about HIV and AIDS, but also to know their attitude towards PLWHA and their families.

As compared to men, a marginally lower percentage of women has heard about HIV and AIDS. However, when it comes to detail, women seem far less knowledgeable than men. While 63 percent of men knew that HIV and AIDS could be prevented, only 51 percent of women knew this fact. Similarly, while 52 percent of men knew where to go for voluntary testing, only 36 percent of women had this information. Again, the gender differences in the knowledge about the right modes of transmission are visible among rural as well as urban respondents; men seem to be better informed as compared to women. While 58 percent of men knew all the modes of transmission, the percentage of women having knowledge about all the modes has is lower at 54 percent. Although, the percentage of people not knowing even a single mode of transmission is very small, it is marginally higher in case of women respondents.

Though both men and women have negative attitude towards PLWHA and their families, men seem to be more accepting and less discriminatory. The gender differences in the attitude are glaring as far as sharing food, availing the same health facilities, allowing the children to play and in accepting the person as a teacher are concerned.

The status of HIV-positive widows

In the 2,068 HIV households surveyed, there were 439 HIV-positive widows, 206 from the rural and 233 from the urban sample. Most of the widows in the sample are in the prime of their youth; nearly 60 percent are less than 30 years of age. Nearly 30 percent of the widows are illiterate.

A comparison of HIV-positive widow households with the other HIV households in terms of their living conditions, the assets and consumer durables they

possess, household income, pattern of consumption and savings and borrowings brings out the pitiable economic condition of the widow households. The average annual income of the widow households is much less than that of the remaining, both in the rural and urban samples. While the average annual income of other HIV households is Rs. 51,111, the same for the widow households is lesser at Rs. 39,711. The difference in the earnings between the two sets of households could be due to the direct impact of death of an earning member in the widow households. The percentage of households below poverty line is much higher in the widow households compared to that in the other households, both in the rural and urban samples.

The widow households are worse off than the other HIV households in terms of availability of basic amenities and ownership of assets as well. A higher percentage of widow households live in kutcha houses. The percentage of households owning agricultural land or having livestock is lesser among widow households than in the remaining HIV households, as the widow households would have disposed off their land and livestock in order to meet the medical expenses of their deceased husbands. The percentage of households owning consumer durables like fans, televisions, telephones, washing machines etc. is also lesser in the widow households, highlighting the weaker economic position of HIV-positive widow households compared to the remaining HIV households.

The average per capita consumption expenditure of HIV-positive widow households is much less than that of the remaining households in both the urban and rural samples. The expenditure of widow households on all items including food, medical care etc. is lower than that of the remaining households, except surprisingly, for expenditure on the education of children. The fact that the HIV widow households are spending less on food, whether cereals, pulses or other food, raises the question of nutritional adequacy for these households.

A much higher percentage of widow households have resorted to liquidation of assets and borrowings after one of the family members tested positive. While 57.2 percent of the HIV widow households have resorted to these, the percentage is less at 39.6 percent in respect of the remaining households. This suggests that the widows might have disposed off their assets to meet the medical and funeral expenditure of their husbands. This is likely to be the reason for lesser percentage of widow households owning assets like agricultural land and livestock.

The HIV-positive widows face double burden (as a widow and an HIV-positive) of stigma and suffer discrimination from the family and society in which they live. The study shows that hardly 10 percent of the widows are living with their husband's family and out of those who are not living with their husband's family, more than 90 percent had stopped living in their marital homes after the death of their husband. Only nine percent of widows reported getting financial support from their in-laws. What has come out as a serious issue is that as high as 79 percent of the widows have complained that they were denied a share in their husband's property.

The HIV-positive widows face double burden (as a widow and an HIV-positive) of stigma and suffer discrimination from the family and society

Conclusion & policy recommendations

According to the present survey more than 40 percent of the sample HIV-

positive women do not have much say in matters relating to if and when to have sex and in making their husbands use condom. Access to female controlled prevention options and improving women's skills in using such options and negotiating safe sex behaviours with their partners will go a long way in their attaining control over their body and protecting themselves from HIV and other infections.

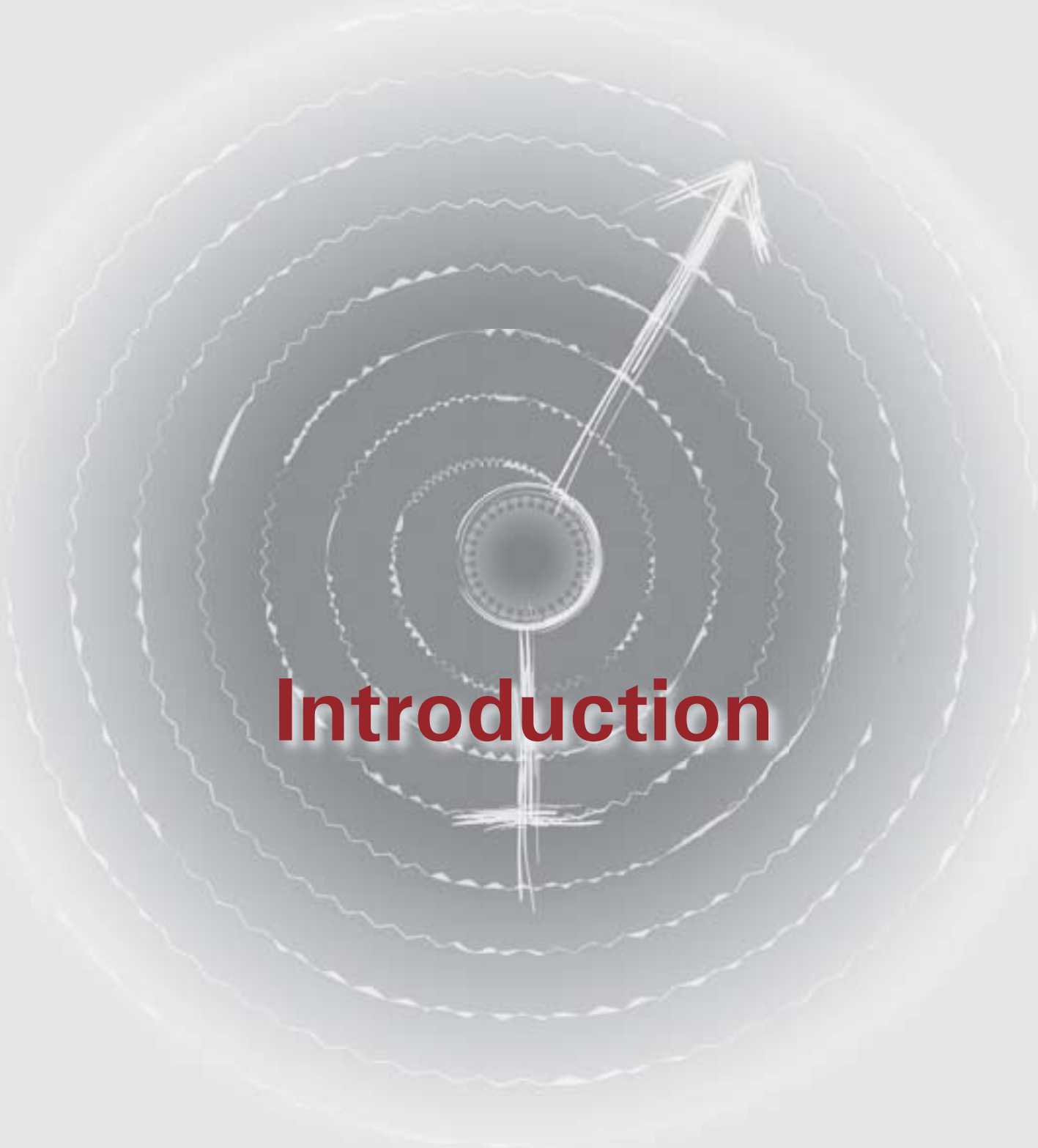
It is imperative to see that women who are affected more by HIV and AIDS get equal opportunities to access treatment

There is a need to empower adolescent girls and women by increasing their knowledge about their body and sexuality as well as about Sexually Transmitted Infection (STI), HIV and AIDS. The facilities for the treatment of STI should be made available and more accessible by strengthening the existing RCH services at the primary and tertiary healthcare facilities.

The present study reiterates the general perception that women are disproportionately affected by HIV and AIDS. The role of caregivers takes a toll on women emotionally, physically and financially. These women not only need training in nutrition, hygiene, drug management, universal precautions and basic nursing skills to handle their sick relatives, but also counselling, and moral and emotional support. Home-based care programmes could be promoted to reduce the burden on women.

The elderly caregivers of the orphans, in particular the elderly women, not only need psychological and economic support, but also access to medical care so that they could maintain their own good health.

It is imperative to see that women who are disproportionately affected by HIV and AIDS get equal opportunities to access treatment. One of the ways is to provide more education to women. Creating livelihood opportunities for more women will reduce their dependency and expand their financial freedom. As the women get more educated and earn more, they get empowered to demand more healthcare facilities.



Introduction

Chapter 1

Introduction

1.1 Background

Globally, HIV and AIDS has become a major public health issue and is posing a serious challenge to the developed as well as the developing world. It has become a leading cause of death in sub-Saharan Africa and in the worst hit countries, HIV and AIDS is reversing the gains of human development including life expectancy. In some of these countries, the epidemic is worsening the progress in human development by affecting the economic growth, human capital formation, health, education, and by increasing poverty and income inequalities (Mahbub-ul-Haq Human Development Centre, 2005). As more and more women get infected & affected by HIV, the target of the Millennium Development Goals (MDG) of arresting and reversing the spread of HIV and AIDS by 2015 may not be met. The MDGs adopted by 189 countries, including India, aim to promote gender equity and achieve universal primary education. It is feared that HIV and AIDS could be an impediment to achieving some of these goals as more and more women and girls get infected and affected by HIV and AIDS (UNDP, 2003).

At the outset of the epidemic in the 1980s, women were considered marginally at risk from a virus that seemed to be mostly confined to the so-called high risk groups-intravenous drug users (IDUs), men who have sex with men (MSM) and sex workers. Now, HIV has infected tens of millions, many of them women, who are practicing monogamy within marriage or in a long-term relationship (Dixit, A.P. 2005).

By the end of 2005, an estimated 40.3 million (36.7-45.3 million) people were living with HIV, worldwide. Close to 5 million people were newly infected with the virus in 2005 (UNAIDS/WHO 2005). Of these 40 million PLWHA, as many as 17.5 million i.e. more than 40 percent were women. As compared to 2003, one million more women were living with HIV in 2005. The “feminisation” of the epidemic is most apparent in sub-Saharan Africa where an estimated thirteen and a half million (12.5 to 15.1 million) women live with HIV and women account for 57 percent of the infection among adults in this region. (Table 1.1) In the South and South–east Asia region, almost two million women now have HIV and women form more than one-fourth of the adults who are infected by the virus.

Globally, there has been a dramatic increase in the number of young women being infected by HIV. Young women

Table 1.1

Region-wise HIV statistics on women 2003 and 2005

Region		Number of women (15-49) living with HIV	Percent of adults (15-49) living with HIV who are women (percent)
Sub-Saharan Africa	2005 2003	13.5 million 13.1 million	57 57
North Africa and Middle East	2005 2003	220,000 230,000	47 50
South and South-east Asia	2005 2003	1.9 million 1.6 million	26 25
East Asia	2005 2003	160,000 120,000	18 17
Oceania	2005 2003	39,000 27,000	55 44
Latin America	2005 2003	580,000 510,000	32 32
Caribbean	2005 2003	140,000 140,000	50 50
Eastern Europe and Central Asia	2005 2003	440,000 310,000	28 26
Western and Central Europe	2005 2003	190,000 180,000	27 27
North America	2005 2003	300,000 270,000	25 25
Total	**2005** **2003**	**17.5 Million** **16.5 Million**	**46** **47**

Source: UNAIDS/WHO 2005

account for over 60 percent of 15 to 24 year old PLWHA and they are 1.6 times more likely to be living with HIV and AIDS than young men (UNAIDS/ UNFPA /UNIFEM 2004).

According to NACO, in India, an estimated 5.21 million PLWHA in 2005, accounting for 13 percent of the PLWHA globally (NACO, 2005). Though the current prevalence rate is less than one percent of the country's population, given the large population base, any rise in this ratio of the HIV-prevalence rates can push up the number of PLWHA to several millions.

The rates of HIV infection amongst women in India are steadily rising. Women account for around 2 million of the approximately 5.2 million estimated cases of PLWHA, constituting 39 percent of all HIV infections (Table 1.2). Of these, only 0.5 percent of the women are sex workers. Of the 1,11,608 cases of AIDS reported in the country till 31 July, 2005, females accounted for nearly 30 percent.

The biggest HIV and AIDS risk for many women and girls is through heterosexual

Table 1.2

Sex-wise distribution of estimated HIV infected population in India (2000-05)

Year	HIV estimates (In millions)			Percentage share of females
	Male	Female	Total HIV infection	
2000	1.94	1.24	3.86	36.8
2001	2.04	1.24	3.97	38.5
2002	2.58	1.21	4.58	31.9
2003	3.22	1.89	5.10	36.9
2004	3.13	2.00	5.13	38.9
2005	3.18	2.03	5.21	39.0

Source: NACO, 2005

sex; almost 85 percent of infections in women result from sex with their husbands or primary partners. In India, women are increasingly getting susceptible to HIV and a large proportion of new infections are occurring in women who are married and are infected by husbands who (either currently or in the past) frequent sex workers (See Suneetha Kandiyala and Barnett, 2004, UNAIDS/ WHO 2005). The surveillance data indicates that in high-prevalence states, the epidemic is spreading gradually from urban to rural areas and from high-risk groups to the general population. The epidemic continues to shift towards women and young people and is slowly moving beyond its initial focus among sex workers. HIV transmission through sex between men is also a major cause for concern in many areas of India as the research shows that many MSM also have sex with women. In 2002, behavioural surveillance in five cities among MSM found that 27 percent reported being married, or living with a female sexual partner.

1.2 Vulnerability of women and girls

There are a number of factors-biological, socio-cultural and economic, which make women and young girls more vulnerable to HIV and AIDS. As already mentioned, the major source of infection is through heterosexual transmission and as compared to men, women are at a biological disadvantage in contracting HIV. HIV is more easily transmitted from men to women than women to men; male-to-female transmission during sex is about twice as likely as female-to-male transmission (UNICEF, 2005; Zena A. Stein and Kuhn Lousie 1996; Dixit A.P. 2005)). Biologically, young women appear to be more susceptible to HIV infection than older women; in sub-Saharan Africa, young women aged 15-24 were 2.5 times more likely to be infected as compared to young men.

The linkages between gender inequality and vulnerability to HIV and AIDS is now fairly well known. In fact, gender inequality and poverty are responsible for the spread as well as disproportionate impact of HIV and AIDS on women. "Faced with economic hardship, women and girls become more vulnerable to prostitution, trafficking and transactional sex in which they have little power to negotiate safe sex." (UNICEF, 2005) In India, women in general enjoy a very low economic and social status; the sex ratio of 933 women to 1000 men is one of the lowest in the world. This is the result of a strong son preference and the widespread sex selective abortion that is prevalent in the country. There is a large gender gap in literacy and employment as well.

Gender inequality and poverty are responsible for the spread as well as disproportionate impact of HIV and AIDS on women

These gender inequalities get reflected in the sexual relations between husband and wife. First, men are more likely to play a dominant role and are more likely to initiate, dominate and control sexual interaction. In the Indian context, women do not have control over their own bodies and they do not have the right to decide when to have sex. As a result, women cannot negotiate safe sex and ask men to use condom. There is also lack of availability of female controlled HIV prevention methods. Secondly, the cultural norms and attitude of condoning multiple partnership or pre-marital or extra-marital sexual affairs of men in the society increases women's risk of getting infected with the virus.

As a result of the low socio-economic status and limited educational opportunities, women and girls often

lack basic information about HIV and AIDS. In India, knowledge and awareness about HIV and AIDS seem to be quite low, especially among women. For instance, the Behavioural Surveillance Survey conducted in 2001 found gender disparities in the knowledge about HIV and AIDS and the awareness was particularly low among rural women in Bihar, Gujarat, Uttar Pradesh (NACO 2001). In addition, cultural taboos like speaking about sex or showing interest in or knowledge about sexual matters acts as a barrier to girls receiving HIV-related information from the elders or for that matter even from their peers.

Women of the HIV households have to not only bear the burden of domestic and economic duties, but also have to take care of the family members who fall ill as a result of HIV

The economic dependency on men is also one of the factors contributing to spread of HIV among women. Discriminatory inheritance rights, lack of access to and control over property and unequal access to education, healthcare and income-earning activities further weakens their position. In addition, the various forms of violence against women further increase the risk of contacting HIV as sex is often forced on them.

Thus, poverty, early marriage, trafficking, sex work, migration, lack of education, gender discrimination and violence against women are some of the factors responsible for the spread of HIV among women and girls in the Asia and the Pacific region (UNAIDS, UNFPA and UNIFEM 2005).

1.3 Impact on women and girls

It has been found that the impact of HIV and AIDS reaches far beyond the health sector with severe economic and social consequences and the impact is much more severe on women than on men. Women and girls seem to bear the brunt of the pandemic in many ways and the HIV and AIDS disproportionately affects them psychologically, socially and economically. The various ways in which women are being affected by the pandemic has been well documented by a number of studies undertaken, especially in Saharan Africa.

To begin with it has been found that women with HIV and AIDS are likely to suffer additional burden of stigma, discrimination and marginalisation. Often, women are blamed for her husband and/or child falling sick, suspected of infidelity by the family and society leading to rejection and expulsion by the family and community at large. Also, women are often first to be tested for HIV during pregnancy and hence blamed for having HIV , even though their male partners could be the true source of infection (UNICEF, 2005). A woman who becomes a widow is often thrown out of her house and is often denied her share in the husband's property and is likely to face isolation and discrimination from the family members.

The illness and the death resulting in loss of income for the family has been found to put additional burden on women; not only does the demand for women's labour at home increase, but the demand for women's paid labour also increases (Mahbub-ul-Haq, Human Development Centre, 2005; UNDP 2003; UNICEF 2005). In order to support themselves and their children, some of these women may have to use sex as one of the avenues of economic support. World over, it has been found that women are the primary caregivers of the sick. Women of the HIV households have to not only bear the burden of domestic and economic duties, but also have to take care of the family members who fall ill as a result of HIV and AIDS. The burden of care and domestic

work is shouldered not only by the female adults of the household, but also by girls who are often withdrawn from the school to share such responsibilities.

1.4 Objectives of the study

This present study is based on the primary survey conducted during 2004-05 by National Council of Applied Economic Research (NCAER) with the support of UNDP and NACO and attempts to assess the impact of HIV and AIDS on women and girls in India. So far, not many such impact studies on women and girls have been attempted in India. Although the recent study undertaken by ILO tried to assess the impact on PLWHA and their families, it did not analyse the disproportionate impact on women in detail (ILO, 2003). There are studies which focussed on the stigma and discrimination faced by women and these were mainly based on case studies and focus group discussions (FGDs) conducted among women (UNAIDS, 2001; Swapna Mukhopadhyay et al 2001). In the present study, the impact of HIV and AIDS on women is being assessed using both quantitative and qualitative research methods. For the first time, an attempt has been made to quantify the gender differences in the stigma and discrimination experienced by the PLWHA. Based on the data collected by NCAER through a field survey and the in-depth interviews and FGDs conducted, the report brings out how HIV has affected the women and girls disproportionately. The field survey collected data from more than 2,000 HIV and 6,000 non-HIV households (controlled group) spread over the rural and urban areas of six HIV high-prevalence states of India.

The study attempts to assess the impact of HIV and AIDS on women and girls in terms of:

(a) the burden of care, domestic work and economic responsibilities on women in the HIV households and the role of women as caregivers;
(b) Health-seeking behaviour and out-of-pocket expenditure incurred by the HIV households on the treatment of OIs (opportunistic infections) suffered by the PLWHA;
(c) Ever and current enrolment of girls in school, gender differences in the reasons for discontinuation of schooling and the type of school attended by the children of HIV and non-HIV households;
(d) Stigma and discrimination experienced by the PLWHA in various contexts such as family, community, workplace and healthcare facilities;
(e) Knowledge, awareness and misconception about HIV and AIDS, and attitude towards PLWHA among the general population; and
(f) the status of HIV-positive widows.

1.5 Structure of the report

The report has nine chapters and in the following chapter, the methodology adopted for conducting the field survey and the case studies and FGDs are described. This chapter also includes a brief profile of the sample HIV and non-HIV households and the sample PLWHA who were interviewed for the study. Chapter three assesses the impact of HIV and AIDS in terms of the burden of care, domestic work and economic responsibilities on women in the HIV households with the help of the data collected on the time-use pattern of adult men and women belonging to both HIV and non-HIV households. Details about caregivers, their employment status and workload are also presented in this chapter. There is likely to be a difference between males and females in not only who provides the care in the home, but

In the present study, the impact of HIV and AIDS on women is being assessed using both quantitative and qualitative research methods

also on who gets how much of care. There could be a difference between male and female sick members in the amount of care, including medical care received by them and the expenses incurred in treating the OIs. The gender differences in the health seeking behaviour and the out-of-pocket expenditure incurred by the HIV households are the focus of Chapter four.

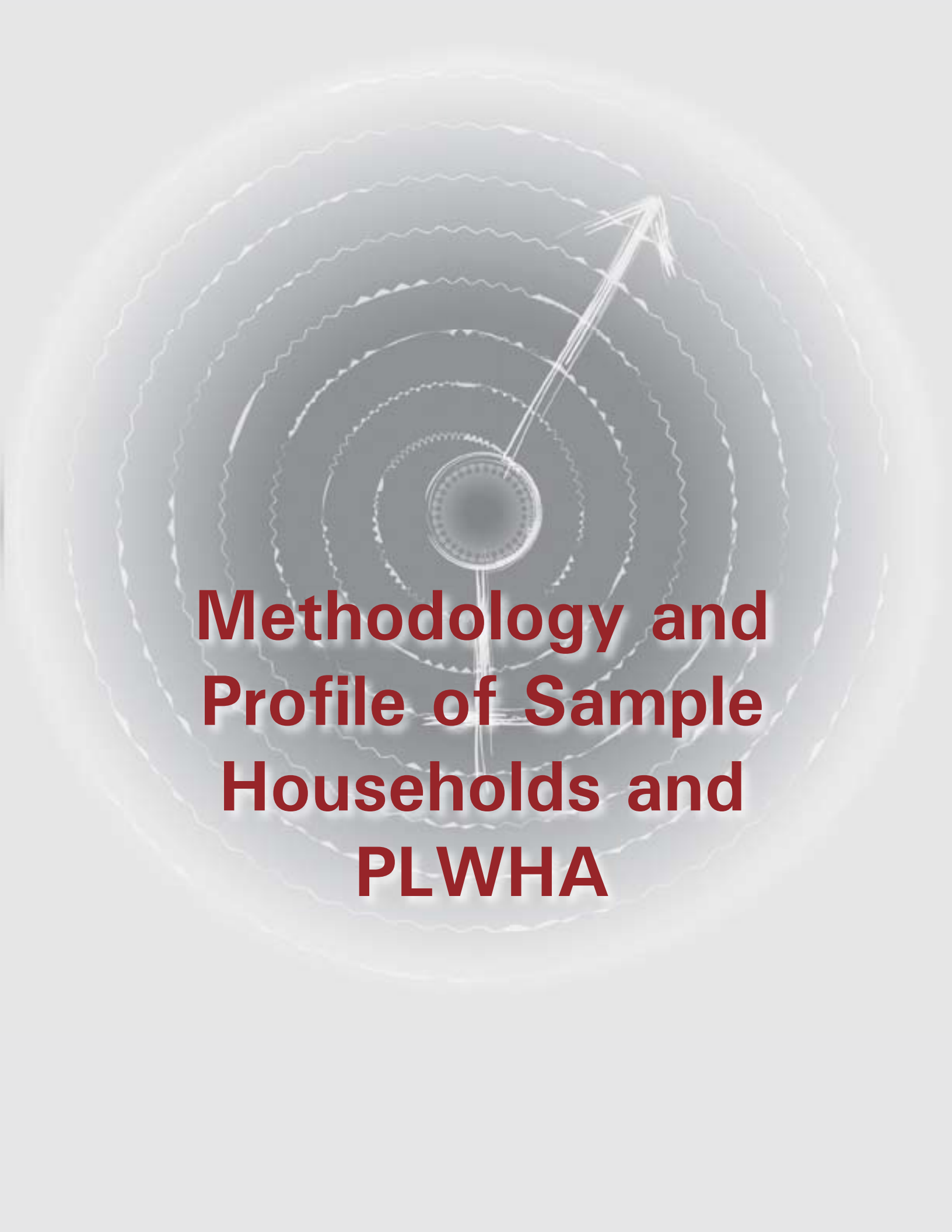
The economic constraints imposed on the household by an earning member falling sick, will not only affect the education of the children, but the amount invested on education of female and male children is also likely to differ. In Chapter five the gender differences, if any, in the impact on schooling are assessed in terms of enrolment, discontinuation and reasons for drop-out and school attendance of children, by comparing the children of HIV and non-HIV households. There could be gender differences in the stigma and discrimination faced by the PLWHA in the various set ups–in the family, community, and health facilities and these are described in Chapter six. This chapter is based on the data collected through the survey as well as on the views expressed by the female PLWHA in the FGDs conducted in the six high-prevalence states. The chapter also includes two case studies.

In a country like India, where women have a low status in the society, an HIV-positive widow is likely to experience tremendous financial burden as well as double stigmatisation–as a widow and as an HIV-positive individual

Lack of knowledge among women about HIV and AIDS and its mode of transmission not only makes them more vulnerable to the HIV but also leads to negative attitude towards PLWHA and their families. Through the survey of non-HIV households, data on knowledge and awareness about HIV and AIDS, misconceptions, if any, about the modes of transmission and their attitude towards HIV infected persons and their families were collected from nearly 6,000 men and women who were in the age group of 18-60 years. Chapter seven presents an analysis of this data to find out the gender differences in the knowledge and awareness as well as in the attitude towards PLWHA.

One of the consequences of AIDS epidemic is the increasing number of widows, that too HIV-positive widows. In a country like India, where women have a low status in the society, an HIV-positive widow is likely to experience tremendous financial burden as well as double stigmatisation–as a widow and as an HIV-positive individual. Chapter eight examines the condition of HIV-positive widows by comparing their living conditions, household income and consumption pattern, saving/ dis-savings, asset position, indebtedness etc., with HIV-positive male-headed households. This chapter describes the stigmatisation and rejection suffered by the HIV widows. The survey findings are supplemented with the case studies conducted with the HIV-positive widows.

The last chapter includes concluding remarks and policy recommendations.



Methodology and Profile of Sample Households and PLWHA

Chapter 2

Methodology and Profile of Sample Households and PLWHA

This chapter has two sections. In the first section, the methodology adopted for conducting the household survey and the qualitative techniques are discussed. The second section provides a brief profile of the sample HIV and non-HIV households.

I. Methodology

A household survey was conducted by NCAER during October 2004 to May 2005 to study the socio-economic impact of HIV and AIDS in India. This study was supported by NACO and UNDP. The survey was conducted in the six high-prevalence states of Andhra Pradesh, Tamil Nadu, Karnataka, Maharashtra, Manipur and Nagaland and it covered both rural and urban areas. The survey included both HIV and non-HIV households (control led group) so that cross-sectional analysis could be carried out by comparing the two types of households. In addition, qualitative research techniques like case studies and focus group discussions were also made use of.

The present study is based on the same data set and focuses on the gender aspect of the impact and consequences of HIV and AIDS in India.

2.1 Sample design for the household survey

2.1.1 Sample size

The survey covered more than 8,000 households in six states. Of this, one-fourth of households had PLWHA(s), i.e. around 2,000 spread across all the six states. In the case of four large states of Andhra Pradesh, Karnataka, Tamil Nadu and Maharashtra, a sample of around 400 HIV-positive households per state was drawn. From the states of Nagaland and Manipur which are small in terms of population, a smaller sample was drawn; both these states put together, a sample of 450 HIV households was drawn. The sample was drawn from both rural and urban areas of the states.

2.1.2 Selection of districts

Based on the sentinel surveillance reports of the respective State AIDS Control Societies (SACS), HIV high-prevalence districts were identified. Out of the districts so identified, in each state five to seven districts were selected for the study in consultation with the respective State AIDS Control Societies. The following districts were selected for the survey in the six HIV high-prevalence states:

Table 2.1

Districts selected for conducting the survey

State	Districts
Andhra Pradesh	Hyderabad, Warangal, East Godavari, Guntur, Krishna, Chittoor, Cuddapah
Karnataka	Bangalore, Belgaum, Dharwad, Bellary, Dakshina Kannada, Mysore,
Maharashtra	Mumbai, Nagpur, Nashik, Aurangabad, Pune, Satara, Sangli,
Manipur	Imphal-East & West, Chandel, Thoubal, Bishnupur, Churachandpur
Nagaland	Dimapur, Kohima, Tuensang
Tamil Nadu	Chennai, Namakkal, Tiruchirappali, Theni, Erode and Tirunelveli

Criteria for selection:

1. In each state, its capital, which also happens to be one of the high-prevalence districts, was selected as one of the sample sites and most of the urban sample were drawn from the state capital.
2. While selecting the districts, it was kept in mind to get as much of a geographic spread as possible in order to get a representative picture of the state.
3. The selection of the districts also depended upon the concentration and distribution of HIV and AIDS cases so as to capture the required number of HIV households. A related concern was that if the district does not have enough number of cases, we might not be able to capture the required number of HIV households.

2.1.3 Selection of HIV households and field investigators

Generally in sample surveys, villages/ urban blocks are first selected and then the household selection is made. However, in this study, this procedure could not be followed for a number of reasons. First, the selection of sample sites depended upon the presence of PLWHA and not on the localities. Secondly, it was not possible for NCAER to get a list of PLWHA and their addresses from which sample households could have been drawn. The Voluntary Counselling & Testing Centres (VCTC) situated at some of the government hospitals do maintain a register with the addresses of those who have tested positive, and the VCTCs could also not provide the list to the NCAER research team due to the confidentiality clause in conducting the HIV tests. Given these constraints and keeping in mind the ethical issues and the directions of the Institutional Review Board at NCAER, it was decided that the NCAER research team would make use of the counsellors of the State AIDS Control Societies and representatives of the NGOs working in this field, so that they could directly approach the HIV households with whom they are in touch.

While in most states, the counsellors working with the VCTC or Prevention of Parent to Child Transmission(PPTCT) centres were used to conduct the survey, there was slight variation in some states. In Andhra Pradesh, some of the PLWHA who had been trained by the Andhra Pradesh State AIDS Control Society (APSACS) to do counselling as well as outreach work, were utilised for canvassing the questionnaires. They could easily access the households affected by HIV and even visit their homes to fill up the questionnaires. In Manipur, persons working with NGOs that provide care and support services to PLWHA were used to select the sample and conduct the survey along with the counsellors of the Manipur State AIDS Control Society (MSACS). In Nagaland, as suggested by the State AIDS Control Society, NEDHIV, the NGO located at Dimapur, was approached and the survey was conducted with the help of the counsellors and outreach workers

working for the various NGOs located in Dimapur, Kohima and Tuensang.

With the exception of Andhra Pradesh, in all the other states, the persons who worked as field investigators for the survey were either post-graduates in social work or psychology or were graduates. In Andhra Pradesh, of the ten field investigators, only four were graduates and others had studied only up to the level of secondary school level. However, all of them had sufficient training to work as counsellors or do outreach work for the PLWHA.

The counsellors were from various selected districts of the state and in every state, both male and female counsellors were selected for canvassing the questionnaires from PLWHA.

These persons were provided training by the NCAER team and advised to select the sample from a diverse socio-economic profile of households and to make an attempt to select PLWHA from both the sexes. Further, the sample was selected from general hospitals, TB hospitals, care and support homes and drop-in centres run by the NGOs, VCTC, Network of Positive People and the residences of PLWHA.

The field investigators were advised to draw the sample of PLWHA, who were at different stages of infection, so that the full impact of HIV on household economy and the problem of social stigma could be assessed. However, due to practical difficulties, the field investigators could not contact/interview many PLWHA in Stage III and IV. Hence, ultimately, the sample had more of PLWHA in Stage I and II.

An attempt was also made to select the sample from people belonging to different economic strata of society. However, in spite of best efforts, the VCTC counsellors who acted as field investigators could not get access to the upper middle class and rich households since they drew their sample mainly from public health facilities and the NGOs, which mostly cater to poor/low income households. Generally, the middle/rich PLWHA would avail only the private health facilities for reasons of anonymity, and the doctors at a reputed private hospital in Tamil Nadu corroborated this. In an informal discussion with the doctors, it was learnt that PLWHA do visit them for treatment of OIs but due to reasons of confidentiality, the counsellors could not approach them.

From each HIV household, a maximum of two adult PLWHA were interviewed. Individuals who do not live in a household set-up (e.g. sex workers, persons living in shelter homes, hostels etc.) were excluded from the sample, as the focus of the study is to examine the impact of HIV and AIDS on the households.

For every HIV household surveyed in a village/urban block, three non-HIV households were interviewed

2.1.4 Selection of non-HIV households

For every HIV household surveyed in a village/urban block, three non-HIV households were interviewed. Since the purpose of surveying non-HIV households is to make comparisons with the HIV households, for each HIV household selected, three non-households belonging to similar socio-economic strata were selected for the study. The towns/cities with HIV-positive households were stratified by type of localities – four categories of slums, low-income localities, middle-income localities and high-income locality were defined. Similar localities from the same city/urban block were selected for non-HIV households. Similarly, in the case of rural areas, in each district, similar

type/size of villages were identified in the same tehsils.

In order to select the non-HIV households (controlled group), a listing of the households in the locality/village was undertaken. In the case of rural areas, if it was a relatively small village, all the households in the village were listed. In the case of a large village, a sampling fraction was used and every second, third or fourth household was listed depending upon the size of the village. A maximum of 150 households were listed in each selected village. Similarly, in urban areas, around 100 households were listed in each block.

In the listing sheet, information on the socio-economic characteristics of the households, mainly income of the household and occupational and educational status of the head of the household, was gathered. At the first step, the matching was done on the basis of the broad income category of the household, i.e. the frequency distribution was in terms of the income groups of the HIV households. At the second stage, the occupational group of the head of the household was matched from within each income category. It was difficult to take it to the next stage of matching the level of education of the head of the household and hence, this variable was ignored. However, since income and education are generally seen to be highly correlated, it was assumed that this might not create very serious problems. Selection of non-HIV households by this process would ensure that the findings of the survey would be better at the aggregate level since we are capturing the variation in the sample.

The respondents from non-HIV households were adult male or female in the age group of 20-60 years since questions on knowledge and awareness about HIV and AIDS could be answered only by this group. Accordingly, any household that did not have a member in this age group was not selected for the survey. An attempt was made to interview equal number of men and women so that we could find out about the level of knowledge about HIV and AIDS as well as capture the views and attitude of both men and women.

In all, the survey covered 2,068 HIV households and 6,224 non-HIV households spread over the rural and urban areas of six HIV high-prevalence states. The number of PLWHA interviewed was higher at 2,386, since wherever there were more than one adult PLWHA in a family, an attempt was made to interview the second person also. Of the 2,386 PLWHA, who were interviewed, 1,043 i.e. nearly 44 percent were women.

The state-wise distribution of the sample households is presented in Table 2.2.

Table 2.2

State-wise distribution of sample HIV households

State	Number of sample HIV households			Number of sample non-HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Andhra Pradesh	189	211	400	528	718	1246
Karnataka	199	202	401	580	622	1202
Maharashtra	147	256	403	439	769	1208
Tamil Nadu	223	187	410	650	553	1203
Manipur	81	173	254	232	529	761
Nagaland	51	149	200	174	430	604
Total no. of households	890	1,178	2,068	2,603	3,621	6,224
No. of PLWHA interviewed	1,045	,1341	2,386	--	--	--

2.1.5 Household questionnaire

The household survey was conducted using a structured interview schedule. Both HIV and non-HIV questionnaires

gathered basic information like socio-economic characteristics of all the household members, household income and expenditure, prevalence of morbidity and differences in enrolment and dropout of children. Both HIV and non-HIV questionnaires had a separate section to collect details about time-use pattern of all the household members above the age of 12 years. The main purpose of collecting this information was to ascertain the burden of workload shouldered by female members of HIV households versus male members as well as women of HIV households versus non-HIV households.

In addition, the interview schedule for non-HIV households had a section on knowledge, awareness and attitude (including their views on stigma and discrimination) towards HIV and AIDS. The questionnaire for the HIV households was designed to gather basic information about HIV status of the person, stigma and discrimination in the family, community, workplace, health facilities and educational institutions. Details on the economic impact on the household like cost of medical treatment, coping mechanisms and loss of income/ employment were also collected.

2.1.6 Qualitative techniques

Case studies and FGDs were conducted to supplement the findings of quantitative survey and probe into questions of how and why. For the purpose of conducting case studies unique and typical cases of PLWHA were selected with the help of field investigators, NGOs and key informants of the locality. In every state two to three case studies, were conducted. The FGDs were conducted with the members of the Network of Positive Persons. The main purpose of conducting the FGDs with the Network of Positive Persons was to understand social problems, in particular stigma and discrimination and the economic issues faced by them. A total of six FGDs, one in each state, were conducted and in every FGD there was a separate session with the female PLWHA to discuss the specific problems confronted by them.

2.1.7 Training of field investigators

The questionnaire was translated into regional languages and those who were fluent in the local language, were selected for conducting the survey. The NCAER researchers provided training to the field investigators, and also supervised the survey. The investigators were given both classroom and field training to enable them to administer the questionnaires. Since the subject of the study is of a sensitive nature, the investigators were trained to conduct the interviews keeping in mind the ethical issues involved. For instance, the respondents were informed about the purpose of the study and that the information collected would be held in strict confidence. The investigators were required to get the verbal consent of the respondents to conduct the interview and not to push the respondents to answer all the questions.

The questionnaire for the HIV households was designed to gather basic information about HIV status of the person, stigma and discrimination in the family, community, workplace, health facilities and educational institutions

II. Profile of sample households and PLWHA

2.2 Sample households

While nearly 60 percent of the HIV household heads were in the age group of 20 to 50 years, in the case of non-HIV households, this percentage was lower at 53 percent (Table 2.3). While about 8 percent of the heads of HIV households belonged to 51-60 age group, only 6 percent of the heads of non-HIV households were in this age group. Only a small percentage was above 60 years, and households with heads aged less than 20 years were negligible.

The sample mostly included households whose heads had poor educational background. The non-HIV household heads were, however, comparatively well educated than the HIV household heads. About 28 percent of the HIV and 20 percent of the non-HIV household heads were illiterate (Table 2.3). About 29 percent of the HIV household heads had completed high school or senior secondary, and in the case of non-HIV households, heads who had completed this level of education were slightly higher at 32 per cent. The percentage of heads who have studied beyond senior secondary was 11 in the case of HIV

Table 2.3

Occupation and level of education of head of the households

(in Percentages)

	HIV households			Non-HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Age (Yrs.)						
<20	0.4	0.5	0.5	0.5	0.4	0.4
20-30	20.9	21.9	21.5	16.2	18.7	17.7
31-40	39.3	36.1	37.5	35.6	35.2	35.4
41-50	17.2	18.8	18.1	28.4	26.9	27.5
51-60	13.6	15.1	14.5	13.8	12.1	12.8
60 and above	8.5	7.6	8.0	5.4	6.6	6.1
Education						
Illiterate	35.1	22.4	27.8	25.7	15.7	19.9
Up to primary school	17.5	14.9	16.0	20.9	15.7	17.9
Up to middle school	18.4	14.3	16.1	18.1	16.5	17.2
High school/senior secondary	23.8	33.4	29.3	27.8	35.1	32.0
Graduate/diploma holders	5.2	15.0	10.8	7.4	17.1	13.1
Occupation						
Cultivation	17.9	2.9	9.3	21.8	2.8	10.8
Agri. wage labour	20.9	5.2	11.9	22.5	3.4	11.4
Non-agricultural wage labour	12.7	14.9	13.9	13.2	17.9	15.9
Salaried	12.5	29.4	22.1	14.8	32.9	25.3
Trade/business	7.9	11.5	9.9	9.3	16.9	13.7
Artisan/self-employed	5.6	6.4	6.0	5.1	7.3	6.4
Transport workers	5.4	7.4	6.5	5.1	7.8	6.6
Income from, pension, rent, interest, dividend etc.	2.1	6.1	4.4	2.2	3.6	3.0
Domestic servant	0.7	2.6	1.8	0.3	1.3	0.9
Others	14.4	13.7	14.0	5.7	5.9	5.8
N	**890**	**1,178**	**2,068**	**2,603**	**3,621**	**6,224**

households and 13 in the case of non-HIV households.

An attempt was made to draw the sample of non-HIV households in such a way that they matched the income and occupational categories of the HIV households. Hence, the percentage distribution of household heads by their occupational categories is more or less the same for both types of households (the pattern of distribution of household heads by their income categories is shown in Table 2.4). A sizeable number of the heads of the households are working as wage labourers, either in the agricultural sector or in other sectors. More than one-fourth of the HIV and non-HIV household heads were wage earners, while about 22 percent of the heads of HIV households and nearly 25 percent of non-HIV household heads were salary earners.

2.2.1 Economic status of the sample households

Although an effort was made to draw the sample of non-HIV households to match the income distribution levels of HIV households, it is seen that it has not been exactly similar.

While nearly 24 percent of HIV households were from the lowest income group of less than Rs. 20,000 per annum, only 10 percent of non-HIV households belonged to this group. While 35 percent of HIV households were in the income range between Rs. 20,001 to Rs. 30,000, the non-HIV households in this range account for 29 percent of the sample. However the percentage of households in the annual income categories Rs. 30,001 - 41,000 and Rs. 84,000 and above, is almost the same for both types of households.

The percentage distribution of household heads by their occupational categories is more or less the same for both types of households

The average household income has worked out to Rs. 47,260 for the HIV households and marginally higher at Rs. 48,900 for the non-HIV households. Thus, it is clear from the table that most of the sample HIV households belong to low economic and educational strata of society. Although, there is enough evidence to show that it is the poor people who are more vulnerable to HIV and AIDS (UNDP, 2003), in the present sample, there are more households from the poor and low-income categories due to yet another reason. As mentioned earlier, in spite of their best efforts, the field investigators could not get access

Table 2.4

Distribution of sample households by household income categories

(in Percentages)

Characteristics	HIV households			Non-HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Annual HH income (Rs.)						
1. Up to 20,000	32.9	17.3	24	14.6	7.2	10.3
2. 20,001-30,000	21.8	18.3	19.8	35.2	24.8	29.1
3. 30,001-41,000	14.2	14.5	14.4	15.7	15.1	15.4
4. 41,001-84,000	24.8	33.6	29.8	27.4	37.5	33.3
5. 84,000 & above	6.3	16.2	11.9	7.1	15.4	11.9
Average HH income (Rs.)	**37,002**	**55,020**	**47,266**	**40,915**	**54,641**	**48,900**

to the middle, upper middle and rich households as they drew their sample mainly from the public health facilities and the NGOs, which mostly cater to poor/low-income households. Generally, the middle/rich PLWHA would seek only the private health facilities for reasons of anonymity.

2.2.2 Profile of sample PLWHA

As expected, most of the sample PLWHA is in the age group of 20 to 40 years (Table 2.5). While majority of men (48%) are in the age group of 30-40 years, majority of women (59%) are in the younger age group of 20-30 years.

Nearly one-fourth of the men and 28 percent of women are working as labourers either in agriculture or in the construction sector or in other non-agricultural activities

While more than 70 percent of men are married, in the case of women, it is lower at 49 per cent. What is significant is that while only 4 percent of men are separated or divorced or abandoned, in the case of female PLWHA, this percentage is higher at 7 percent. Similarly, while more than one-third of the sample female PLWHA are widows, the percentage of widowers among sample male PLWHA is much lower at 4 percent. The percentage of unmarried women is less than the percentage of unmarried men.

The level of education of the sample PLWHA is also quite low, as 24 percent of men and 30 percent of women are illiterate. There are very few persons in the sample survey who have studied beyond high school. Not only is the percentage of illiteracy higher among women, but also, generally at every level of education, the percentage of women is less than that of men.

In Table 2.6, the pattern of occupation of the sample PLWHA at the time of the survey, is compared with the occupation pattern at the time when these people were detected HIV-positive. The sample

Table 2.5

Profile of sample PLWHA

(in Percentages)

	Male	Female
Age		
≤ 20	6.4	9.5
20-30	31.6	59.2
31-40	48	25.9
>40	14	5.3
Marital status		
Currently married	71.1	48.8
Separated/divorced /abandoned	3.7	7.4
Widowed	4.3	36.1
Unmarried	20.9	7.7
Education		
Illiterate	23.8	29.6
Up to primary	15.2	17.1
Up to middle	16.5	15.7
High school	23.3	22.2
Senior secondary	8.1	6.9
Graduate/diploma	13.1	8.4
N	**1,476**	**1,227**

is generally spread over all occupations. While 22.6 percent of men are transport workers, hardly any woman is employed in this sector. More than 40 percent of the women are not employed. Among women, the salaried (13.3%) form the highest percentage. Nearly one-fourth of the men and 28 percent of women are working as labourers either in agriculture or in the construction sector or in other non-agricultural activities.

It is seen that in the case of both male and female PLWHA, the percentage under most of the categories of current occupation is less than the corresponding at the time of detection of their status, the striking observation is that regarding the percentage that is currently unemployed.

Table 2.6

Current and the past occupation of the sample PLWHA

(in Percentages)

	Current occupation		Occupation at the time of detecting HIV status	
	Male	**Female**	**Male**	**Female**
Cultivation	8	2.9	9.2	3.3
Agri. wage labour	10.4	10.7	11.1	12.2
Construction worker	5.1	1.9	6	2.4
Other non-agricultural labor	9.6	6.9	11.5	7.4
Salaried	22.6	13.3	24.7	13.6
Trade/business	11	6.7	11.5	7.2
Artisan/self-employed	7.1	8.3	8.1	8.2
Transport workers	10.7	0.1	12.9	0.3
Income from, pension, rent, interest, dividend etc	0.9	1	0.1	0.9
Domestic servant	0.1	4	0.2	4.5
House wife	--	39.3	--	36.9
Student	0.2	--	0.2	--
Unemployed	14.2	4.5	4.3	2.9
Others	--	0.3	0.1	0.3
Total	100	100	100	100
N	**1,342**	**1,043**	**1,342**	**1,043**

While only four percent of HIV-positive men were unemployed at the time of detection of their status, the percentage has now gone up to 14 percent. Similarly, in the case of women, not only has the percentage of unemployed increased from 2.9 to 4.5, but the percentage of women as housewives has also increased from 36.9 percent to the current 39.3 percent. This shows that a number of HIV-infected persons have given up their occupation due to their deteriorating health condition, resulting in loss of income to the household.

2.2.3 The decision making power of HIV-positive women

The women in South Asia generally have a very low status in society and as mentioned in Chapter one, as a result of their low status, they are more vulnerable to contracting HIV infection. The survey attempted to find out the status of sample HIV-positive women by asking them about how much say they have in certain matters and extent to which they could take a decision independently. The findings of the survey are presented in Table 2.7

It is clear from the above table that only with regard to seeking healthcare for self and the children, most of the women seem to take the decision independently. However, when it comes to the question of refusing sex or making the husband use condom, more than forty percent

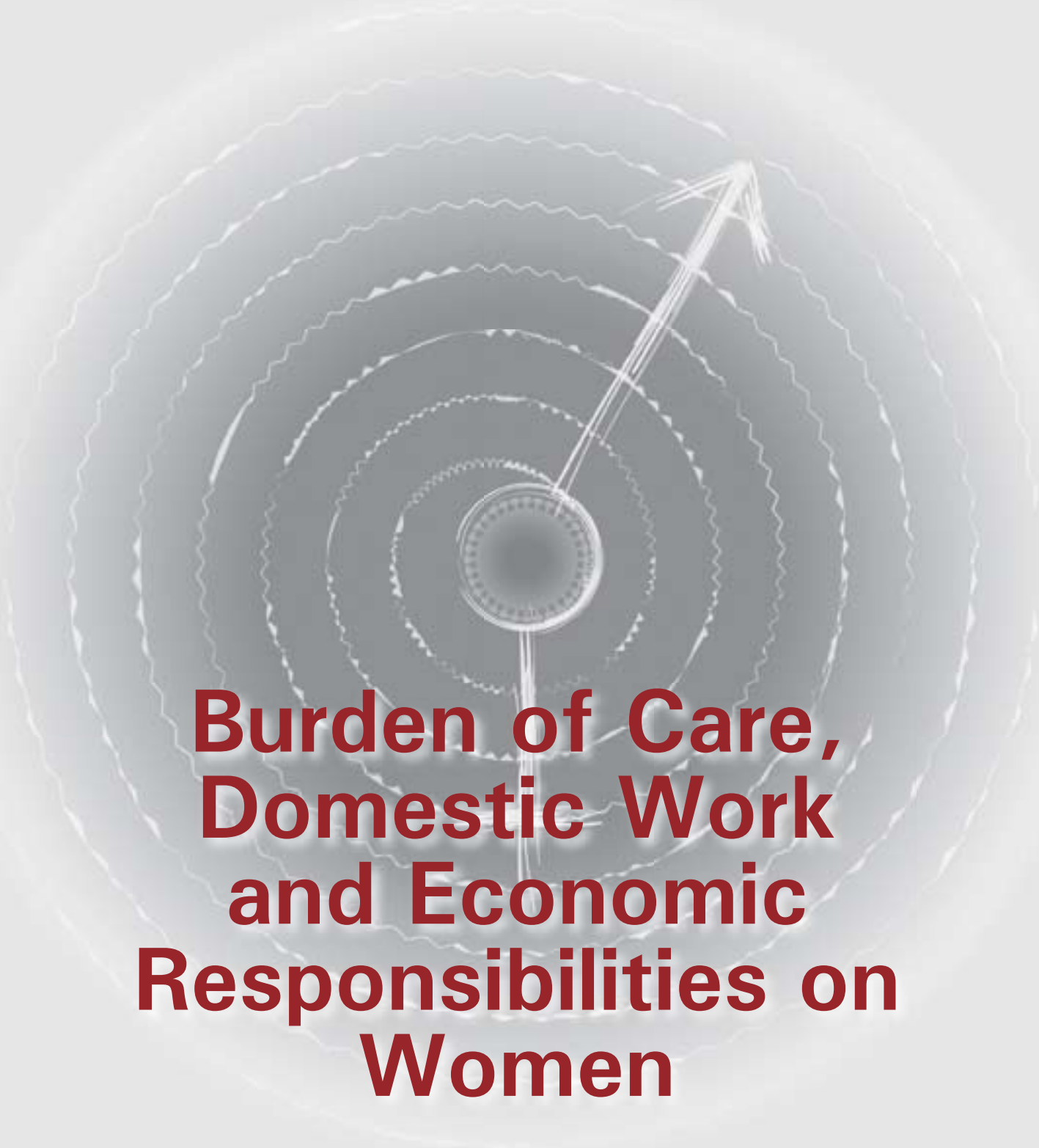
Table 2.7

Distribution of HIV-positive women by their decision-making power

(in Percentages)

	Large extent	Some extent	Not at all	Total
Buying household assets like land, house, flat etc.	24.8	36.3	38.9	100
Seeking healthcare for self	58.1	29.4	12.5	100
Seeking healthcare for children	58.1	25.4	16.5	100
Whether or not to have a child	35.5	31.6	32.9	100
Whether can refuse to have sex with husband at any time	19.9	38.3	41.8	100
Make husband use condom during intercourse	25.7	28.8	45.5	100

do not have any say in the matter. This shows that women have very little control over their body. This has a very serious implication in the context of HIV and AIDS.



Burden of Care, Domestic Work and Economic Responsibilities on Women

Chapter 3

Burden of Care, Domestic Work and Economic Responsibilities on Women

In the developed as well as the developing world, women are primarily responsible for domestic work, bringing up children and providing care for the sick and the elderly and India is no exception to this. It is well known that women in India tend to bear the burden of most of the household chores like cooking, cleaning the house, washing, bringing up children and taking care of the elderly and the sick and in rural India in addition to these activities, they have to travel a long distance to fetch water and fuel. In households where an earning male member is infected by HIV, women may be forced to complement earning along with other household activities. They may have to take up paid work, and in addition to the routine household activities, they may have to take care of the patients suffering from AIDS related illnesses as well (UNDP, 2003). They face emotional exhaustion, fatigue and burn out, in addition to the depletion of financial resources to meet the mounting medical expenses. Their role as a caregiver could be extremely taxing in terms of time as well as physical exertion. This would result in what is now termed as "time poverty" for women. In addition there is also an 'empowerment cost" when women's time is taken away from other productive work to unpaid care of those who have AIDS related illnesses. There is an opportunity cost which women have to pay since their ability to participate in income generating activities, skill building and leisure activities are reduced drastically. (UNAIDS Task Team on Gender and HIV and AIDS).

Most of the activities that women perform go unrecognised and the burden of work load on women go unnoticed. The contribution of women to the household and the economy and the time spent by them on these activities are not valued either. In this chapter, an attempt has been made to assess the burden on women by comparing the time-use pattern of women of HIV households with men of these households as well as with women from non-HIV households. The technique of Time-Use Surveys is considered as an important tool for measuring the amount of time individuals spend on various activities and on the paid and unpaid work of men and women. According to the Central Statistical Organisation, (CSO) Government of India, time-use studies were first introduced in the early 1990s to analyse various social phenomena and provide comprehensive information on life styles of families and pattern of social life (CSO, 1999). Over the years, time-use studies are increasingly used for estimating the value of household production and in developing countries where market oriented work and workers

are grossly underestimated, the main objective of time-use studies has been to provide realistic statistics on production and workforce. In addition, estimation of time and value of domestic work has also been an important objective of time-use surveys. In the context of HIV affected households, time-use survey could be an useful tool in providing information about the burden of work and leisure time enjoyed by men and women, in particular, about the overburden of work on the caregivers of AIDS patients.

In the context of HIV and AIDS affected households, time-use survey could be an useful tool in providing information about the burden of work and leisure time enjoyed by men and women, in particular, about the overburden of work on the caregivers of AIDS patients

In the Time-Use Survey conducted by CSO, time-use data were collected for three types of days, namely normal, weekly variant and abnormal, to capture possible variation in the activity pattern. However, it was found that the respondents had not reported many incidences of weekly variant and abnormal days. In the present survey, all the household members who were 12 years of age and above were asked to report various activities performed by them on a normal working day.

In all, the survey covered 5,829 persons–2,769 men and 3,060 women–from the sample HIV households and 19,710 persons–10,062 men and 9,648 women–from the non-HIV households. Following the classification of activities adopted by the CSO, these activities were classified in such a way that all the activities could be grouped into three those pertaining to the System of National Accounts (SNA), extended SNA and non-SNA. According to the CSO's classification, the SNA activities include all primary production activities like farming, animal husbandry, processing and storage, mining and quarrying and secondary activities like construction, manufacturing, trade, business and services. Extended SNA activities consist of household maintenance, care for children, sick and elderly. Other activities relating to learning, social and cultural activities, mass media like reading newspapers, magazines, watching television and listening to radio, personal care and self- maintenance are grouped under non-SNA activities.

The information collected on time-use from the members of both HIV and non-HIV households are analysed to compare the time spent in SNA activities by women of HIV households with men as well as women from the non-HIV households. The burden of work on women and the amount of time left with women of HIV households for non-SNA activities like leisure, entertainment etc. are also looked into to assess the position of women in the HIV households. The chapter also has a section containing details about the family caregivers of AIDS patients.

3.1 Time spent in SNA activities

The average time spent per day by men and women of both HIV and non-HIV households in various SNA activities which include paid and unpaid work is presented in Table 3.1. A few significant observations emerge from the table. First, as expected, irrespective of the type of household i.e. whether HIV or non-HIV households, as compared to women, on an average men spend more time in SNA activities. While 15-59 age group men from HIV households spend 6.85 hours per day in SNA activities, women spend only 3.41 hours. Similarly, while men in 15-59 age group from non-HIV households spend 7.02 hours per day in SNA activities, their female counterparts spend much less time i.e. 2.46 hours.

Secondly, if we look at the 15-59 age group to which almost all the sample PLWHA belong, as compared to men

Table 3.1

Time spent per day in various SNA activities by sex

Age group (15-59 years) **(daily average in hours)**

HIV households	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
Paid work at Home	6.23	3.16	6.28	2.41	6.26	2.73
Paid work within home	0.06	0.21	0.04	0.18	0.05	0.19
Other productive work	0.18	0.17	0.09	0.09	0.13	0.13
Travel to work	0.25	0.06	0.29	0.09	0.27	0.08
Fetching fodder, water & fuel	0.17	0.32	0.12	0.25	0.14	0.28
Total	6.89	3.92	6.82	3.02	6.85	3.41
Number of persons	**1,082**	**1,262**	**1,523**	**1,666**	**2,605**	**2,928**
Non-HIV households						
Paid work at home	6.20	2.05	5.94	1.20	6.05	1.55
Paid work within home	0.07	0.16	0.04	0.14	0.05	0.15
Other productive work	0.21	0.22	0.11	0.13	0.15	0.16
Travel to work	0.47	0.16	0.59	0.10	0.54	0.13
Fetching fodder, water & fuel	0.25	0.51	0.21	0.44	0.23	0.47
Total	7.20	3.10	6.89	2.01	7.02	2.46
Number of persons	**4,123**	**3,823**	**5,496**	**5,375**	**9,619**	**9,198**

Age group 60 years and above

HIV households	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
Paid work at home	4.03	1.32	3.13	1.08	3.57	1.18
Paid work within home	0.00	0.04	0.00	0.09	0.00	0.07
Other productive work	0.57	0.33	0.46	0.23	0.52	0.27
Travel to work	0.05	0.00	0.07	0.00	0.06	0.00
Fetching fodder, water & fuel	0.13	0.40	0.23	0.27	0.18	0.33
Total	**4.78**	**2.09**	**3.89**	**1.67**	**4.33**	**1.85**
Number of persons	**80**	**57**	**84**	**75**	**164**	**132**
Non-HIV households						
Paid work at home	3.36	0.87	3.16	1.07	3.25	0.99
Paid work within home	0.01	0.14	0.05	0.03	0.04	0.07
Other productive work	0.44	0.31	0.25	0.13	0.33	0.20
Travel to work	0.19	0.05	0.44	0.13	0.33	0.10
Fetching fodder, water & fuel	0.14	0.19	0.09	0.11	0.11	0.14
Total	**4.14**	**1.56**	**3.99**	**1.47**	**4.06**	**1.50**
Number of persons	**187**	**176**	**256**	**274**	**443**	**450**

Women of HIV households are required to supplement the earnings of the male members in order to compensate for the mounting medical expenses and loss of income of HIV infected male members

from non-HIV households, men from HIV households spend marginally less time in SNA activities. On the contrary, women from the HIV households are spending more time in SNA activities as compared to their counterparts from the non-HIV households (the average time spent in SNA activities works out to be 3.41 hours and 2.46 hours respectively for women of HIV and non-HIV households). This clearly suggests that women of HIV households are required to supplement the earnings of the male members in order to compensate for the mounting medical expenses and loss of income of HIV infected male members.

The third important observation that emerges from the table pertains to 60 and above age group members. As compared to non-HIV households, both men and women from the HIV households are spending more time in SNA activities. This is in line with the general view in the literature that there is a need for the elderly members of the HIV households to earn and support the household. Finally, all the three above observations hold good for the rural as well as urban households. In other words, the pattern of time-use is more or less similar in both rural and urban areas.

3.2 Burden on women (extended SNA activities)

In this section, the average time spent in extended SNA activities like household work, care of children, elderly and the sick is discussed to assess the burden of work on women. Here again, the findings are on expected lines; as compared to men, women are spending more time on household work in both HIV and non-HIV households.

A closer look at the time spent by men and women in the 15-59 age group in extended SNA activities clearly shows that women not only spend more time

Table 3.2

Burden on women- time spent in extended SNA activities

Age group (15-59 years) **(daily average in hours)**

HIV households	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
1. Household work	0.18	3.51	0.24	3.59	0.21	3.56
2. Shopping for the HH	0.19	0.22	0.18	0.33	0.18	0.28
3. Care of children	0.05	0.59	0.05	0.54	0.05	0.56
4. Teaching/accompanying children	0.02	0.06	0.03	0.11	0.03	0.09
5. Care of elderly/disabled	0.00	0.02	0.01	0.02	0.00	0.02
6. Care of AIDS patient	0.12	0.37	0.12	0.33	0.12	0.35
7. Care of any sick member in the HH	0.01	0.01	0.00	0.02	0.00	0.01
8. Any other	0.03	0.01	0.03	0.02	0.03	0.02
Total	**0.60**	**4.79**	**0.66**	**4.96**	**0.62**	**4.89**
Number of persons	**1,082**	**1,262**	**1,523**	**1,666**	**2,605**	**2,928**

Non-HIV households						
1. Household work	0.15	3.85	0.18	3.68	0.17	3.75
2. Shopping for the HH	0.24	0.32	0.23	0.44	0.24	0.39
3. Care of children	0.02	0.63	0.02	0.69	0.02	0.67
4. Teaching/accompanying children	0.01	0.06	0.04	0.12	0.03	0.10
5. Care of elderly/disabled	0.01	0.01	0.01	0.02	0.01	0.02
6. Care of AIDS patient	0.00	0.00	0.00	0.00	0.00	0.00
7. Care of any sick member in the HH	0.00	0.00	0.00	0.00	0.00	0.00
8. Any other	0.06	0.03	0.07	0.07	0.07	0.05
Total	0.49	4.90	0.55	5.02	0.54	4.98
Number of persons	**4,123**	**3,823**	**5,496**	**5,375**	**9,619**	**9,198**

Age group 60 years and above

HIV households	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
1. Household work	0.28	2.47	0.26	2.61	0.27	2.55
2. Shopping for the HH	0.19	0.18	0.32	0.23	0.26	0.20
3. Care of children	0.13	0.39	0.06	0.32	0.09	0.35
4. Teaching/accompanying children	0.01	0.02	0.13	0.03	0.07	0.02
5. Care of elderly/disabled	0.01	0.00	0.00	0.03	0.01	0.02
6. Care of AIDS patient	0.24	0.40	0.17	0.32	0.20	0.36
7. Care of any sick member in the HH	0.00	0.02	0.02	0.03	0.01	0.02
8. Any other	0.03	0.00	0.14	0.27	0.09	0.15
Total	**0.89**	**3.48**	**1.10**	**3.84**	**1.00**	**3.67**
Number of persons	**80**	**57**	**84**	**75**	**164**	**132**

Non-HIV Households						
1. Household work	0.18	2.25	0.21	1.85	0.20	2.01
2. Shopping for the HH	0.25	0.18	0.25	0.22	0.25	0.20
3. Care of children	0.03	0.22	0.04	0.23	0.04	0.22
4. Teaching/accompanying children	0.01	0.02	0.01	0.01	0.01	0.02
5. Care of elderly/disabled	0.02	0.00	0.01	0.01	0.01	0.00
6. Care of AIDS patient	0.00	0.00	0.00	0.00	0.00	0.00
7. Care of any sick member in the HH	0.00	0.01	0.00	0.00	0.00	0.01
8. Any other	0.09	0.05	0.06	0.03	0.07	0.03
Total	**0.58**	**2.73**	**0.58**	**2.35**	**0.58**	**2.49**
Number of Persons	**187**	**176**	**256**	**274**	**443**	**450**

on household chores, but also on other activities like shopping for the household, taking care of the children, sick and the elderly. The data does not show any difference between the HIV and non-HIV households as far as the average time spent in these activities is concerned. However, as we move to the older age group of 60 and above, it can be seen that as compared to non-HIV households, on an average the men and women of HIV households are devoting more time in extended SNA activities. This once again reiterates the point that in the HIV households, the older people are required to put in more effort to run the household.

The women of HIV households seem to get less time for their personal activities not only when compared to men of HIV households but also as compared to women of non-HIV households

It is interesting to note that for both 15-59 and 60 years and above age group women, the average time spent in the care of AIDS patients is 0.36 hours. This may not appear very significant, but what has to be remembered is that this average has been worked out taking into account all the household members, although all of them are not caregivers. Even here, it can be seen that women are spending more time than their male counterparts in taking care of the AIDS patients.

3.3 Time spent in personal care and self-development

In Table 3.3, the time spent in various personal activities like personal hygiene, leisure and recreational activities, mass media etc. by men and women belonging to HIV and non-HIV households are shown.

The women of HIV households seem to get less time for their personal activities not only when compared to men of HIV households but also as compared to women of non-HIV households, although the differences may be only marginal. In fact, the difference in the time spent in personal activities is much more pronounced between 60 years and above women of HIV and non-HIV households, once again indicating that

Table 3.3

Time spent in personal activities

Age group (15-59 years) **(daily average in hours)**

HIV households	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
1. Eating and drinking	2.95	2.87	2.90	2.85	2.92	2.86
2. Personal hygiene	1.48	1.26	1.45	1.24	1.46	1.25
3. Participation in social activities	0.34	0.18	0.32	0.28	0.33	0.24
4. Reading newspaper etc.	0.18	0.05	0.27	0.10	0.23	0.08
5. Recreation	1.09	0.91	1.39	1.27	1.26	1.12
6. Going to school/college/ studying/learning	0.54	0.28	0.69	0.48	0.62	0.39
7. Rest & relaxation	1.72	1.62	1.26	1.65	1.45	1.64
8. Sleeping	8.22	8.10	8.25	8.14	8.24	8.12
Total	**16.52**	**15.27**	**16.53**	**16.01**	**16.51**	**15.70**
Number of persons	**1,082**	**1,262**	**1,523**	**1,666**	**2,605**	**2,928**

Non-HIV households						
1. Eating and drinking	2.96	2.89	2.93	2.88	2.94	2.89
2. Personal hygiene	1.29	1.17	1.31	1.19	1.30	1.18
3. Participation in social activities	0.54	0.34	0.46	0.44	0.49	0.40
4. Reading newspaper etc.	0.24	0.09	0.35	0.17	0.30	0.14
5. Recreation	1.18	1.37	1.43	1.90	1.32	1.68
6. Going to school/college/ studying/learning	1.07	0.84	1.10	1.05	1.09	0.97
7. Rest & relaxation	1.05	1.36	1.00	1.36	1.02	1.36
8. Sleeping	7.97	7.93	7.98	7.97	7.98	7.96
Total	**16.30**	**15.99**	**16.56**	**16.96**	**16.44**	**16.58**
Number of persons	**4,123**	**3,823**	**5,496**	**5,375**	**9,619**	**9,198**

Age group 60 years and above

HIV households	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
1. Eating and drinking	2.90	2.95	2.93	2.76	2.91	2.84
2. Personal hygiene	1.50	1.32	1.35	1.21	1.42	1.26
3. Participation in social activities	0.54	0.70	1.00	0.92	0.77	0.83
4. Reading newspaper etc.	0.16	0.04	0.44	0.13	0.30	0.09
5. Recreation	1.23	0.75	1.76	1.36	1.50	1.10
6. Going to school/college/ studying/learning	0.00	0.00	0.00	0.00	0.00	0.00
7. Rest & relaxation	3.20	3.81	2.93	3.23	3.06	3.48
8. Sleeping	8.82	8.88	8.60	8.89	8.71	8.89
Total	**18.35**	**18.45**	**19.01**	**18.50**	**18.67**	**18.49**
Number of persons	**80**	**57**	**84**	**75**	**164**	**132**

Non-HIV households						
1. Eating and drinking	3.01	2.90	2.94	3.03	2.97	2.98
2. Personal hygiene	1.25	1.30	1.41	1.40	1.34	1.36
3. Participation in social activities	1.21	1.26	1.21	1.40	1.21	1.34
4. Reading newspaper etc.	0.32	0.11	0.58	0.23	0.47	0.18
5. Recreation	1.39	1.59	1.72	1.93	1.58	1.80
6. Going to school/college/ studying/learning	0.02	0.01	0.02	0.02	0.02	0.02
7. Rest & relaxation	3.25	3.53	2.78	3.31	2.98	3.40
8. Sleeping	8.86	9.01	8.75	8.87	8.80	8.92
Total	**19.31**	**19.71**	**19.41**	**20.19**	**19.37**	**20.00**
Number of persons	**187**	**176**	**256**	**274**	**443**	**450**

the older women of HIV households have to shoulder greater household responsibilities.

3.4 Time spent in SNA, extended SNA and non-SNA activities by men and women

When compared to men, women from both HIV and non-HIV households are spending much more time in extended activities which include household work, child care and care of the sick and elderly

The data on the time-use reveals interesting gender differences in the time spent in SNA, extended SNA and non-SNA activities not only between HIV and non-HIV household members but also between both the 15-60 and 60 and above age groups (Table 3.4).

In both HIV and non-HIV households, men spend much more time in SNA activities as compared to women, the difference is much more pronounced in the non-HIV households. In the 15-59 age group, while on an average as compared to women, the men in HIV households daily spend twice more time in SNA activities, in the non-HIV households the men spend 2.85 times more time in SNA activities. In the case of 60 and above age group also, as compared to women, men in HIV households spend 2.3 times more time in SNA activities, whereas in the non-HIV households men spend 2.7 times more time than their female counterparts. In other words, as compared to women of non-HIV households, on an average, women from HIV households are devoting more time to productive activities in an effort to supplement the household income.

As expected, when compared to men, women from both HIV and non-HIV households are spending much more time in extended SNA activities which include household work, child care and care of the sick and elderly. Although there is not much difference in the average time spent in extended SNA activities between women of HIV and non-HIV households as far as 15-59 age group is concerned, there is a considerable difference in the time spent by older women. While on an average, the 60 years and above women

Table 3.4

Time spent in SNA, extended SNA and non-SNA activities

Age group 15-59 years **(daily average in hours)**

HIV households	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
(a) SNA activities	6.88	3.94	6.83	3.02	6.85	3.41
(b) Extended SNA	0.56	4.77	0.62	4.94	0.60	4.87
(c) Non-SNA activity	16.56	15.29	16.55	16.04	16.55	15.72
Total	24.00	24.00	24.00	24.00	24.00	24.00
Number of persons	**1,082**	**1,262**	**1,523**	**1,666**	**2,605**	**2,928**
Non-HIV households						
(a) SNA activities	7.20	3.10	6.90	2.01	7.02	2.46
(b) Extended SNA	0.44	4.87	0.48	4.96	0.46	4.92
(c) Non-SNA activity	16.36	16.03	16.62	17.03	16.52	16.62
Total	24.00	24.00	24.00	24.00	24.00	24.00
Number of persons	**4,123**	**3,823**	**5,496**	**5,375**	**9,619**	**9,198**

Age group 60 years and above

(a) SNA activities	4.78	2.09	3.89	1.67	4.32	1.85
(b) Extended SNA	0.85	3.47	0.96	3.56	0.91	3.52
(c) Non-SNA activity	18.37	18.44	19.15	18.77	18.77	18.63
Total	24.00	24.00	24.00	24.00	24.00	24.00
Number of persons	**80**	**57**	**84**	**75**	**164**	**132**
Non-HIV households						
(a) SNA activities	4.14	1.56	4.00	1.46	4.06	1.50
(b) Extended SNA	0.49	2.68	0.53	2.32	0.51	2.46
(c) Non-SNA activity	19.37	19.76	19.48	20.22	19.43	20.04
Total	24.00	24.00	24.01	24.00	24.00	24.00
Number of persons	**187**	**176**	**256**	**274**	**443**	**450**

of HIV households spend 3.52 hours in extended SNA activities, the older women from the non-HIV households spend only 2.46 hours. This suggests that the older women from the HIV households are shouldering additional burden of taking care of the PLWHA and/or household work.

As a consequence of women from HIV households spending more time in SNA and extended SNA activities, they are left with lesser time to spend in non-SNA activities not only as compared to their male counterparts, but also when they are compared with women from non-HIV households. While 15-59 age group women from HIV households daily spend 15.72 hours in non-SNA activities, their male counterparts spend 16.55 hours and women from non-HIV households spend 16.62 hours. If we move to the higher age group of 60 years and above, as compared to non-HIV households, both men and women from HIV households get lesser time to spend in non-SNA activities, although the difference between HIV and non-HIV households is more marked in the case of older women than men. These averages clearly indicate that women from the HIV households get lesser time for relaxation, leisure, and self-maintenance.

3.5 Comparison of findings of present survey with CSO's time-use survey

Here we attempt to compare our results with the Time-Use Survey conducted by the Central Statistical Organisation, Government of India (CSO, 1999). The CSO survey:

- Was conducted in 1998-99,
- Covered six states, namely Haryana, Madhya Pradesh, Gujarat, Orissa, Tamil Nadu, and Meghalaya,
- The survey was carried out with the sole purpose of studying the time-use pattern,
- The survey was based on a randomly selected, large sample of more than sixty thousand persons,
- The sample included all household members who were of age six years and above.

The present survey by NCAER:

- Was conducted during 2004-05,
- Covered six HIV high-prevalence states of Andhra Pradesh, Karnataka, Maharashtra, Tamil Nadu, Nagaland and Manipur,

Women from the HIV households get lesser time for relaxation, leisure, and self-maintenance

- The time-use pattern formed just one section of the questionnaire, which was designed to gather many other types of socio-economic data from the sample households,
- Covered around six thousand persons from the HIV and twenty thousand from the non-HIV households.
- The sample covered all household members who were of 12 years of age and above.

The findings of the survey (for the six states combined) on the average time spent in SNA and extended SNA and non-SNA activities are presented in Table 3.5. The weekly average time spent in hours as given by the CSO is converted into daily average for comparative purpose.

The findings of the present study on the time-use pattern of the household members who are 15 years of age and

Table 3.5

Average time spent in SNA and extended SNA activities (CSO survey)

(daily average in hours)

Activities	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
(a) SNA activities	6.04	3.22	5.87	1.31	5.99	2.67
(b) Extended SNA	0.53	4.85	0.49	5.21	0.52	4.95
(c) Non-SNA activity	17.43	15.93	17.64	17.49	17.49	16.37
Total	24.00	24.00	24.00	24.00	24.00	24.00
Number of persons	**22,285**	**21,130**	**10,305**	**9,549**	**32,590**	**30,679**

Source: Report of the Time-Use Survey, CSO, Government of India, 1999

Table 3.6 (a)

Average time spent in SNA and extended SNA activities (NCAER)

(daily average in hours)

Non-HIV households	Rural		Urban		Total	
(a) SNA activities	7.07	3.03	6.76	1.98	6.89	2.41
(b) Extended SNA	0.44	4.77	0.49	4.83	0.47	4.81
(c) Non-SNA activity	16.49	16.20	16.75	17.19	16.64	16.78
Total	24.00	24.00	24.00	24.00	24.00	24.00
Number of persons	**4,310**	**3,999**	**5,752**	**5,649**	**10,062**	**9,648**

Table 3.6 (b)

Average time spent in SNA and extended SNA activities (NCAER)

(daily average in hours)

HIV households	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
(a) SNA activities	6.74	3.85	6.68	2.96	6.70	3.35
(b) Extended SNA	0.58	4.72	0.64	4.88	0.62	4.81
(c) Non-SNA activity	16.68	15.43	16.68	16.16	16.68	15.84
Total	24.00	24.00	24.00	24.00	24.00	24.00
Number of persons	**1,162**	**1,319**	**1,607**	**1,741**	**2,769**	**3,060**

above are presented separately for the non-HIV and HIV household members respectively in Table 3.6 (a) and 3.6 (b).

The data gathered by the CSO shows that men spend six hours per day in SNA activities, whereas women spend only 2.67 hours per day. When it comes to extended SNA activities, the situation completely changes; while on an average, men spend 0.52 hrs per day, women spend nearly five hours in extended SNA activities which include mainly household work, and care of children, sick and the elderly. Almost a similar pattern is found in the present study as well. Secondly, the CSO survey did not find any significant rural-urban variation in time-Use for males. But according to the CSO survey, in the case of females, the participation in SNA activities in urban areas was much lower as compared to rural areas and this was attributed to general participation of women in agricultural activities in the rural areas. The present study also observes similar rural-urban differences in the time spent in SNA activities as far as women are concerned, especially in the non-HIV households, although not to the same extent.

The CSO study shows that women get much less time for non-SNA activities; the average works out to be 16.37 hours for women as against 17.49 hrs for men. In the present study, a similar difference is observed as far as HIV household members are concerned. However, in the case of non-HIV households, no such difference exists between men and women in the time spent in non-SNA activities.

3.6 Role of women as caregivers

It has been estimated that globally, up to 90 percent of the care due to AIDS is provided in the home by women and girls (UNAIDS/UNIFPA/UNIFEM, 2004). This workload is in addition to the routine household chores, taking care of the children and the elderly and paid work outside and inside the house. A recent household survey in South Africa showed that two-thirds of caregivers were females with almost a quarter of them over the age of 60 (UNICEF, 2005). In South Africa where the HIV and AIDS crisis has deepened, girls are being taken out of school to provide home based care. (UNAIDS/UNIFPA/UNIFEM, 2004).

The non-availability of adequate public health services and poverty are responsible for increasing the care burden for many women. For instance, in Africa, since hospitals do not have adequate resources, there has been a gradual shift from hospital-based care of PLWHA to home-based care (Olagoke Akintola 2004). This increasing burden on women could lead to physical, emotional, social and economic stress and result in burn out.

The non-availability of adequate public health services and poverty are responsible for increasing the care burden for many women

In the present study, details about the family caregivers were collected from the HIV households to understand the role of women as caregivers. Of the total 2,376 PLWHA interviewed, 683 reported that they needed care and 882 household members were providing care to these persons who were at the advanced stage of HIV infection. The details about these caregivers are presented in Table 3.7.

The survey data shows that women account for more than 70 percent of the caregivers. This is in line with the studies undertaken in the other parts of the world, which shows that women are the principal caregivers of AIDS patients. Most of the caregivers are in the 15-59 age group. It is a matter of concern that nearly 20 percent of caregivers themselves are

Table 3.7

Details about caregivers of PLWHA

	Male	Female	Total
1. Number of caregivers	255	627	882
2. Age group of caregivers (Percentage)			
Up to 15 years	16.1	5.1	8.3
15-59	75.3	91.2	86.6
60 years and above	8.6	3.7	5.1
3. (A) Caregivers who are HIV-positive (Percentage)	16.5	20.7	19.5
(B) If positive, stage of infection (Percentage)			
Stage I	28.6	46.2	41.9
Stage II	28.6	42.3	39.0
Stage III	35.7	10.0	16.3
Stage IV	7.1	1.5	2.9
4. Number and percentage of caregivers currently working	149(58)	199(32)	348(39)
5. Loss of income due to absence from work			
(A) Persons/percentage reporting	31(21)	68 (34)	99(28)
(B) Average amount lost during last one year	5313	4532	4777
6. Number and percentage of caregivers who had to give up the job	11(4.3)	12 (1.9)	23(2.6)

Even though among men a higher percentage are currently employed, when it comes to the question of taking leave from work to take care of the sick relative and losing income, more women seem to be sacrificing

HIV-positive; the percentage of PLWHA among the caregivers is marginally higher among women; it is 21 among women as against 17 among men. A study conducted in Mumbai found married women taking care of their positive husbands despite being positive themselves and in need of care, without support from the in-laws (D'Cruz 2004). Fortunately, more than 80 percent of the HIV-positive caregivers are at the early stage of the infection, i.e. Stage I or II. These findings support our study.

It can be seen from the table that nearly one-third of the female caregivers are also employed. Although the percentage employed is much higher among the men (58%), it is to be remembered that in the case of women, in addition to these two responsibilities (of care giving and employment) there will be burden of household chores as well. It is interesting to note that even though among men a higher percentage are currently employed, when it comes to the question of taking leave from work to take care of the sick relative and losing income, more women seem to be sacrificing. While 34 percent of the currently employed women caregivers have reported losing income due to absence from work during last one year, in the case of men, this percentage is much lower at 21. However, while four percent of men had to give up their job in order to take care of the AIDS patient, only two percent of the women had to do so.

With the rising death toll due to AIDS, the number of AIDS orphans is

increasing worldwide and in the absence of community-based child care, the burden of caring for these orphans very often falls on the grandparents. There are enough evidences to show that it is mostly the grandmother who has to shoulder the physical burden of feeding the children, sending the children to school etc. Instead of relying on the support of their adult children, these old persons have to take care of their children who are dying from AIDS related illnesses as well as take care of the orphaned grandchildren after the death of their children. A case study conducted in Manipur shows how loving and caring grandmothers could be taking care of the orphaned grandchild in spite of there old age and economic hardships (Box 1).

3.6.1 Time-use pattern of caregivers

The survey gathered details about the time spent on various activities by the caregivers on a normal day from 809 family caregivers and these are presented in Table 3.8.

Expectedly, a comparison of this table with Table 3.6 shows that as compared to other members of the HIV as well as non-HIV households, both male and female household members who are playing the role of caregivers of AIDS patients are spending much more time in extended SNA activities. As a result, the caregivers are left with lesser time for non-SNA activities, which include relaxation, sleep and other leisure activities. Here again, there is a gender difference. In both rural and urban areas, the average time left for non-SNA activities works out to be marginally less for women caregivers as compared to their male counterparts.

A look at the details of time spent in extended SNA activities by caregivers shows that although both men and women caregivers are devoting time for the care of the AIDS patient, women are spending marginally more time. Besides, women have the burden of household work as well as looking after children; women caregivers are spending more time in these activities, which increases the over all burden on them.

Box 1

Case study 1: Grandparents become parents all over again

This elderly couple from Tuensang in Nagaland are doting grandparents. In fact, they are very fond of their eight-year-old grandson. They send him to school, where he is studying in class II. They also fuss over their grandson and provide him with the best possible care – nutritious food, good clothing and timely medical check-ups.

But this is also a story of strong love, affection, perseverance and grit against all odds. Every day, these aging grandparents do all they can to make sure their eight-year-old HIV-positive grandson is able to lead a positive and healthy life. So they make sure that they are in regular touch with the local counsellors. They are also very particular that he should be given good care in order to avoid opportunistic infections.

Having lost their son and daughter-in-law to AIDS related illness, their grandson is their treasure, a treasure that other relatives have not come forward to help. So they support their little family by leasing out their small piece of agricultural land, which is their only source of livelihood. In fact, they are lucky that they do not have to resort to manual labour to earn this livelihood at their age. In most cases, ageing grandparents have to perform physically demanding tasks to fulfill the needs of the household.

And yes! Like all ambitious grandparents, they want their grandson to do very well in school.

Table 3.8

Time spent in SNA, extended SNA and non-SNA activities by caregivers

(daily average in hours)

	Rural		Urban		Total	
	Male	**Female**	**Male**	**Female**	**Male**	**Female**
(a) SNA activities	7.15	3.67	5.38	2.40	6.21	2.96
(b) Extended SNA	1.77	5.83	2.35	5.99	2.08	5.92
(c) Non-SNA activity	15.08	14.50	16.27	15.61	15.71	15.12
Total	24.00	24.00	24.00	24.00	24.00	24.00
Number of persons	**100**	**263**	**114**	**332**	**214**	**595**

3.7 Observations

The survey results show that as compared to women from the non-HIV households, women from HIV households have the additional burden of caring for the AIDS patients as well as the responsibility of compensating for the mounting medical expenses or loss of income of the HIV infected male members of the household. Mostly, the women are the caregivers of the sick family members. All these additional demands take a toll on women both emotionally and physically by overloading them.

Due to lack of adequate healthcare facilities for PLWHA, they rely mostly on the family members, women in particular for care. Since the family caregivers do not have any kind of prior training in handling AIDS patients, they not only need psycho-social support but also training in nutrition, drug

Table 3.9

Time spent on extended SNA activities by caregivers

(daily average in hours)

Average time spent (hours) on activities	Rural		Urban		Total	
	Male	**Female**	**Male**	**Female**	**Male**	**Female**
Household work	0.12	3.27	0.46	3.40	0.30	3.35
Shopping for the HH	0.21	0.26	0.29	0.44	0.25	0.36
Care of children	0.06	0.56	0.01	0.38	0.03	0.46
Teaching/accompanying children	0.00	0.03	0.04	0.06	0.02	0.05
Care of elderly/disabled	0.01	0.00	0.02	0.04	0.01	0.02
Care of AIDS patient	1.36	1.69	1.52	1.62	1.44	1.65
Care of any sick member in the HH	0.01	0.02	0.01	0.05	0.01	0.03
Any other	0.02	0.00	0.00	0.00	0.01	0.00
Total	1.79	5.83	2.35	5.99	2.07	5.92
Number of persons	**100**	**263**	**114**	**332**	**214**	**595**

management, universal precautions and basic nursing techniques, to provide efficient and quality care for their sick relatives (UNAIDS, 2003).

In South Africa and Uganda, various models of home-based care programmes have been promoted mostly by the NGOs, which rely on volunteers from the affected communities to carry out basic nursing and caregiving activities in patients homes. Such experiments could be replicated in India as well.

The old people play a crucial role in taking care of the AIDS orphans and this burden of caring for the HIV infected children, and care for the grandchildren after the death of their children have increased their physical, emotional and financial stress. There is enough evidence to suggest that the burden is borne primarily by older women. Efforts must be made to support and address the problems of these older people. In this context, it is worth mentioning about the innovative programme in Vijayawada in Andhra Pradesh, where the grandmothers of AIDS orphans are being trained to start income-earning activities in order to take care of their grandchildren (Box 2).

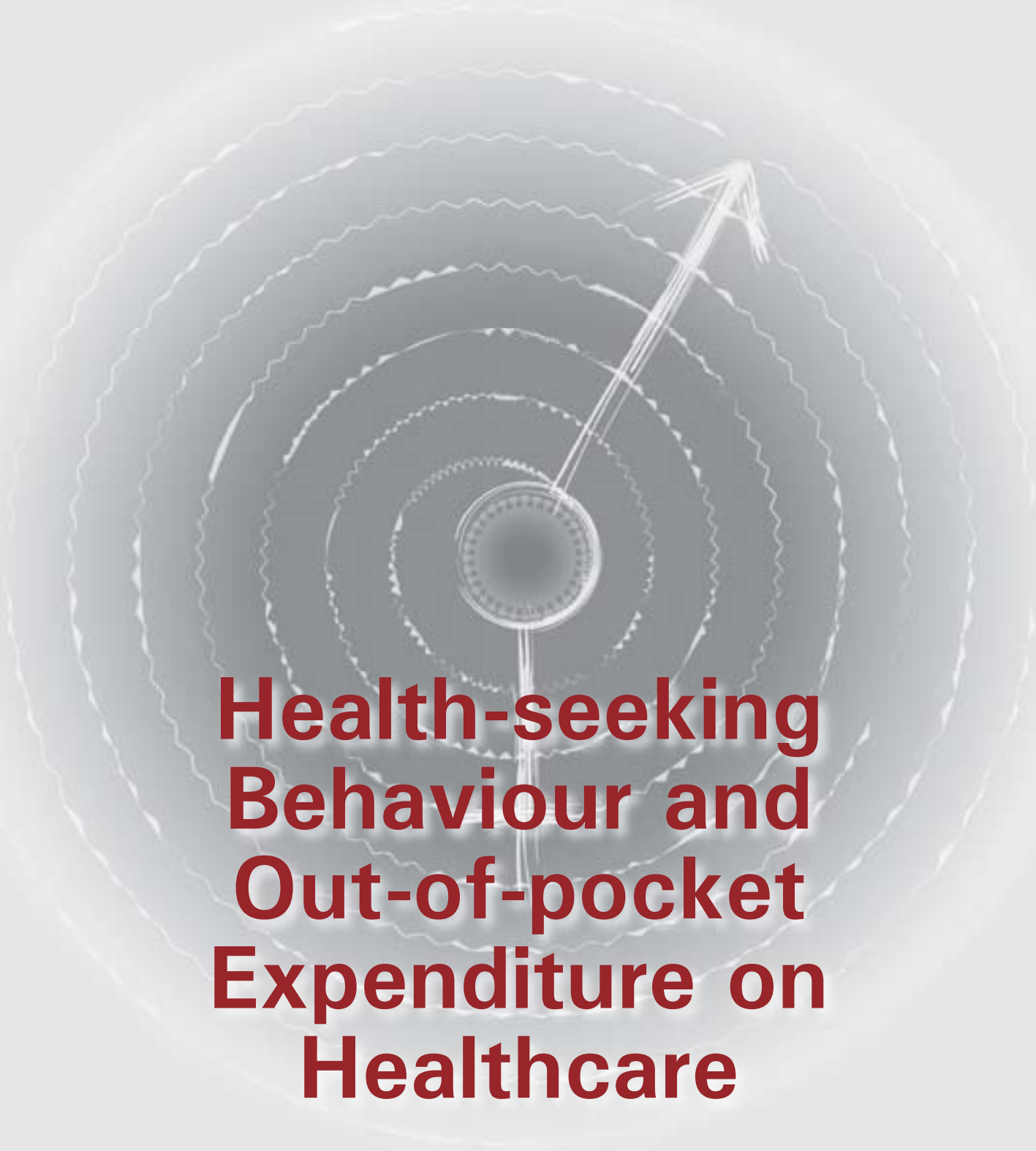
Box 2

Case study 2: Grooming grandmothers to take care of children orphaned by AIDS

Since 1994, Vasavya Mahila Mandali has been working in Payakapuram, a low-income locality in the city of Vijayawada in Andhra Pradesh to create awareness about HIV and AIDS and organise support groups for adults and children. Besides these activities, this NGO works with HIV-positive women and the children of PLWHA.

The most important achievement of this NGO has been in undertaking an innovative programme to empower grandmothers in raising their grandchildren orphaned by AIDS. The NGO organised skills development programmes for the grandmothers to help them become self-employed and self-sustained and, therefore, be able to look after their grandchildren. As a result, many old ladies are undertaking petty businesses and, therefore, supporting their grandchildren. The NGO also conceptualised activities for the children in order to strengthen the bonds between the grandchildren and grandmothers as this would make the children feel more secure and ensure a better future for these children. To further strengthen their sense of community, the relationships within the extended families are also explained to the children with the help of family trees.

These efforts are of critical importance in a locality an area where an estimated 10 to 15 persons die of AIDS related illness in a year. As a result, the most vulnerable groups in the locality are the orphaned children. This is especially so because of two patterns prevailing in the locality: First, ensuring basic survival is a daily struggle in the locality since most of the inhabitants are daily wage labourers without any fixed income. Secondly, since the earnings are very low, a number of women have to supplement their household income through commercial sex work. As a result, the children are exposed to a multitude of vulnerabilities and, therefore, need an environment that is safe and conducive to their development. The initiatives of the NGO have helped in ensuring a brighter future for these children, both physically and emotionally.



Health-seeking Behaviour and Out-of-pocket Expenditure on Healthcare

Chapter 4

Health-seeking Behaviour and Out-of-pocket Expenditure on Healthcare

Biologically, women are likely to live a longer life than men, but in the context of South Asia this biological advantage is reduced by the deprivations suffered by women in all aspects of life and as result, women in South Asia, suffer from illnesses more than men (Mahbub-ul-Haq, Human Development Centre, 2005). Not only women suffer from more illnesses, but they also lack access to quality healthcare services. In India, it has been found that women in general have limited access to healthcare because of various social, cultural and economic reasons. Women's access to healthcare is limited due to their low status in society and household arising from illiteracy, economic dependence on men and structures of patriarchy. (Cehat, 2001, Sasendran Pallikadavathi, 2003, UNDP, 2003).

The low economic and social status of women and their limited access to healthcare and nutrition has profound implications on the HIV epidemic. HIV weakens the body's immune system i.e. the ability to fight diseases and as a result, PLWHA become susceptible to various infections. HIV virus causes chronic infection and the course of the infection could vary from individual to individual depending on their level of immunity, which is reflected by the CD4+T cell count. PLWHA very often fall sick, and these could be instances of illnesses, which may or may not require hospitalisation.

The gender differences in the health-seeking behaviour of general population have been well documented by a number of the health surveys (Sundar et al 2002, Cehat 2001, Madhiwala et al 2000). In this chapter, an attempt has been made to assess the gender differences in the number of illnesses reported and the health-seeking behaviour of the sample PLWHA based on the data collected from the six HIV high-prevalence states. This chapter describes the nature of opportunistic infections, sources of treatment, whether treatment was sought, if not, reasons for not seeking treatment, expenditure incurred etc; in respect of both hospitalised and non-hospitalised illnesses suffered by the PLWHA.

4.1 Prevalence rate of illness

4.1.1 Prevalence rates of illnesses for all HIV household members

The prevalence rates of illnesses are calculated for both non-hospitalised illnesses and hospitalised cases from the

information collected on all the members of the HIV households first and then separately, only for the PLWHA so that gender differences in HIV households as well as gender differences among PLWHA can be studied.

In all, the survey covered a sample of 2,068 HIV households spread across six high-prevalence states and the total number of persons in these households was 8,252; 4,032 male and 4,220 female.

As compared to women, men have reported higher prevalence rates of hospitalisation of cases

The prevalence rate of non-hospitalised illnesses is calculated based on the reporting of illnesses by the households in the last one month preceding the date of interview. The non-hospitalised illnesses include acute as well as chronic illnesses that were prevalent during the one month reference period. The prevalence rate of hospitalisation is calculated based on the number of hospitalisation cases reported for the household members during the last one year preceding the date of interview. These are presented in the Tables 4.1.

It is seen that the prevalence rate of both non-hospitalised illnesses and hospitalisation cases is lower for women compared to men. Analysed age group-wise, it shows that for non-hospitalised illnesses while the rates are marginally higher for females in the age groups 0-14 and 60 and above years, it is lesser in the age group 15-59 years which consists of most of the PLWHA. However, as far as hospitalisation cases are concerned, the rates are marginally higher for females only on the lowest age group of 0-14 years. In the four of the six states in which the survey was conducted, the prevalence rates of non-hospitalised illness was much lower for women*. Only in Manipur and Nagaland, the overall prevalence rates were higher for women than for men and in Manipur the rates were higher for females than males in the age group 15-59 years.

In case of the reported number of hospitalisation cases, except in the state of Nagaland, in all the other states, as compared to women, men have reported higher prevalence rates of hospitalisation cases. However, even in Nagaland, the prevalence rate of hospitalisation for the females in the age group 15-59 years is almost similar to that of the males.

4.1.2 Prevalence rates of illnesses for PLWHA

The prevalence rates for hospitalised and non-hospitalised illnesses are calculated for the PLWHA by the stage of their

Table 4.1

Prevalence rate of non-hospitalised illness in one month reference period and in hospitalisation in last one year

(per'000 Population)

Age group	Non-hospitalised illnesses			Hospitalisation cases		
	Male	Female	Total	Male	Female	Total
0-14	306.0	323.1	314.1	50.9	56.3	53.5
15-59	1041.6	731.7	877.5	462.6	225.4	337.0
60 and above	749.0	800.0	774.1	226.7	145.8	186.9
All Ages	794.2	625.6	708.0	319.7	175.4	245.9
(N) No. of persons	**4,032**	**4,220**	**8,252**	**4,032**	**4,220**	**8,252**

*See State Reports on Socio-economic Impact of HIV and AIDS

infection and by the number of years since the infection was detected. The WHO classifies the HIV infection into four clinical stages based on the diseases and the performance scale. At Stage I, it is asymptotic and the individual would be able to carry on the normal activities. In the clinical Stage II, it is symptomatic (with symptoms like weight loss of less than 10 per cent, recurring upper respiratory tract infection and other illnesses), but the person is able to carry on normal activities. In Stage III, along with symptoms like weight loss, the individuals 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 infection and/or would be bedridden for less than 50 percent of the days during last one month. In the last stage i.e. Stage IV, along with the wasting syndrome, the person may suffer from any of the diseases 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.

Of the 2,068 HIV households interviewed, there emerged 2,703 cases of PLWHA, including children in the age group of 0-14 years, and others who were less than 18 years old i.e. non-adults. The interviews were however, held only with adult HIV-positive members. Also, not all of them could be interviewed and hence the number of PLWHA who were interviewed in detail was 2,385. Although Table 4.2 gives information regarding stage-wise prevalence rates for all the 2,703 positive people, the tables thereafter give information only for 2,385 PLWHA who were interviewed.

The prevalence rates for hospitalised and non-hospitalised illnesses are calculated for the PLWHA by the stage of their infection and by the number of years since the infection was detected

The prevalence rates of both non-hospitalised and hospitalised illnesses go up with the increase in the stage of infection for both males and females. While the prevalence rates of non-

Table 4.2

Prevalence rate of illness and hospitalisation for PLWHA by stage of infection

(per'000 Population)

	Stage I	Stage II	Stage III	Stage IV	All
Non-hospitalised illnesses during last one month					
Male	943.9	1582.2	2390.3	2500.0	1722.2
Female	844.8	1330.3	2164.0	2424.2	1375.5
F/M	0.90	0.85	0.91	0.97	0.80
Hospitalisation during last one year					
Male	312.8	617.5	1204.1	1707.1	799.5
Female	178.9	359.6	980.0	1469.7	477.6
F/M	0.57	0.58	0.81	0.86	0.60
Number of persons					
Male	374	570	392	140	1,476
Female	464	445	250	66	1,225
Total	**838**	**1015**	**642**	**206**	**2,701**

hospitalised illnesses are only slightly lower for females compared to that of males at each stage, the reported number of hospitalisation cases shows greater variation. There could be a number of reasons for women reporting lower prevalence of illnesses, especially hospitalisation. First, women may not be taking minor ailments very seriously. Generally, as far as possible women, would try to avoid going to the doctor, in particular, avoid getting hospitalised as the household routine is likely to be disrupted more by the sickness of women of the household. In households where both men and women are sick, more importance could be given to get the man who is the breadwinner and he could be treated first.

While the prevalence rates of non-hospitalised illnesses are only slightly lower for females compared to that of males at each stage, the reported number of hospitalisation cases shows greater variation

However, the gender gap in the prevalence rate of hospitalisation cases reduces once the PLWHA crosses Stage II. The female/male ratio of hospitalisation goes up from 0.57 in Stage I to 0.86 in Stage IV. This could be due to the fact that at the early stage of infection, the female PLWHA may be avoiding hopitalisation as they may not be taking their ailments seriously. However, as the stage of infection advances, due to the severity of their ailments, it may not be possible for them to neglect their health, hence they have no choice but to get hospitalised.

As mentioned earlier, 2,385 PLWHA –1,208 men and 1,069 women–were interviewed in detail with the help of a semi-structured questionnaire. The questionnaire gathered details about the nature and frequency of illnesses suffered by them, their health-seeking behaviour and the out-of-pocket expenditure incurred by the households in treating the OIs. These findings are presented below.

4.2 Details about non-hospitalised illness episodes

4.2.1 Frequency of illnesses (non-hospitalised)

HIV weakens the body's immune system the ability to fight diseases and as a result, PLWHA can get many infections which are called opportunistic infections (OIs). They are called so because they take advantage of the opportunity offered by the weakened immune system. The prevention and treatment of OIs is an important component of management of HIV.

Table 4.3 shows the frequency at which the sample PLWHA were falling ill during the last one year and during last one month. While one-fourth of male PLWHA have reported frequently falling ill during the last one year, among the female PLWHA, only one-fifth of them have reported the same. For the remaining

Table 4.3

Frequency of OIs reported by PLWHA by stage of HIV infection (Non-hospitalised illness episodes)

	Number of times ill in the last one year			Number of times ill in the last one month			No. of persons
	Average number*	Frequently ill (percent)	Continuously ill (percent)	Average number*	Frequently ill (percent)	Continuously ill (percent)	
By sex							
Male	2.25	24.1	4.0	1.12	17.0	2.5	1,343
Female	1.90	20.0	3.0	0.93	15.3	2.1	1,044

* Averages are calculated after excluding persons reporting frequently and continuously ill.

persons, i.e. those who had not reported frequently or continuously ill, the average number of times they had fallen ill has been worked out. Once again, it is seen that all these percentages and averages have been lower for female PLWHA as compared to males. Of the six states in which the survey was conducted, in all the states, except in Manipur and Nagaland, these figures were higher for males than females. How do we explain this gender difference in the prevalence of illnesses reported by the PLWHA? One of the reasons could be the gender difference in the stage of infection. The sample includes more female PLWHA in the early stages of infection. While the number of females in the first stage is more than that of the male PLWHA, from the second stage onwards, the number of males is more than that of the females and in the last stage females are less than half the number of males. This could partly account for the difference in the illness rate between men and women. However, this alone could not be accounting for such a huge gender differences in the reported morbidity. The gender differences in the perception of illness could provide some explanation. As far as women are concerned, even if they are suffering from an illness, most of the times they do not perceive themselves to be ill, due to socio-cultural reasons.

More detailed information about the illnesses suffered by the PLWHA during the last one month prior to the date of interview were asked to know about the nature of illness, type of treatment sought and the amount of expenditure incurred on the treatment of these illnesses.

4.2.2 Nature of illnesses (non-hospitalised illness episodes)

In Table 4.4, the percentage distribution of all the illness episodes reported by the sample PLWHA in the last one month reference period by nature of illness is presented.

Table 4.4

Distribution of non-hospitalised illness episodes reported by male and female PLWHA by nature of illness

(in Percentages)

Nature of illnesses	Male	Female	Total
Respiratory infection	9.2	9.0	9.1
Malaria	1.4	0.8	1.2
Fever	32.8	35.7	34.0
Headache, body ache	4.7	7.0	5.6
Weakness	6.5	7.8	7.1
Loose motion/diarrhoea	18.4	12.6	16.1
Typhoid	1.0	0.6	0.8
Jaundice	1.4	0.4	1.0
Tuberculosis (TB)	9.0	5.0	7.1
Skin diseases	5.5	5.5	5.5
Sexually transmitted diseases/RTI	2.8	2.9	2.8
Gynaecological problems	--	5.7	2.3
Others	7.4	7.2	7.2
Total	**100**	**100**	**100**
Number of illness episodes	**1,469**	**983**	**2,452**

In all 2,452 illness episodes were reported by PLWHA during the one-month reference period. There are no major gender differences in the nature of illnesses reported by the PLWHA. Fever, loose motion/diarrhoea, TB and respiratory infections were cited as the most common ailments by both male and female PLWHA.

4.2.3 No treatment of illness

The opportunistic infections result in more rapid decline in CD4 T-cells and hence providing treatment for the opportunistic infections is required in order to reduce the sufferings of the PLWHA and allow them to lead an active life. The survey results show interesting

Table 4.5

Illness episodes receiving no treatment and reasons for no treatment among PLWHA

(in Percentages)

	Male	Female	All
Illness episodes for which no treatment was sought	4.4	9.7	6.5
Reasons for not seeking treatment			
Illness not considered serious	79.7	63.2	69.8
No medical facility nearby	3.1	4.2	3.8
Financial constraints	10.9	25.3	19.5
Doctors not willing to treat	--	1.1	0.6
Lack of time	3.1	2.1	2.5
No cooperation from family	--	2.1	1.3
Others	3.1	2.1	2.5
Total	**100**	**100**	**100**

The percentages of episodes which were untreated for lack of funds was higher for women than men

gender differences in the percentage of untreated illnesses as well as in the reasons for no treatment.

While in the case of men, only 4.4 percent of the illness episodes were left untreated, in the case of women this percentage was more than double at 9.7, clearly indicating a gender gap in the treatment seeking behaviour. Although the gender gap in untreated illnesses could be partly explained by the differences in stage of infection between men and women, this cannot be completely ignored. Such big gender differences in untreated illnesses were observed by other studies undertaken on general population in India (Sundar et al. 2002, Madhiwala et al 2000). Though for both men and women, "illness not considered serious" has been reported as a major reason for not seeking treatment, there is a considerable difference in the percentages. Also, in as many as one-fourth of the cases, women have not sought treatment due to financial constraints, while this percentage is only 11 in case of men. It was noticed that in all the six states where the survey was done, the percentages of episodes which were untreated for lack of funds was higher for women than men. In Andhra Pradesh, Manipur and Tamil Nadu, it did not even emerge as a reason for not taking treatment in case of men, reiterating the gender differences that exist. This is understandable, since more than one-third of the positive women in the sample are HIV-positive widows and in all probability, these women would be left with very little money after meeting the medical expenses of treating their husbands. In a study conducted on HIV treatment, Zambian women reported that when money was limited, households often chose to spend on treatment for the men rather than for the women (UNAIDS/UNFPA/UNIFEM, 2004).

According to a study on gender and HIV and AIDS in Delhi, women found it difficult to access healthcare and treatment of sexually transmitted infections. Many felt uncomfortable in talking to male doctors and while women wished to be seen by a female doctor, their husbands usually mediated such appointments. This in turn, discouraged women from seeking further treatment, and as a result, a lot of STIs could have been left untreated (Mukhopadhyay Swapna 2001).

Besides, in another two percent of the cases, women could not seek treatment due to lack of cooperation from the family. This point was raised in one of the FGD's conducted as well. A few of the female participants mentioned in Mumbai that women generally do not get much family support to access health facilities. A number of women reported that when they fall ill, none of the family members accompany them to hospital, while for seeking medical treatment for their husbands, the women (even if they themselves

were HIV-positive), are expected to accompany their husbands.

In this context, it is worth mentioning that not all the female PLWHA who were interviewed seem to have full freedom to seek healthcare when required. Only 58 percent of the sample PLWHA mentioned that they have full power and around 12 percent said that they do not have any right to take such decisions and seek healthcare for themselves.

Table 4.6

Distribution of non-hospitalised illness episodes by source of treatment

(in Percentages)

Source of Treatment	Male	Female	Total
Government	42.7	45.4	43.7
Private	41.3	29.8	36.9
Charitable trust/NGO	13.7	19.4	15.9
Faith healer/religious person	0.2	--	0.1
Others	2.1	5.4	3.4
Total	**100**	**100**	**100**

4.2.4 Source of treatment

The percentage distribution of illness episodes for which treatment was sought is presented in Table 4.6 by source of treatment.

It is seen from this table, that in the case of male PLWHA, both government and private facilities had been utilised almost to the same extent. As compared to men, the percentage of illness episodes for which treatment has been sought from government facilities is marginally higher, while those for which treatment has been taken from private facilities is considerably lower for women. The women PLWHA seem to rely more on government and NGO health facilities, which could mainly be due to the fact that the treatment in these facilities is much cheaper than in private health facilities.

While a similar pattern was observed in the states of Karnataka, Maharashtra and Tamil Nadu, in Andhra Pradesh nearly 46 percent of PLWHA went to NGOs for treatment, where the treatment was cheaper than government facilities for men and nearly the same for women. In Manipur and Nagaland slightly higher

Table 4.7

Expenditure incurred by PLWHA for treatment of non-hospitalised illness episodes by source of treatment (Average per illness episode)

(in Rupees)

Source of treatment	Rural		Urban		Total		
	Male	Female	Male	Female	Male	Female	All
Government	510	301	650	347	589	324	482
Private	1,179	759	1,225	803	1,202	781	1,070
Charitable trust/NGO	245	132	352	577	305	342	322
Faith healer/religious person	600	--	150	--	300	--	300
Others	452	431	92	1061	229	759	559
All	770	410	817	566	796	487	676
(N) Number of episodes	**641**	**449**	**764**	**439**	**1,405**	**888**	**2,293**

percentage of women took treatment from private facilities compared to men, although these percentages were small.

4.2.5 Out-of-pocket expenses incurred on treatment

The out-of-pocket expenditure incurred by the households includes amount spent on fees and medicines, clinical tests, transport cost and bribes and tips. In Table 4.7, the average expenditure incurred by the PLWHA on the treatment of illness episodes is presented by the source of treatment.

There is a big gender gap in the average expenditure incurred per illness episode, irrespective of the source of treatment for both rural and urban areas

It is observed that there is a big gender gap in the average expenditure incurred per illness episode, irrespective of the source of treatment for both rural and urban areas. While for men, the average expenditure per episode is Rs. 796, this average is much lower at Rs. 487 for women. It was only in the state of Nagaland that expenditure per episode, considering all sources, was more for women than men in both the urban and rural samples. The least difference in the cost for men and women was noticed in Maharashtra – Rs. 555 for men and Rs. 513 for women.

Thus, even after controlling for the source of treatment, the gender differences in the out-of-pocket expenses persist. Since both men and women have reported similar pattern of illnesses (as seen in Table 4.4), the huge difference in expenditure per episode could possibly be explained only by gender bias in treatment. The 52nd round of NSS also reported gender differences in the expenditure incurred for non-hospitalised illnesses, among general population, although the difference was not huge. (NSSO,1998).

4.3 Details about hospitalisation cases

4.3.1 Frequency of hospitalisation reported by PLWHA

All the 2,385 sample PLWHA were asked details about how frequently they were hospitalised after testing HIV-positive and number of times hospitalised during the last one year prior to the date of interview. These details are presented below in Table 4.8.

The percentage reporting hospitalisation was higher for men as compared to women. While more than half of the men were hospitalised, in the case of women only around 30 percent had sought treatment in a hospital as an in-

Table 4.8

Frequency of hospitalisation reported by PLWHA

	Hospitalisation since detected HIV-positive		Number of times hospitalised in the last one year		No. of persons
	Percent reporting hospitalisation	Average number of times	Percent reporting hospitalisation	Average number of times	
By sex					
Male	54.6	1.75	53.3	1.53	1,343
Female	31.9	1.86	30.7	1.52	1,044
All	**44.4**	**1.78**	**43.4**	**1.52**	**2,385**

patient. However, the average number of times was slightly higher for women. Similar trends were seen in all the states, except Andhra Pradesh and Nagaland, where the average number of times hospitalised was slightly higher for men. This is contrary to the findings of some of the morbidity surveys conducted on the general population where such huge gender differences in the reporting of hospitalisation were not found (NSS 1998; Sundar 1995; Sundar et al. 2002). As pointed out earlier the gender gap in hospitalisation among the sample PLWHA could be partly explained by the gender differences in the stage of infection and partly by the economic, social and cultural factors which may be preventing female PLWHA from getting hospitalised.

4.3.2 Nature of illness (hospitalisation cases)

In all 1,550 hospitalisation cases, 1,071 by men and 479 by women PLWHA, were reported during the last one-year reference period by 2,385 persons who were interviewed in detail. As reported in the case of non-hospitalised illness episodes, in the case of hospitalisation also, fever, tuberculosis and loose motion/diarrhoea emerge as common health problems for which both men and women had been hospitalised during last one-year reference period (Table 4.9). It is also seen that the percentage of illnesses reported is similar for men and women in respect of most of the illnesses.

The average number of days admitted in a hospital at a time is more or less

Table 4.9

Distribution of hospitalisation cases by nature of illness suffered by HIV-positive men and women and number of days hospitalised

(in Percentages)

Nature of illness	Percentage of cases			Average no. of days hospitalised		
	Male	Female	Total	Male	Female	Total
Respiratory infection	4.2	4.8	4.4	12.3	9.9	11.5
Malaria	1.2	0.2	0.9	9.8	20.0	10.5
Fever	20.1	13.9	18.2	8.8	10.8	9.2
Headache	2.9	2.5	2.8	8.3	15.8	10.4
Weakness	7.2	7.6	7.3	9.5	8.9	9.4
Loose motion/diarrhoea	27.0	24.6	26.2	9.1	6.9	8.5
Typhoid	1.7	1.5	1.6	7.8	9.9	8.4
Jaundice	2.1	1.5	1.9	7.5	8.4	7.7
Tuberculosis (TB)	18.8	15.0	17.6	12.5	13.11	12.7
Skin diseases	2.5	3.8	2.9	8.2	11.6	9.6
STD/gynaecological/ reproductive problems	0.8	7.0	2.7	13.9	6.0	11.0
Meningitis and viral encephalitis	1.6	1.1	1.4	11.5	15.4	12.4
Others	10.1	17.4	12.3	7.9	9.1	9.8
All illnesses	100	100	100	9.85	9.79	9.83
No. of hospitalisation cases	1,071	479	1,550	--	--	--

Table 4.10

Distribution of hospitalisation cases by source of treatment

(in Percentages)

Source of treatment	Male	Female	Total
Government hospital	46.6	57.2	50.0
Private nursing home	30.3	23.4	28.2
Charitable trust/NGO	22.5	19.0	21.4
Faith healer/religious person	0.6	0.6	0.5
Total	**100**	**100**	**100**
No. of hospitalisation cases	1,071	479	1,550

the same for men and women in most diseases barring malaria, headache, and STD. However, there is no gender difference in the average number of days admitted considering all the diseases (9.8 days).

4.3.3 Sources of treatment (hospitalisation)

The percentage distribution of the hospitalisation cases by source of treatment is presented for male and female PLWHA in Table 4.10.

There are significant gender differences in the source of treatment. While in as many as 57 percent of the cases women had sought treatment from a government hospital, only for 47 percent of the cases men had sought admission in a government hospital. The percentage seeking treatment in a private nursing home/hospital as an in-patient is lower for women, as compared to their male counterparts. This probably indicates that the households are willing to spend more on the treatment of a male family member as compared to a female member.

A similar trend in the source of treatment was seen in all the states except Karnataka where percentage of women taking treatment from private health facilities was slightly higher than that of the men availing similar facilities. In Manipur, although, there was negligible difference between the two, three percent men and 5 percent women, the percentage itself was very small with a high percentage of the PLWHA opting for treatment from NGOs.

4.3.4 Household expenditure on hospitalisation

The direct cost of hospitalisation includes amount paid as room rent, doctor's fee and cost of medicines, clinical tests, surgery and transport. In addition, there could be expenses like special diet for the patients and lodging, food and travel costs for the caregivers. At times the households may have to pay tips/bribes to the hospital staff to get better care and attention. Table 4.11 shows the average amount spent by the

Table 4.11

Expenditure incurred per hospitalisation case by PLWHA by source of treatment

(in Rupees)

Source of treatment	Male	Female	All
Government	1,529	1,261	1,434
Private	6,244	3,875	5,637
Charitable trust/NGO	1,688	1,698	1,691
Faith healer/religious person	1,190	675	1,061
Total	**2,994**	**1,953**	**2,672**

household per hospitalisation case by source of treatment.

The average household expenditure per hospitalisation is Rs. 2,672 and there is substantial gender gap in the average cost of hospitalisation; while the average expenditure per hospitalisation is Rs. 2,994 for men, this average is much lower at Rs. 1,953 for women. This could partly be explained by the fact that a much higher percentage of women have sought treatment from the government hospitals and only a small percentage of women had gone to a private nursing home/hospital which is more expensive. However, even after controlling for the source of treatment, the average expenditure for women in all the different sources excepting treatment from NGOs works out to be much lower than the expenses incurred on men. Taking into consideration treatment from all sources, expenditure per treatment is for women in all the states without exception although the difference in the amount varies from state to state. Once again, considering that similar percentages of men and women are hospitalised for the same illnesses and also have been hospitalised for more or less the same number of days, the gender gap in the expenditure could only be explained by the gender bias that exists in society. Similar differences in the hospitalisation expenditure have been found among the general population as well (NSS0, 1998).

4.4 Observations

The results of the survey reveal gender differences not only in the prevalence rates of illnesses, but also with regard to illnesses for which no treatment is taken, the source of treatment as well as the amount spent on these treatments.

- It is seen that both the prevalence rates of non-hospitalised illnesses as well as reported number of hospitalisations are lesser for females than males in the HIV households. While in the case of non-hospitalised illnesses the prevalence rate for the male member of HIV households is 794 during the one-month reference period, the rate is much lower at 626 for the female members. Similarly the hospitalisation cases for the one-year reference period for the male members is 320 per thousand population and for the women the number is much lesser at 175. This could be due to the difference in perception of illness between men and women, or due to the gender differences that exist in the system.
- Even among the PLWHA, the prevalence rate of non-hospitalised illness as well as reported number of hospitalisations are less for women than men. However, the stage-wise analysis shows that in case of non-hospitalised illness, the difference in the prevalence rate is quite small at each stage and it also decreases as the infection progresses. This is even more noticeable in hospitalised illnesses, where in Stage I the hospitalisation for women is around 55 percent of that of the men and gradually increases and is around 85 percent of that reported by men in Stage IV. This would lead to the inference that women would avoid seeking medical aid as long as they can, and only resort to it when it is unavoidable. The reason for this could once again be the preference given to men, generally the bread earners, fear of disruption in the family or monetary problems particularly in a widow household.
- It is seen that while in the first stage, the number of female PLWHA is more

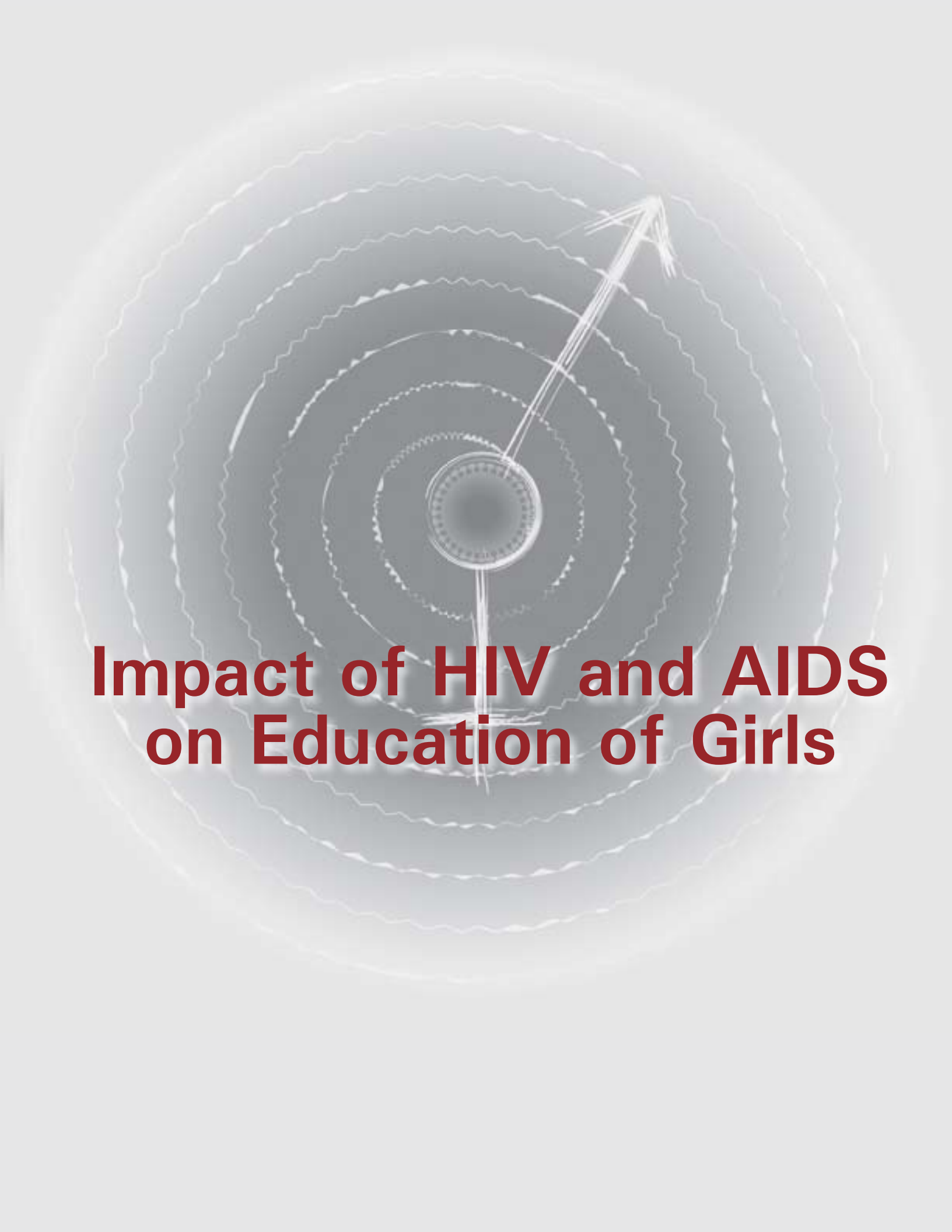
Both the prevalence rates of non-hospitalised illnesses as well as reported number of hospitalisations are lesser for females than males in the HIV households

than that of the male PLWHA, from the second stage onwards the number of males is more than that of the females and in the last stage females are less than half the number of males. This could partly account for the huge difference in the illness rate between men and women particularly in the age group of 15 to 59.

- The gender difference becomes more noticeable from the fact that not only the percentage of women's illnesses, which go untreated, is higher than that of men, but in the case of most of the women financial constraints turn out to be the reason for taking no treatment.
- The source of treatment indicates that a lesser percentage of women take treatment from private hospitals than men, the costs in private being more than that of government health facilities, whether for non-hospitalised or hospitalised illnesses. For both hospitalised and non-hospitalised illnesses, in spite of the fact that nearly the same percentage of men and women suffer from the same diseases, and with even the number of days of hospitalisation being nearly the same, the cost per treatment in case of women is less than that of men, be it in a government health facility or a private one.
- Of the six states where the survey was conducted, it is seen that in Manipur and Nagaland, a small but higher percentage of women than men took treatment from private health facilities. The expenditure per non-hospitalised illness was also slightly more for women in Nagaland. An analysis of the profile of the sample households indicates that the sample households in these two states have higher annual income compared to others. Also, the level of education of the female PLWHA is better than that in the other states. Percentage of female PLWHA who are salary earners is also slightly higher in these two states. The reason being in both the states matriarchy is practiced. This would lead to the conclusion that women who are better educated and have better income are also likely to have better access to health facilities.

Creating earning opportunities for more women will reduce their dependency and expand their financial freedom

The study shows that as compared to men, women have poorer access to healthcare. It has also been pointed out that in the states where sample female PLWHA who were generally better educated, were having better access to health facilities. The financial constraint is a big impediment for getting proper healthcare and it is more so for women. It is imperative to see that women, who are affected more by HIV and AIDS, get equal opportunities to access treatment. One of the ways is to provide more education to women. Creating earning opportunities for more women will reduce their dependency and expand their financial freedom. As women get empowered with education and employment, they can demand better healthcare.



Impact of HIV and AIDS on Education of Girls

Chapter 5

Impact of HIV and AIDS on Education of Girls

HIV and AIDS can have a large impact on the education of children by affecting the demand and supply and quality of education. On the demand side, children's school enrolment may get affected due to several reasons. First, families may not be able to afford to pay for their children's education due to reduced family income or increased health expenditure. Secondly, PLWHA may become reluctant to educate their wards since they may not live long enough to reap the benefit of their children's education. Thirdly, children, may be pulled out of school in order to supplement the family income and girls in particular may be withdrawn from school in order to take care of sick family members or to participate in the income earning activities.

There are a number of reports quoting from studies undertaken especially in several African countries to suggest an adverse impact of HIV and AIDS on the education of children (UNICEF, 2005; Mahbub-ul-Haq, Human Development Centre, 2005; UNDP, 2003; Coombe Carol, 2002). While most of these studies indicate fall in the demand for schooling which could be attributable to HIV and AIDS, no conclusive evidence exists to suggest widening gender gap in children's schooling, as a result of HIV and AIDS. Based on a study undertaken in African countries, a World Bank report suggests that there is considerable variation in gender gap in enrolment among children with both parents living and children whose parents have both died. These studies show that in most cases the gender gap among double orphans is similar to the gender gap among children living with their parents (World Bank, 2002)

In this chapter an attempt has been made to examine the household impact of HIV and AIDS on the education of girls by comparing the gender gap in the ever and current enrolment as well as dropout percentages of children from HIV and non-HIV households. In India, the available data shows that there is a considerable gender gap in the school enrolment of children; in the year 2002-03, at the level of elementary education while the enrolment ratio for boys was 85.4, the same for girls was much lower at 79.3. (Selected Educational Statistics, 2002-03). Hence in this chapter, it would be examined whether HIV and AIDS would widen the already existing gender gap in children's schooling. This chapter tries to capture the gender differentials, if any, not only by finding out whether the child is going to school, but also by finding out the child's school attendance, the type of school attended, reasons for dropout etc. Since the survey

included both HIV-positive households and non-HIV households, by keeping the socio-economic characteristics of the two sets of households similar, the chapter tries to compare the gender gap in children's education in these two sets of households.

5.1 Gender gap in ever and current enrolment percentages

In this section, the household impact on enrolment and continuation of school education of boys and girls belonging to two sets of sample households, namely HIV households and non-HIV households are assessed based on the survey results. The gross enrolment rate is calculated as, number of children in the age group 6-14 and 15-18 who were ever enrolled as a percentage of total number of children in the respective age groups. The current enrolment rate is calculated by taking the number of children who are currently studying, as a percentage of total number of children in that age group.

Table 5.1

Ever and current enrolment of boys and girls in HIV and non-HIV households

(in Percentages)

Age 6-14 years	HIV household			Non-HIV household		
Ever enrolled	**Rural**	**Urban**	**Total**	**Rural**	**Urban**	**Total**
Boys	93.00	94.93	94.08	96.56	97.83	97.33
Girls	91.64	93.21	92.41	97.45	95.89	96.50
Total	**92.30**	**94.16**	**93.28**	**96.96**	**96.95**	**96.96**
F/M	0.99	0.98	0.98	1.01	0.98	0.99
Currently enrolled						
Boys	90.76	92.73	91.86	93.97	96.91	95.75
Girls	88.51	88.59	88.55	95.13	94.32	94.64
Total	**89.59**	**90.88**	**90.27**	**94.50**	**95.73**	**95.25**
F/M	0.98	0.95	0.96	1.01	0.97	1.00

Age 15-18 years	HIV household			Non-HIV household		
Ever enrolled	**Rural**	**Urban**	**Total**	**Rural**	**Urban**	**Total**
Boys	92.50	92.37	92.42	95.96	97.10	96.61
Girls	92.86	91.30	91.98	95.63	98.21	97.15
Total	**92.67**	**91.90**	**92.22**	**95.81**	**97.64**	**96.87**
F/M	1.00	0.99	0.99	1.00	1.01	1.01
Currently enrolled						
Boys	68.75	69.49	69.19	80.27	82.96	81.80
Girls	61.43	67.39	64.81	78.92	79.96	79.54
Total	**65.33**	**68.57**	**67.22**	**79.64**	**81.50**	**80.72**
F/M	0.89	0.97	0.94	0.98	0.96	0.97

The ever and current enrolment rates for children in the age group 6-14 years, which corresponds to class I-VIII and in the age group 15-18 which corresponds to class IX-XII are presented in Table 5.1.

The sample included 1,562 children from HIV households (811 boys and 751 girls) and 4,861 children (2,661 boys and 2,200 girls) from non-HIV households in the age group 6-14 years. Expectedly, as compared to 6-14 age group, there were fewer children in the age group 15-18; there were 360 children (198 boys and 162 girls) from HIV households and 1981 (1,033 boys and 948 girls) from the non-HIV households.

Although both ever and current enrolment percentages are lower for the children of HIV households as compared to non-HIV households for both the age groups, the differences in the gender gaps between the two types of households is not very clear. In fact, there is hardly any gender gap in the ever enrolment percentages for the children of HIV as well as non-HIV households.

However, with the exception of 6-14 years age group children of non-HIV households, the current enrolment percentages are lower for the girls. This gender gap in the current enrolment percentages is marginally more for the HIV households as compared to non-HIV households for both the age groups, suggesting that in the HIV households girls are more likely to be withdrawn from school. The gender difference is most marked in the case of rural children in the age group 15-18 belonging to HIV households.

5.1.1 Dropout rates and number of years of schooling

Table 5.2 compares the dropout rates and the average number of years of schooling completed by boys and girls of HIV households with non-HIV households.

As compared to non-HIV households, the dropout percentages are higher for the 6-14 age group children of HIV households. Also, expectedly, as compared to 6-14 age group, the dropout rates, are much higher for the 15-18 age group of children of both HIV and non-HIV households. Although there are gender differences in the dropout rates for both types of households (with an exception of rural children of non-HIV households in 6-14 age group), there is no clear indication to show that the gender gap is more in the HIV households. As far as 6-14 age group is concerned, the gender gap in the dropout percentages is much higher for the children of HIV households. But in the case of 15-18 age group, the gender gap is higher in HIV households only for the rural children.

In comparison to the children of non-HIV households, not only is the percentage dropping out of school more for the children of HIV households, but also, the number of years of schooling completed by the dropout children is less for them.

As far as 6-14 age group children are concerned, with the exception of rural children of HIV households, boys are withdrawn from school earlier than the girls. In fact among the older children also, the boys of HIV households have dropped out of school earlier than the girls, whereas among the children of non-HIV households, it is the other way round; girls are withdrawn from school earlier than the boys. The boys of HIV households are probably withdrawn from school to take up a job to supplement the family income.

Although both ever and current enrolment percentages are lower for the children of HIV households as compared to non-HIV households the differences in the gender gaps between the two types of households is not very clear

Table 5.2

Dropout rates and number of years of schooling completed by dropout children of HIV and non-HIV households

Age 6-14 years	HIV			Non-HIV		
Children who dropped out of school	Rural	Urban	Total	Rural	Urban	Total
Boys	2.41	2.32	2.36	2.68	0.95	1.62
Girls	3.42	4.96	4.18	2.38	1.64	1.93
Total	**2.93**	**3.49**	**3.23**	**2.54**	**1.26**	**1.76**
F/M	1.42	2.14	1.77	0.89	1.73	1.19
Average number of years of schooling completed by dropouts						
Boys	4.25	3.90	4.06	4.78	4.13	4.55
Girls	3.92	4.71	4.38	4.90	4.62	4.76
Total	**4.05**	**4.41**	**4.26**	**4.83**	**4.42**	**4.65**
F/M	0.92	1.21	1.08	1.03	1.12	1.05
Age 15-18 years						
Boys	25.68	24.77	25.14	16.36	14.56	15.33
Girls	33.85	26.19	29.53	17.47	18.58	18.13
Total	29.50	25.39	27.11	16.87	16.53	16.67
F/M	1.32	1.06	1.17	1.07	1.28	1.18
Average number of years of schooling completed by dropouts						
Boys	6.11	6.85	6.54	8.10	7.96	8.03
Girls	7.00	7.36	7.18	7.23	7.52	7.41
Total	**6.58**	**7.08**	**6.86**	**7.68**	**7.72**	**7.69**
F/M	1.15	1.07	1.10	0.89	0.94	0.92

5.1.2 Current enrolment of children by annual household income categories

Household income is one of the important demand side factors that determine the schooling of children. The current enrolment percentages have been worked out for the boys and girls of both HIV and non-HIV households by the annual household income categories to see whether gender differences persist at all levels of income.

It is interesting to note that in the case of 6-14 age group children, in both types of households the gender gap in the current enrolment percentages is not only very marginal, but also does not seem to vary much with the income levels of the households. However, when we move to the older age group (15-18 years), as far as non-HIV households are concerned, the gender gap in the current enrolment percentages is fairly significant for the poor/lower income households and the gap completely disappears when the household income crosses Rs. 41,000 per annum. On the other hand in the HIV households, the gender difference persists at all levels of income. In other words, even at higher levels of income, in the HIV households girls are more likely to be withdrawn from school.

5.1.3 Current enrolment of children by the level of education of household head

The educational level of the household is another important determinant of demand for education. Since educated families are more likely to value education, they are more likely to educate their children. In this section, we would examine the influence of the level of education of the household head on the education of male and female children, and thereby analyse the gender differences, if any, by the level of education of the head.

The gender differences in the current enrolment percentages by level of education of household head are almost similar to the differences observed by the level of household income. As far as 6-14 age group is concerned, although there is a gender gap in the enrolment percentages at all levels of education, the gap is very marginal and similar among the children of both HIV and non-HIV households. However, when we move to the next age group, among the children of non-HIV households, no clear picture emerges about the relationship between the education of the household head and enrolment of the children and the gender gap in enrolment is also marginal. But in the case of the older children of HIV households, as compared to non-HIV households, the gender gap is more at all levels of education and the gender gap persists even when the household head is well educated. In other words, even at high level of education, when it comes to education beyond elementary level, the girls from the HIV households are less likely to continue their studies.

5.2 Reasons for dropout

It has been noted in the earlier sections that in both HIV and non-HIV households,

Table 5.3

Current enrolment rates among children by annual household income categories

(in Percentages)

Annual household income (Rs.)	HIV households			Non-HIV households		
	Boys	Girls	F/M	Boys	Girls	F/M
6-14 age Group						
Up to 20,000	87.02	85.38	0.98	94.0	93.24	0.99
20,001-30,000	92.45	86.34	0.93	93.71	92.95	0.99
30,001-41,000	93.23	85.85	0.92	96.65	94.71	0.97
41001-84,000	92.77	92.31	0.99	96.98	95.60	0.98
Above 84,000	98.68	96.10	0.99	98.20	97.43	0.99
N	**811**	**751**		**2,661**	**2,200**	
15-18 age group						
Up to 20,000	55.10	48.39	0.87	76.71	66.67	0.86
20,001-30,000	56.76	57.14	1.00	79.08	75.10	0.94
30,001-41,000	64.29	52.17	0.81	78.36	70.30	0.89
41001-84,000	80.95	77.78	0.96	83.33	85.16	1.02
Above 84,000	95.24	84.20	0.88	91.06	92.66	1.01
N	**198**	**162**		**1,033**	**948**	

Table 5.4

Current enrolment rates among children by level of education of household head

(in Percentages)

Education of household head	HIV households			Non-HIV households		
	Boys	Girls	F/M	Boys	Girls	F/M
6-14 years						
Illiterate	84.84	82.22	0.96	91.14	88.79	0.97
Up to middle	90.64	87.11	0.96	95.64	95.0	0.99
High school/ Higher secondary	97.30	92.91	0.95	97.20	96.56	0.99
Graduate/diploma	97.06	96.88	0.99	98.82	97.24	0.99
N	**811**	**751**		**2,661**	**2,200**	
15-18 years						
Illiterate	50.00	43.14	0.86	68.02	68.51	1.00
Upto middle	66.04	69.05	1.04	79.19	75.79	0.95
High school/ higher secondary	88.89	77.59	0.87	88.76	85.95	0.96
Graduate/diploma	91.67	81.82	0.89	91.86	89.53	0.97
N	**198**	**162**		**1,033**	**948**	

there is a gender gap in the percentage of children dropping out of school among 6-14 as well as 15-18 age groups. It has also been observed that as compared to non-HIV households, the gender gap in the dropout percentages is more among the children of HIV households for the 6-14 age group and for the rural children of 15-18 age group. In Table 5.5, the reasons for dropping out of school are presented for boys and girls of both HIV and non-HIV households.

It is not surprising that for both boys and girls of HIV and non-HIV households, "could not afford " has been reported as a reason for discontinuation of schooling, as it has already been seen that the dropout percentages are fairly high among the children of poor households. However, other than this there are interesting gender differences as well as differences between HIV and non-HIV households in terms of reasons for dropout.

In the HIV households, boys are mostly withdrawn from school to take up an income-earning activity and girls are discontinuing schooling in order to take care of their younger siblings and household chores

As far as the children of HIV households are concerned, boys are mostly withdrawn from school to take up an income-earning activity and girls are discontinuing schooling in order to take care of their younger siblings and household chores. Let us consider the 6-14 age group children of HIV households. In the case of boys, in more than 40 percent of the cases, "had to take up a job" are reported as a reason for dropout and in the case of girls, in nearly one-third of the cases, " had to take care of their younger siblings and household chores" are reported as reasons. This gender difference in the reasons for dropout clearly brings out the gender differences in the roles expected from boys and girls in our society.

As far as children of non-HIV households are concerned, "child not interested in studies" emerges as the most important reason for discontinuation of schooling. Although in the case of these children also, reasons like "had to take up a job" for boys and "had to take care of younger siblings and household work" for girls have been reported, the percentages are much lower as compared to HIV households.

5.3 Type of school attended

There are interesting differences between HIV and non-HIV households as far as type of school attended by children is concerned. First, as seen in Table 5.6, the percentage of children studying in government schools is higher for the children of HIV households as compared to the non-HIV households. While 63 percent of the children belonging to HIV households are studying in government schools only 55 percent of the children in the age group 6-14 and 51 percent of the children in the age group 15-18 belonging to non-HIV households attend government schools. From the gender perspective, more importantly, in the case of HIV households, the percentage of girls attending government schools is much higher than the percentage of boys attending government schools. While 67 percent of girls are attending government schools, the percentage of boys works out to be lower at 60 percent. In the case of non-HIV households, this gender gap is much lower among 6-14 age group children and no such gender difference is seen among children belonging to 15-18 age group; in fact, the percentage of boys attending government schools is more.

Since the expenses in the government schools are comparatively lower, it is not surprising that more children from the HIV households are studying in them. They are much cheaper, if not free, and also come with other benefits like free

Table 5.5

Reasons for dropout

(in Percentages)

Age 6-14 years	HIV households			Non–HIV households		
	Boys	Girls	Total	Boys	Girls	Total
Could not afford	11.8	14.3	13.3	17.1	14.3	15.7
Had to take care of sick	5.9	3.6	4.4	2.4	-	1.2
Had to take care of younger sibling/ take up other household work	5.9	32.1	22.3	2.4	11.9	7.2
Had to take up a job	41.2	28.6	33.3	24.4	14.3	19.3
Child too sick to attend school	11.8	-	4.4	4.9	7.1	6.0
School is inaccessible	5.9	-	2.2	-	2.4	1.2
Expelled from school because of other reasons	-	-	-	-	2.4	1.2
Child not interested in studies	17.7	7.1	11.1	39.0	35.7	37.4
Education not considered necessary	-	7.1	4.4	2.4	7.1	4.8
Repeated failure	-	-	-	4.9	2.4	3.6
Others	-	7.1	4.4	2.4	2.4	2.4
Total	**100**	**100**	**100**	**100**	**100**	**100**
No. of dropout children	**17**	**28**	**45**	**41**	**42**	**83**
15-18 years						
Could not afford	15.2	20.5	17.8	14.9	12.6	13.7
Had to take care of sick	6.5	2.3	4.4	0.7	-	0.3
Had to take care of younger sibling/ take up other household work	2.2	22.8	12.3	2.7	6.6	4.6
Had to take up a job	30.4	6.8	18.9	25.3	6.6	15.6
Child too sick to attend school	8.7	2.3	5.6	3.3	1.8	2.5
School is inaccessible	2.2	2.3	2.2	0.7	3.6	2.2
No separate school for girls	-	4.6	2.2	-	1.2	0.6
Expelled from school	2.2	-	1.1	1.4	2.4	1.9
Child not interested in studies	8.7	27.3	17.8	26.6	40.7	34.0
Education not considered necessary	6.5	2.3	4.4	2.0	5.4	3.7
Quality of education is bad	2.2	-	1.1	0.7	0.6	0.6
Repeated failure	13.0	6.8	10.0	9.1	9.0	9.0
Others	2.2	2.3	2.2	13.0	9.6	11.2
Total	**100**	**100**	**100**	**100**	**100**	**100**
No. of dropout children	**46**	**44**	**90**	**154**	**167**	**321**

Table 5.6

Distribution of currently enrolled children by type of school attended

(in Percentages)

Type of school	HIV households			Non-HIV households		
6-14 age group	**Boys**	**Girls**	**All**	**Boys**	**Girls**	**All**
Government	60.36	66.54	63.35	54.30	56.51	55.29
Private*	38.91	32.88	36.00	45.39	43.40	44.49
Informal/others	0.73	0.58	0.66	0.31	0.10	0.22
Total	**100**	**100**	**100**	**100**	**100**	**100**
15-18 age group	Boys	Girls	All	Boys	Girls	All
Government	60.51	66.87	63.29	51.48	50.27	50.91
Private*	38.97	33.11	36.42	48.52	49.73	48.97
Informal/others	0.51	--	0.29			
Total	**100**	**100**	**100**	**100**	**100**	**100**

*Includes government-aided private schools. For only English medium private schools, the differences could have been sharper.

Since the expenses in the government schools are comparatively lower, it is not surprising that more children from the HIV households are studying in them

uniform, mid-day meals, free books etc. These findings are corroborated by the views expressed by the participants of the Focus Group Discussions conducted by our research team with the members of the Network of Positive People at various places. A number of them expressed their unhappiness over sending their wards to government schools and their inability to afford English-medium private schools, which are perceived to be better (to a large extent rightly so) in terms of quality of education. In Karnataka, a female participant of the Focus Group Discussion lamented that since she needed money for the treatment of her husband, her child had to be shifted from an English-medium school to a Kannada-medium government school. Not only did the child find his studies difficult at present, he would also probably find it difficult to revert back to English later, particularly in higher classes. Many of the PLWHA who participated in the Focus Group Discussions conducted during the ILO study also talked about children being shifted to cheaper schools due to economic constraints. (ILO, 2003).

The present study is revealing more than what has been mentioned above. Even though the HIV-positive parents do feel unhappy about shifting their wards from the private to government school, when they actually have to decide between their daughters and sons, they seem to be discriminating against their girls. This again suggests that given the limited resources, the HIV households are likely to spend more on the education of boys than on girls.

5.4 School attendance

The survey attempted to find out whether presence of an PLWHA in the household affects the school attendance of children and whether there is any difference between boys and girls as far as their regular attendance in the school is concerned. While the findings do suggest that as compared to non-HIV households, on an average the children of HIV households were absent from school for more number of days, there is no evidence to suggest that girls were more irregular as compared to boys (Table

5.7). While the average number of days absent during the last academic session is more or less same for boys and girls in the case of non-HIV households; in the case of HIV households, for girls it is less in the 6-14 age group and more in the 15-18 age group.

Similarly, while there are differences between the HIV and non-HIV households in the reasons for absence not much gender difference is observed in the reasons for absence. The only gender difference worth mentioning is in the case of older children of HIV household. While 32 percent of the boys had absent themselves from school due to their parent' ill health, more than 40 percent of the girls had to dropout from the school in order to take care of their ailing parents. This shows that when parents fall sick, as compared to boys, more often, it is the girls who may be required to take up the responsibility.

5.5 Observations

Although there is hardly any gender difference in ever enrolment percentages, there are differences in the current

While 32 percent of the boys had absent themselves from school due to their parent' ill health, more than 40 percent of the girls had to dropout from the school in order to take care of their ailing parents

Table 5.7

School attendance of children in the last academic year by type of household

(in Percentages)

Age 6-14 years	HIV households			Non-HIV households		
	Boys	Girls	All	Boys	Girls	All
No of days absent during last academic year (Averages)	11.11	9.88	10.53	7.01	7.03	7.02
Reasons for absence (percent)*						
Child unwell	50.0	51.7	50.8	67.3	70.5	68.7
Parent unwell	31.5	25.3	28.6	6.6	6.6	6.6
Went out of station	29.1	27.4	28.3	39.5	36.5	38.1
Not paid fees/not allowed to attend	4.7	4.0	4.4	0.7	0.7	0.7
Child refused to attend	18.7	17.9	18.3	22.0	22.6	22.3
Had to attend social function	12.5	8.9	10.8	23.5	23.8	23.7
Had to look after younger siblings/attend to HH chores	3.5	4.9	4.2	2.5	2.9	2.7
Others	6.5	6.8	6.6	5.4	4.5	4.9
15-18 years						
No of days absent during last academic year (Averages)	9.23	10.12	9.62	6.70	6.56	6.65
Reasons for absence (percent)*						
Child unwell	43.5	45.2	44.2	65.6	67.8	66.6
Parent unwell	31.5	41.1	35.8	11.1	9.4	10.3
Went out of station	31.5	20.5	26.7	46.2	42.2	44.4
Not paid fees/not allowed to attend	2.2	1.4	1.8	1.2	1.3	1.2
Child refused to attend	12.0	9.6	10.9	13.0	8.1	10.7
Had to attend social function	18.5	16.4	17.6	25.1	27.3	26.1
Had to look after younger siblings/attend to HH chores	13.0	13.7	13.3	4.2	6.6	5.3
Others	6.5	6.8	6.7	5.0	6.5	5.8

* The percentages do not add to 100 due to multiple answers.

enrolment percentages and as compared to non-HIV households, this gender gap in the current enrolment percentages is marginally more among the children of HIV households. The impact of HIV and AIDS on the education of the girls may not look very significant if compared to the gender gap in schooling between HIV and non-HIV households. However, what is to be remembered is that even though the differences in the gender gap may not be very significant, in absolute terms, the current enrolment percentages are quite low for the girls. Any further fall in these percentages is going to have a significant impact on the number of girls being educated. Also, as compared to other studies on the subject, in the present study the children of HIV households have at least one of the parents alive. The impact may be much more severe when these children become orphans. Though both boys and girls would be affected, girls may be worse off, given the social conditions in the country.

In the HIV households, not only the dropout rates are higher for the girls but the reasons for dropout also clearly bring out the gender stereotypes expected in the Indian society. The boys are mostly withdrawn from school to take up income earning activities and girls are withdrawn in order to take care of their younger siblings and household chores.

Stigma and Discrimination

Chapter 6

Stigma and Discrimination

Stigma is not new to public health, nor is it unique to HIV and AIDS. History provides an abundance of unfortunate examples of "prejudice, discounting, discrediting and discrimination" towards persons who are sick or perceived to be sick. People suffering from such diseases as leprosy, cholera, and syphilis have been subjected to stigma in the past (Herek G M, 1998). Sexually transmitted diseases in particular are notorious for triggering socially divisive responses and reactions (See UNAIDS 2000). UNAIDS characterises HIV-related stigma as a process of devaluation of those living or associated with the epidemic and it defines the discrimination, that may follow, as the unfair and unjust treatment of an individual based on real or perceived HIV status.

The factors that contribute to HIV and AIDS- related stigma are:

1. HIV is a life-threatening virus and hence people are scared of contracting it.
2. The virus is associated with behaviours (such as sex between men and injecting drug use) that are already stigmatised in many societies. Sex outside marriage is also stigmatised.
3. People living with this virus are often held responsible for the infection.
4. Unlike other leading causes of mortality, HIV selectively affects young adults, the most productive members of society. The effects of ill health and death among these individuals are amplified because of their dependents.

HIV and AIDS-related discrimination, stigmatisation and denial can appear in a variety of forms, at various levels and in different contexts. The important contexts are the family and the local community, employment and the workplace, and the healthcare system. This stigma has been compounded by fear arising from lack of knowledge about the modes of transmission of the infection. Because of the stigma attached to it, PLWHA have experienced violent attacks, have been deserted by spouses and families, rejected by communities and workplace, refused medical treatment and been denied even the last rites. Apart from this, stigma and discrimination associated with HIV and AIDS is one of the greatest barriers to preventing further infections and to accessing the care, support and treatment services that allow PLWHA to lead productive lives.

In our society where gender differences exist in all walks of life, is it that all HIV affected are stigmatised to the same extent, or are men and women infected by HIV treated differently? There are evidences to show that stigma and

discrimination surrounding HIV and AIDS has particularly heavy impact on women. According to UNAIDS in many parts of the world, HIV and AIDS is incorrectly perceived as 'women's disease' or 'prostitute's disease' preventing women from going in for HIV testing or seeking care to avoid being ostracised, abused, and viewed as promiscuous. In this chapter an attempt has been made to study the gender differences in the stigma attached to HIV and AIDS, based both on the data collected through the field survey as well on the case studies and Focus Group Discussions conducted with female PLWHA in the six selected states. Before studying the differences in stigma, an attempt has also been to find the differences, if any, in the ways of discovering their status, their initial reaction to it and the reaction of spouse and family.

6.1 Discovering HIV status

An HIV-infected person would not know his/her HIV status for a long time unless he/she goes in for a blood test. This could be either after a prolonged illness of unknown cause when doctors recommend it, or at the time of donating blood or during pregnancy. Health counsellors also recommend the spouses of those who test HIV-positive to go in for voluntary testing.

Table 6.1 gives the percentage distribution of PLWHA by ways of discovering their HIV status. It is noticeable that there is a gender difference in the percentage of the PLWHA who have discovered their status in a given way. It is seen that while nearly 55 percent of the men who had tested HIV-positive had gone in for the test after prolonged illness,

Table 6.1

Distribution of PLWHA by different ways of discovering their HIV status

(in Percentages)

Characteristics	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
Discovering HIV status						
Voluntary testing	31	55.8	45.6	58.3	39.3	57.2
After prolong illness	63.3	28	48.7	23.8	54.9	25.7
During pregnancy-spouse/self	0.9	11.5	0.5	12.3	0.7	12.0
Blood test at the time of joining a job	1.1	0.2	1.7	--	1.4	0.1
Others	3.8	4.5	3.5	5.6	3.6	5.1
Place of testing						
Government hospital	52.9	67.5	58.5	64.6	56.1	65.9
Private hospital/clinic	47.1	32.5	41.5	35.4	43.9	34.1
Mode of Infection						
Sexual contact (Heterosexual)	76.1	89.3	67.1	87.3	71	88.2
Sexual contact (Homosexual)	1.7	1.9	2.7	1.2	2.3	1.5
Blood transfusion/donation	3.3	2.1	2.4	2.6	2.8	2.4
Needle sharing	13.9	2.6	24	2.8	19.7	2.7
Others	5	4.1	3.8	6.1	4.3	5.2
N (Number of persons)	**577**	**468**	**766**	**576**	**1,343**	**1,044**

this percentage was less than half in case of women (26%). However a high percentage of women (57%) had gone in for voluntary testing and comparatively the percentage of men under this is lower (40%). The above differences in percentages indicate the possibility of the infection being transmitted from men to women in a higher percentage of cases. It is also, now becoming evident that in a higher percentage of cases HIV is being transmitted from men to women, particularly in Asian countries (UNAIDS 2005). Not only are more and more women getting infected, but one of the main reasons for this is the gender difference that exists in society. It is indeed sad that not only are these women getting the infection because of the gender differences that exist, but that they have to again suffer more discrimination than men.

Around 12 percent of the women discovered their HIV status during pregnancy and a few men also discovered their status when they got themselves tested after their wives tested positive during pregnancy.

Even with regard to the place of testing, it is seen that a higher percentage of females have got the test done in government hospitals as compared to men. Consequently, percentage of females getting tested in private health facilities, which are much costlier, is less than that of the males. This is in line with the findings in chapter 4 on gender differences in the source of treatment of opportunistic infections. It was found that men had sought treatment from the private health facilities for a much higher percentage of cases.

In India, the main route of HIV transmission is through sexual contact and this route accounts for approximately 86 percent of the HIV infections in the country. The remaining 14 percent are by other routes such as blood transfusion, parent-to-child-transmission and injecting drug use, particularly in North-eastern states and some metropolitan cities (NACO, 2005). The present sample, which includes PLWHA from two North-eastern states also, shows that the main mode of transmission of HIV infection is through sexual contact, that too heterosexual contact, although the percentage is slightly lower than the average. Here again, it is seen that the percentage of women who have got it through heterosexual contact is higher than that of men in both rural and urban sample. The percentage of women who have got it through needle sharing is however much less than that of men.

In India, the main route of HIV transmission is through sexual contact and this route accounts for approximately 86 percent of the HIV infections in the country

6.1.1 Initial reaction

The survey tried to find out how the affected persons and their family members reacted as soon as the HIV status was discovered and Table 6.2 presents these findings.

There were a variety of reactions from the PLWHA when they first came to know about their positive status. A high percentage of the PLWHA (more than 65%) were shocked to know that they were positive. More than about 35 percent of the sample could not believe the fact that they were positive. While a little more than 20 percent of the PLWHA were embarrassed because of this, around 11 percent did not want to face their families. About 12 percent of them decided to keep their HIV-positive status a secret, as they feared discrimination and rejection. A few of them decided to stay away from family and spouse. Although there are slight differences in the percentages of men and women under different reasons, there are no marked gender differences.

Table 6.2

Distribution of sample PLWHA by reaction to their HIV status

(in Percentages)

Characteristics	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
Initial reaction (Self)*						
Shocked	64	67.3	69.8	71.4	67.3	69.5
Embarrassed	25.5	21.8	22.5	21.4	23.8	21.6
Could not believe	35.4	34.8	37.3	35.1	36.6	35.0
Didn't want to face the family	12.5	9.0	13.3	9.72	13	9.4
Decided to stay away from the family & spouse	4.9	1.5	3.4	2.3	4.02	1.9
Decided to keep HIV status secret	13.3	10	13.2	12	13.2	11.1
Others	0.4	0.4	0.7	1.2	0.5	0.9
Initial reaction of spouse/family members *						
Shocked	47.8	28.6	42.4	29.3	44.7	29.0
Denied/disappointed	18.7	14.7	21.8	14.4	20.5	14.6
Empathized	16.3	21.4	14.9	18.6	15.5	19.8
Embarrassed	10.9	8.3	8.8	6.2	9.7	7.18
Supportive	41.4	44.4	42	44.8	41.8	44.6
Disowned by the family	1.2	6.8	1.4	6.1	1.3	6.4
Spouse deserted	2.4	2.3	1.7	2.1	2.0	2.2
Not informed anybody	13.7	13.4	16.7	16.3	15.4	15
Others	1.6	2.8	2.7	4.7	2.2	3.8
Current attitude of spouse/family members*						
Neglected, isolated, verbally/ physically teased	6.8	11.5	7.1	12.9	6.9	12.3
Leave home	1.7	5.6	2	5.4	1.9	5.5
All are supportive	61.9	55.1	55.6	55	58.3	55.1
Family is not but spouse is supportive	11.8	7.7	12.8	9.2	12.4	8.5
Initial hesitation, but then supportive	11.3	12.4	19.5	11.3	15.9	11.8
Others (Deprived of using basic amenities at home asked to leave home)	5.5	7.7	4.7	7.6	5.1	7.6
Total number	**577**	**468**	**766**	**576**	**1,343**	**1,044**

*Multiple Responses

What is interesting here is that, of those households where the initial reaction was one of shock, it is seen that the percentage of families shocked when the PLWHA is a male is much higher than when the PLWHA is a female. This could be indicative of the fact that a large number of females had tested positive after their husbands had already tested positive, and hence the spouse and family probably expected it and hence the disclosure of the status did not come as a shock.

6.1.2 Current attitude of spouse/family members

Although the initial reaction of the family members does not show marked gender differences as to their being supportive and empathising with the PLWHA, it is the reaction after the news sinks in, that is the current attitude, which is of greater interest. The current attitude of the family members as seen in the survey is quite encouraging, as 74 percent of male and 70 percent of female sample have reported that their families are quite supportive in spite of there being slight hesitation initially by a few (in the case of females 'family support' includes support from natal family also). This speaks of the strong family ties in India. In fact, in most families, the family members feel that it is their duty to take care of the affected members and the family keeps diseases like leprosy and TB as a closely guarded secret.

However, it also points out the gender gap in the percentage receiving support from the family, and this gender gap exists irrespective of whether the sample is urban or rural. The gender difference is more noticeable when we see that while nearly 5.5 percent of female PLWHA have been asked to leave home, only 1.9 percent of the male PLWHA have been subjected to this. Also, in cases where the family is not supportive but the spouse is, it is noticed that more women are supportive of their HIV-positive husbands (12.4%) than men are of their HIV-positive wives (8.5%). Again the percentage reporting problems like "deprived of using basic amenities" is more in the case of women than men and this gender difference is irrespective of the place of residence. Discrimination in the form of neglect, isolation, verbal teasing was reported by a higher percentage of women in both urban and rural areas. On the whole, although the family support is only marginally higher for male PLWHA, it is their discriminatory attitude towards women that is worse.

6.1.3 Coping with the situation

As seen earlier, when their HIV-positive status was detected, initially most of the people were shocked, disbelieving or embarrassed. The survey tried to find out from the PLWHA how they managed to cope up with the situation and how they got over the initial shock. Table 6.3 presents the percentage distribution of the PLWHA by various types of coping mechanisms adopted by them and the nature of moral support received by them from various people. Around 40 percent of the HIV-positive men and 32 percent of HIV-positive women reported that the counselling received from the counsellors helped them to come to terms with the situation.

The gender difference is more noticeable when we see that while nearly 5.5 percent of female PLWHA have been asked to leave home, only 1.9 percent of the male PLWHA have been subjected to this

However, once again it is seen that family support to women is less than that to men. What is to be appreciated is that in

Table 6.3

Distribution of PLWHA by coping mechanism adopted to get over initial shock/disbelief

(in Percentages)

Characteristics	Male	Female
Counselling	39.7	32
Confidently	6.8	6.9
Family support	17.7	11.9
Friend support	1.6	3.8
Became alcoholic	--	0.4
Decided to keep HIV status secret	1	0.5
Help others	0.2	0.3
NGO support	1.9	1.6
Wanted to know how to live with HIV status	31.2	42.7
Total	**100**	**100**

spite of this, the percentage of male and female PLWHA who faced the situation confidently is the same and a higher percentage of women wanted to know more about the infection and the ways and means of leading a quality life in spite of their HIV-positive status.

6.2 Disclosure of HIV status

While 84 percent of women in the sample informed their spouses immediately, the percentage of men who did the same is lower at 69 percent

Disclosure of HIV status, particularly disclosure to spouse and hospitals is linked to the spread of HIV. However it is noticed that whether an individual who is infected by HIV would disclose his/her status to others would depend upon the kind of reaction that the individual expects from them. About 12 percent of the sample PLWHA initial reaction was not to disclose their status to anyone. It is seen from Table 6.4 that while 84 percent of women in the sample informed their spouses immediately, the percentage of men who did the same is lower at 69 percent. But of those who have not informed their spouses even after one year, it is seen that the percentage of women is slightly higher at 7.5 percent as against 7.1 percent for men. This could probably be because if the woman is HIV-positive without her husband being the same, her perception would probably be that the husband/family would not support her or keep her. It has been found in a study in sub-Saharan Africa that fewer than one in two women who learn during their pregnancy that they are HIV-positive had not told their partners because of the fear of being abandoned by their husbands (Annabel DESGREES du LOU, 2005).

Even in Karnataka an in-depth interview conducted shows that due to insecurity, a HIV-positive woman does not disclose her status when her husband is not positive. Due to fear of losing the economic, physical and emotional support provided by her husband she did not want to disclose her status to her husband.

Nearly one-fourth of the sample PLWHA has not disclosed their HIV-positive status in the community, fearing, in all probability, the stigma and discrimination they will fall victim to. No gender difference or urban rural divide is seen in this.

Table 6.4

Distribution of PLWHA by disclosure of status

(in Percentages)

Characteristics	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
Who initially decided to keep HIV status a secret	13.3	10.0	13.2	12.0	13.2	11.1
Who informed their spouse						
Immediately	72.9	84.3	66.4	83.3	69.3	83.7
Within six months	14.2	6.1	16	5.8	15.2	5.9
Within one year	4.0	2.9	7.2	1.6	5.8	2.2
After one year	2.1	0.3	3.0	0.9	2.6	0.6
Not informed their spouse	6.9	6.4	7.3	8.4	7.1	7.5
Not disclosed to anyone in the community	**23.4**	**23.9**	**25.2**	**27.4**	**24.4**	**25.9**

*Multiple Response

Box 3

Case Study 3: Disclosure of HIV status and security

This is the story of an illiterate woman, aged about 25 years, from a village near Dharwar. She was married at a young age to a man who works in a hotel. Due to some differences, she left her husband and got married again to another person who was a driver. In 2002, she became pregnant and as per the doctor's advice, went to a VCTC. Both she and her husband were given complete information regarding HIV and their blood was tested. While the woman tested HIV-positive, the husband was HIV negative. She feels that she may have contracted the infection from an infected syringe in her village. The husband was very supportive of her and assured the counselor that he would take good care of his wife. Till the time that she went to the government hospital, in Hubli, her husband was very good to her. But the hospital staff there turned him against her and advised him to separate from her, asking him why he wanted to waste his life by spending with her. Thereafter, he stopped coming home and abandoned her. She had nobody to take care of her or the baby. She was badly in need of money; the child was also not well. With the help of an NGO she wanted to file a case against him for money to look after the child. However, before this could be done, the child died. At this time, her mother was her only support.

Now she has gone back to her first husband who looks after her very well. But she has not informed him about her HIV-positive status, nor does she following safe sex procedures. She does not want her husband to become suspicious. This is in spite of knowing that she could well be transmitting HIV to him, coupled with the fact that he has been nice enough to accept her after knowing that she was with someone else for a long time. Because of past experience she now feels that if her husband knows about her status he will surely leave her, and she does not want to be forsaken by everybody.

6.3 Stigma and discrimination faced by PLWHA

Stigma and discrimination experienced by the PLWHA at different settings, namely family, community, workplace and healthcare facilities are presented in this section.

6.3.1 Stigma and discrimination in the family and community

It has already been seen from Table 6.2 that quite a big percentage of the PLWHA have been getting support from their families. However it has also been seen that more women are being discriminated against as compared to men. In the FGDs that were held in the six states, while there were some fortunate ones who were being looked after by their families, there were also those who were being discriminated against in some way or the other in the family. But one thing that came out clearly was that the daughters-in-law were treated much worse than the sons, and some even said that there was no place in the family for a daughter-in-law if the son died.

Some of the ways in which HIV-positive women were being discriminated against, which came out in the FGDs are as under.

1. In the case of a widow in Maharashtra, who had one son and one daughter, both HIV-negative, her in-laws were willing to take care of only the son and not the daughter. The reason given was that the boy was the last hope of continuing the lineage of the family, as there was no other male child in the family.
2. Whenever the men needed to go to the hospital, the wives accompanied them. However, when the women

had to go for treatment or collecting ART drugs etc, no one accompanied them.

3. Some of the men knew their HIV-positive status before their marriage. However they did not inform the brides about this. Whether the men came to know about their status before or after the marriage, generally the in-laws abetted them in keeping it a secret from the wife. Some of the female participants came to know of their HIV status only after the death of their husbands. While the family gave care and support to their sons who were HIV-positive, there was no such consideration for their wives. In fact, many a times the daughters-in-law were abused as being the cause for their sons' infection.
4. The HIV-positive women felt that they have more problems than men. They have to look after their husbands, families and children and also have to worry about financial problems. Even though the men know that their wives were also HIV-positive, and could not do a lot of physical work, they did not help them in the household chores. In a number of cases, apart from the household duties, they had also been forced to take up jobs because of monetary problems.

In the case of women, the family is supportive in lesser percentage of cases and a higher percentage of women were deprived of using basic amenities at home

In a case study conducted in Maharashtra, the parents-in-law knowingly did not reveal the son's positive status to his wife, and she too became infected. When the husband was very sick and was admitted to the hospital, she was sent back to her parent's house along with the two kids. When he died, she was not even allowed to see the body for the last time. Even after she took treatment, and wanted to go back to the in-laws, she was prohibited from returning and also deprived of her legitimate share in the family property (See Box).

These findings are also in line with the existing literature on the subject. In a study by Bharat, it was found that in most developing countries, the families and communities were generally providing supportive environment for illness management and treatment. However the same study also found that although majority of those who disclosed their HIV status with their families received care and support, it was generally men rather than women who qualified for such care. Gender seems to be a strong determinant of the type of response one receives from the family: daughters, wives and daughters-in-law experience higher levels of discrimination than men (Bharat et al 2001). Daughters-in-law are commonly accused of infecting the husband and removed from the familial home after the death of a son. Married women respondents were forced to have intercourse with positive husbands, despite having knowledge of his status. HIV-positive mothers have also reported separation from children or being forced to give up their babies (Bharat et al 2001,ILO 2003).

In a study sponsored by UNIFEM and jointly conducted by Centre for Advocacy & Research (CFAR) and the Positive Women's Network (PWN+), Chennai in 2002 in Kerala, Karnataka and Tamil Nadu, it was reported that women faced harassment and violence within and outside the family. Humiliation in both marital and natal homes and lack of programmatic response from the state drove women to destitution.

In the present study, it was found that as compared to men, in the case of women, the family is supportive in lesser percentage of cases and a higher percentage of women were deprived of basic amenities at home. The case studies and the FGDs also brought out stories of ill treatment by the in-laws.

Box 4

Case Study 4: How unsupportive family members can ostracise their own

Soon after completing matriculation, she was forced to marry someone who was 17 years older than she was, even though she was keen to study further. After marriage, she started living in a large joint family consisting of husband's parents, uncles, aunts, brothers and sisters and was happy.

Things were fine for a while, but after some time, she started noticing changes in the behaviour of her husband who began to leave home early and return late in the night. Sometimes he used to go out of town for a couple of days. In the meantime she became pregnant and gave birth to a girl child in her parental home. Soon after, her husband became ill with tuberculosis. After some improvements, he was out of bed.

When she became pregnant for the second time, her husband was again bedridden due to constant fever, loss of weight and mouth ulcers. Subsequent to this illness, the doctors confirmed that he was HIV-positive. Since then, her husband and she began to receive inhuman and unsympathetic treatment from the family. They were kept in a separate room as if in quarantine. Their clothes, utensils and other necessary things were kept separately and were not allowed to mix with others.

Since her husband's illness was kept a secret from her, she was unable to understand the reason for such behaviour from her in-laws. Then she gave birth to a son, but unfortunately she could not feel the joy as she too tested HIV-positive. When her husband realised that the situation was going out of control, he explained the nature of his illness to her and on hearing that she collapsed.

The situation continued to steadily deteriorate. When her husband was admitted to a hospital, she was sent back to her parents' house with her two kids, with instructions not to disclose her illness to anyone, to save the reputation of the family.

Forcibly separated from her husband, she could do nothing except pray for him.

While discharging him, doctors had instructed his family members not to keep him at home when he breathed his last since the viruses in his body might affect other people. Hence, his family took him to a remote field and left him alone to die. Even his wife who might have given him the most needed company, was forcibly driven to her parental home. He died alone.

Even after his death he was not spared. People were so afraid that nobody came forward to perform his last rites and the body was wrapped in a plastic sheet for its journey to the cremation ground. Not a single vehicle owner was ready to carry the body and even the men at the cremation ground refused to touch the body. Of course money played the trick and he was cremated.

His wife was not allowed to see his body, she was told by her in-laws not to come back to the house, since they were afraid that if she was allowed to stay with them, they might also get infected. She was also deprived of her legitimate share in the family property.

The community's perception about the epidemic also influences the family's responses to the infected individual. If the family expects isolation and ostracism from the community, then the family may not include the HIV-positive individual in the family. Table 6.5 presents stigma and discrimination faced by PLWHA in the community and neighbourhood. It has already been seen in Table 6.4 that nearly 25 percent of the PLWHA have not disclosed their status in the community. Of those who have disclosed their status, about 10 percent have reported discrimination mostly in the form of isolation and neglect. They have also been subjected to other kinds of discrimination like-teasing, social boycott, their children are not allowed into the anganwadi centres etc. In some

The presence of an HIV-positive individual does seem to affect the marriage and job prospects of other family members to some extent

cases they have also been refused houses on rent. In the present study gender differences or rural/urban divide is not seen. In the FGDs that were held in the states during the survey, most of the participants informed that they had not revealed their status in the community. Of those whose status was known to others, while some had no problems, others had been subjected to some form of rejection. Some had faced problems in getting houses on rent. In the FGD held in Mumbai, one of the female participants said "HIV-positive women are looked down upon as if they were sex workers". Other studies also give evidence of reactions like ostracism, differential treatment at death, and discrimination in schools towards children of infected parents (Bharat et al 2001; ILO 2003).

The presence of a PLWHA does seem to affect the marriage and job prospects of other family members to some extent. While in the case of marriage prospects, the relatives of female PLWHA seem to be more discriminated against, in case of employment prospects both seem to be equally affected.

6.3.2 Discrimination at workplace

Every person has a right to gainful employment and right to earn a living. For a person affected by HIV it becomes more important to earn in order to have nutritious diet to keep the opportunistic infections at bay. Since a working person spends most part of the day in the workplace it is also essential that the atmosphere is conducive to work. One does generally think of workplace as a likely location for the spread of the infection. However, for a number of PLWHA, getting gainful employment could become a problem due to stigma and discrimination against such persons. In a workplace, stigma and discrimination against PLWHA can manifest through discriminatory hiring and promotion practices and work allocation, establishment of unfair benefit packages and negative attitude of employers, co-workers and managers. In the present study, details about

Table 6.5

Stigma and discrimination faced by PLWHA in the community and neighbourhood by sex

Characteristics	Male	Female	Rural	Urban	Total
Reporting that they are treated differently or badly	9.5	10.7	10.6	9.6	10.1
Type of discrimination faced by those reporting stigma/discrimination*					
Neglected, isolated	67.2	65.2	63.1	69.0	66.3
Verbally abused, teased	38.3	36.6	37.8	37.2	37.5
Children not allowed to play with other children/anganwadi centre	29.7	27.7	30.6	27.1	28.8
Socially boycotted or debarred from public amenities	33.6	25.9	28.8	31.0	30.0
Mahila Mandal	3.9	4.5	8.1	0.8	4.2
Refused house for renting	5.5	5.4	2.7	7.8	5.4
Others	14.1	10.7	11.7	13.2	12.5
PLWHA whose siblings' marriage prospect were affected	1.1	2.0	1.6	1.4	1.5
PLWHA whose family members' job prospects was affected	1.2	1.1	1.2	1.1	1.1

*Multiple Response

disclosure of the status in the workplace, discrimination and support by the employer etc were collected.

Out of the total of 2,387 PLWHA who were interviewed during the survey, it was found that 1,152 of them were employed. A vast majority of them (74%) have not disclosed their status at their work place and the most important reason for not disclosing their HIV status turned out to be fear of losing the job. The percentage of women working in comparison to men in the sample is low. And most of them have not disclosed their HIV status at their workplace. Most of the women who have disclosed their status are employed in NGOs working in HIV and AIDS sector. Hence, a gender comparative study of discrimination at workplace could not be done.

6.3.3 Discrimination at health facilities

PLWHA are prone to many opportunistic infections and need to visit hospitals very often. While one expects that they would be treated with care and consideration, the healthcare setting has emerged as the most frequently encountered place of discrimination, followed by familial and community contexts. Table 6.6 presents percentage distribution of sample PLWHA reporting discrimination at health facilities. It is possible that some of the PLWHA who are in the early stages of infection may not have visited health facilities and this could be a reason why the percentage of those who have reported discrimination is quite low even though many such cases were reported during the FGDs.

Table 6.6

Discrimination at health facilities

(in Percentages)

Characteristics	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
PLWHA reporting discrimination at health facilities	13.9	11.1	14.8	12.7	14.4	12
Place of discrimination						
PHC/CHC	13.8	11.5	4.4	2.7	8.3	6.4
Government hospital	51.3	67.3	64.6	72.0	59.7	70.4
Private doctor/hospital	35.0	15.4	28.3	24.7	31.1	20.8
Type of discrimination*						
Neglected, isolated	38.8	36.5	39.8	39.7	39.4	38.4
Verbally or physically abused, teased	30	28.9	31.9	26	31.1	27.2
Refused medical treatment	26.3	28.8	22.1	28.8	23.8	28.8
Referred to another health facility	31.3	11.5	27.5	32.9	29	24
Refused access to basic facilities	2.5	3.9	3.5	1.4	3.1	2.4
Unnecessary use of protective gear	22.5	32.7	17.7	15.1	19.7	22.4
Excuses	5	7.7	7.1	11	6.2	9.6
Shunting	10	13.5	12.4	9.6	11.4	11.2
Others**	3.8	1.9	8.8	5.5	6.7	4

(Contd...)

Table 6.6 (Contd...)

Attitude of other patients						
Neglected, isolated	18.8	23.1	31	27.4	25.9	25.6
Verbally or physically abused, teased	12.5	9.6	8.8	9.6	10.4	9.6
Refused to seek treatment with HIV	12.5	7.7	14.2	8.2	13.5	8
Restrictions on movement in ground	7.5	9.6	4.4	5.5	5.7	7.2
Status not known to others	37.5	28.9	33.6	37	35.2	33.6
Not discriminated	30	25	16.8	17.8	22.3	20.8
Others (Refused to seek treatment along with PLWHA)	3.8	7.7	9.7	5.5	7.3	6.4
Reporting Denial of admission at health facility	4.7	3.6	6.3	4.2	5.6	3.9

*Multiple response

**Others i
hospitals, doctor did not touch/gave wrong information.

There are no noticeable gender differences either in the percentage of those who reported discrimination, or the ways in which they were discriminated against in the health facilities

About 14.4 percent of male and 12 percent of female sample PLWHA reported that they had faced discrimination at health facilities, the percentage being slightly higher in urban areas. Among them more than 65 percent of male PLWHA and more than three-fourths of female PLWHA have faced discrimination at government health facilities. The fact that only 30 percent of men and 20 percent of women among those reporting discrimination, have reported discrimination at private health facilities, may give an impression that there is less discrimination in the private set up. It has already been seen in the chapter on profile that the economic background of the PLWHA is very bad. Hence, one can reasonably assume that only a small proportion of the PLWHA are likely to go to private health facilities, while the majority may be going to government hospitals.

Of those PLWHA who reported discrimination, about 25 percent were either refused medical treatment or were referred to another health facility, nearly 40 percent felt that they were neglected and isolated, about 30 percent were abused and teased. About 4.5 percent reported that they were denied admission at health facilities. Unnecessary use of protective gear by hospital authorities was reported by about 20 percent.

There are no noticeable gender differences either in the percentage of those who reported discrimination, or the ways in which they were discriminated against. There were also no noticeable gender differences in the attitude of other patients.

In the FGDs that were conducted in the states where the survey was done, most of the participants mentioned that they had been discriminated against by hospital officials in both government and private hospitals. The discrimination ranged from not agreeing to treat PLWHA patients to ill treating them, not touching the patient, informing others about the patient's HIV-positive status, charging additional fees from them etc. In fact, the participants narrated instances where they were forced to go to the hospital without revealing their status out of fear that if they reveal their HIV-positive status they would be denied treatment. However, the PLWHA

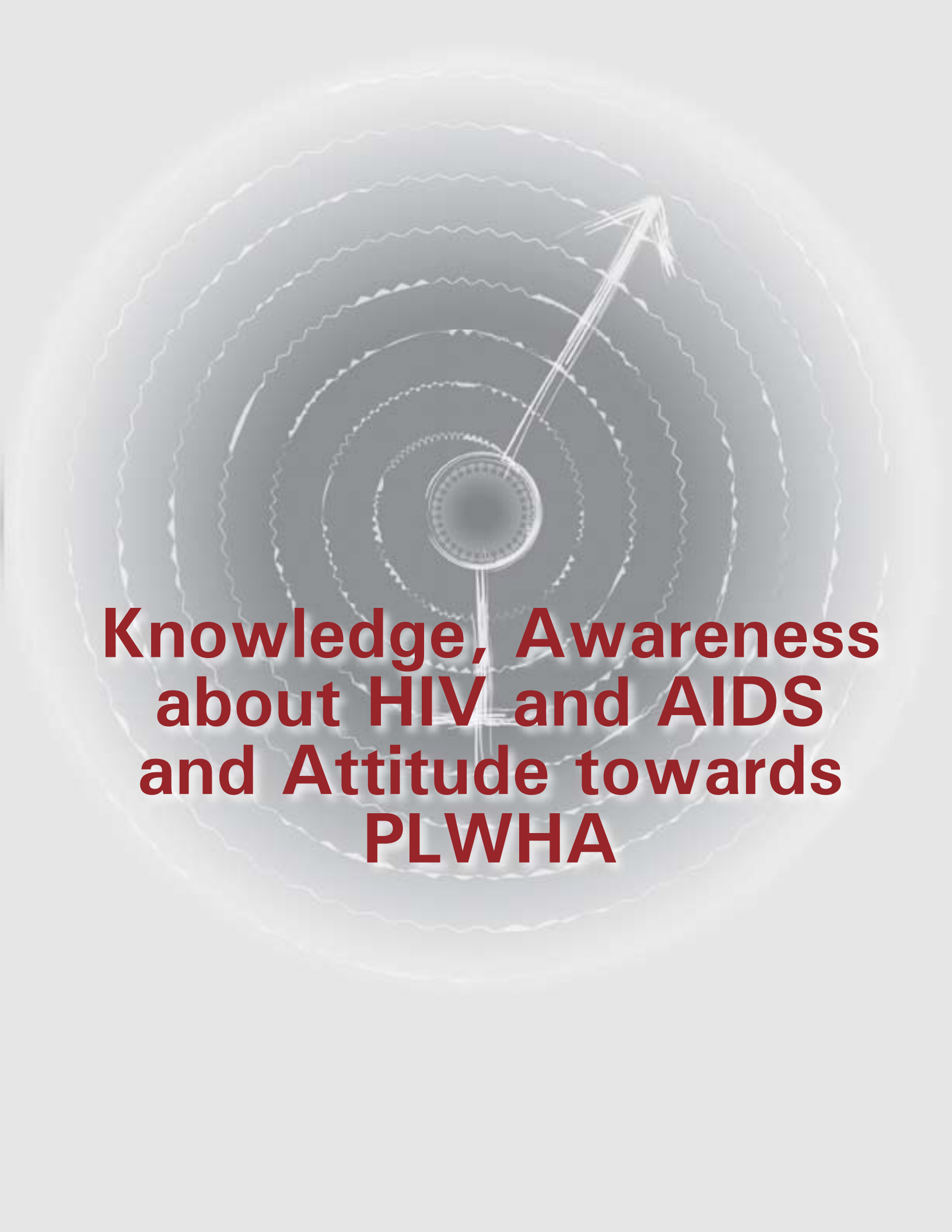
were discriminated against because of their positive status and not because of their sex. But, in the FGD held in Andhra Pradesh, the female PLWHA felt that the nursing sisters behaved rudely with female PLWHA and called them names and put them under tremendous psychological pressure in government hospitals.

6.4 Observations

It is clear from the above that there is a strong gender bias in HIV and AIDS related stigmatisation, discrimination and denial, especially in the family and women and men are treated differentially in the family. While men are more likely to be accepted, women are blamed even when they get infected by their husbands. One could easily infer from the survey that most of the women have been infected by their husbands. A significant percentage of men have not disclosed their HIV status to their wives immediately after discovering their status. Husbands not taking their wives into confidence indicates poor communication and understanding between couples on such a serious issue like HIV and AIDS. To begin with, women do not have equal status inside Indian households in general. The HIV infection widens the gender inequality within the household.

As rightly emphasised by the UNAIDS Inter-Agency Task Team on Gender and HIV and AIDS, equality and non-discrimination should not only be important principles of human rights law, but are also vital for HIV and AIDS prevention and for ensuring equitable access to care, treatment and support for those affected by the infection. It is essential that the lives of women affected by HIV be improved. It however appears that legal solutions alone will not help solve the problem. What is required, is a change of attitude, particularly among women. As seen from the in-depth interviews, in most of the cases, discrimination in the family starts from the mother-in-law.

There is a strong gender bias in HIV and AIDS related stigmatisation, discrimination and denial, women and men are treated differentially especially in the family



Knowledge, Awareness about HIV and AIDS and Attitude towards PLWHA

Chapter 7

Knowledge, Awareness about HIV and AIDS and Attitude towards PLWHA

The success of any programme to prevent the spread of HIV and AIDS would depend on improving people's knowledge about HIV and AIDS and their attitude towards those who are already affected. The lack of knowledge about the modes of transmission leads to stigma and discrimination against the PLWHA and this in turn could further accelerate the spread of the virus since due to fear of stigma and ostracism, PLWHA would hide their status. The low levels of knowledge resulting in the general population not being aware about the methods of reducing risk of HIV infection has been one of the factors responsible for the spread of HIV in South Asian countries. (UNDP, 2003). The data collected on knowledge about HIV and AIDS in a number of countries show that globally, most of the women do not have sufficient knowledge about how HIV and AIDS is transmitted and little or no information on protection methods. (UNAIDS/UNFPA/UNIFEM, 2004). This lack of knowledge about the modes of transmission of HIV and AIDS makes women more vulnerable since they do not know the ways and means of protecting themselves.

This chapter presents the gender differences in knowledge and awareness about HIV and AIDS among the general population in India based on the survey of non-HIV households conducted in the sample districts of six HIV high-prevalence states. Through the survey of non-HIV households, 3,299 men and 2,925 women residing in the rural and urban areas of the sample states were interviewed. These men and women were asked a series of questions to not only to judge their knowledge and awareness about HIV and AIDS, but also to know their attitude towards PLWHA and their families.

7.1 Profile of the respondents

All the respondents were currently married, and in the age group 20-60 years. Most of them were in the age group of 31 to 40 and around one-fourth of men and 35 percent of women were below the age of 30 years. (Table 7.1). As compared to men, women were less educated; while 30 percent of men were illiterate, the percentage of illiterates among women was higher at 45. Nearly 36 percent of men and less than one third of the women had studied upto high school/higher secondary. As compared to men (17 %), the percentage of women who had studied beyond high school was lower at 13.

It has already been mentioned that most of these respondents come from low income households. Only a

Table 7.1

Distribution of respondents by age and level of education

(in Percentages)

	Male	Female
Age (Years)		
<30	24.8	34.9
30-40	42.6	45.3
41-60	32.6	19.8
Level of education		
Illiterate	30.0	45.1
Upto middle school	17.3	17.8
High school/ higher secondary	35.5	32.3
Graduate/diploma	17.2	13.0
(N) number of respondents	**3,299**	**2,925**

small percentage of the households belong to upper income households. (For details see Chapter two)

7.2 Knowledge and awareness about HIV and AIDS

The survey attempted to find out the extent of knowledge about HIV and AIDS among the general population and these findings are presented in this section.

A very high percentage of both men and women, although the percentage is marginally lower in rural areas as compared to urban, have at least heard about HIV and AIDS. However, although everyone has heard about HIV and AIDS, not all of them seem to have information on other details like whether HIV and AIDS transmission could be prevented and where to go for voluntary testing etc. More importantly, not many have come across any one suffering from HIV and AIDS or heard of anyone who died of AIDS, indicating that HIV and AIDS is still a rare phenomenon. The urbanites seem to be more knowledgeable about the details as compared to their rural counterparts.

In addition to these rural-urban differences, what strikes the most are the gender differences in knowledge and awareness about HIV and AIDS. As compared to men, marginally lower percentage of women have heard about HIV and AIDS. However when it comes to detail, women seem far less knowledgeable than men. While 63 percent of men knew that HIV and AIDS could be prevented, only about 51 percent of women knew this fact. Similarly, while 52 percent of men knew where to go for voluntary testing, only 36 percent of women had this information.

Table 7.2

Knowledge and awareness about HIV and AIDS

(in Percentages)

	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
Heard about HIV and AIDS	97.2	95.3	98.5	96.5	98.0	96.0
Think that HIV can be prevented	62.6	52.7	62.9	49.5	62.8	50.8
Know where to go for voluntary testing for HIV	49.0	34.3	54.0	37.1	51.9	35.9
Willing to go for an HIV test	49.0	34.3	54.0	37.1	51.9	35.9
Know someone suffering from HIV and AIDS	33.7	25.9	39.1	26.7	36.9	26.4
Know anyone who died of AIDS	44.2	35.7	48.4	35.6	46.7	35.6
Total	**1,378**	**1,225**	**1,921**	**1,700**	**3,299**	**2,925**

If we compare the results of the present survey with the Behavioural Surveillance Survey (BSS), one could see some improvement in the level of awareness about HIV and AIDS. In the year 2001, although in states like Andhra Pradesh, nearly 96 percent have heard of HIV and AIDS, in the other HIV high-prevalence states like Karnataka, Tamil Nadu and Maharashtra the percentage was 82 percent to 89 percent. (NACO, 2001). However, unlike the present survey the BSS 2001 showed a substantial gender difference in the percentage that have ever heard about HIV and AIDS, with the exception of Andhra Pradesh. At the all-India level, while 82 percent of the men had heard of HIV and AIDS, in the case of women this percentage was much lower at 70 (BSS, 2001). The gender differences in the awareness level has been brought out by a number of other surveys in India. For example, a survey conducted in the Bellary district of Karnataka found that not only the level of awareness about HIV and AIDS and STI was quite low across all sections of society, but also compared to men, women were much less aware of these issues. (Mahila Samakhya Karnataka, 2002). The National Family Health Survey II (NFHS II) conducted in 1998-99 found that 60 percent of women in India had never heard of AIDS (IIPS, 2000). Since then the level of awareness even among women seems to have increased as revealed by the present survey. One reason could be more people are aware about HIV and AIDS in high-prevalence states than in general. However as we would see in the next section, all may not have the right information about the modes of transmission etc.

A survey conducted in the Bellary district of Karnataka found that not only the level of awareness about HIV and AIDS and STI was quite low across all sections of society, but also compared to men, women were much less aware of these issues

7.2.1 Knowledge about modes of transmission

Obviously, it is not sufficient that people have just heard about HIV and AIDS. What is more important is to know the right modes of transmission, so that they could protect themselves from getting infected. Also, knowledge about the right modes of

Table 7.3

Knowledge about modes of transmission of HIV and AIDS

(in Percentages)

	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
Reporting right mode of Transmission						
All modes	59.1	56.5	56.3	52.7	57.5	54.3
Some modes	39.8	41.1	42.8	46	41.5	44
Not at all	1.2	2.5	0.9	1.2	1	1.7
Misconception that HIV can spread through						
Hugging/kissing	17.2	16.4	13.5	12.8	15.1	14.3
Sharing food /utensils	10.2	11.1	7.1	7.7	8.4	9.2
Mosquito bite	40.8	41.2	32.7	35.6	36	37.9
Touching/shaking hands	8.4	10.9	8.7	10.9	8.6	10.9
Sharing toilet	18.4	20.1	13.8	14.3	15.7	16.7
Sharing shaving kits/razors	79.3	69.9	81.1	72.9	80.4	71.7
Have heard of any other disease transmitted through sexual contact	46.6	31.6	56.1	39.6	52.2	36.3
Know that a person suffering from STI has greater chance of getting HIV/AIDS	53.2	38.4	62.5	45.9	58.7	42.8

transmission could reduce stigma and discrimination and help in overcoming the negative attitude towards those infected. Table 7.3 presents the gender differences in the knowledge about the various modes of HIV transmission.

A little more than 50 percent of the sample could mention all the right modes of HIV transmission, which includes sexual contact, sharing needle with an infected person, transfusion of infected blood and transmission from mother to child. Interestingly, the percentage knowing all the right modes as well as the percentage not able to mention even a single right mode are marginally more for the respondents living in rural areas.

While 58 percent of men knew all the modes of transmission, the percentage of women having knowledge about all the modes was lower at 54 percent

Again, the gender differences in the knowledge about the right modes of transmission are visible among rural as well as urban respondents; men seem to be better informed as compared to women. While 58 percent of men knew all the modes of transmission, the percentage of women having knowledge about all the modes was lower at 54 percent. Although, the percentage of people not knowing even a single mode of transmission is very small, it is marginally higher in case of women respondents. The surveys conducted in sub-Saharan Africa found that in 24 sub-Saharan countries, two-thirds or more of young women (aged 15-24 years) lacked comprehensive knowledge of HIV transmission. Data from 35 of 48 countries in sub-Saharan Africa show that on an average young men are 20 percent more likely to have the correct knowledge of HIV than young women (UNAIDS/WHO 2005).

Although a fair percentage of respondents knew the various modes of transmission, many of them also had misconceptions about the modes of transmission. These myths and misconceptions about the modes of transmission accentuate the stigma and discrimination against PLWHA. The most common misconceptions seem to be that sharing of razors (more than 75%) and mosquito bites (about 36%) could spread AIDS. The misconception about mosquito bites seem very common not only in India, but in other countries as well. For instance, according to a study conducted in Vietnam almost half of young women believed that they could get HIV from a mosquito bite (UNAIDS/UNFPA/UNIFEM, 2004). Fortunately, only few of the respondents believe that hugging and kissing a PLWHA or sharing food and utensils and touching or shaking hands with the PLWHA could infect them as well.

Generally, the misconception about the modes of transmission was marginally higher among women except for two of the misconceptions (i.e. hugging/kissing and sharing shaving kits and razors could spread HIV infection) where the percentages were marginally higher for men.

It has been estimated that the Sexually Transmitted Diseases (STDs) can trigger the spread of HIV infection by increasing the risk of acquiring the virus two to five times (Mahbub-ul-Haq, Human Development Centre, 2005). In some of the HIV high-prevalence states in India, the prevalence rate of HIV among those attending STI clinics is as high as 16 percent. Hence, the survey attempted to find out whether people were aware of this link between STDs and HIV. The general level of awareness seems quite low and as compared to men, women seem far less knowledgeable; while more than 50 percent of men knew about STI, only about 36 percent of women have heard of HIV. Again a much higher percentage of men (59%) than women (42%) knew that a person suffering from

STI has greater chance of getting HIV. Awareness about sexually transmitted diseases is essential if women want to protect themselves.

7.2.2 Knowledge about condom

Knowledge and awareness about condom assumes significance in the context of controlling the spread of HIV infection. Unprotected sex with multiple partners and non-regular partners is an important mode of HIV transmission.

In the present study, a higher percentage of men than women reported knowing all the three benefits of condom use namely; avoiding pregnancy, STI and HIV prevention. While the maximum number of people are aware of the use of condoms for avoiding pregnancy, lesser number are aware that its use can protect them from HIV infection, and people are least knowledgeable about its use in prevention of STI. In the present study, nearly two-thirds of men and almost half of women know that use of condom can prevent HIV transmission. The BSS Survey also showed a huge gender difference in the knowledge about use of condom. While 70 percent men knew that HIV could be prevented through consistent use of condom, only 48 percent of women had this knowledge in 2001 (BSS, 2001). Similarly, the BSS also showed that the knowledge about linkages between sexually-transmitted diseases and HIV and AIDS was not only low among the general public, but in most of the states as compared to men, women were far less knowledgeable. The male condom is the most efficient available technology to reduce the sexual transmission of HIV and other sexually transmitted infections. Unfortunately, even if women knew these facts, not many of them can negotiate safe sex with their partners, given their low status.

7.3 Exposure to media and knowledge about HIV and AIDS

A number of countries are using mass communication to create awareness among the general public about various aspects of HIV and AIDS. In India, one of the targeted interventions of NACO is to create correct, and complete awareness about HIV and AIDS among the people through mass media like television, radio, newspapers, magazines, hoarding etc. The survey attempted to find out which of these media have been helpful in creating awareness about HIV and AIDS. As we have already seen, 98 percent of men and 96 percent of women reported that they have heard about HIV and AIDS. These respondents were further asked to tell details about their source of information.

Knowledge about linkages between Sexually-Transmitted Diseases and HIV and AIDS was not only low among the general public, but in most of the states as compared to men, women were far less knowledgeable

Table 7.4

Knowledge about usage of condom

(in Percentages)

	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
People knowing usage of condom for						
Avoiding pregnancy /as FP method	79.6	70.7	80.9	73.5	80.4	72.2
Preventing STI	23.3	19.7	28.8	23.3	26.5	21.5
Preventing HIV	61.5	50.8	63.2	53.9	62.5	52.6
People reporting using condom	**12.1**	**9.5**	**20.8**	**12.4**	**17.2**	**11.2**

Table 7.5

Source of information about HIV and AIDS

(in Percentages)

Source of information*	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
Radio	36.2	37.1	32.6	28.2	34.1	31.9
T.V	59.2	61.7	63.2	71.3	61.5	67.3
Cinema hall	3.0	2.6	6.6	5.0	5.1	4.0
Newspapers/books/magazines	26.8	16.3	35.2	25.8	31.7	21.9
Posters/hoarding/drama/puppet show etc.	11.7	10.7	13.4	11.6	12.7	11.3
School/workplace	13.5	7.3	10.5	6.8	11.8	7.0
Doctor/health workers	15.2	18.7	10.9	14.9	12.7	16.5
Relatives/friends	25.9	34.4	20.7	29	22.8	31.2
Others	2.2	3.2	3.0	1.7	2.7	2.3
No of respondents	**1,378**	**1,225**	**1,921**	**1,700**	**3,299**	**2,925**

*Multiple response

The electronic media seems to be playing an important role in creating awareness about HIV and AIDS as more than 60 percent have come to know about them through various television channels

The electronic media seems to be playing an important role in creating awareness about HIV and AIDS as more than 60 percent have come to know about the disease through various television channels. In addition more than 30 percent have become aware of HIV and AIDS because of programmes or advertisements on the radio. Comparatively, the percentage mentioning print media like newspapers, magazines etc. as a source of information, is not high. This is understandable since the percentage of illiterates among the respondents is fairly high.

There are interesting gender differences, however marginal they may be, in the source of information. Although for both men and women, television has turned out to be the most important source of information, as compared to men, the percentage mentioning television was higher for women, especially for urban women. However, since the percentage of illiteracy is higher among women, the percentage mentioning print media as a source of information is lower for women. In addition, comparatively, relatives and friends seem to be an important source for information for women. Thus, rural as well as urban women seem to have come to know about HIV and AIDS through radio, television, friends and relatives. In the case of men, in addition to these sources, the print media has also played a role in creating awareness. It is not surprising that most of the men and women have come to know about HIV and AIDS through television messages considering that a very high proportion of the respondents are in the habit of watching television quite regularly (Table 7.6).

There is no gender difference in the exposure to television; nearly 79 percent of men and women watch television at least once a week. However, as compared to men, percentage having exposure to other media like radio, cinema and print media is lower for women. The glaring difference is in the case of newspapers and magazines. While more than 40

Table 7.6

Exposure to media

(in Percentages)

Characteristics	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
Listen to radio						
Daily/weekly	53.2	50.4	49.2	44.4	50.9	46.9
Occasionally/monthly	18.6	17.6	20.4	18.7	19.6	18.2
Never	28.2	32.1	30.4	36.9	29.5	34.9
Watch TV						
Daily/weekly	72.4	73.2	83.3	82.4	78.7	78.5
Occasionally/monthly	15.2	14.7	10.8	10.3	12.6	12.1
Never	12.4	12.1	5.9	7.3	8.6	9.3
Go to cinema						
Daily/weekly	4.9	3.9	5.3	4.7	5.1	4.4
Monthly	11.5	7.7	10.9	7.6	11.2	7.7
Occasionally	40.5	36.6	41.6	36.3	41.1	36.4
Never	43.1	51.8	42.3	51.3	42.6	51.5
Read newspaper/magazines						
Daily	35.2	19.8	47.6	27.4	42.4	24.2
Weekly/monthly	5.8	5.1	7.9	7.2	7.0	6.3
Occasionally	23.7	28	18.7	23.5	20.8	25.4
Never	35.3	47.2	25.9	41.9	29.8	44.1
Total	**100**	**100**	**100**	**100**	**100**	**100**

percent of the male respondents are in the habit of reading newspaper daily, not even one-fourth of the women seem to be doing so. This could be directly linked to the differences in the level of literacy among male and female respondents. Hence, in the next section, we would see the link between education, knowledge and awareness about HIV and AIDS.

7.4 Level of education and knowledge and awareness about HIV and AIDS

Among other things, ignorance and low level of educational attainment have been found to be important factors responsible for the spread of HIV infection in the developing countries like India. The term "education vaccine" was coined in 2000 by experts to indicate that education is the first line of defence against the spread of HIV and it has been proved as a means to prevent the spread of HIV and AIDS. (World Bank, 2002; Boler Tania and Kate Carroll, undated; Vandemoortele, Jan and Enrique Delamonica, 2000). Like any other infection, an inverse relationship between education and HIV infection seems to exist and it has been hypothesised that after the initial phase, education would reduce the risk of contracting HIV infection. Hence it has also been predicted that as a country's prevalence rate increases, the proportion of young illiterate women among the newly-infected would rise. (Jan and Enrique Delamonica, 2000). In this

section, an assessment of the relationship between the level of education of the respondents and the level of knowledge and awareness about HIV and AIDS has been attempted. An effort has also been made to see whether increase in the level of education reduces the gender differences in the level of awareness.

A few important observations emerge from the table. First, in the case of male as well as female respondents, with the increase in the level of education, generally, the awareness level also seems to increase. While only 95 percent of illiterate men and 93 percent of illiterate women have heard about HIV and AIDS, as far as graduates are concerned, all of them seem to have heard about HIV and AIDS. Similarly, with the increase in the level of education, there seems to be greater knowledge about other details like where to go for HIV testing, the link between STD, HIV, use of condom to prevent the spread of STI and HIV etc.

Secondly, although in the case of women respondents the level of knowledge increases with the level of education, as compared to men they seem less knowledgeable. In other words, even after controlling for the educational level the gender difference in the level of knowledge and awareness about HIV and

Table 7.7

Knowledge and awareness about HIV and AIDS by level of education

(in Percentages)

	Male				Female			
	Illiterate	Upto middle school	High school/ higher secondary	Graduate/ diploma	Illiterate	Upto middle school	High school/ higher secondary	Graduate/ diploma
Heard about HIV and AIDS	95.0	98.9	99.1	100.0	92.7	97.1	99.2	100
Know right modes of transmission								
All modes	57.8	60.9	57.3	53.4	51.1	51.8	58.1	62.3
Some modes	39.8	38.6	42.2	46.2	45.8	47.0	41.4	36.9
Not at all	2.3	0.5	0.5	0.4	3.1	1.2	0.5	0.8
Non-response								
Think that HIV can be prevented	45.5	62.0	66.2	79.4	35.5	48.8	62.6	73.4
Know where to go for HIV testing	36.0	43.3	55.3	75.3	25.2	26.9	45.0	64.8
Know that person suffering from STI has high chance of exposure to HIV	48.6	52.3	60.1	72.7	35.0	38.2	39.4	57.8
Know that condom could be used for								
Avoiding pregnancy	38.7	81.1	6.5	87.5	60.2	79.9	84.2	80.3
Prevention of STI	27.6	26.1	25.8	26.3	23.2	21.9	24.1	25.8
Preventing HIV	53.0	62.5	66.4	71.3	47.4	54.7	62.5	69.4
(N) Number of respondents	**940**	**565**	**1,160**	**567**	**1,224**	**506**	**833**	**244**

AIDS persists. However, with the increase in the level of education the gender difference in the level of awareness seems to get reduced. Once, both men and women are educated beyond high school level, the gender difference gets narrowed, except in their knowledge about the link between HIV and STI where men seem far more knowledgeable than women.

In India, other surveys have also found a strong positive association between the level of education and awareness about HIV and AIDS among women. For instance, the NFHS–2 conducted in 1998-99 found that knowledge about AIDS increased from only 18 percent among illiterate women to 92 percent among women who had completed at least high school education (IIPS 2000).

7.5 Attitude of people towards PLWHA

Stigma and discrimination associated with HIV and AIDS and the existing misconceptions regarding the spread of the infection have led to negative responses and attitudes of people towards PLWHA.

In order to gauge the attitude of people towards HIV-infected and affected persons, a series of hypothetical questions were asked and the responses of the men and women are presented in Table 7.8. It is clear from the table that both men and women have negative attitude towards PLWHA and their families. Whether it is a question of interacting with the affected families, or sharing food or availing the same health facilities, men

With the increase in the level of education the gender difference in the level of awareness seems to get reduced

Table 7.8

Attitude of people towards PLWHA

(in Percentages)

	Rural		Urban		Total	
	Male	Female	Male	Female	Male	Female
Interact with the family having PLWHA	75.0	69.3	77.2	70.0	76.3	69.6
Share food with the PLWHA	56.5	45.1	68.4	51.7	63.4	48.9
Avail the health facility used by the PLWHA	45.9	33.3	56.4	40.2	52.0	37.3
Allow their children to play with the children from a family having PLWHA	52.3	41.6	60.5	45.4	57.1	43.8
Send their children to a school where PLWHA study	48.3	38.5	62.3	51.1	56.5	45.8
Purchase fruits vegetables etc from a shop keeper who is PLWHA	56.7	47.1	69.3	59.5	64.1	54.3
Accept a PLWHA as a teacher	52.5	38.7	62.9	48.3	58.6	44.3
Their community would allow PLWHA to live in the same community	62.6	52.2	72.5	62.2	68.4	58.0
N (Number of respondents)	**1,378**	**1,225**	**1,921**	**1,700**	**3,299**	**2,925**

seem to be more accepting and less discriminatory. The gender differences in the attitude was very glaring as far as sharing food, availing the same health facilities, allowing the children to play and in accepting the person as a teacher are concerned.

Educating women and children should be the first line of defence against the infection

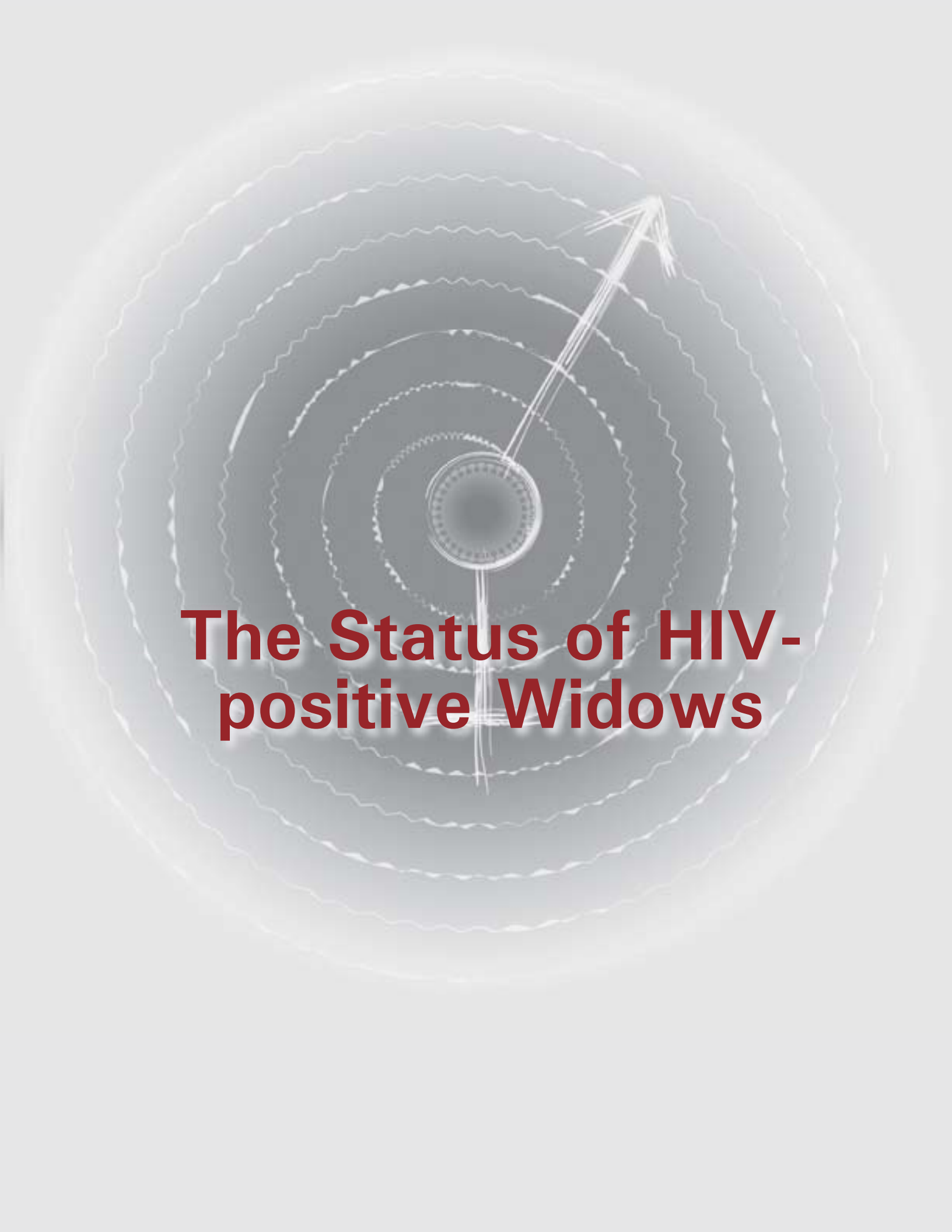
This gender difference in the attitude could partly be explained by the difference in the knowledge about the modes of HIV transmission and partly by the difference in the level of education.

7.6 Observations

The survey results show that as compared to men, women are far less knowledgeable about HIV and AIDS and other related aspects like the link between STI and HIV etc. This difference in the knowledge and awareness to a large extent can be explained by the difference in the level of education. These findings suggest that with the increase in the level of education, there is an improvement in the awareness level. Hence, educating women and children should be the first line of defence against the infection. Empowering women with knowledge about the infection would help them to protect themselves from HIV.

The negative responses arise mainly due to their misconceptions about the modes of transmission of HIV. Thus, creating greater awareness among people would go a long way in accepting the PLWHA in the family and society at large.

The survey shows that most of the people have come to know about HIV and AIDS through television, and in states like Manipur, radio has played a crucial role in creating awareness about HIV and AIDS. Since, even less educated women could be made aware about HIV and AIDS, these powerful mass media tools can be fully utilised to provide preventive information.



The Status of HIV-positive Widows

Chapter 8

The Status of HIV-positive Widows

8.1 Introduction

The Constitution of India not only guarantees equality, right to life and personal liberty but also lays a duty on all citizens to renounce practices derogatory to the dignity of women. Apart from the constitution, there are institutions like National Commission for Women, National Human Rights Commission and Chief Commissioner Disabilities for protection of various sections of population including women. The "National Policy for Empowerment of Women 2001" also emphasises the need to take measures for protection and empowerment of vulnerable sections of women, which include widows and the elderly. The Hindu Succession Act has provided for equal co-parcenary rights for women in property (applicable only for Hindus). Section 125 of the Code of Criminal Procedure, 1973 (as amended in 2001) provides for maintenance rights, among others, of widows. The Legal Services Authorities Act, 1987 provides for free legal aid and advice to all women irrespective of their financial status. Despite the constitutional guarantees and the legal safeguards, women in India, especially widows are a discriminated lot and are subjected to various forms of violence and sexual abuse.

In India, widows have a very low status in the society and in spite of efforts by social reformers through the ages, discrimination against them continues. The practice of Sati still continues in some parts of the country. Though the society is gradually changing widows are supposed to give up all the pleasures of life, wear white clothes; even their presence is considered inauspicious on certain occasions. The position of HIV widows is worse than that of widows and HIV infected women put together. HIV widows not only have to bear the grief of the death of their husbands, and economic repercussions, but also have to face the stigma attached to HIV, take care of their own health and the health of children who may be positive. They have to cope with the additional financial burden on health expenditure, and in the worst cases may even have to face the death of their positive children. The HIV virus infects people in their prime, and since wives in India are generally much younger than their husbands, HIV widows are mostly very young and also generally have young children. Also, since the OIs related to HIV tend to progress more rapidly with age, older HIV-positive husbands are more likely to die before their younger wives.

In the present chapter, an attempt has been made to study the plight of HIV widows and also to compare their households with other HIV households, based on the results of the field survey undertaken in the six high-prevalence states of India and the FGDs and case study conducted with HIV-positive women, including the positive widows.

8.2 Profile of HIV-positive widows

The field survey covered 2,068 HIV households spread over rural and urban areas of the six high-prevalence states. Out of the HIV households surveyed, there were 439 HIV-positive widows, 206 from the rural and 233 from the urban sample. Details regarding their age, education and occupation are given in Table 8.1.

Table 8.1

Profile of HIV-positive widows

(in Percentages)

	Rural	Urban	Total
Age (Yrs.)			
<20	2.4	2.1	2.3
20-30	59.2	55.3	57.1
31-40	33.0	34.0	33.6
Above 40	5.4	8.5	7.0
Education			
Illiterate	35.0	26.4	30.4
Upto primary school	18.9	14.9	16.8
Upto middle school	16.5	14.9	15.7
High School/senior secondary	24.3	37.5	31.3
Graduate/diploma holders	5.3	6.4	5.9
Occupation			
Cultivation	6.3	0.9	3.4
Agricultural wage labour	22.3	3.0	12.0
Non-agricultural wage labour	12.1	11.1	11.6
Salaried	15.5	24.3	20.2
Trade/business	6.3	11.5	9.1
Artisan/self-employed	9.7	11.5	10.7
Transport workers			
Income from pension, rent, interest, dividend etc.	0.5	2.6	1.6
Domestic servant	1.9	10.2	6.4
Housewives	25.2	25.1	25.2
Total	**100**	**100**	**100**
N	**206**	**233**	**439**

The table clearly indicates that most of the widows in the sample are in their prime of youth. Nearly 60 percent are less than 30 years of age and another one third are in 31-40 years age group. Only seven percent are above 40 years, confirming that most of the HIV widows are young. Nearly 30 percent of them are illiterate, with the percentage being slightly higher in the rural sample. Only about six percent of them are graduates or diploma holders. As far as occupation is concerned, six percent of the rural and nearly one percent of the urban sample are cultivators. In the rural sample percentage, the agricultural wage labourers were much higher than those in the urban sample. Nearly equal percentage of the rural and urban sample are non agricultural wage labourers. The salaried class and those in trade and business and the self-employed are represented by a higher percentage in the urban sample. The percentage of domestic servants is much higher in the urban sample compared to the rural sample. Not surprisingly, nearly 75 percent are employed gainfully since they have to support themselves financially. However, nearly 30 percent of them are wage labourers whose income is likely to be very low, and who are not likely to be receiving any social security, and 25 percent are housewives without any source of income.

8.3 Details about their HIV status

In Table 8.2, details about how these widows discovered their HIV status,

the number of years since they tested positive and the mode of contracting the infection are presented.

It is important to note that nearly 64 percent of the widows discovered their HIV status when they voluntarily went in for an HIV test and more than 80 percent of those did so because their husbands were already infected. Nearly 80 percent of the sample HIV widows were tested positive in the last three years and only a small percentage of the widows discovered their status more than five years ago. As high as 94 percent of women had contracted HIV through heterosexual contract. As many as two-thirds of the widows are currently in Stage I or II; another 28 percent in Stage III of the infection and only 5 percent are in Stage IV. From this evidence, we might conclude that these widows are most likely to have contracted the HIV infection from their husbands. The situation seems similar to South Africa where it is estimated that a majority, around 80 percent, contracted HIV from their husbands. In this context it is worth mentioning the observation made by UN Secretary General Kofi Annan that in both the countries it is not promiscuity but marriage that is the cause of transmission of the infection to women (Viji Sundaram, 2005)

8.4 Economic status of HIV-positive widows

In this section, the economic status of the HIV widow households is compared with the other HIV households in terms of their living conditions, the assets and consumer durables they possess, the household income, pattern of consumption, savings and borrowings. The incidence of poverty in the two types of households is also calculated to bring out the adverse impact of death of an earning member on the family.

Table 8.2

Discovering the HIV status

(in Percentages)

Characteristics	All		
	Rural	Urban	Total
Discovering HIV status			
Voluntary testing	62.6	64.8	63.8
After prolonged illness	27.7	20.2	23.7
During pregnancy	5.3	6.9	6.2
Others	4.4	8.1	6.3
If voluntary testing, reasons for testing			
Reason for voluntary testing			
Sickness	7.0	1.3	3.9
Health worker suggested	7.8	11.9	10.0
Partner infected	83.0	82.1	82.5
No. of years since HIV was detected			
Less than a year	45.6	36.9	41.0
1 - 3 years	35.0	40.8	38.0
3 -5 years	13.6	15.0	14.4
5 years and above	5.8	7.3	6.6
Mode of infection			
Sexual contact (Heterosexual)	96.1	92.3	94.1
Others	3.9	7.7	5.9
Total	**100**	**100**	**100**

8.4.1 Annual income of HIV widow households and other HIV households

It can be seen from Table 8.3 that in terms of household income, the widow households are much worse off than the other HIV households.

The percentage of households is the highest in the lowest income group for HIV widow households while it is much lesser in case of the remaining HIV households. In the higher income categories, the percentage of widow households is lesser than the others. In other words, the average annual income of the widow households is much less than that of the other, both in the rural and urban samples. While the average annual income of other HIV households is Rs. 51,111, the same for

Table 8.3

Distribution of sample widow and other HIV households by household income categories

(in Percentages)

Characteristics	Widow households			Other HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Annual HH income (Rs.)						
1. Up to 20,000	56.3	40.3	47.8	25.9	11.6	17.6
2. 20,001-30,000	18.9	19.7	19.4	22.7	18.0	20.0
3. 30,001-41,000	7.3	9.0	8.2	16.2	15.9	16.0
4. 41,001-84,000	13.1	22.3	18.0	28.4	36.4	33.0
5. 84,000 & above	4.4	8.6	6.6	6.9	18.1	13.4
Average HH income (Rs.)	28,006	37,403	32,993	39,711	59,363	51,111
Number of households	**206**	**233**	**439**	**684**	**945**	**1,629**

the widow households is much lesser at Rs. 32,993. The difference in the earnings between the two sets of households could be due to the direct impact of death of an earning member in the widow households.

8.4.2 Availability of basic amenities in the households

Widow households are much worse off than the other HIV households in terms of availability of basic amenities and ownership of assets

Table 8.4 gives the percentage distribution of the two households by availability of basic amenities. It can be seen that the widow households are much worse off than the other HIV households in terms of availability of basic amenities and ownership of assets as well.

The percentage of families living in pucca and semi-pucca houses is slightly higher in case of other HIV households, and percentage of households living in kutcha houses is higher for widow households. Percentage of households who have private taps, tube wells, toilet, electric supply at home, and who use LPG for cooking is lesser in widow households than the remaining households. Similarly, percentage using public taps, firewood and kerosene are higher in widow households, suggesting that their status is much lower than the remaining HIV households, which is already low.

8.4.3 Ownership of assets and consumer durables in the households

Percentage of households owning agricultural land or having livestock is lesser among widow households than in the remaining HIV households. It is quite possible that the widow households would have disposed off their land and livestock in order to meet the medical expenses of their deceased husbands. As it would be seen later in this chapter, a much higher percentage of widow households have resorted to liquidation of assets. Also as would be seen later since many of the widows do not get a share in their husbands' property, they may not own agricultural land.

However, percentage of households owning house/plot/flat is nearly the same in both the categories as is seen from Table 8.5. The percentage of households owning consumer durables like fan,

Table 8.4

Distribution of sample widow and other HIV households by the availability of basic amenities

(in Percentages)

Characteristics	Widow households			Other HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Type of house						
Pucca	21.4	36.9	29.6	23.4	36.0	30.7
Semi-pucca	43.2	37.8	40.3	46.1	43.3	44.4
Kutcha	35.4	25.3	30.1	30.6	20.7	24.9
Drinking water						
Private tap/hand pump	18.5	34.8	27.1	21.1	40.4	32.3
Public tap/hand pump	56.8	52.8	54.7	53.7	38.9	45.1
Tubewell	5.3	4.3	4.8	7.8	5.7	6.6
Supply tanker	1.5	2.6	2.1	1.6	4.7	3.4
Well/river/pond	14.6	3.9	8.9	13.9	9.2	11.2
Any other	3.4	1.7	2.5	2.1	1.0	1.5
Sanitation facility						
Households having toilet	39.8	67.0	54.2	42.7	69.2	58.1
Electricity at home						
Households having electricity	79.1	90.1	85.0	86.8	92.0	89.8
Type of fuel for cooking						
Firewood	65.5	28.3	45.8	58.9	32.7	43.7
Coal	0.5	3.0	1.8	1.3	1.3	1.3
Kerosene	6.8	22.8	15.3	10.2	17.5	14.4
(LPG) Gas	26.7	45.1	36.5	29.0	48.5	40.3
Others	0.0	0.0	0.0	0.4	0.0	0.2
Total	**100**	**100**	**100**	**100**	**100**	**100**

television, telephone, washing machine etc. is also lesser in the widow households compared to other HIV households. These details once again bring out the weaker economic position of HIV widow households compared to the remaining HIV households.

8.4.4 Consumption pattern of the widow and other HIV households

The household survey collected details about household income, consumption, savings and borrowings for the last one year prior to the date of interview. These are analysed to compare the economic condition of widow households with other HIV households.

The pattern of consumption of both types of households as presented in Table 8.6 shows the share of expenditure on some important items in the total household consumption expenditure. It is seen that the share of items like food, fuel and light, clothing and footwear as well as education of children is higher in the widow households compared to other households. However, as far as expenditure on health is concerned,

Table 8.5

Distribution of sample widow and other HIV households by ownership of assets and other consumer durables

(in Percentages)

Characteristics	Widow households			Other HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Owning agricultural land	6.1	3.0	4.4	11.7	3.9	7.2
Households having livestock	20.4	6.4	13.0	30.9	11.4	19.6
Owning house/flat/plot	61.7	48.9	54.9	63.3	47.4	54.1
Owning consumer durables						
Fan	56.8	65.7	61.5	64.6	70.2	67.8
Bicycle	31.6	23.6	27.3	53.1	45.2	48.5
Radio/transistor	35.6	39.5	37.8	43.3	44.9	44.6
Tape recorder	18.9	28.3	23.9	32.2	45.7	40.0
Television (b/w)	25.7	27.5	26.7	33.6	33.4	33.5
Television (colour)	13.1	26.2	20.1	18.6	36.8	29.2
Refrigerator	3.9	11.9	7.7	5.3	20.1	13.9
Telephone/mobile	11.7	15.9	13.9	13.3	30.2	23.1
Washing machine	1.0	1.7	1.4	1.5	6.8	4.5
Computer	0.5	1.3	0.9	0.9	2.0	1.5
Two wheelers	6.8	9.4	8.2	12.4	19.6	16.6
Car/jeep etc.	1.5	0.4	0.9	1.3	2.2	1.8
N	**206**	**233**	**439**	**684**	**945**	**1,629**

The expenditure of widow households on all items including food, medical care etc. is lower than the remaining households, except for expenditure on the education of children

the share in widow households (6.8%) is much less than the remaining households (11.5%). This is probably due to the fact that while in the widow household, the additional burden of expenditure on health due to HIV would have to be made only on the widow and HIV-positive children, if any, while in other households, there is the possibility of both husband and wife being HIV-positive, apart from any HIV-positive children. It is also possible that since the average income of the remaining households is higher than the widow households, they may be able to afford better medical care, thereby incurring slightly higher expenditure. The comparison of the consumption expenditure will be sharper by finding out the per capita expenditure of both types of households on these items.

Table 8.7 gives the comparison of the average per capita per month expenditure of the two sets of households on some important items. It is seen that the expenditure of HIV widow households is much less than that of the remaining households in both the urban and rural samples. This is to be expected since the income of widow households is also lesser than that of the remaining households. However, one interesting thing to be seen is that the expenditure of widow households on all items including food, medical care etc. is lower than the remaining households, except for expenditure on the education of children.

The fact that the HIV widow households are spending less on food, whether cereal, pulse or other food, also raises the question of food security for these households. "Households are said to be food-secure when the four elements–food availability, equal access to food, stability of food supplies and quality of food are in balance with each other" (Anthony Barnett and Rugalema Gabriel, 2001). The sample HIV widow households are not only spending less on food compared to the remaining households, but percentage of households owning agricultural land and livestock is also less. The high cost of healthcare, labour shortages, declining assets, and breakdown of social bonds are all said to contribute to food insecurity.

Table 8.6

Share of expenditure on some of the major items

(in Percentages)

Item	Widow households			Other HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Cereals	14.2	12.3	13.1	12.3	10.9	11.4
Pulses	2.6	2.5	2.6	2.4	2.0	2.1
Other food	32.0	29.5	30.5	29.2	28.2	28.5
Total Food	48.9	44.3	46.2	43.9	41.0	42.0
Fuel and Light	8.9	10.1	9.6	7.5	8.7	8.3
House rent	2.2	5.9	4.4	2.7	6.4	5.1
Clothing & footwear	5.1	5.1	5.1	4.8	4.5	4.6
Durables	1.4	1.1	1.2	1.3	1.3	1.3
Education of children	4.0	4.8	4.4	2.9	3.0	3.0
Medical	7.2	6.4	6.8	13.7	10.2	11.5
Other non-food	22.4	22.4	22.4	23.3	24.8	24.3
Total	**100**	**100**	**100**	**100**	**100**	**100**

Table 8.7

Average per capita per month expenditure on some of the major items

(in Rupees)

Item	Widow households			Other HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Cereals	99	107	103	105	125	116
Pulses	18	22	20	20	22	21
Other food	223	257	242	250	324	292
Total food	342	387	366	376	472	431
Fuel and light	62	87	76	64	100	84
House rent	15	51	34	23	73	52
Clothing & footwear	35	44	40	41	51	47
Durables	9	9	9	11	14	13
Education of children	27	41	35	24	34	30
Medical	50	56	53	117	117	117
Other non-food	156	195	177	199	285	249
Total	**696**	**870**	**790**	**855**	**1,146**	**1,023**

It has been found that widows and their households face critical shortage of food and income, primarily due to lack of inheritance, lack of sufficient assets, lack of labour supply and exclusion from wider kinship networks. Households headed by survivors, notably widows, orphans and the elderly, are more highly dependent on outside sources of support, further compromising their access to food (Anthony Barnett and Rugalema Gabriel, 2001).

In the present sample, widow households are also spending less on healthcare compared to the remaining HIV households. This could probably be either due to lack of funds to seek healthcare or due to lower morbidity in these households. Since most of the sample widows are in the first two stages of HIV infection, there could be lower prevalence of OIs. Also in the other households, there could be more than one person with HIV infection resulting in higher expenditure on healthcare.

While the percentage of negative savers is same in both widow and other HIV households, the percentage of zero savers is much higher and positive savers much lower among the widow households

8.4.5 Household savings

In Table 8.8, the average household savings of widow and other HIV households are presented for one year. The table shows that the average annual saving of HIV households is only about one-third of the other households. Particularly affected seem to be households in the urban sample, where the saving in the widow households is only about one tenth of the remaining households.

However, one aspect which is common between both sets of households is that most of their assets are held in cash/ bank deposits, which clearly indicate their need for liquidity. This, in turn, is likely to affect their returns in terms of interest, dividend etc. While the average rate of saving of the widow households comes to 4.5, it is nearly double, at 8.5, for the other households. The reason for this is evident from Table 8.9 which gives the distribution of savers and non-savers in the two categories. While the percentage of negative savers is same in both widow and other HIV households, the percentage of zero savers is much higher and positive savers much lower among the widow households.

It is also seen that the percentage of negative savers and zero savers is higher in the urban sample of widow households compared to that of urban sample in the remaining households. The percentage of positive savers in widow households is only half of that of the remaining households, causing the savings of urban widow households to be around one-tenth of the remaining urban households.

Table 8.8

Average annual household savings

(in Rupees)

	Widow households			Other HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Cash/bank deposit	2,374	1,666	1,999	3,222	6,058	4,867
Jewellery	-181	-1008	-620	-655	-415	-516
Agricultural land	0	-279	-148	-895	-803	-842
Assets (house/plot)	57	178	121	-372	950	395
Financial (shares etc.)	138	117	127	199	574	417
Total	**2,388**	**674**	**1478**	**1,498**	**6,364**	**4,321**

Table 8.9

Distribution of savers and non-savers

(in Percentages)

Item	Widow households			Other HIV households		
	Rural	Urban	Total	Rural	Urban	Total
Negative savers	17.0	19.3	18.2	22.1	15.2	18.1
Zero savers	60.7	62.7	61.7	49.7	49.4	49.5
Positive savers	22.3	18.0	20.1	28.2	35.3	32.4
Total	**100**	**100**	**100**	**100**	**100**	**100**

8.4.6. Household borrowings in the last one year

Table 8.10 gives the borrowings of the two sets of households during the last one year before the survey and it is seen that both sets of households seem to borrow to meet their expenses. However, the percentage of borrowers is higher in the widow household in every income category. While 56 percent of widow households had resorted to borrowings, in the case of other HIV households, the percentage of borrowers is lower at 43. However, the average amount borrowed per household is lesser for widow households, as their capacity to borrow would be limited, given their low asset and income position.

The fact that the HIV households have resorted to liquidation of assets and to borrowings is evident from the next two tables. These households have to incur a lot of expenditure on both hospitalised and non-hospitalised illnesses, as they are susceptible to opportunistic infections. The share of expenditure as well as per capita expenditure has worked to be lesser for HIV widow households compared to the remaining households. That is generally to be expected since the widow households are likely to have atleast one less HIV-positive member in the family and also, as among these sample households, it is likely that the infection has been transferred from husband to wife. In view of this, generally husbands are in a more advanced stage of HIV than the wives, and hence more expenditure is likely on them. Even otherwise, it has been seen that expenditure on women is less than that on men, whatever be the source of treatment and even if they are in the same stage of infection.

While 56 percent of widow households had resorted to borrowings, in the case of other HIV households, the percentage of borrowers is lower at 43

8.4.7 Coping mechanism

An important question for the HIV households is the method by which they can cope with the additional financial burden imposed on them because of a family member turning out to be HIV-positive. One of the methods could be liquidation of assets and borrowings. The HIV households were specifically asked whether they had resorted to liquidation of any assets or borrowings to cope with loss of income or increased expenditure since their family member was tested positive.

Table 8.11 compares the liquidation of assets or borrowings by the two sets of households after being tested positive. It is seen that at every income level, the percentage of those who have borrowed or liquidated assets is higher in the widow households. On the whole, while 57.2 percent of the HIV widow households have resorted to these, the percentage is less at 39.6 percent in respect of the remaining households. From these figures, one could possibly conclude

Table 8.10

Borrowings in last one year

Annual income class	Widow households		Other HIV households	
	Percentage of HH that borrowed	Average borrowing per household (Rs)	Percentage of HH that borrowed	Average borrowing per household (Rs)
Upto Rs. 20,000	64.3	7,889	59.9	10,122
20,001-30,000	58.8	6,952	49.9	9,334
30,001-41,000	47.4	5,433	50.0	11,545
41,001-84,000	45.5	12,031	35.8	14,241
84,001-and above	24.1	19,536	21.1	18,852
Total	**55.8**	**8,442**	**43.3**	**11,877**

that the widow households might have had assets which they would have disposed off to meet the medical and funeral expenditure of their husbands. This is likely to be the reason for lesser percentage of widow households owning assets like agricultural land and livestock, as already seen.

8.5 Poverty in the households

The link between HIV and AIDS and poverty is by now well established. However, what is being highlighted here is that even among the HIV households, the HIV widow households is further pushed down the poverty ladder.

Table 8.12 gives the distribution of households by income poverty in the sample. It is seen that the percentage of households below poverty line is much higher in the widow households compared to that in the other households, both in the rural and urban samples. As is to be expected, the family size is lesser in the widow households.

Table 8.11

Liquidation of assets or borrowings to cope with financial burden

Annual income class	HIV Widow HHs		Other HIV HHs	
	Percentage of HH that borrowed or liquidated assets	Average borrowing or liquidation of assets per household (Rs)	Percentage of HH that borrowed or liquidated assets	Average borrowing or liquidation of assets per household (Rs)
Upto Rs. 20,000	63.8	16,180	50.5	21,033
20,001-30,000	57.7	27,196	44.3	19,363
30,001-41,000	42.1	24,750	46.1	24,994
41,001-84,000	54.6	42,417	34.7	29,869
84,001-and above	34.5	39,600	21.6	31,722
Total	**57.2**	**24,200**	**39.6**	**24,697**

The income of widow households is lesser than that of the remaining households in both below poverty line households as well as above poverty line households, and once again it is true of households in both urban and rural samples. The increase in poverty in the widow households could push them into making sub-optimal choices like entering sex trade as the last option, as was found in one of the case studies undertaken in Manipur. (See Box)

8.6 Impact on the education of children

According to the existing literature on the HIV hard-hit countries, the burden of HIV and AIDS has a direct impact on the education of children. HIV households are seen to spend less on the education of their children than similarly placed non-HIV households. However, in the present sample, it has already been seen that widow households are spending more on education of their children as compared to other households. Table 8.13 gives the ever and current enrolment rates for children from HIV widow households and the others, age group wise.

It is seen that for the age group 5-13 years which corresponds to class I to VIII, while the ever enrolment rates are higher for widow households, the current enrolment rates are comparatively higher for the remaining households, thereby indicating that the dropout rates are higher for the children of widow households. This could be because of two reasons: first, in the absence of earning members, the children of widow households may have to take up jobs, and secondly, they may also have to take care of the ailing mother. It is, however, seen that in this group, the dropout rates for boys are higher than that for girls in the widow households, while it is higher for girls in the other household. As against this, in the higher age group, 14-17 years, both the ever enrolled and current enrolled rates are higher for children from other households, indicating that it is difficult for the widow households to continue the education of children. In

The income of widow households is lesser than that of the remaining households in both below poverty line households as well as above poverty line households

Table 8.12

Distribution of households by income poverty in the sample

	Percent share in			Average household		No. of households	Rate of saving	Family size
HIV widow HHs								
BPL	37.4	16.2	38.8	-2114	14,283	164	-14.8	3.9
APL	62.6	83.8	61.2	3,621	44,152	275	8.2	3.6
Total	**100**	**100**	**100**	**1,478**	**32,994**	**439**	**4.5**	**3.7**
Other HIV HHs								
BPL	17.7	6.5	21.2	-5081	18,645	288	-27.3	4.9
APL	82.3	93.6	78.8	6,340	58,085	1,341	10.9	3.9
Total	**100**	**100**	**100**	**4,321**	**51,112**	**1,629**	**8.5**	**4.1**

Box 5

Case Study 5: Vulnerability of HIV-positive widows

She belongs to one of the tribes in the Chandel district of Manipur. Since her husband's death due to AIDS related illnesses nine years ago, life has not been easy.

She stays with her parents on the outskirts of the town Churachandpur along with her daughter. Initially, when she returned to her parent's house, ensuring basic survival was a problem. While her father was too old to work, her married brother was a daily wage earner and had to support his family.

This meant that she was not able to meet her basic expenses. Due to this desperate situation, she was forced to resort to commercial sex work one year after her husband's death. She is now a non-brothel based sex worker and operates through pimps at various hotels. After giving a certain commission to the hotel owner, she is able to earn between Rs. 3,000 to Rs. 4,000. She uses this money to provide for her family and educate her nine year old daughter, who is currently studying in class II.

Some years ago came bad news. Since she was frequently falling sick and suffered from STDs, a test was done which confirmed her HIV status. She is now in the second stage of infection and in the last one year she has been suffering from a number of health problems like hypertension, sinusitis, skin infection and STD related ailments.

When she works, she insists that her clients use condoms but some clients refuse. It isn't always in her power to bargain.

This case study highlights the vulnerability of a widow, of a single mother, of a HIV-positive woman and also of the vicious cycle between livelihoods, low-income households and HIV and AIDS.

Table 8.13

Ever and current enrolment of children

HIV widow households **(in Percentages)**

(5-13 years of age)	Boys	Girls	Total	F/M
Ever enrolled	94.9	94.5	94.7	1.0
Currently enrolled	89.8	90.8	90.3	1.0
Children who have dropped out of school	5.4	3.9	4.6	0.7
Average number of years of schooling completed by dropouts	4.2	5.6	4.8	1.3
(14-17 years of age)				
Ever enrolled	88.6	95.0	91.7	1.1
Currently enrolled	68.2	60.0	64.3	0.9
Children who have dropped out of school	23.1	36.8	29.9	1.6
Average number of years of schooling completed by dropouts	7.3	2.3	6.9	0.3

Other households

(5-13 years of age)	Boys	Girls	Total	F/M
Ever enrolled	93.8	91.5	92.7	1.0
Currently enrolled	92.6	87.6	90.2	0.9
Children who have dropped out of school	1.3	4.3	2.7	3.5
Average number of years of schooling completed by dropouts	3.8	3.9	3.9	1.0
(14-17 years of age)				
Ever enrolled	93.6	91.0	92.4	1.0
Currently enrolled	69.7	66.4	68.2	1.0
Children who have dropped out of school	25.5	27.0	26.2	1.1
Average number of years of schooling completed by dropouts	6.4	7.4	6.8	1.2

this age group, the dropout percentage of girls is higher in both the categories of households, but more so in widow households.

Table 8.14 shows that irrespective of the category of households, the percentage of children studying in government schools is much higher than private schools. However, while in case of widow households, it is noticed that almost an equal percentage of boys and girls study in government and private schools in both the age groups, in case of the other households, percentage of girls studying in government schools is higher than that of boys in both the age groups. This goes to show that although widow households may find it difficult to continue the education of their children, wherever possible, they are giving equal opportunities to girls. It is possible that being HIV-positive widows, they realise the importance of education of their daughters. Even in the FGDs held, the female PLWHA, specially the widows, wanted to educate their children as much as possible, so that atleast they could be economically independent and stand on their own feet. In fact, many of them wanted to as long as they could to educate their children.

8.7 Stigma and discrimination experienced by HIV widows

As it has been rightly said, "Discrimination against widows and HIV are inter-related

Table 8.14

Distribution of currently enrolled children by type of school attended

HIV widow households **(in Percentages)**

Type of school	(5 – 13 years)			(14 – 17 years)		
	Boys	Girls	All	Boys	Girls	All
Government	62.2	63.1	62.7	68.6	68.3	68.5
Private	37.1	36.3	36.7	31.4	31.4	31.5
Informal	0.7	0.6	0.6	-	-	-
Total	**100**	**100**	**100**	**100**	**100**	**100**

Other households

Type of school	(5 – 13 years)			(14 – 17 years)		
	Boys	Girls	All	Boys	Girls	All
Government	59.9	68.3	63.8	57.6	65.4	61.0
Private	39.4	31.2	35.6	41.7	34.6	38.6
Informal	0.7	0.6	0.7	0.7		0.4
Total	**100**	**100**	**100**	**100**	**100**	**100**

in two ways: HIV and AIDS significantly adds to the burden of the already inferior status of widows. At the same time, this economic, social and political inferiority makes widows and women in general more vulnerable to HIV infection. It is a vicious circle of discrimination and poverty." (Bridget Sleap, 2001).

There is widespread stigma and discrimination against those who are HIV-positive. HIV-positive widows face double burden of stigma. They suffer discrimination from the family and the society in which they live. In this section, we would examine the stigma and discrimination faced by the widows in the family and community.

It is clear from Table 8.15 that hardly 10 percent of the widows are living with their husband's family and out of those who are not living with their husband's family, more than 90 percent had stopped living in their marital homes after the death of their husband. While more than 40 percent of the widows are living alone, nearly none of them are living with their natal family. During the FGDs, a number of HIV widows mentioned that even if they are living alone they are getting financial and moral support from their natal family. Hence, although more than 50 percent have mentioned that their family are supportive, mostly they are talking about their natal family. This finding is corroborated by another study conducted in rural India where the HIV widows in the in-depth interview had mentioned that they are mostly supported by their parental family members. (Gujjarappa L et. al. 2004).

Not only are a very high percentage of the widows not living with their in-laws, most of them are also not getting any financial support either. Only nine percent of widows reported getting financial support from their in-laws. What has come out as a serious issue is that as high as 79 percent of the widows have complained that they were denied share in their husband's property. A joint report by UNAIDS/ UNFPA/UNIFEM has highlighted the findings from a number of studies to show how the HIV widows are denied their rightful share in the husband's property even if the law is in their favour. According to the Positive Women's Network of South India, widows rarely inherit property, which they shared with their husbands during marriage. In a study conducted in 1995 in Bangladesh, it was found that only 32 percent of the widows received their rightful share in the husbands' property. (UNAIDS/UNFPA/UNIFEM 2004).

During the FGDs conducted with the female PLWHA and in particular the widows, it was seen that in addition to discrimination against them as PLWHA by the community, health facilities etc, the worst discrimination came from the in-law's family. Most of the widows complained that they were thrown out of their houses after they were widowed. The husband's share of property to which they were entitled, was also not given to them, because the in-laws felt that being HIV-positive, the daughter-in-law is also likely to die soon. Some of the widows got help from their parents, while others were less fortunate, particularly those who had married against the wishes of the family, and had nowhere to go. These women faced the worst possible discrimination of not being allowed to touch their own children or in some cases had to give up their children.

Prior to experiencing problems after the death of their husbands, some of them also faced humiliation at the time of death of their husbands due to AIDS. When the husband died of AIDS, 4 percent of the sample widows had faced problems in the

Box 6

Case Study 6: HIV-positive widow with daughters

Even though she hails from Pune district of Maharashtra, her story is representative of many others all over India. This story highlights how underlying vulnerabilities of women get further exacerbated due to HIV and AIDS and leaves them in a situation of utter despair.

Her two daughters were not enough for her in-laws. They of course wanted a grandson. Despite not wanting a third child, she became pregnant with her third child. It was during this period, her husband started falling ill frequently and she had to sell her jewellery to meet the medical expenses of her husband. When she went to her parent's home for the delivery of the third child, she was totally unaware of the fact that ill health of her husband had forced him to stop working. In fact, she was also unaware that he was HIV-positive.

When she gave birth to her third daughter, she came to know about her HIV status and realized that her husband was actually suffering from AIDS related illnesses.

Before she could recover from the shock, another blow struck. She received the news of her husband's death just two days after the delivery. Luckily, thanks to timely medication (Nevropine) and care, her third daughter too turned out to be HIV negative.

However when she returned to her in-laws house, she realized that she was not welcome there. Firstly, her in laws made it very clear that they cannot afford to take care of her and her three daughters and if she wanted to stay with them she had to earn for the family.

Her mother in law blamed her for her son's death and separated her utensils, clothes, etc and her sister-in-law did not allow her to enter the kitchen and participate in household chores. She could not go back to her parental home, since she had lost her father and even her mother had to earn her livelihood as a daily wage labourer. Although she had studied up to 8th standard, since she could not get any other job in her village, she had to work as a daily wage labourer. However her earnings are not sufficient to take care of her self and her daughters. At least when her husband was alive, he was earning a monthly income of around Rs. 2500.

Her life is fraught with uncertainties. She does not know whether she should worry about her deteriorating health or take care of her three daughters. She has even contemplated committing suicide at some point, but with the help and the moral support given by an NGO she is somehow surviving. Her HIV infection is presently at Stage II and she knows for sure that her health would deteriorate in the course of time. If she does not earn, she and her children would hardly have anything to survive. Though the first two daughters are currently studying in a school, she is not sure who is going to educate them and take care of them after her death.

hospital in the form of the staff refusing to touch the dead body and lack of transport to carry the body. Another 7 percent had suffered humiliation at the time of cremation in the form of social boycott, lack of transport and refusal to perform the last rights.

8.8 Observations

The survey results clearly show that as compared to other HIV households, the HIV widow households are economically worst affected. The HIV widow households have less income, and spend lesser than the remaining HIV households. The widow households' expenditure on food, which is required for their continued good health, is also less than that of the other households. This raises serious concern about their food security. Their saving is also less, and a higher percentage of these widow households are below the poverty line compared to others. The lack of income and employment opportunities could push them to making sub-optimal choices like entering sex trade.

Economic independence of HIV-postive widows is the first step towards

Table 8.15

Attitude and treatment of husband's family towards HIV-positive widows

(in Percentages)

	All		
	Rural	**Urban**	**Total**
Current attitude of spouse/family members			
Neglected, isolated,	11.6	11.1	11.4
Verbally/physically teased	4.4	3.0	3.6
Deprived of using basic amenities	1.5	1.3	1.4
Property taken away	1.5	2.1	1.8
Asked to leave home	7.3	6.9	7.1
All are supportive	51.9	52.8	52.3
Initial hesitation, but then supportive	11.9	12.8	12.3
Living with			
a) Husband's family	9.2	10.0	9.6
b) Parents	36.4	28.1	32.0
c) Alone	42.2	44.6	43.5
d) Other relatives/friends	2.4	4.8	3.7
e) Care & support home	0.5	-	0.2
f) Others (Specify)	9.2	12.6	11.0
If not living with husband's family, when stopped living with them			
a) After husband was tested positive	4.3	2.9	3.5
b) After tested positive	1.6	2.9	2.3
c) After husband's death	90.3	93.7	91.6
d) Others	3.8	0.5	2.6
Getting financial support from husband's family?	7.8	10.0	8.9
Reporting denial of share in family property after husband's death	79.6	77.5	78.5

betterment of their life. This, however, is not enough. Ensuring education of their children is also essential. In this context, it is important to note that, in spite of monetary problems, the widow households are spending comparatively more on education to see that their children are able to stand on their own feet. It is also necessary to enhance their access to treatment of OIs as well as to ART in order to prolong their life prolongs and their general health conditions. It has rightly been pointed out by the Global Coalition on Women and AIDS, protecting women's property and inheritance rights would increase their economic security and empowerment, which in turn would reduce their vulnerability to unsafe sex and domestic violence and would strengthen their ability to manage the adverse impact of HIV.

Conclusion and Recommendations

Chapter 9

Conclusion and Recommendations

The HIV infection in India is no longer confined to high-risk population such as the intravenous drug users, men who have sex with men, truck drivers and commercial sex workers. The infection is gradually spreading from urban to rural areas and from high-risk groups to women who are mostly in monogamous marriages. Though the "feminisation" of the pandemic is most apparent in sub-Saharan Africa, in India too women are increasingly susceptible to HIV infection, as they account for around 2 million of the approximately 5.2 million estimated cases of PLWHA. Of these, only 0.5 percent of the women are sex workers.

The fact that, in India, most of the women who are newly infected with HIV are practicing monogamy within marriage shatters the myth that marriage provides natural protection from AIDS. During the FGDs conducted with the HIV-positive women in the sample states, it was found that though in most of the cases the husbands of these women did not know their HIV status at the time of marriage, in a few cases the men were already aware of their status. But, in spite of knowing their status, these men entered into wedlock without disclosing their status. In a country like India, where women have a low status in society and low bargaining power in the marriage market, it is not possible for them to insist on a HIV test at the time of marriage.

Not all those who discover their HIV status after their marriage seem to disclose their status to their spouses immediately after testing. The survey results show that a significant percentage of men did not disclose their HIV status immediately after testing positive. During the FGDs, a number of positive women expressed their unhappiness over the fact that their husbands did not take them into confidence. Had they known their husbands' HIV status, they could have taken precautions and perhaps could have been saved from getting infected. However, even if women know the HIV status of their husbands, how many of them have the ability and power to negotiate safe sex and insist on the use of condom in their relations with their husbands? The gender inequalities that exist in society are also reflected in the sexual relations. According to the present survey more than 40 percent of the sample HIV-positive women do not have much say in matters relating to: if and when to have sex and in making their husbands use condom. Does the solution for this lie in female–controlled preventive technology that women can use without the knowledge/support of their partners? Studies among married women as well as sex workers in some

African countries and Thailand showed that female condom gave them the advantage of control over their sexual health. Microbicides are another new prevention tool being developed; these are available as gels which women could apply vaginally without the partners' knowledge to prevent sexual transmission of HIV. Microbicides can also prevent other sexually transmitted infections, such as syphilis and gonorrhea. However, the female condoms and microbicides are still at the experimental stage and are not easily available in India. Besides, these methods would be expensive for poor women and might not be easily accessible. Increasing the prevention options and improving women's skills in using such options and negotiating safe sex behaviours with their partners will go a long way in their attaining control over their bodies and protecting themselves from HIV and other infections.

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There is a need to empower adolescent girls and women by increasing their knowledge about their bodies and sexuality as well as about STI and HIV. The survey of non-HIV households reveals that as compared to men, women have poor knowledge about various modes of HIV transmission and only a small percentage of women know the link between STI and HIV. The STI services should be made available and more accessible by strengthening the existing RCH services at the primary and tertiary healthcare facilities.

The present study reiterates the general perception that women are disproportionately affected by HIV and AIDS. The demand for women's labour increases at home, in addition to the increased demand for paid labour. The study of time use pattern of women from HIV and non-HIV households suggests that women from HIV households are left with less time for leisure, sleep and personal care. Expectedly, more than 70 percent of the family caregivers of AIDS patients in the sample households are women. The role of caregivers takes a toll on women emotionally, physically and financially. As recommended by the experts, who attended the meeting on advocating access to care and sharing experiences, these women not only need training in nutrition, hygiene, drug management, universal precautions and basic nursing skills to handle their sick relatives, but also counselling and moral and emotional support (UNAIDS, 2003).

Due to lack of resources and inadequate healthcare facilities in India, all those living with HIV and AIDS who need care may not get access to hospital-based services. In South Africa and Uganda, various models of home-based care programmes have been promoted mostly by the NGOs, which rely on volunteers from the affected communities to provide basic nursing and caregiving activities to patients in their homes. Such services would reduce the burden on women. In the case of terminally-ill cancer patients, facilities like hospices, which provide palliative care, have come up in many cities of India. There is a need for such hospices for terminally ill AIDS patients as well, so that they could spend their last days in a peaceful atmosphere without being stigmatised and could die with dignity. In Karnataka, near Bangalore, the research team visited one such centre run by Snehadaan (Camillian Care and Support Centre for PLWHA) which is providing excellent services not only as a drop-in centre but also to the terminally ill AIDS patients. More such efforts are required so that the family members, in particular women, are relieved of the emotional, physical and financial burden of caregiving.

As far as the health-seeking behaviour of the PLWHA is concerned, the survey results reveal gender differences with regard to opportunistic infections for which no treatment is taken, sources of treatment as well as in the amount spent on these treatments. The gender difference becomes more noticeable from the fact that not only is the percentage of women's illnesses which go untreated higher than that of men, but in the case of women, financial constraints turn out to be an important reason for not seeking treatment. It is imperative to see that women, who are affected more by HIV and AIDS, atleast get equal opportunities to access treatment. This can be achieved only if they are educated and are also capable of earning a livelihood and hence are empowered enough to demand equal right to healthcare.

As per the survey data, HIV and AIDS does not seem to have much of an impact on the education of female children, if we compare the gender gap in schooling between HIV and non-HIV households. However, even though the gender gap may not be very significant, in absolute terms, the current enrolment percentages were quite low for the girls. Any further fall in these percentages is going to have a significant impact on the number of girls being educated. It is important to remember that in the present study atleast one of the parents is alive and the impact may be much more severe when these children become orphans. Though both boys and girls would be affected, girls may be worse off, given the social conditions in the country. If girls are pulled out of school and are not given an opportunity to educate themselves, it makes them vulnerable to all sorts of exploitation.

The present study reinforces the fact that as compared to men, women face more discrimination in the family and community. Though in a large number of cases, the family has been quite supportive of the persons living with HIV and AIDS, which speaks of the strong family ties in India, the support is less for women than men. The attitude of family and society at large seems much more negative when it comes to female PLWHA. Discrimination in the form of "neglect, isolation, verbal teasing" is being reported by a higher percentage of women. The survey of non-HIV households also indicate that as compared to men, women seem to have much more negative attitude towards PLWHA and this negative attitude arises mostly out of misconceptions about the modes of transmission of HIV. Empowering women with knowledge about HIV and AIDS would help them to protect themselves from the infection and creating greater awareness among people, women in particular, would go a long way in accepting the positive persons in the family and society at large.

The survey brings out the deplorable condition of HIV-positive widow households. As compared to other HIV households in the sample, their household income is much lower and living conditions are poorer and they have very few amenities at home. The widow households have huge debts and are left with very little assets since they have already incurred a lot of expenditure on their husbands' medical treatment and thereby a number of households are pushed below the poverty line. As the case study conducted in Manipur points out, unless these widows are engaged in productive work and have steady income, they would be driven to sex trade as one of the avenues of economic support and in the process infect many more people. During the informal interviews with the key informants like the out-reach workers of NGOs and medical officers in the Theni

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district of Tamil Nadu, it was learnt that for many of the HIV-positive widows in that area, sex trade is the main source of livelihood.

The HIV-positive widows could be encouraged and trained to form self-help groups and could be given micro-credit facilities to start income-generating activities. Besides, it is essential to ensure access to healthcare facilities for the treatment of OIs as well as to anti-retroviral therapy (ART) so that the life of the positive widows is prolonged and their health status improve. Already the Government of India is providing free supply of ART in the HIV high-prevalence states and women are included in the treatment on a priority basis. However, since the ART centres are not located in all the districts, for many of them accessibility is a problem. Women from the rural areas are specially affected since they may have to commute a long distance. The present study shows that generally women do not get much support from the family for seeking treatment and no one accompanies them when they have to visit health facilities to collect ART drugs. The accessibility of ART should be improved and regular supply of drugs needs to be ensured, so that their children do not lose both the parents. During the FGDs, most of the HIV-positive widows said that they would like to live atleast till their children stood on their own feet.

The HIV-positive widows could be encouraged and trained to form self-help groups and could be given micro-credit facilities to start income-generating activities

The present survey reiterates the findings of other studies, which show that the HIV-positive widows generally do not get a share in their husband's property and are thrown out of their marital homes, after the death of their husbands. Improving women's legal position relating to inheritance and property ownership alone would not work, unless women are educated and empowered to fight for their rights. Already forums like the Lawyers Collective are playing an important role in fighting for the legal rights of PLWHA.

The present study shows that the in-laws of the widows generally do not take care of their widowed daughter-in law and the grandchildren. It was also learnt during the focus group discussions that if at all, the paternal grandparents are willing take care of their grandsons, and not the granddaughters for the sake of continuing the family lineage, provided the boy is HIV negative. This again shows the kind of gender bias that exists in the society.

In most of the cases, the maternal grandparents take the responsibility of bringing up their grandchildren. This increases the financial and physical burden on the elderly, in particular the elderly women. They practically have to take the role of a mother and bathe, feed and provide other needful services for the grand children. Now even more than before, these old people not only need psychological and economic support, but also access to medical care so that they could maintain their own good health.

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National AIDS Control Organisation (NACO) in the Ministry of Health & Family Welfare, Government of India, directs and co-ordinates the National HIV/AIDS Prevention and Control Programme across the country. NACO is the nodal organisation for formulation of policy and implementation of programmes for prevention and control of HIV and AIDS so as to ensure a need-based, demand-driven, and people-centered response.

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This study details the impact of HIV and AIDS on women and girls by examining a cross-section of issues such as income, savings, consumption as well as education, health, and levels of stigma and discrimination.

Conducted by NCAER in collaboration with NACO and UNDP, the study is based on a primary survey covering 8,292 households spread over the rural and urban areas of the six states i.e. Andhra Pradesh, Tamil Nadu, Karnataka, Maharashtra, Nagaland and Manipur.

The findings indicate that HIV tends to exacerbate gender disparities. Besides the increased workload at home, women are also required to take up employment to supplement lost earnings. In particular, the economic situation of women headed households is very fragile.

The burden of caring for People Living with HIV and AIDS (PLWHA) is proportionately higher in the case of women, whether or not they are themselves HIV positive. In comparison to men, nearly double the cases of illnesses of women PLWHA were left untreated. It is the girl child who is more likely to be withdrawn from school to cope with household chores including caring for the ill. Though all PLWHA face stigma and discrimination, the women face the worst forms of discrimination even within the family.

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